

WOMEN THINKING TRANS ISSUES

A Report on Findings of Participatory Action Research on the
Inequality of Access to NHS Services by Trans Women.



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1. SUMMARY

Engender seeks to increase women's power and influence; make visible the impact of gender inequality on women and on Scotland's social, economic and political development; and support people, organisations and our government to make equality a reality. At the end of 2009 Engender began work on 'Equality Counting', a project funded by the UK Equality and Human Rights Commission. The project identified transsexual women as a group disadvantaged by a public service provision. Engender's role was very much a supportive one, providing the group with training and tools in order for the group to carry out their own research to lever change.

Using personal experience the group members chose Gender Reassignment (GR) Health Service as the top priority. The group aimed to improve access to Gender Reassignment Services and the transitioning experience of trans women. The group's research project had two strands:

Strand 1: How long do trans women wait for Gender Reassignment Services and what effect do waiting times or refusal of funding for treatment have? The group used an online survey and focus groups to gather data for this research since these were seen to be the most effective way of reaching this 'hidden' community. The online "Waiting Times and Funding Refusal Survey" was publicised widely within the trans community. The survey produced 49 respondents from 9 Scottish Health Board areas.

The survey produced a positive finding that 92% of respondents reported good support from their General Practitioner (GP). The survey then asked about GR treatment experience. In Facial Hair Removal 43% of respondents paid for private treatment and only 20% had National Health Service (NHS) funding for this essential treatment. For Gender Reassignment Surgery (GRS) 29% of respondents had Health Board funding for private surgery. Only 6% had NHS surgery funded by the National Services Division (NSD) and 4% had funding refusals. The survey asked about waiting times and 18% waited over two years for this surgery. The survey asked if waiting times had affected their personal well-being with 61% of respondents indicating episodes of anxiety, depression, self-harm and attempted suicide.

The research shows a need for greater funding in Gender Clinics and GR treatments. Funding decisions need to be given much greater priority to reduce the incidences of mental health problems. A funded patient pathway would help to improve the treatment of trans women and reduce the effect of funding delays and refusals.

Strand 2: Do Health Boards' Equality Impact Assessment (EIA) processes consider the needs of trans women effectively and do they result in positive outcomes in improved services for trans women? Small group interviews took place with Health Service managers in three Health Board areas regarding their processes for conducting EIAs, staff training for EIAs and the impact on services so far.

It was apparent that the Health Boards we interviewed had been largely unable to include the needs of trans women as a particular strand within their EIA training. However they all believed that the needs of trans women were being considered and met, though they were largely unable to offer hard evidence to support this. One Health Board had developed a 'trans etiquette' with support and input from the trans community. All of the Health Boards interviewed were happy to cooperate and expressed a wish to continue with meaningful dialogue in this area.

2. BACKGROUND AND INTRODUCTION

Engender works to make Scotland a fairer, safer place where women can flourish and contribute to both the social and market economies with dignity, freedom and justice.

To this end Engender seeks to create and facilitate opportunities for women to influence policy and practice and hold public bodies to account, promote gender mainstreaming, support other women's organisations and work on shared agendas with a wide range of equalities groups to make equality a reality.

Equality Counting

At the end of 2009 Engender began work on "Equality Counting," a project funded for two years by the UK Equality and Human Rights Commission.

The aim of the project was to enable women disadvantaged by a public service provision to come together in 'communities of interest' around specific issues of concern. In Year One, 2010/2011, Engender has worked with three discrete communities of interest through "Equality Counting" comprising (1) Transsexual Women, (2) Women with Disabilities and (3) Women with Diverse Communication Support Needs.

Engender has supported each of these communities of interest to:

- Organise and access appropriate information
- Understand policy e.g. equality duties
- Carry out Participatory Action Research (PAR)
- Develop and articulate gendered equalities analysis
- Work out the opportunity in legislation and apply it to their situation
- Take up or establish opportunities for dialogue with the service provider
- Take action using their research and analysis e.g. advocating for change and holding public services to account

Women Thinking Trans Issues

At the end of January 2010 an email went out through the Scottish Transgender Alliance network targeting transsexual women to let them know about the project and ask if they were interested in taking part.

In March/April 2010, eight transsexual women joined together for an initial six-week training period on PAR methods. Some of the women already knew each other from other groups or networks but most did not, and given that none of the women had had any previous contact with Engender it was a new and exciting venture for all concerned.

It should be noted that in joining in the project the women were already coming with an idea of the issue(s) that they wished to address. "Equality Counting" offered to use support and training to organise around the issue(s), to research and use opportunities in equalities legislation to change and challenge policies. One of the first tasks of the group was to decide on its name. Members quickly agreed that 'Women Thinking Trans Issues' (WTTI) was suitable and clearly identified their purpose. Following the initial training a core group of five women continued to work together to plan and conduct PAR. Using personal experience and knowledge of the difficulties faced by other transsexual women, group members considered many areas of life but Health Service issues related to GR clearly emerged as the top priority.

The women found a perception in their community that there was no consistency in medical treatment for transsexuals from area to area, that problems are suffered with delays in aspects of the transition process and that funding is sometimes refused.

Therefore, WTTI considered the most telling research would be to highlight inconsistencies in NHS treatment, funding and waiting times for those seeking Gender Reassignment Services.

3. KEY ISSUES FOR TRANS WOMEN REGARDING ACCESS TO SERVICES

In the process of learning about PAR and studying equality duties and human rights legislation, a range of issues were identified by trans women in the group.

Access to Gender Reassignment Services

- Participants were angry about the inconsistency of treatment across Health Boards and claimed that access and entitlement to treatment was a 'postcode lottery.'
- Women at different stages of transition complained of the powerlessness they felt in the process of GR and talked of the emotional and mental impact of such disempowerment.
- GPs were often supportive of GR patients, though sometimes their lack of experience and knowledge could make a patient's pathway very difficult and distressing.
- Trans women often have to educate GPs in issues of GR in order to facilitate treatment.
- Patients are able to refer themselves to a gender specialist if their GP will not do so but such information was not readily available. Trans women argued for a formal patient pathway for transitioning.
- Transitioning often meant 'jumping through hoops' while trying to hide any mental health or social issues from a gender specialist so that progress was made as swiftly as possible.
- Mental health problems were known to be common amongst trans women but it was felt that when they need the most support they are least likely to receive it.
- Services such as Speech Therapy, Hair Removal and classes in dress, make up, deportment and confidence building were recognised as being very important to successful transitioning.
- There was a general lack of opportunity for trans women to have a dialogue with Health Services or input to service design.

Identity

The transitioning process can be painfully slow. When a trans woman takes the step of presenting publicly, she may struggle to convince family, friends and public agencies to address her as a woman.

The process of changing gender and name with large agencies such as the NHS requires special documentation, can take time to complete and can create real problems. Failure to update patient records successfully does result in the distressing experience of a trans woman's appointments being announced publicly in their former (male) name and title while presenting as a woman.

Acceptance

Ultimately, society needs to accept trans women. Isolation emerged as an issue during our discussions, and the group were also aware of the prevalence of hate incidents such as verbal abuse and other hate crimes experienced by trans women, which they are often unwilling to report.

The group acknowledged the difficulty of transitioning as a school pupil. While supporting the idea of educating school children and their parents about trans experience, the group felt this was too ambitious to be taken on.

However there were examples of good practice examples in this area:

- The police were seen to be very supportive of LGBT rights and safety, were well trained and aware of how to address trans people.
- Other medical service providers, such as opticians and alternative health practitioners, were identified as providing a service that was personalised and sensitive to the identity change of their customer.

4. RESEARCH AIMS, OBJECTIVES AND DESIGN

In considering Gender Reassignment Services, the group came to the conclusion that carrying out research over the whole of Scotland would lead to a project that might be beyond their resources. It was agreed that the research should focus on access to services in four Health Boards in the central belt of Scotland:

- Forth Valley
- Greater Glasgow and Clyde
- Lanarkshire
- Lothian

Through their research, the group aimed to improve access to Gender Reassignment Services and to enhance the transitioning experience by raising awareness of the needs and views of trans women, and by highlighting the problems experienced in accessing services.

The group's research project had two strands:

Strand 1

How long do trans women wait for Gender Reassignment Services, and what effects do short or long waiting times or refusal of funding for treatment have on their lives?

The group used an online survey to gather data on this strand, since this was seen to be the most effective way of reaching this 'hidden' community. Using LGBT, trans community and voluntary sector networks, the survey was publicised widely via emails, in newsletters, on websites and with postcards.

Strand 2

Do Health Boards' EIA processes consider the needs of trans women effectively and do they result in positive outcomes in improved services for trans women?

Small group interviews were planned with Health Service managers in the four Health Board areas about their processes for conducting EIA, staff training for EIA and the impact on services so far.

To gather more qualitative data on transitioning experiences and to develop a clear picture of trans women's priorities for improvement of Gender Reassignment Services, three focus groups of trans women were facilitated.

5. WAITING TIMES AND FUNDING REFUSAL SURVEY

5.1 Research Methodology

5.1.1 Design

The survey was designed to follow the journey of GR also known as transition. At each stage in this process trans women require access to different services and make contact with different health professionals. We wanted to know the experience people had in obtaining the funding for GR treatments and the funding refusals, waiting times or delays in obtaining these treatments.

Funding delays and refusals have an impact on the lives of trans women so we asked about these experiences and any further health problems that may have resulted from this process. We also wanted to know about expectations of treatment waiting times and any good experiences.

The questions in the survey followed the pathway to treatment:

- GP support
- Gender Clinic
- Hormone Treatment
- Facial Hair Removal
- Speech Therapy
- Gender Reassignment Surgery
- Additional surgeries

In addition we asked about personal experiences including:

- Experiences with family and friends
- Experiences in education and employment
- Effects of funding refusals and waiting times

The following sections describe the publicity for the survey and the results obtained.

5.1.2 Publicity

The survey was created using an online account from Equality Network and we are grateful for this support. The survey took place from August to October 2010 and the publicity was extensive in both website and email based communication. We also created some handouts for trans women without internet access.

The website publicity included:

- Equality Network National LGBT Forum
- Edinburgh Trans Women support group
- Facebook pages and groups

Email publicity included:

- Edinburgh Trans Women Yahoo group
- Sandyford Support Group Yahoo group
- Central Scotland Transgender group

- Equality Network LGBT News
- Scottish Transgender Alliance News

UK National publicity with:

- Press for Change
- Transsexual-uk Yahoo Group
- Transgender Zone Forum

Handouts were distributed at the:

- Sandyford Initiative Gender Clinic
- Edinburgh Royal Infirmary Gender Clinic

The survey produced a total of 56 trans women responses with 49 Scottish, 6 English and 1 duplicate entry. Only the 49 Scottish responses are used in the findings description.

In comparison the Scottish Transgender Alliance survey “Transgender Experiences in Scotland” [1] was published in 2008 and obtained 71 valid responses of transgender people. In this survey 34 respondents identified as transsexual women.

Other surveys include the “NHS and University of Glasgow Scottish Transgender Survey” [2] in 2005 with 52 respondents of transgender people. In 2007 Press for Change published the UK wide survey “Engendered Penalties” [3] which was commissioned by the Equalities Review. This survey had the largest number of survey respondents of any international research and had a Scottish sample of 73 transgendered people.

Our sample of 49 Scottish trans women compares well with previous research and may be the largest sample of trans women in Scotland.

5.2 Survey Respondents

5.2.1 Demographics

Survey respondents’ Health Boards

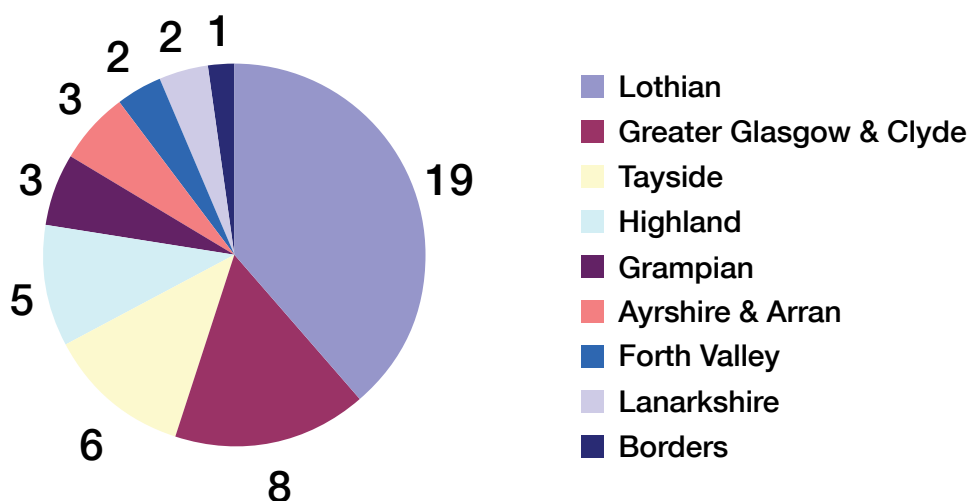


Figure 5.1 Survey respondent numbers within each Health Board

The majority of survey respondents live within the NHS Lothian area followed by NHS Greater Glasgow and Clyde, NHS Tayside and NHS Highland. The other five Health Board areas have a smaller number of responses in the survey.

We had expected to get more interest in the survey along the central belt of Scotland. It is interesting to see that there are 19 trans women from NHS Lothian area, more than double the 8 trans women respondents from NHS Greater Glasgow and Clyde, despite the larger population size there. A possible explanation could be some greater publicity from Edinburgh but the findings also show more funding refusals and general dissatisfaction within the NHS Lothian area.

Survey Respondents' Age Range

The survey respondent age ranges show a sample that peaks at the 41 to 55 age range. This agrees with other research which shows the greatest number of trans people start GR in the middle of life. Some recent research was published by the Gender Identity Research and Education Society in November 2010: "The Number of Gender Variant People in the UK: An Update" [4]. This research shows that the median age to present for treatment is now 42 and this is within our largest age group.

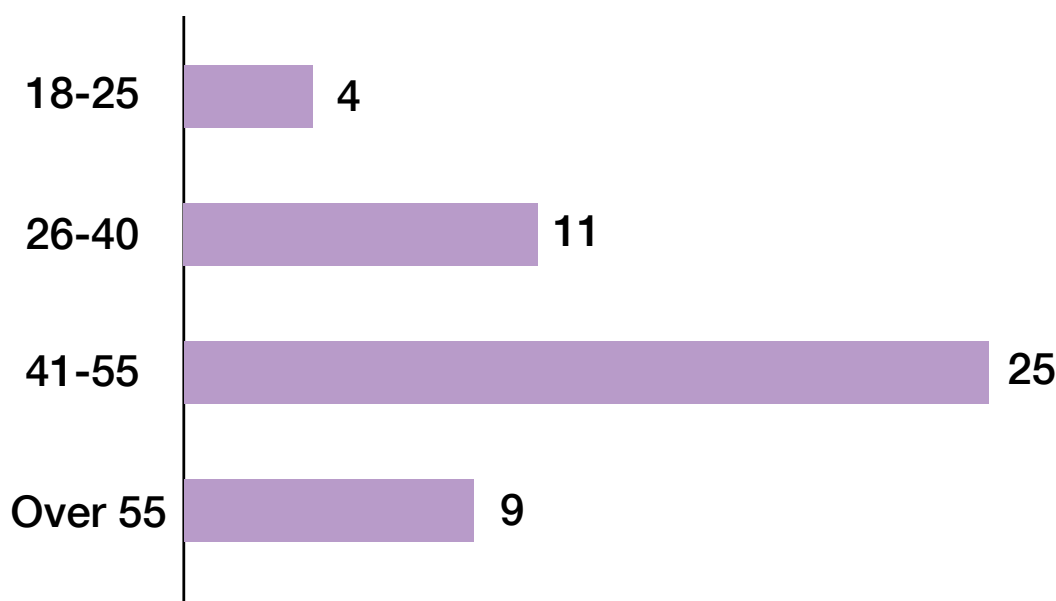


Figure 5.2 Survey respondents' age

5.2.2 General Practitioner Support

The survey asked about support and knowledge from GPs. The survey respondents reported 45 responses with good GP support and 4 responses with poor support. This is a good response but the survey showed that many GPs are inexperienced with GR and may be unaware of the treatment requirements. The Department of Health in England publishes a booklet to guide GPs and other health professionals [5].

Survey respondents were asked to provide comments about their GP experiences and here are some of the responses below:

"She has been totally supportive of both myself and my family."

"All the members of staff I have seen have been extremely helpful and caring towards me."

"She has been very supportive, if not quite fully understanding of the process."

"GP is fully supportive and working to understand the issues involved."

5.2.3 Gender Identity Clinic

Most of the survey respondents are located within the NHS Lothian and NHS Greater Glasgow and Clyde areas. This shows that the majority of these trans women attend the main Gender Identity Clinics in Edinburgh and Glasgow.

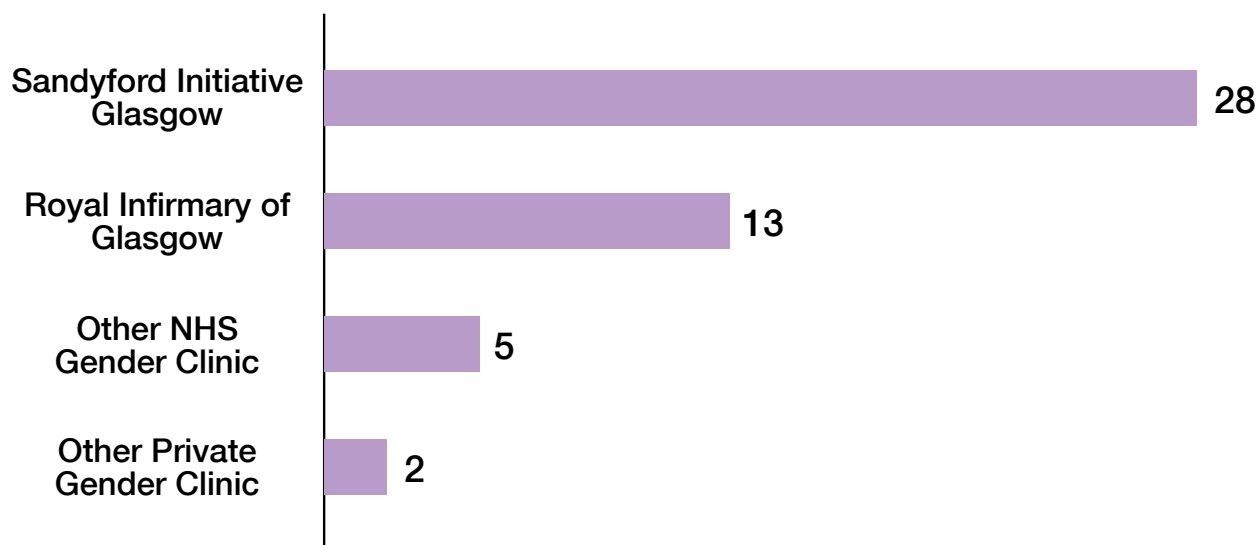


Figure 5.3 Survey respondents' Gender Clinic

The Sandyford Initiative is the largest Gender Clinic in Scotland and accepts patients from all over the country. Survey respondents from the Health Boards NHS Lothian, NHS Greater Glasgow and Clyde, NHS Tayside, NHS Highland, NHS Ayrshire and Arran, NHS Forth Valley and NHS Lanarkshire attend this clinic.

The Edinburgh Royal Infirmary has a much smaller Gender Clinic with longer waiting times. Only survey respondents from NHS Lothian attend this clinic.

Both the Sandyford Initiative and Edinburgh Royal Infirmary accept GP and direct patient referrals to their Gender Identity Clinics. Of the survey respondents 21 trans women referred themselves, 21 were referred by their GP and 7 were referred by other health professionals.

The median year for a first clinic appointment for our survey respondents was 2007 with the majority starting between 2002 and 2010.

5.3 Treatment Findings

5.3.1 Hormone Treatment

Trans women require Hormone Treatment to make physical changes to the body including changing the body shape and smoothing the skin. The hormones also provide emotional support to help trans women. The visible changes are a big gain to trans women and it is beneficial to start Hormone Treatment prior to GR especially in a workplace transition situation.

In the survey, we asked respondents about waiting times for Hormone Treatment after starting at the Gender Clinic.

Just over a quarter (26%) reported that they received this treatment within three months. Of the remaining respondents, 36% received treatment within one year, 24% waiting up to two years and 13% were not given Hormone Treatment for over two years.

Analysing those who waited over one year for this treatment there were 8 from Lothian, 6 from Greater Glasgow and Clyde and the rest all single responses from different NHS areas. Significantly it should be noted that the total respondents from the NHS Greater Glasgow and Clyde area who answered this question was 8, of whom 6 had to wait over a year.

We do not know how long the respondents took to transition after starting at the Gender Clinic. The starting date for Hormone Treatment would be affected by a delayed transition date.

5.3.2 Facial Hair Removal

Permanent Facial Hair Removal is an essential treatment for trans women. Removing the hairs prevents visible roots showing and allows the pores to close. With Hormone Treatment this can result in the skin becoming smooth and appearing more feminine. This change in appearance is a major factor to improve acceptance.

Of the respondents who completed the section on Facial Hair Removal, 46% went private, 24% had funding refused and 11% waited over a year and some over two years. The remainder is made up of those who did not want this treatment or had it started within a year.

Significantly, every single respondent from the Greater Glasgow and Clyde area and the Highland area either went private, waited over two years or had funding refused.

There is a similar picture for the Lothian area with only one respondent reporting starting this treatment in less than a year.

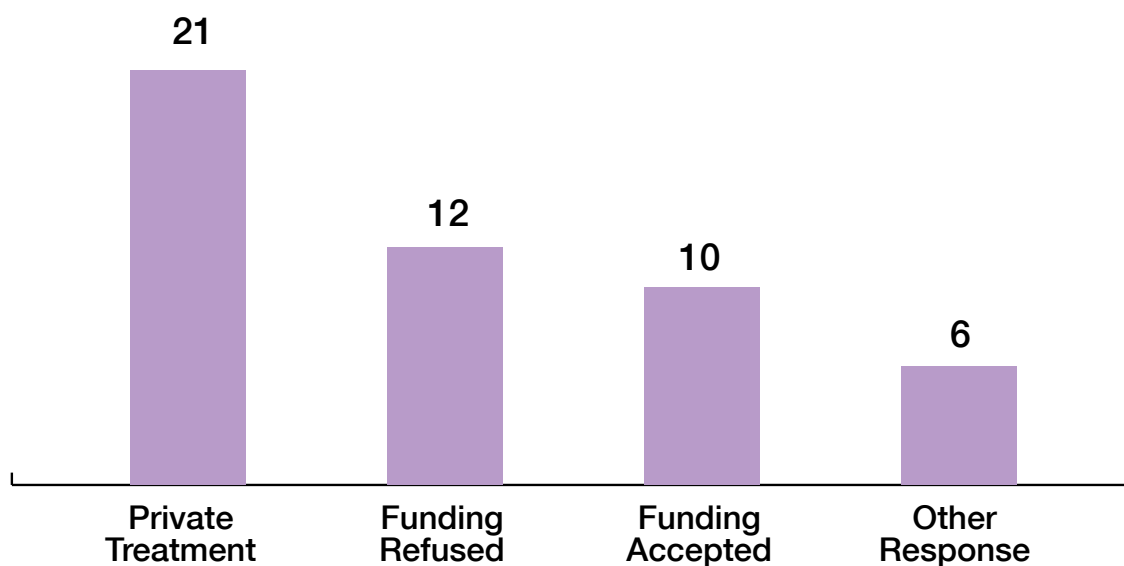


Figure 5.4 Facial Hair Removal funding

5.3.3 Speech Therapy

Hormone Treatment does not change the voice pitch for trans women. It is possible to change the voice through neck muscle control and different resonance techniques. These techniques have to be taught by a speech therapist and take many months of practice. A convincing female voice is a huge gain in acceptance for one to one and telephone communication.

The survey asked about waiting times for Speech Therapy. While 25% of the respondents did not require this treatment, 30% waited up to one year and 26% over one year and some over two years. The remainder started Speech Therapy in three months.

Again, all but two respondents from the Greater Glasgow and Clyde area who wanted Speech Therapy had to wait over a year. In the Lothian area the majority of respondents started this treatment in under a year with 3 having to wait over a year.

5.3.4 Gender Reassignment Surgery

Hospitals and Funding for Gender Reassignment Surgery

Survey respondents were asked if they had completed GRS. From the total 49 survey responses there were 19 respondents who had completed GRS, 18 respondents who had not completed GRS, 9 respondents gave no information, 2 respondents had funding refusals and 1 respondent did not want surgery.

The survey asked if the GRS was done at an NHS or private hospital and if the funding for this was from the NHS, self funded or if NHS funding was refused. The graph below shows the number of respondents and their hospital and funding sources.

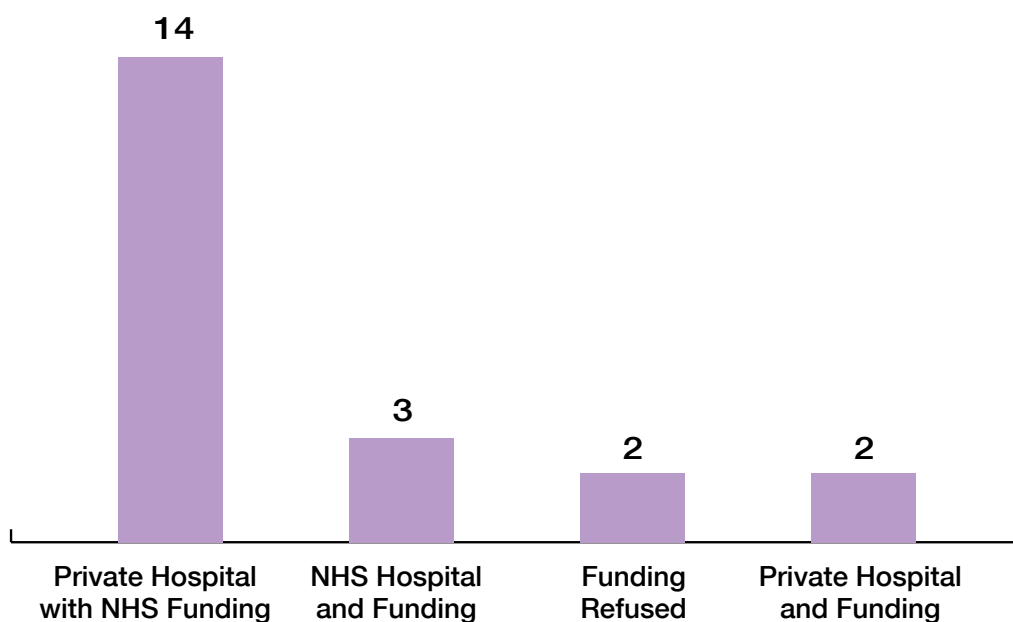


Figure 5.5 Gender Reassignment Surgery hospitals and funding

The largest column on the graph shows 14 respondents had GRS at a private hospital paid for by their NHS board. The private hospitals were in Brighton and London. The second largest column shows 3 respondents who had GRS paid for by the NHS through the NSD. This surgery was done at an NHS hospital in London.

The third column shows that NHS funding was refused to 2 of our survey respondents. Finally the last column shows that 2 respondents chose to pay privately for GRS and the private hospitals were in Brighton and Thailand.

Private Hospital with NHS Funding	NHS Hospital with NHS Funding	NHS Funding Refused
NHS Greater Glasgow and Clyde	NHS Lothian	NHS Lothian
NHS Forth Valley		
NHS Highland		
NHS Borders		
NHS Grampian		
NHS Ayrshire		
NHS Lothian		

Figure 5.6 Gender Reassignment Surgery hospitals and funding with NHS Health Boards

The table in figure 5.6 represents the first three columns of the graph in figure 5.5. The first table column shows that 7 NHS Health Boards funded private treatment. The second column shows that only 1 Health Board funded GRS at an NHS hospital, a requirement of the NSD. The third column shows that only 1 Health Board refused funding for GRS.

Health Boards have a choice to pay for private surgery or choose funding from the NSD. The NSD has funded GRS in England since 2007 on behalf of NHS Health Boards but will only fund treatment in an NHS hospital. This is often more expensive and with longer waiting times than a private hospital. In the survey results, NHS Lothian was the only Health Board to choose NSD funding for GRS and funded private surgery prior to 2000.

Waiting Times for Gender Reassignment Surgery

The survey respondents indicated the waiting time for GRS from the end of their Real Life Experience (RLE). The waiting time may include a delay waiting for funding, a delay waiting for an appointment with the GRS surgeon and the actual waiting list for the surgery.

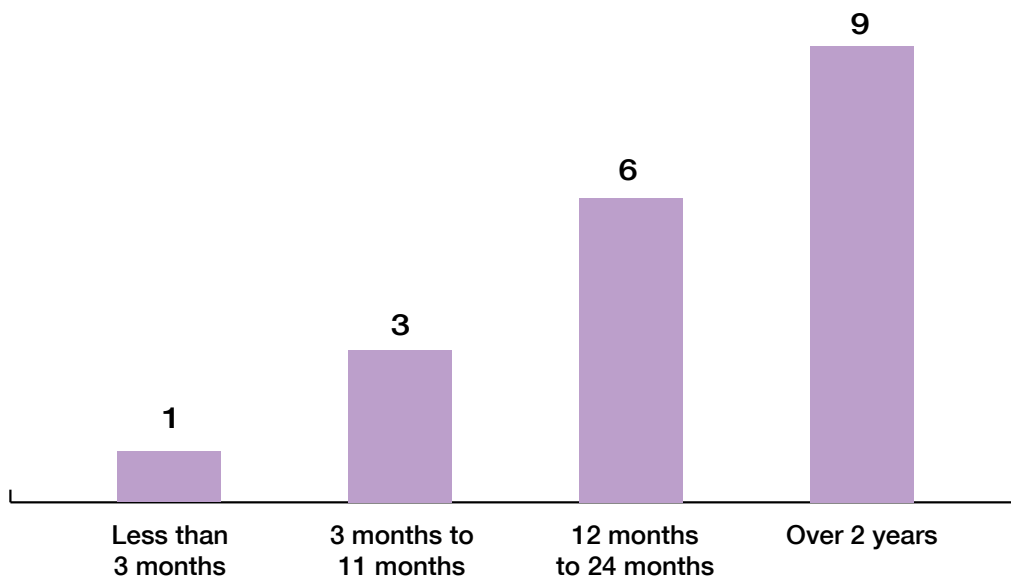


Figure 5.7 Waiting times for Gender Reassignment Surgery after Real Life Experience.

The bar chart of figure 5.7 shows that most respondents waited over two years for GRS after their RLE. The next largest column shows that 6 respondents waited from one to two years for GRS. From the total of 19 survey respondents 15 of the total waited at least one year for GRS. Only 4 respondents obtained GRS treatment in under a year.

Impact of Funding Delays and Refusals for Gender Reassignment Surgery

The survey respondents showed the impact of the delays and funding refusals in getting their GRS treatment. There were several instances of stress, depression and self harm from delays. One respondent reported a suicide attempt.

We asked survey respondents to provide comments about their experiences and here are some of the responses below:

"7 years from start to finish caused mental anguish and stress with not too pleasant thoughts."

"Increased stress in continuously feeling incomplete and not really being able to move on with your life."

"I got very down between the period after RLE completed and funding available for GRS."

"They left me depressed and feeling hopeless."

"Yes, oh yes. Made recent suicide attempt following delays and disappointments."

5.3.5 Breast Augmentation

Hormone Treatments for trans women may not produce sufficient breast growth to match their body size and body frame. Many trans women wish to have Breast Augmentation to increase their breast size and improve their appearance.

The survey asked respondents if they had completed Breast Augmentation surgery and how long they waited for this after completing RLE.

Waiting Time after RLE and Funding Decision	Number of Respondents
Not completed Real Life Experience	18
Breast Augmentation surgery not wanted	13
Funding refused	7
Waiting time of over 2 years	6
Waiting time of 12 to 24 months	1
Waiting time of 3 to 11 months	1
Chose private treatment	1

Figure 5.8 Waiting times, funding and interest in Breast Augmentation Surgery

The respondents showed that 13 trans women did not want Breast Augmentation Surgery while 16 did. 7 were refused funding, 8 received NHS treatment and 1 chose private surgery. The research shows that 6 trans women waited over two years for this surgery when funded by the NHS.

Funding was refused for 4 trans women from NHS Lothian and 1 trans woman from each of the Health Boards NHS Lanarkshire, NHS Greater Glasgow and Clyde and NHS Highland.

5.3.6 Facial Feminisation Surgery

Hormone Treatments do not change the bone structure in the face so some trans women choose to have Facial Feminisation Surgery (FFS) to improve their appearance. This can include a reduction in brow bossing, a reduction in the nose and some reshaping of the chin. There are many other procedures in addition to this and many are very invasive.

Survey respondents were asked if they had completed FFS and how long they waited for this after completing RLE.

Waiting time and funding decision	Number of Respondents
Not completed Real Life Experience	12
Facial Feminisation Surgery not wanted	21
Funding refused	7
Waiting time of over 2 years	4
Waiting time of 12 to 24 months	1
Waiting time of 3 to 11 months	1
Chose private treatment	2

Figure 5.9 Waiting times, funding and interest in Facial Feminisation Surgery

The respondents showed that the majority of 21 did not want any FFS. There was funding refusal for 7 trans women and 6 respondents obtained NHS surgery. 2 trans women chose to have private treatment. For the survey respondents with NHS funding, 4 trans women had a waiting time of over two years for surgery.

Funding was refused for 3 trans women from NHS Greater Glasgow and Clyde, 2 trans women from the NHS Lothian and 1 trans woman from each of the Health Boards NHS Highland and NHS Lanarkshire.

5.3.7 Tracheal Shave

Some trans women have prominent cartilage ('Adam's Apple') near the voice box. This can be a very male defining characteristic and some trans women wish to have this cartilage reduced. This procedure is called thyroid cartilage reduction and sometimes known as a Tracheal Shave.

Survey respondents were asked if they had completed Tracheal Shave Surgery and how long they waited for this after completing RLE.

Waiting Time and Funding Decision	Number of Respondents
Not completed Real Life Experience	14
Tracheal Shave Surgery not wanted	27
Funding Refused	2
Waiting time of 12 to 24 months	1
Waiting time of 3 to 11 months	1
Waiting time of 3 to 11 months	1

Figure 5.10 Waiting times, funding and interest in Tracheal Shave Surgery

The respondents showed that a majority of 27 trans women did not want Tracheal Shave Surgery. Only 4 respondents showed interest with 2 having funding refused and 2 receiving treatment within two years.

The respondents showed that there is only low interest in this procedure as many trans women do not need it. Even with the low interest there were funding refusals from Health Boards NHS Lanarkshire and NHS Greater Glasgow and Clyde.

5.4.1 Personal Well-being

Of 49 respondents to the online survey, 30 (61%) indicated that their personal well-being had been affected by waiting times. Many respondents reported episodes of anxiety and depression including incidents of self-harming and attempted suicide. Others self medicated to avoid delays.

Typical responses include the following:

"Yes, oh yes. Made recent suicide attempt following delays and disappointments. It made my life just impossible."

"They left me depressed and feeling hopeless."

"Depression got worse, a lot worse!"

"Caused self-harm."

"The longer you wait for anything that'll help you pass, the more grief you get from the world at large. Many of my episodes of suicidal thoughts were when I was refused funding, refused the procedure, or kept at the gate with NHS protocols, when I was getting it in the neck from the world at large."

"Yes, I risked self-medicating because the Gender Identity Clinic didn't prescribe me hormones soon enough."

"When my GID [Gender Identity Disorder] exploded I really needed to speak to a specialist, but it took 10 months to get that first appointment organised."

"I got very down between the period after RLE completed and funding available for GRS."

Stress due to financial insecurity or working additional hours to fund treatments that are refused or delayed was a key factor for several respondents. Most women undergoing GR will finance some treatments that can only be seen as essential if their transition is to be successful.

Typical responses included the following:

"Waiting for funding for Laser Hair Removal left me so poor despite working full time. I had to do 50 hour weeks (if overtime was available) otherwise I basically didn't get to eat."

"For my own sanity, I have gone private for major interventions (like FFS) and will be going private for GRS. I have issues with the poor levels of communication within the clinic, leading to significant delays in hormone regime changes that are long overdue."

"I paid for Hair Removal privately because the clinic told me this could not be provided and have incurred debt that is causing me stress."

"The lack of progress in funding Hair Removal is unfair, given that it is available to people in surrounding areas. I am conscious that I still have growth on my face and chest, even after funding laser hair removal myself. This makes me self-conscious."

Most, perhaps all, women undergoing GR feel a pervading sense of incompleteness. Many feel unable to progress with their lives until this process is complete.

Typical responses included the following:

"Poorer concentration than normal."

"I believe that having a delay in having things seen to has had a damaging effect that I am slowly trying to overcome. The damage was caused by not having the issue looked at sooner. Transgender issues need to be taken more seriously and help given as soon as possible."

"Anxiety and depression because of body image and therefore I am reluctant to socialise."

5.4.2 Family and Friends

GR is a hugely complicated procedure. The patient will most likely have suffered many years of discomfort and depression. A significant proportion will have attempted suicide at some time in their lives. Even those who are in treatment with specialist clinicians and counselling continue to feel depressed and isolated. 17 of the respondents (35%) believed that their funding and treatment delays had affected their relationships with family and friends.

Typical responses include the following:

"While self-medicating I had mood swings while trying to establish the correct dosages on my own. This put a strain on my personal relationships."

"Debt incurred from private procedures has caused me a lot of stress and has affected my personal relationships."

"I was angry and unsociable and it was the only thing on my mind. No one else understood how I felt in regards to my appearance (and why would they, it's understandable that they didn't) and I isolated myself."

"It kept my relationships with family up in the air, as they kept hoping that the longer it took the more likely I am to change my mind. It should be quick to get it over with, just like pulling off a plaster. Then moving forward would be easier."

"I upset my mother and father with my depression and fluctuating moods."

5.4.3 Experience in Employment and Education

17 of the respondents (35%) felt that they had experienced problems at work or in education due to problems arising from treatment delays or refusals.

Typical responses include the following:

"The mood swings I suffered while I was self-medicating caused problems with colleagues and bosses at work. This probably irreparably damaged my career progression."

"I left university after three months due to stress waiting for hormone blockers ... my confidence was shattered by having five o'clock shadow but hair removal was not offered."

"I had to delay college studies due to not wanting to take time off in the middle of a semester."

"Having the issue not attended to for so long has had a great effect on work and study."

"Things would have been much better and less damaging had the issue been dealt with earlier."

5.5 Impact of Delays and Funding Refusal

Fyodor Dostoyevsky suggested that the degree of civilization in a society could be judged by studying the way that it treats those it imprisons [6]. A corollary might be found in considering the way Health Service providers and society treat those who have Gender Dysphoria.

Gender Dysphoria is a recognized medical condition but not a mental illness. A sense of gender is innate and inescapable. That the sense we have of our gender can be wholly incongruent with our physical bodies is a simple fact of life for those few who live like this.

For the vast majority of those who undergo GR culminating in Gender Confirmation Surgery, the outcome is life changing and life saving. Few procedures available through the NHS have a greater chance of complete patient satisfaction.

In this journey patients may be forced to say goodbye to family and friends, to careers and their own past selves, only to discover that the NHS gatekeepers, who know the cost, cannot understand the value of treatment and bar the way.

It is not possible to live happily with profound Gender Dysphoria in any other role than that with which we know is our own. The delays and denials of service and treatment often lead to anxiety, depression and other mental health problems, which are not inherent to a diagnosis of Gender Dysphoria.

We have no real knowledge of the rate of attempted suicide among transsexual women. A recent figure of 38% must be seen as too low; a survey like this can only be carried out among those who survived. We cannot account for those who died.

The irony of our situation lies in the fact that once we submit to treatment via the NHS and are suitably diagnosed, we find that the clinicians responsible for our treatment recommend treatments and procedures that are to be denied and delayed, and withheld by the funding providing gatekeepers.

Clinicians involved in the treatment of Gender Dysphoria are generally agreed that a difficult situation can be greatly improved by a uniformity of available treatments, so that a patient can begin treatment as soon as they are confident that the patient is ready to progress to the next stage. This is so rarely the case.

Most patients will be denied funding for Facial Hair Removal. In particular Scotland's two largest Health Boards (NHS Greater Glasgow & Clyde and NHS Lothian) currently will not consider funding this essential treatment.

After years of struggle patients will find themselves at the end of the process, awaiting Gender Confirmation Surgery, and faced with long delays due in part to a lack of funds, and also due in part to the system whereby this treatment is funded. Despite the fact that private health care providers are often able to provide suitable surgeries with little or no delay, and at a lower cost than the NHS, this option is not available due to restrictions on the use of the funding resource from the NSD.

"Recently ... waiting on NHS getting back to me in regards of genital hair removal have led me to being off work with severe anxiety."

"Eventually purchased hormones on the Internet because I came so close to suicide."

"I had been seeing the specialist for over two years at this point making little progress."

"I had an appointment every 6-8 months, which is simply not enough."

"I am reluctant to travel and interact with others because of poor body image and anxiety."

"I was angry and unsociable and it was the only thing on my mind. No one else understood how I felt in regards to my appearance (why would they, it's understandable that they didn't) and I isolated myself."

"No dialogue with surgeon, and not knowing the healing times, at least a year or more of my life is on hold, and I have no control on the outcomes."

"My entire worldview has changed as a result of transitioning. I'm looking for employment in areas I'd never have thought I would be motivated to."

5.6 Survey Key Findings

- 92% of survey respondents reported good GP support and only 8% had poor support.
- 29% of survey respondents had NHS funding for GRS surgery at a private hospital, 6% were funded at an NHS hospital and 4% had NHS funding refused.
- 18% of survey respondents having completed RLE waited over two years and 12% waited over a year after RLE for GRS surgery.
- 27% of survey respondents did not want Breast Augmentation Surgery, 14% had NHS funding refused and 16% were funded but with 12% having delays of over two years.
- 43% of survey respondents did not want FFS, 14% had NHS funding refused and 12% were funded but with 8% having delays of over two years.
- 55% of survey respondents did not want Tracheal Shave Surgery, 4% had NHS funding refused and only 4% were successful.
- 61% of survey respondents indicated that their personal well-being had been affected by waiting times and reported episodes of anxiety, depression, self-harming or attempted suicide.
- 35% of survey respondents believed that their funding and treatment delays had affected their relationships with family and friends.
- 35% of survey respondents felt that they had experienced problems at work or in education due to problems arising from treatment delays or refusals.

6. EQUALITY IMPACT ASSESSMENT INTERVIEWS

[Full length interviews are available on the Engender website].

The researchers made the decision to interview senior officers within the target NHS Health Boards. The object of this was to discover if meaningful and measurable action for trans women had resulted from the duty to undertake EIAs.

A semi-structured interview of two or more officers from each Health Board was proposed and requested. Because of their acquaintance and particular interest in equality matters we had hoped not to interview 'equality officers' and requested that we might be able to interview officers who fulfilled a clinical or managerial role within the organisation.

Interviews took place with NHS Forth Valley, NHS Lanarkshire, and NHS Lothian.

We were not able to interview officers from NHS Greater Glasgow & Clyde. The officers proposed found it impossible to timetable a convenient meeting. Finally in February 2011 messages to our contact within this Health Board were unanswered.

We greatly regret this, in particular because of the unique position of NHS Greater Glasgow and Clyde's Sandyford Initiative which not only treats the patients from that area but also welcomes patients from throughout Scotland. Staff and doctors at the Sandyford Initiative were able to assist us in other ways.

During each interview, the NHS staff were asked five questions in regard to EIAs.

1. When and why do you complete Equality Impact Assessments?

NHS Forth Valley had completed around 40% of all areas and while responding to those with a negative impact, used those showing a positive impact to be shared with other areas.

NHS Lanarkshire were only completing EIA's for new policies and procedures, although some are only completed during or after the process development. They hoped to complete EIA's on existing policies and procedures as they come up for review.

NHS Lothian set up a procedure to complete EIA's in 2006, and this exceeded the then legal minimum requirement. In this 'transgender' was not considered separately but within the broader gender heading. The carrying out of EIA's took some time to implement with only a handful being done by 2007, and 67 by 2010. During 2011 to date there have been 31 EIA's completed.

2. Who, how and where in the organisational system are Equality Impact Assessments completed?

NHS Forth Valley always uses teamwork when completing EIA's. This will generally include a department manager and up to eight other people. There is also a Peer Review Group which receives every EIA and reviews the findings. Also the Equality and Diversity Project Manager screens every policy.

NHS Lanarkshire also uses teamwork for EIA's with a named person being responsible. In some cases external consultants and service users are involved in the process.

NHS Lothian consult service users and other agencies such as the police, local authorities and the voluntary sector when appropriate. The EIA's are reviewed by a Monitoring and Equality Governance Committee, and they have an EIA Steering Group. Apart from carrying out the EIA and routinely monitoring them, some are subjected to a quality assurance test.

3. How do you know your staff members adequately understand trans women issues when undertaking Equality Impact Assessments?

While NHS Forth Valley managers are trained in Equality and Diversity they do not specifically train staff in trans issues, they have developed their "Trans Etiquette" document that was developed with input from the trans community. This document is given to every staff member and outlines some of the issues and advises on dealing with trans people. This document has also been adopted by other NHS authorities and several other public services including the Central Scotland Police.

NHS Lanarkshire accepted that they did not know if staff undertaking EIA's adequately understood trans issues. They only received a small number of requests for trans services and generally refer them to Glasgow for GR treatment.

NHS Lothian train staff in completing EIA's and while this covers trans issues it is not covered in much detail. To date about 350 managers have completed this half day training course. They too accepted that not many staff understood trans issues but are presently redesigning their Sexual Health Services which will include more emphasis on trans issues.

4. Can you describe your Equality Impact Assessment training programme and how it incorporates the needs of trans women?

Apart from the very successful “Trans Etiquette” NHS Forth Valley are concentrating on addressing all trans issues within their Single Equality Scheme. As part of their examination of EIA’s which have highlighted a number of issues to be addressed, NHS Forth Valley is developing links with trans people and organisations that support trans people. These links will promote genuine engagement with the trans community and involve them in the equality process.

While having no training on the needs of trans women NHS Lanarkshire has prepared new EIA guidance that includes appendices with ‘tips’ on how to work with trans patients.

NHS Lothian developed its training programme in conjunction with the LGBT Centre for Health and Wellbeing, Edinburgh, and one LGBT representative is now a training consultant. While not verifying that trans issues were specifically covered in the half day training course, they were certain that trans issues were discussed.

5. Can you talk about any actionable priorities that have arisen as a result of completing Equality Impact Assessments?

While not setting out any specific actionable priorities, NHS Forth Valley is working on several issues involving trans people including the question of gender based violence. Also they have identified that equality training includes trans matters and are considering a short course on this issue alone.

NHS Lanarkshire were also unable to identify any specific actionable priorities, but considered this would change as new documentation was introduced. They did indicate a willingness to promote equality and best practice in relation to all protected characteristics within the Equality Act 2010.

NHS Lothian gave several examples of action being taken following the completion of EIA’s. These included:

- Involvement in the Scottish Government “Keep Well” programme which revealed some health factors in relation to trans people.
- An EIA on the revised Patient Identification Policy included some actions around transgender status.
- An EIA of the “Investors in People” programme highlighted the need to change the sampling method to take account of the fact that some staff members are transgender.

In general we found the three interviews informative and positive. We also think that these interviews have helped develop links with the three Health Boards, and would like to thank all the managers who gave their time so freely to assist us in this valuable part of our research.

7. FOCUS GROUPS WITH TRANS WOMEN

Initially the group members had considered interviewing each volunteer singly and in person. However, when the online survey had been decided upon as the best means of achieving our purpose, it was still felt necessary to meet and to speak directly to as many women as possible.

To achieve this we decided to hold a series of focus groups, and to utilise the pre-existence of social and support groups for trans women that had developed around the Gender Clinic at the Sandyford Initiative in Glasgow and the LGBT Centre for Health and Wellbeing in Edinburgh. To both of these institutions, we are very grateful.

In the end, three focus groups were held: one in Glasgow and two in Edinburgh, though a significant group of women from Glasgow and the west of Scotland attended the third and last group in Edinburgh.

WHERE AND WHEN

- TTime Transgender Drop-In
LGBT Centre, Howe Street, Edinburgh.
Saturday 28 August 2010 led by Carrie Buchanan.
There were 9 participants. [Appendix: 4, pp. 47-48].
- Sandyford Trans Women Support Group
Sandyford Initiative, Sauchiehall Street, Glasgow.
Wednesday 01 September 2010 led by Lesley Stafford.
There were 5 participants. [Appendix: 4, pp. 48-50].
- Edinburgh Trans Women Support Group
LGBT Centre for Health and Wellbeing, Howe Street, Edinburgh.
04 September 2010 led by Lesley Stafford.
There were 11 participants. [Appendix: 4, pp. 50-52].

NOTE: We know that many of the women who attended the focus groups had also completed the online questionnaire. We were equally aware that some of the focus groups' participants had not completed the questionnaire and that this was their first and only opportunity to contribute to the research.

FORMAT

The group sessions were split into 3 phases:

- Gallery of ideas: using post-it notes, the groups marked up specific themes and issues that they believed were important.
- Group interaction to arrange the gallery items into distinct themes.
- Rank the importance of these themes (via collective voting, each participant had several votes to use) and articulate personal statements for each of these themes.

Taken across the three sessions a number of themes emerged which broadly reflected the findings of the online survey with significant changes in emphasis.

- Emotional well-being / mental health – 25 votes.

“worried about post-op aftercare”

“anxiety about unneeded second psychiatric assessment regarding Breast Augmentation”

“need more trans-aware counsellors”

“counsellors needed”

“specialist counsellors needed”

“initially labelled gay not trans by NHS”

“specialist is distant”

- Funding - 25 votes

"cost of self funded electrolysis a problem"

"financial hardship re. electrolysis"

"no funding for Hair Removal"

"even after approval GRS is slow – the NHS could give private treatment if cheaper and appropriate"

"no funding for Facial Feminisations Surgery"

"no funding for Breast Augmentation"

- Delays - 12 votes

"waited 18 months for my first appointment"

"whole process too slow due to waiting times"

"long delay in Hormone Treatment starting"

"waited too long"

"too long"

"long wait for / between appointments with specialist"

- Uncertainties about the process and aftercare – 13 votes

"no co-ordination / communication between gender specialist and other agencies involved in family care"

"living in one Health Board area while being treated in another leading to confusion"

"need better communication among health professionals"

"need to have better understanding of trans issues within Health Service"

Worthy of Mention

We believe that it is worth mentioning here the findings of an earlier online survey among trans men and women in 2008. This survey: "Transgender Experiences in Scotland" [1] was carried out online by the Scottish Transgender Alliance. The survey discovered some alarming trends with regard to employment and income amongst the respondents. The key findings are easily summarised:

- A disability rate of 37%.
- High unemployment – with 37% in receipt of benefits.
- 55% of respondents had an HND, a Degree or Post Graduate Degree.
- Only 30% had a gross annual income in excess of £20,000.
- 48% had a gross annual income under £10,000.
- 20% of the respondents were self-employed. This is unusually high for the population in general, and most likely reflects the difficulty the respondents experienced in securing gainful employment elsewhere.

Focus Group Findings [Charts: Appendix 3]

While issues around waiting times and the funding of treatments had been the focus of our online survey and were expected to be the principle outcome of the focus groups also, we were surprised at the emphasis given to certain areas of concern by the women who attended the groups. In particular, we were surprised at the depth of concern over issues relating to emotional well-being.

- **Waiting Times:** It is worth remembering that most mature patients will have endured decades of discomfort about their gender, and often seek help following a crisis in their lives.

Their GP and local mental health team are often unable to offer a definitive diagnosis, and while they wait for an appointment with a specialist they are often in a distressed mental state.

For women living within certain Health Boards there are considerable waiting times before seeing a specialist who can make a definitive diagnosis. In one Health Board area an initial appointment is subject to a wait of 24 months, and though in practice this is often reduced due to cancellations a wait of nine months to one year is quite typical.

- **Hair Removal:** Specialist clinicians working in the field of Gender Incongruence and Reassignment agree that the removal of facial hair is a necessary first treatment and should accompany the start of Hormone Therapy.

A successful transition cannot be achieved while the patient is in possession of a fully androgenised male beard. Even if it were possible to hide the need to shave perhaps even several times daily, the effect is socially and emotionally crippling, yet so few Health Boards are prepared to assist with the cost of this treatment.

It is necessary to grow out facial hair before treatments such as electrolysis and Laser Hair Removal can be effective and this can cause acute embarrassment. Therefore this treatment should be completed before the patient has reached the stage of a RLE.

This is not a cosmetic treatment for a male to female transsexual, it is a necessary first stage of treatment. It is worth noting again, as illustrated above, that many transsexuals live in relative poverty. Financing Facial Hair Removal is not possible for many women, thus leaving the sufferer victim to a 'postcode lottery' with regard to the most basic treatment. Often only those with the means to finance this treatment themselves can expect a meaningful transition.

- **Emotional Well-being:** It is quite obvious that we have a two-tier health system with regard to GR, and that only those who are geographically blessed or who have the means to pay for much of their treatment can have a meaningful transition. There are delays at every stage of treatment.

Gender Incongruence is not recognised in the UK as a whole or in Scotland as a mental illness. A sense of gender is innate and inescapable. That the sense we have of our gender can be wholly incongruent with our physical bodies is a simple fact of life for those few of us who live like this.

For the vast majority of those who undergo GR culminating in Gender Confirmation Surgery, the outcome is life changing and life saving.

Few procedures available through the NHS have a greater chance of patient satisfaction. Available figures indicate that 97% of patients who undergo GR culminating in Gender Confirmation Surgery are completely satisfied with the outcome.

The attempted suicide rate among those suffering from Gender Incongruence is very high, though the precise figure is debated. It is clear that as many as 50% and certainly at least 34% [4] will attempt suicide at some time, even after they have begun treatment.

There were suggestions at all three focus groups that we need to train counsellors to assist patients while undergoing this process. Scotland has only two part-time counsellors: their contribution to the well-being of two of the authors of this report was life saving, and there was a clear need expressed for this to continue and be more readily available at each of our sessions.

8. STAKEHOLDERS' MEETING

8.1 Equality Counting With Stakeholder Event

Following the successful survey results, and before writing this report, the Research Group decided to hold a meeting of those who had been involved in aspects of the project to date. NHS Managers and Equality Officers, LGBT organisations, Equalities and Human Rights Commission staff and Engender staff were invited to the meeting which was held in Edinburgh on 17.11.2010.

The aim was to reflect on some of the survey and focus group findings so that practical actions to address the issues could be considered.

Attendees:

Lynn Waddell, Equality and Diversity Project Manager, NHS Forth Valley

Lesley Boyd, Equalities Officer, NHS Lothian

Laura Hutchison, Senior Enforcement Officer, Legal team, EHRC Scotland

Douglas Guest, Grants and Stakeholder Development Manager, EHRC

Karen Grieve, Equality Unit, Scottish Government

Hina Sheikh, Equality and Diversity Manager, NHS Lanarkshire

Kelly Muir, Senior Equality Project Officer, Equality Team, NHS Health Scotland

Maruska Greenwood, Director, LGBT Centre for Health and Wellbeing

Carol Flack, Projects Director, Engender

Rosaria Votta, Projects Worker, Engender

Iyaah Warren, Participatory Researcher, Engender

WTTI research group:

Katherine Burrows

Caroline Crozier

Helen Ratcliffe

Lesley Stafford

After outlining the rationale behind the research project and explaining the decision to concentrate on NHS services, there was a presentation to reveal some of the survey findings of trans women's experiences of accessing and waiting for services related to their transition.

Attendees were then shown various statements made by survey respondents that demonstrated the severe anguish that results from inconsistencies in treatment policy, long waiting times for aspects of treatment and refusal of funding.

A further presentation set out priorities for GR service improvements as identified during three focus groups of trans women.

Following the presentations the stakeholders together considered various questions concerning the inconsistencies, time delays and funding refusals identified by trans women.

A very interesting and informative discussion took place on various ways in which improvements could be made ranging from the part played by GP's, inconsistency in policies by the various NHS Health Boards, shortage of appropriate services in Scotland, funding difficulties, and the well-being of trans women.

The research group felt that this Stakeholders' Meeting was a most valuable part of the research process, and allowed some early comments and encouraging feedback on the findings so far.

8.2 Trans Women Stakeholder's Meeting

A meeting of Edinburgh Trans Women on 04 December 2010 allowed us to provide some initial feedback to the respondents of the "Waiting Times and Funding Delay Survey" and the attendees at the trans women focus groups. We presented some initial findings from the survey and the combined results of the focus groups. This produced some interest and discussion among attendees.

This event was publicised through Edinburgh Trans Women Yahoo group, the Facebook page and the LGBT Forum events calendar.

Both of the Stakeholder meetings form part of the Participatory Research feedback process.

9. CONCLUSIONS AND RECOMMENDATIONS

Gender Clinics in Edinburgh and Glasgow

In this research most trans women live in the central belt of Scotland and attend the two clinics at the Royal Infirmary of Edinburgh (RIE) or the Sandyford Initiative in Glasgow. There are differences in these two clinics and this is shown by the trans women responses. The initial comments were about access to the Edinburgh Gender Clinic. An RIE patient reported that they *"waited 18 months for a first appointment."* Another said they had experienced a *"long wait between appointments."*

The 18 month waiting time for a first appointment at the RIE may be a significant factor in choosing a clinic, with the Sandyford Initiative waiting time currently around six months. The survey showed that 20% of NHS Lothian respondents travel to the Sandyford Initiative in Glasgow and avoid the clinic at the RIE. Only NHS Lothian respondents chose to go to the Edinburgh clinic when they preferred not to travel to Glasgow. There should be a priority action to reduce the first appointment waiting time at the RIE Gender Clinic.

Most of our research respondents managed to get an RIE Gender Clinic appointment within six months through the cancellation list. The most vulnerable patients may not be aware of this and are the most at risk of mental health problems. One survey respondent commented about clinic delays. *"When my GID exploded I really need to speak to a specialist, but it took 10 months to get that first appointment organised."* Also, *"The lack of specialist care meant I had to endure an extended period of stress and anxiety and depression."*

In the survey 20% of patients at the RIE described incidences of anxiety, depression or suicidal thoughts. The research shows that there is a need for counselling support within the Edinburgh Gender Clinic. The Sandyford Initiative has a specialist counsellor for Gender Clinic patients.

Existing RIE patients also require more access to appointments and this could be achieved with a monthly drop-in clinic. This would allow trans women to attend the Gender Clinic without an appointment and reduce the anxiety and stress caused by waiting for a booked appointment. The Sandyford Initiative Gender Clinic has a drop-in clinic and this is very successful and popular to the patients that attend this clinic.

There is no Consultant Psychiatrist working at the Edinburgh Gender Clinic. The International Standard of Care [7] is used by the NHS Gender Clinics in the treatment of trans women. This standard requires two referrals for GRS and in the UK at least one of these is written by a Consultant Psychiatrist. The Edinburgh Gender Clinic is unable to provide both of these assessments and patients frequently travel to see Psychiatrists in London. A survey respondent commented: *"needed to travel twice to London for psychiatric assessments."* This must be unnecessary in terms of cost and time when all these assessments could be done in Scotland. A Consultant Psychiatrist needs to be appointed to the Edinburgh Gender Clinic so that all the assessments could then be done in Edinburgh.

The research showed that patients from the Sandyford Initiative reported: *"need more trans aware counsellors."* There is one part-time specialist counsellor at the Sandyford Initiative and this support needs to be expanded. The research showed that 37% of patients at the Sandyford Initiative wrote about stress, anxiety, depression and suicidal thoughts.

Gender Reassignment Surgery

Many of the survey respondents waited over two years for GRS so there is a major lack of capacity for this specialist surgery. One survey respondent reported: *"I got very down between the period after RLE completed and funding available for GRS."* Another wrote: *"Seven years from start to finish caused mental anguish and stress with not too pleasant thoughts."*

There is a need to increase the number of surgeons that provide GRS and reduce the current waiting times. The resources of both the NHS and private sector also need to be combined to help overcome these delays. A major current problem is the requirement that NSD funding can only be used at an NHS hospital. This causes limitations on the hospitals used, long delays and often greater costs. It should be possible for the NSD to fund GRS at a private hospital and this will result in much more flexibility in the referral system, reduce costs and benefit trans women.

Currently NHS Lothian patients from the Edinburgh Gender Clinic are treated at the NHS Charing Cross hospital in London. This hospital requires all GRS patients to have psychiatric assessments at the NHS Charing Cross Gender Clinic before GRS surgery. This is an additional cost for using Charing Cross NHS hospital. With NSD private hospital funding and Edinburgh Gender Clinic assessments, it will be possible to refer to private hospitals at lower costs and reduced waiting times. The Sandyford Initiative Gender Clinic already provides the two psychiatric assessments for GRS and refers directly to a private hospital when the Health Board funds this.

Gender Reassignment Additional Procedures

All trans women require Facial Hair Removal and many need Breast Augmentation, Tracheal Shave and FFS. These procedures improve appearance, increase confidence and assist successful integration within a mainstream community. Few Health Boards fund these procedures and they would have a major positive benefit for trans women acceptance.

Without these treatments survey respondents reported that *"the lack of breast enhancement, Hair Removal, and facial surgery has left me open to abuse in the street and crippled my mental health."* Another respondent refused funding for Facial Hair Removal and FFS said *"I receive transphobic abuse on an almost daily basis because I am unable to pass."*

The research showed that not all trans women need a Tracheal Shave or FFS so these costs would be reduced. Facial Hair Removal is essential for all trans women and should be funded as essential treatment.

Priority of Funding Gender Reassignment Treatments

Trans women are often seen as a low priority by Health Boards and this causes the funding and treatment delays we see in this research. In the survey 80% of respondents reported that waiting times had affected their personal well-being, relationship with family and friends or education and work. Health Boards need to understand that funding delays and refusals result in cases of stress, depression, self harm and suicidal behaviour shown in this research. Health Boards should understand the priority needed for these treatments and the effect this has on the health and future lives of trans women.

Research by GIRES [4] shows that the rate of incidence of trans people first reporting at a Gender Clinic doubles every 6½ years. There needs to be additional funding for Gender Clinics and GR treatments to allow for this. Without any change the situation will get even worse with greater incidences of mental health problems and poor outcomes for many trans women. There is evidence that trans women, who have the GR treatments they need, have a successful life and positive health benefits from this. An example of this is shown by Lawrence [8] who published a survey of 232 trans women in 2003. This research showed that participants were overwhelmingly happy with their GRS results and this had greatly improved their quality of life.

Conclusions for Gender Reassignment Services

This research shows that there is a need for greater funding in Gender Clinics to reduce waiting lists and provide more support. There is a need for more capacity in GRS and a need to use both NHS and private hospitals to overcome delays. The funding for GR treatments needs to be given much greater priority to reduce the incidences of mental health problems and improve the lives of trans women. A funded patient pathway for GR will improve the treatment of trans women and reduce the effects of funding delay and refusals. With correct treatment trans women can be productive members of society and maintain employment, a social life and contribute to others in the transgender community.

The key recommendations of this research are shown below:

- There should be a priority action to reduce the 18 month waiting time for a first appointment at the RIE Gender Clinic.
- Existing RIE patients also require more access to appointments or a drop-in clinic like the Sandyford Initiative.
- A Consultant Psychiatrist needs to be appointed to the RIE Gender Clinic to remove the time and expense of travel to London for GRS referrals.
- There is a need for counselling support within the RIE Gender Clinic. Incidences of anxiety, depression or suicidal thoughts were described by 20% of survey patients at the RIE.
- The Sandyford Initiative requires more trans specialist counsellors. In the survey 37% of Sandyford patients wrote about stress, anxiety, depression and suicidal thoughts.
- The resources of both the NHS and private sector need to be combined to help overcome delays with GRS. This will reduce the mental health issues found in this research.
- It should be possible for the NSD to fund GRS at a private hospital and this will result in much more flexibility in the referral system, reduce costs and provide shorter waiting times for trans women.
- All trans women require Facial Hair Removal and many need Breast Augmentation, Tracheal Shave and FFS. These procedures improve appearance, increase confidence and assist successful integration within a mainstream community. Funding for these procedures is essential.
- Health Boards need to understand that funding delays and refusals result in cases of stress, depression, self-harm and suicidal behaviour shown in this research. Health Boards should understand the priority needed for these treatments and the effect this has on the health and future lives of trans women.
- A patient pathway for GR will improve the treatment of trans women and reduce the effects of funding delay and refusals. Trans women can be productive members of society and maintain employment, a social life and contribute to others in the transgender community.
- Central funding for the patient pathway will assure equal treatment across Scotland and remove the 'postcode lottery'.

The Engender group "Women Thinking Trans Issues" supports the work of the NHS Gender Reassignment Protocol Working Group, in the development of a new Gender Reassignment Services Protocol.

We welcome the work towards a GR patient pathway and hope that these recommendations from our research, form part of the new protocol in 2011.

APPENDIX 1: Abbreviations

PAR	Participatory Action Research
GR	Gender Reassignment
GP	General Practitioner
NHS	National Health Services
GRS	Gender Reassignment Surgery
NSD	National Services Division
EIA	Equality Impact Assessment
WTTI	Women Thinking Trans Issues
LGBT	Lesbian Gay Bisexual and Transgender
RLE	Real Life Experience
FFS	Facial Feminisation Surgery
PFPI	Patient Focus Public Involvement
IA	Impact Assessments
RIE	Royal Infirmary of Edinburgh

APPENDIX 2: Terminology

Trans: The terms 'trans person' and 'transgender person' are both often used as umbrella terms for people whose gender identity and/or gender expression differs from their birth sex. The term 'trans person' is more commonly used to describe a transsexual person (who intends to undergo, is undergoing or has undergone a process of Gender Reassignment to live permanently in their acquired gender).

Trans Women: A term often used to describe a transsexual woman (who intends to undergo, is undergoing or has undergone a process of Gender Reassignment to live permanently as a woman),

Transgender: An umbrella term for people whose gender identity and/or gender expression differs from their birth sex. They may or may not seek to undergo gender reassignment hormonal treatment/surgery.

Transsexual Person: A person who intends to undergo, is undergoing or has undergone Gender Reassignment (which may or may not involve Hormone Therapy or surgery). Transsexual people feel the deep conviction to present themselves in the appearance of the opposite sex. They may change their name and identity to live in the acquired gender. Some take hormones and have cosmetic treatments to alter their appearance and physical characteristics. Some undergo surgery to change their bodies to match their acquired gender after completing a successful Real Life Experience.

Transsexual Woman: A woman who intends to undergo, is undergoing or has undergone Gender Reassignment (which may or may not involve Hormone Therapy or surgery). A transsexual woman feels the deep conviction to present themselves in the appearance of a woman. They may change their name and identity to live as a woman. Some take hormones and have cosmetic treatments to alter their appearance and physical characteristics. Some undergo surgery to change their bodies to match their female gender after completing a successful Real Life Experience.

Participatory Action Research: This is a form of experimental research focusing on the effects of a researcher's direct actions within a participatory group which aims to improve the quality of performance of the group or an area of concern.

Gender Reassignment (GR)/Transition: Gender Reassignment or transition involves the transsexual person changing their name and identity to live in the acquired gender. Some may take hormones and have treatments to alter their appearance and physical characteristics. Some undergo surgery to change their bodies to match their acquired gender after the completion of the Real Life Experience.

Real Life Experience (RLE): The Real Life Experience is a period of at least a year, where a transsexual person starts the process of Gender Reassignment and lives successfully in the acquired gender. The transsexual person is required to have experience of education, employment or voluntary work in the acquired gender. There should also be improved social functioning. A successful period of 12 months Real Life Experience is required before Gender Reassignment Surgery.

Gender Reassignment Services: Services pertaining to Gender Reassignment.

Gender Clinic: A specialist outpatient clinic that has doctors and/or psychiatrists specialising in the treatment of transsexual people, transgender people and other people with Gender Dysphoria. In some hospitals the clinic may be part of a sexual problems clinic or psychosexual services department.

Focus Group: A form of qualitative research in which a group of people are asked about their perceptions, opinions, beliefs and attitudes towards a product, service, concept, advertisement, idea, or packaging.

Communities of Interest: A community of people who share a common interest or passion. These people exchange ideas and thoughts about the given passion, but may know (or care) little about each other outside of this area.

Gender Reassignment Surgery (GRS)/Gender Confirmation Surgery: A term for the surgical procedures by which a person's physical appearance and function of their existing sexual characteristics are altered to resemble that of the other sex. It is part of a treatment for Gender Identity Disorder/Gender Dysphoria in transsexual and transgender people. It may also be performed on intersex people, often in infancy.

Gender Identity Disorder (GID): The formal diagnosis used by psychologists and physicians to describe persons who experience significant Gender Dysphoria (discontent with the biological sex they were born with).

Gender Dysphoria: The medical term for the condition with which a person who has been assigned one gender (usually at birth on the basis of their sex), but identifies as belonging to another gender, or does not conform with the gender role their respective society prescribes to them.

Gender Variant: Behaviour or gender expression that does not conform to dominant gender norms of male and female.

Transphobia: A range of negative attitudes and feelings towards transsexual or transgender people based on the expression of their internal gender identity.

Passing: A term often used to describe a transsexual or transgender person about in public and assumed to be of their acquired gender.

APPENDIX 3: FOCUS GROUP CHARTS

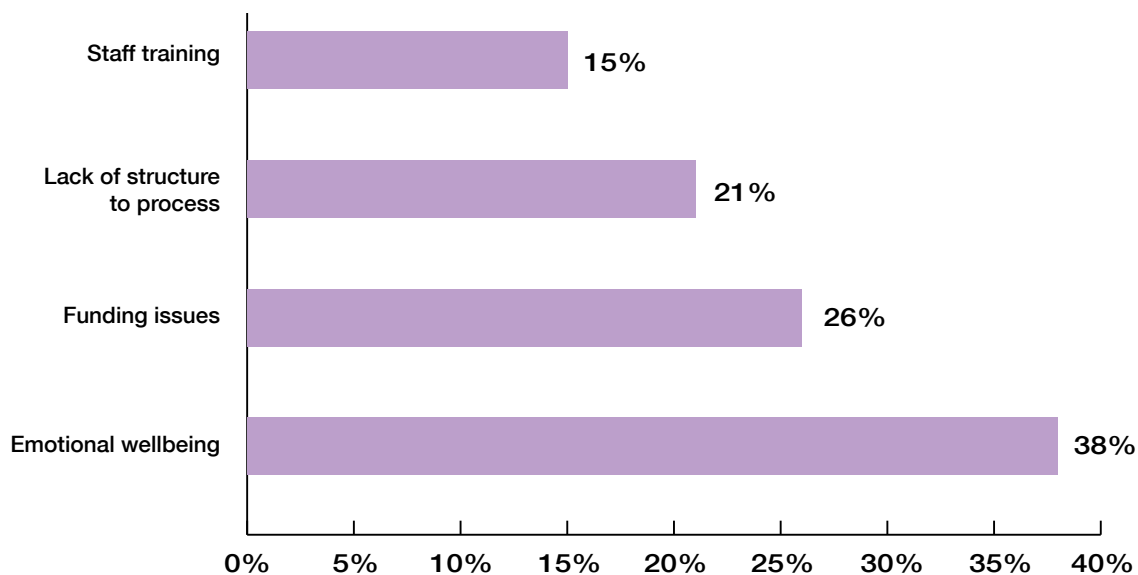
FOCUS GROUP ONE

T-Time Transgender Drop-In - LGBT Centre for Health and Wellbeing, Howe Street, Edinburgh.

Saturday 28.08.2010 - led by Carrie Buchanan.

There were 9 participants.

THE KEY ISSUES



STATEMENTS (this is a selection of statements made by participants)

STAFF TRAINING

"[NHS] needs to be more understanding and responsive to people with mental health needs – don't label everyone as the same, treat us as individuals."

"When you ask for help under mental health they assume it is because of being trans, which is not the case."

"Counselling was so important for me. Complicated parent / child relationship needed to be cleared away before I was certain what I needed."

LACK OF STRUCTURE

"No structure to treatment. No patient pathway."

"Prompt access to Speech Therapy / Hormones / Surgery."

FUNDING ISSUES

"Access to funding. Will NHS pay for what?"

"Surgery Options – funding options!"

"So little choice. Just one overworked specialist in Lothian."

"Travel getting to appointments is expensive."

EMOTIONAL WELLBEING

"Post transition support – abandonment."

"Mental health and physical change - service integration needed."

"Being Trans blamed on mental issues or vice versa".

"Isolation and rejection."

"Counselling Services?"

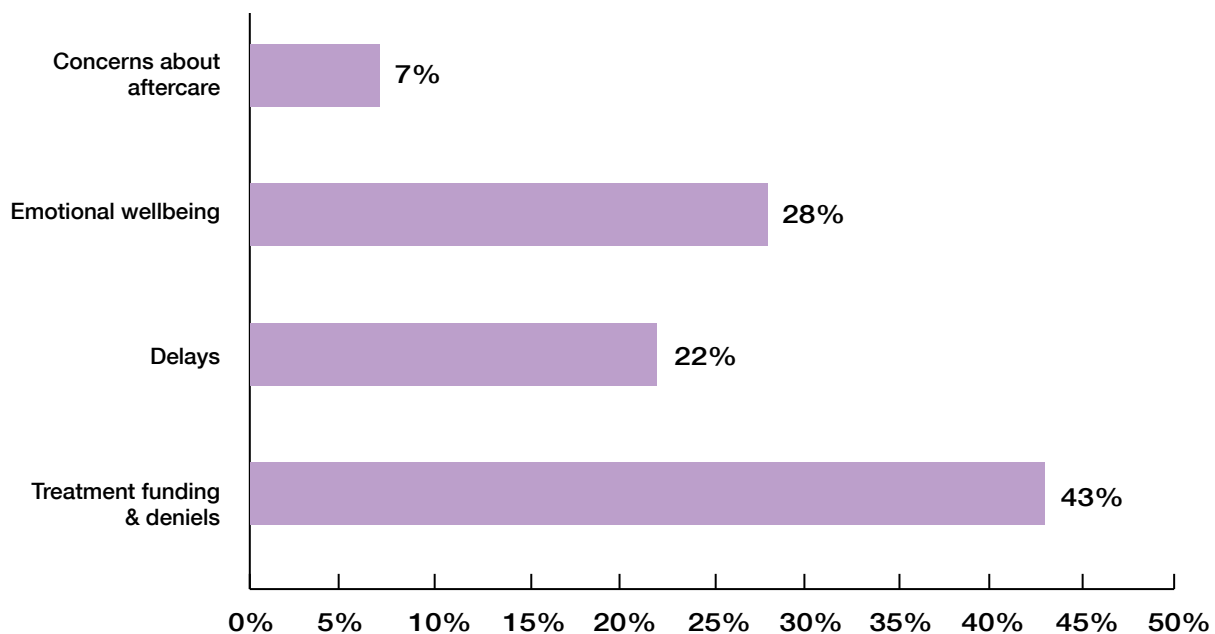
FOCUS GROUP TWO

Sandyford Trans Women Support Group - Sandyford Initiative, Sauchiehall Street, Glasgow.

Wednesday 01.09.2010 led by Lesley Stafford.

There were 11 Participants.

THE KEY ISSUES



STATEMENTS (this is a selection of statements made by participants)

AFTERCARE

"Want better post-op aftercare."

"Concerned about post transition aftercare – NHS staff unaware of special needs."

EMOTIONAL WELLBEING

"Need more trans aware counsellors."

"Counsellors needed."

"Lack of information for those apprehensive about own GP."

"Anxiety about referral for second psychiatrists opinion RE Breast Augmentation."

DELAYS

"Awaiting approval FHR [Facial Hair Removal]."

"Referral by GP too long."

"Delay in referral by GP."

TREATMENT FUNDING AND DENIALS

"Hair Removal body, face, genital area."

"Hair Removal delayed / denied."

"FFS, Speech Therapy, Hair Transplantation."

"Voice Therapy."

"Hair Transplantation."

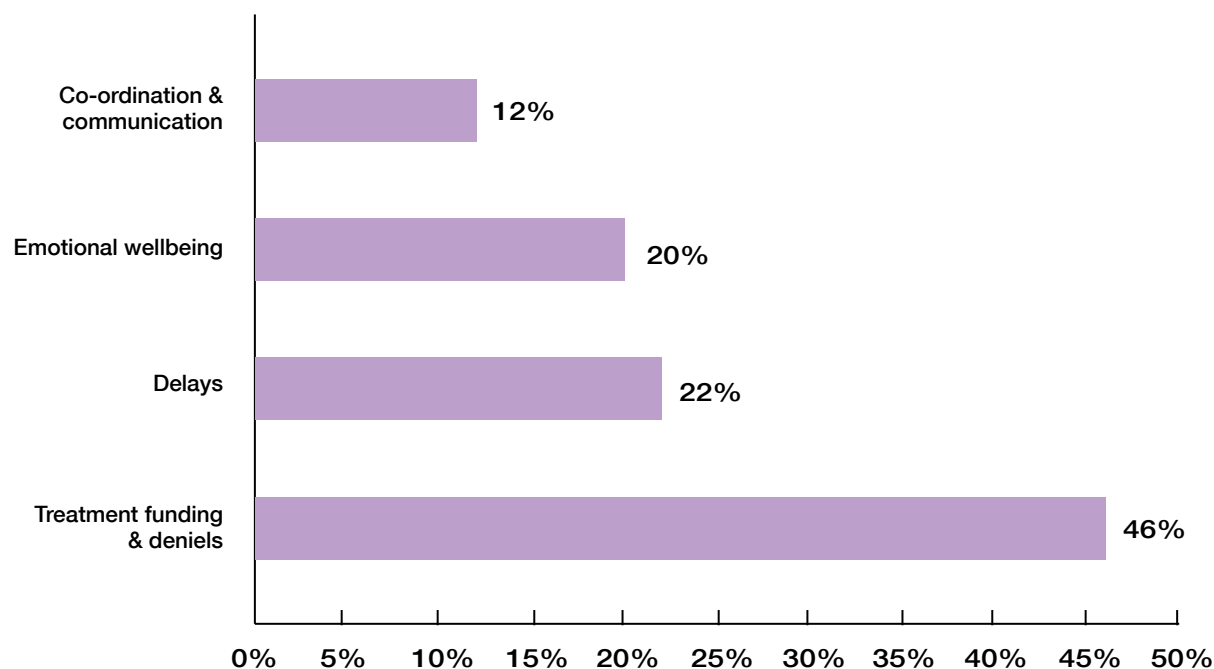
FOCUS GROUP THREE

Edinburgh Trans Women Support Group - LGBT Centre for Health and Wellbeing, Howe Street, Edinburgh.

Saturday 04.09.2010 led by Lesley Stafford.

There were 11 participants.

THE KEY ISSUES



STATEMENTS (this is a selection of statements made by participants)

CO-ORDINATION & COMMUNICATION

"No co-ordination / communication between gender specialist and other agencies ie. social work involved in family care."

"Living in one Health Board area and being treated in another for gender issues leading to confusion."

"Need better communication between health professionals."

"GP refuses to monitor self medicating patient."

"NHS staff need to have improved knowledge of trans health issues within Health Service."

EMOTIONAL WELLBEING

"Labelled gay not trans by NHS psychologist."

"Need more FT psychologists / counsellors."

"Specialist counsellors needed."

"Psychological help needed."

"Worried about post-op aftercare."

"Specialist is distant."

DELAYS

"Waited 18 months first appointment."

"Process too slow due to waiting times."

"Long delay in HRT treatment."

"Long wait for / between appointments with specialist."

"Need better waiting times."

"Improved waiting times needed."

"Waited so long."

"All took too long."

"Breast Augmentation - long delay post op."

TREATMENT FUNDING AND DENIALS

"Cost of self funded electrolysis."

"NHS should fund HR [Hair Removal] and Breast Augmentation."

"Financial hardship RE Electrolysis."

"Cost of self funded treatments."

"No funding for HR."

"No funding for HR Breast Augmentation, wigs."

"GRS slow after approval – NHS could fund private treatment if cheaper and appropriate."

"No help with simple everyday things ie. make-up, walking like a woman, deportment."

"No funding for FFS."

APPENDIX 4: REFERENCES

- [1] Morton, J. 2008, "Transgender experiences in Scotland." *Scottish Transgender Alliance*.
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- [6] Dostoyevsky, Fyodor Mikhaylovich, 1861, "The House of the Dead," *Vremya*.
- [7] Harry Benjamin International Gender Dysphoria Association, 2001, "Standards Of Care For Gender Identity Disorders, Sixth Version," *World Professional Association for Transgender Health*.
- [8] Lawrence, Anne A, 2003, "Archives of Sexual Behavior, 01.08.2003."

APPENDIX 5: BIOGRAPHIES

Katherine Burrows is an accountant by profession, and worked in the pharmaceutical industry for a major multinational company for over 23 years. Following the successful Management Buy-out and re-sale of a Group subsidiary, Katherine became Chief Executive of an English Cathedral, spending a further 13 years in that post before retiring in August 2010.

Katherine represents the trans community in various organisations, including the Police, NHS and Local Authorities.

Helen Ratcliffe is the founder and facilitator of Edinburgh Trans Women support group. The group was founded in 2008 and Helen provides support, social events and campaigns for trans women in Scotland. Helen is also a volunteer and steering group member for the Transition Support Service, Life Skills project. Professionally, Helen is a graduate from Hull University and registered as a Chartered Engineer. She works in microelectronics design for a new technology company.

Lesley Stafford After a career which embraced teaching and librarianship, Lesley opened her own book and record store. She now sells long playing classical records, music memorabilia and books on the Internet.

Other members of the group preferred not to submit a biography.



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