

# Gender Reassignment Protocol Development Community Engagement Report

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## Introduction

This report summarises the findings of 10 focus groups held by the Scottish Transgender Alliance across Scotland in May 2011. The 10 focus groups had a total of 56 participants.

The age range of the participants was from 18 to 64 inclusive with a mean average of 40.3, a median average of 42.5 and a mode average of 44.

The NHS Health Board areas in which the participants lived were: Ayrshire & Arran (1 participant), Borders (2 participants), Dumfries & Galloway (3 participants), Grampian (7 participants), Greater Glasgow & Clyde (6 participants), Highland (5 participants), Lanarkshire (2 participants), Lothian (27 participants) and Tayside (3 participants).

The participants self-described their gender reassignment status as follows: 8 stated they are considering undergoing gender reassignment, 24 stated they are currently undergoing gender reassignment, and 22 stated they have already undergone gender reassignment. 34 participants stated that their direction of gender reassignment was from Male-to-Female (MTF) and 19 stated their direction of gender reassignment was from Female-to-Male (FTM).

## Initial access to Gender Identity Clinics (GIC)

The majority of participants had been **referred to the GIC by their GP**, though many found that their GP had to research referrals as they had not worked with trans patients before; others found that they **had to do their own research** on GICs and “next steps” before their GP would make a referral. Others again had self-referred after contact with GPs, and in two cases, GPs had chased up self-referrals that had not resulted in an appointment within the time given as likely waiting time.

Most people reported that their GP was supportive and helpful, whether experienced in trans issues or not, though a minority had negative experiences with GPs and GP surgery staff.

Several people had **self referred** to the GIC they were attending and valued this opportunity, in particular because it meant that their gender status was not on their GP records until they felt ready for it to be there.

The vast majority **did not want a non-specialist psychology/psychiatry assessment** first prior to a gender specialist assessment at a GIC, though some felt that they “wouldn’t mind” if it was a quick process. One group agreed that the involvement of psychiatrists should be in “checking whether there is a mental illness”, and not in diagnosing GID.

Many groups did not reach a consensus on waiting times for initial appointments, but all emphasised the stress and difficulty of waiting, in some cases for well over a year from referral to initial appointment. Most people did not hear that their referral had been received until an appointment was available, and most received no information about interim support before the first appointment.

When consensus was reached, “**less than 6 months**” was the preferred option, and **clear information soon after the referral is received** about waiting times and where to find support in the meantime was also wanted. Some people suggested that GICs could provide an earlier appointment with a Community Psychiatric Nurse or an Occupational Therapist before the initial GIC doctor’s appointment.

Many people were also concerned for **support to be provided to family**, one specifically mentioning that partners and children should be included in the pathway. A couple of participants mentioned that GIC doctors seemed to assume that “families will have broken up by now”.

The group of younger people, in particular, were concerned about the **effects of moving home**, studying in one place and living in another, on access to services. In particular, those with a home address in England but resident in Scotland were concerned that they would not be able to access services in Scotland. This fear was supported by the experiences of those who had attended more than one gender clinic: in general, a clinic required contact with an individual for at least a year before a surgical referral would be made, and contact with another clinic was not accepted in place of this.

### **Experiences of initial appointment at GIC**

Some people found the experience “affirming” or “a relief”, while others were **disappointed only to have a brief appointment** of 15 or 20 minutes; appointment times seemed to differ between different GICs, with Sandyford offering shorter appointments on average.

The most frequently mentioned experiences of initial appointments were of being asked about **childhood gender experiences/ behaviour** and about **sexual orientation**. Participants’ reactions to these differed: while all those who mentioned it felt that sexual orientation was irrelevant, some felt “pressured” to

give the account they felt was expected of their childhood, while others said that reporting experiences congruent with their assigned gender was “fine”.

Some participants shared bad experiences with individual doctors, and one specified that they were not able to get appointments with a different doctor when they requested.

### **Assessment for hormones**

Experiences of access to hormones were extremely variable. A small minority had seen an endocrinologist, and their experiences were generally positive, with reports of knowledgeable practitioners and regular follow-up. Most participants, however, were not aware that seeing an endocrinologist was a possibility.

Waiting time between initial GIC appointment and hormone prescription was also very variable. Some reported being prescribed hormones at the first appointment, and some waited over a year; in some cases people had been living in their true gender for some months or years, but this did not always seem to correspond to quicker access to hormones. A few participants said that they had chosen their own time to start hormones, and appreciated not being “hurried”.

Several participants with unrelated medical conditions, including heart conditions and diabetes, spoke of very poor communications between professionals and lack of knowledge about possible treatment interactions.

Several participants reported having used non-prescribed hormones themselves and/or knowing of others who had, including buying them on the internet. Some were doing this before accessing the GIC, some in addition to prescribed hormones and some because access to hormones had been refused. Many agreed that “desperation” to get access to hormones does lead some people to this. Two women said that using non-prescribed hormones appeared to have allowed them a fast-track to hormone prescriptions.

Two participants mentioned that they or someone they knew had been denied progress towards GRS (MTF genital surgery) because they were medically unable to take hormones.

Many of the groups discussed the timing of hormone prescription with respect to the RLE. Many people, particularly people transitioning FTM, felt that attempting the **RLE without hormones can be dangerous**, as presenting successfully as male is very difficult without hormones. Some participants said that, before starting hormones, they did not have the confidence to start the RLE, including one who said “you feel like a freak”. All participants said that they **felt ready to start hormones at the beginning of their RLE** if not before.

All participants agreed that starting hormones was an individual process, and needed to happen at different times for different people. Many had needed to try different hormone regimes before finding the right one, but some people in each of the meetings had felt **they had little information** about options and alternatives. There were, among MTF participants, some strong views that animal-derived hormones were unsafe and inappropriate, with all who expressed a preference saying that they felt synthetic hormone treatment was better. However, some participants had never been offered synthetic hormones.

Interactions of timing between hormones and other aspects of transition featured strongly, relating to hair removal for MTF people and chest surgery for FTM people; these are discussed later in this report.

Finally, participants who had transitioned some time ago often mentioned that they had had **very little follow-up** on their continuing use of hormones, and there was some **concern about the lack of monitoring** on the risk of embolism and stroke among trans women taking oestrogen. Some were receiving regular tests from their GP, a few from an endocrinologist, and some not at all.

## **Other non-surgical services**

### **Hair removal**

For all MTF participants, access to **facial hair removal was regarded as absolutely crucial** to success and confidence in the RLE, and to safety during the RLE. Some stated it was the most important aspect of transition.

However, **physical and financial access to facial hair removal was very variable**. Some participants were funding all their own treatment, for up to several thousand pounds, others had been treated privately but the treatment invoiced to or reimbursed by the NHS, and a few had had treatment directly from the NHS. Conditions for funding treatment varied, with many accessing facial hair removal well before beginning hormones, but some encountering refusal of funding and treatment before their hormone level had been “female” for six months, a year or even 18 months. Some people had to travel significant distances to access hair removal on the NHS.

**Access to genital hair removal**, which is often necessary before MTF genital surgery to avoid complications, was equally variable, and some participants were very uncomfortable about accessing it from mainstream beauty salons even where NHS funding is available. In addition, even surgeons were reported as seeming unsure which areas hair needed to be removed from. The seriousness of the need was emphasised by one participant who spoke of needing a vaginectomy after ingrown hairs caused an infection. Further discussion related the difference in patients’ experiences in part to individual surgeons’ preferences and practices in surgery.

FTM participants spoke of a lack of clarity about whether genital hair removal was needed for FTM genital surgery, and if so what particular surgeries.

## **Counselling**

Many participants spoke of a **need for psychological support**, often termed specifically as “counselling”, for themselves and for family members. Some mentioned that the Sandyford provided some limited access to counselling, and others specifically that other Scottish GICs do not. Participants in general felt that there was very little support in going through the major life changes involved in gender transition, and that a 20-minute appointment with a doctor every few months was not enough to address the issues that arose, particularly during the RLE.

## **Fertility**

The majority of participants who mentioned fertility said that **preserving fertility had not been discussed** at any point in their transition; all participants agreed that the subject had not been raised with them and that it would be helpful if it had. However, two MTF women who raised the subject themselves said that they had got **positive responses**, and had got free access to sperm banking after some “pushing” on their own behalf. One participant said that “it’s important [for doctors] to mention that during this process you will be rendered infertile”.

## **Speech Therapy**

All the participants who had accessed speech therapy – all of whom were trans women – spoke **positively** about the experience. All but one had found it easy and quick to access, with experiences coming from those using all the different GICs in Scotland.

Several participants spoke of speech therapy sessions having **other benefits**, including psychological support and advice on other aspects of self-presentation, including “deportment” and “behaviour”. The impact of speech therapy on ability to present as female on the telephone was also mentioned by several people. One person said that, along with facial hair removal, it was one of the **two key points to safe self-presentation** in the RLE.

Other participants, mostly trans men, said that they felt speech therapy was not necessary, in one case because they were “not interested” in changing their mannerisms, and in several others because testosterone usually has enough of a deepening effect on the voice that further change isn’t felt necessary. However, one trans man thought speech therapy might be useful for trans men who chose not to use hormones.

## Binders

All of the trans men who participated spoke of the **importance of having binders which were effective and safe to use**. Several mentioned back and chest pain from using binders, and one of ending up with pneumonia because he was unable to clear his chest during a cold. Another mentioned meeting men who are using gaffer tape to bind their breasts and doing themselves damage. The **financial cost** of safe and effective binders was also mentioned several times. Several participants agreed that binders are something about which information is shared between trans men rather than given through other channels, and all who commented agreed that **NHS services need to get involved** in advice and provision.

## Breast prosthetics

One woman raised the question of **whether breast prostheses are available** from the NHS “while waiting for breasts to develop”.

## Packers

Several trans men raised the issue of **obtaining good genital prosthetics**, and that these were not available through the NHS. One said: “If decent prosthetics were available people might not want phalloplasty.”

## Wigs

Several trans women raised the issue of **provision of wigs** to those who experienced male pattern baldness. As with other issues, cost was relevant to participants, and a few raised parallels with patients undergoing chemotherapy, or other women who have hair loss, for whom it was felt that wigs were regarded as a necessary part of their treatment for a medical condition.

## Accessing “gendered” medical services

Many of the trans male participants spoke of **difficulties in continuing to access cervical screening**. One expressed it as “an IT problem”, in which the system could not call patients with male-coded CHI numbers for smear tests, or, in at least one case, process the test itself. This participant spoke of a nurse putting the test through in her own name as no other solution could be found. Another participant found that, after going for a smear test, the title on his medical records was changed from “Mr” to “Ms”. Some participants also spoke of an assumption that they would have a hysterectomy and that therefore the issue would not arise long-term. It was clear that, for some FTM people, the issue would be present long-term, and that **accessing cervical screening while living as male would be an issue for almost all** at some point.

## Surgical aspects of transition

There was general discussion of **access and attitude to relevant surgical options** in all the groups, with the issue of all surgeries being regarded as “cosmetic” being raised several times. Across all surgeries, there was a high degree of agreement on wanting to see **before and after pictures of surgeries**, in particular those carried out by the surgeon who was going to operate on the individual.

More FTM than MTF participants spoke about making **choices about which surgeries to have**, and the importance of services around transition providing information to aid in those decisions. One FTM participant said that policy makers and clinicians assumed that surgeries were a “logical progression”, and that this view needed to change. One MTF participant also mentioned an assumption by medical staff that everyone will want to have genital surgery. Participants agreed that care pathways both for accessing surgeries and appropriate care following surgery, and for accessing care if surgery is not pursued are necessary.

### FTM chest surgery

Chest surgery for trans men was discussed by all FTM participants, in relation to results, waiting times, interaction with RLE and with starting to take hormones. All FTM participants had either had chest surgery or were intending/ waiting to have it.

Several participants said that they had been **disappointed with the outcome of their chest surgery**. Three participants stated that they had wanted to have their nipples grafted as is usual for FTM chest surgery but the NHS surgeon they were referred to in Glasgow completely refused to attempt nipple grafts therefore leaving patients without any nipples. However, **others had been very happy** with their surgery from other surgeons, including one man who needed a revision of surgery, which he felt was done quickly and well. Several participants had accessed chest surgery privately, and these people were all happy with the process and results, having had a choice of surgeons and positive discussion about surgical options.

The trans men at the Glasgow consultation session spoke of **accessing their chest surgery through a “cancer clinic”**, which all felt was inappropriate and had led to some misunderstandings and, in at least one case, staff regarding trans patients as having less valid needs.

Three participants specifically expressed a **preference for having chest surgery before beginning hormones**, as the effects of testosterone can make binding more uncomfortable, with some men experiencing breast growth and

increased sensitivity when first taking testosterone. No participants expressed disagreement with this.

### **FTM hysterectomy**

Participants' **experiences of hysterectomy were variable**, with some describing aftercare as "excellent" and "fantastic" but several saying that information and aftercare focussed on women was inappropriate for them. Two participants said that there was "an assumption" that all trans men would have a hysterectomy. There was some lack of clarity for some participants about whether minimally invasive keyhole hysterectomy was available; many participants expressed a preference for keyhole surgery.

### **FTM genital surgery**

The most frequently mentioned surgery was phalloplasty, though **none of the mentions were wholly positive**, with several people speaking of restricted access to surgery, and of the limits of surgery. Aspects of the surgery "do not last long term" and one participant said: "You're tying yourself into a lifetime of surgery".

Many FTM participants spoke of receiving **no information about genital surgery**, and the primary source of information mentioned was personal stories from other trans men, in support groups or on the internet. One participant said that 20-minute appointments at the GIC could not be long enough to discuss the complexities of surgery options; another was disappointed that a private consultation with a surgeon lasted only 15 minutes.

### **MTF genital surgery**

Several participants said that they felt that it would be appropriate for people to be put on **waiting lists for funding and surgery** at the beginning of transition, rather than when readiness had already been assessed, and then waiting an additional year or more. Some felt it was important to have a timetable to work to as early in the process as possible.

Others wanted to make it clear that they felt a **funding barrier for necessary surgery was wholly unacceptable**, and that the waiting list should be for surgery, not funding.

There was, for many people, a **lack of clarity about what constituted the first and second opinions** required before referral for surgery, and what those opinions involved. One participant said that it seemed those opinions were purely about a diagnosis of Gender Identity Disorder rather than anything to do with the RLE and so did not understand why they could not take place earlier in the process; another was disappointed that a psychologist connected to the GIC was

not accepted as a second opinion. Several people reported that they had not been required to get a second opinion by the Charing Cross clinic. Contrastingly, some people had waited over a year for a second opinion in order to begin waiting for surgery, and others had begun waiting for surgery before a second opinion could be obtained, leading to anxiety about surgery being delayed. One woman had got her official second opinion while in her hospital bed awaiting surgery.

Participants all agreed that **individual needs around surgery** might mean that waiting times would vary, and that this was fine. However, they all wanted clarity on what factors would be taken into account, and clear explanations of their own circumstances.

### **MTF breast augmentation**

While not all MTF participants mentioned breast augmentation, about half did. Participants in Aberdeen had had **positive experiences of getting funding** from NHS Grampian. Participants in other groups had **very different experiences**, with some reporting failing to obtain funding, finding that funding was only available for one night in hospital when more might be needed, and one woman who arrived for a surgical appointment to find that the surgeon had left and his replacement would not do the surgery.

The Aberdeen group felt that breast augmentation should not be carried out until **after genital surgery**, as the amount of hormone-driven growth of breast tissue could not be determined until then. Participants across groups agreed that breast augmentation is not necessary or wanted by every trans women, but some felt there should be a standard way of assessing what was “enough” breast growth, while others felt the criterion should be the amount of distress caused to an individual.

### **MTF facial surgery**

The group held in Aberdeen and the MTF group in Glasgow were the only ones which discussed facial surgery. Some participants in each of these groups felt that **sometimes facial feminisation surgery is “essential”**. These participants felt that these surgeries are “not cosmetic” and that it is very difficult to get funding for them, in part because some of the surgeries which are covered by the term “facial feminisation” are also practiced purely as cosmetic surgery and therefore excluded from NHS funding by guidelines. Some participants had found funding for surgery in Aberdeen, while those in Glasgow had, for the most part, not succeeded in obtaining funding. Participants in Glasgow questioned why the Canniesburn plastic surgery unit **“wouldn’t touch a transsexual”**. Several participants said that they, or someone they knew, had travelled abroad for facial surgery.

## **Support while awaiting surgery**

Many participants felt that waiting for surgery was **one of the most debilitating aspects of the process**. As previously mentioned, many felt that there was little **psychological support** during the process of transition, particularly for those attending GICs other than the Sandyford, and that this would be helpful. Others emphasised again that the **effect of lack of clarity** about waiting times and the steps required was a major factor in the negative mental health effects of waiting for surgery, and that a clear individualised timetable would help. Given that people experienced such different waiting times, some participants felt that they could not express relief or pleasure about their own progress at support groups where others may have waited longer.

## **Summary**

While the views of participants varied widely, there were some themes in responses that relate to transition as a whole. The **lack of a support structure** within the NHS for the psychological needs of those going through transition was clearly noted by all groups. The **differences in participants' experiences and the frustration engendered by this** were another theme, clearly supporting the need for a patient pathway. Alongside this, participants clearly recognised that people's circumstances and choices meant that **transition needed to be an individualised process**, with no obvious "order" for stages to be reached in either MTF or FTM transition, or universally applicable periods of time for those stages. The most commonly agreed timing was that people should wait **less than 6 months from referral** to initial consultation at a GIC.

Participants in these focus groups also agreed that **information provision was patchy** and needed to be improved, with information while awaiting initial GIC appointment and information about hormone and surgical options highlighted as the key areas.

Other key areas highlighted were **psychological support** for those going through gender transition and their families, and **financial support** for specific items such as binders, packers and breast prostheses.

**Research needs** were also highlighted, in areas including issues for trans people with unrelated medical conditions, long term outcomes for trans people using hormones, and post-surgical outcomes. Participants felt that there was little medical interest in what became of trans people once transition was "finished".

Overall, participants in these focus groups **strongly supported a clear care pathway** for gender transition, which also recognised individual needs and circumstances.