The Audit, Information & Analysis Unit

Survey of Patient Satisfaction with Transgender Services

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Glossary and Abbreviations

FtM (trans man)	Someone who is transitioning from living as a woman to living as a man.
GIRES	Gender Identity Research and Education Society. A group committed to improving the way in which trans people live by changing the way in which society treats them. They do this through developing good practice guidelines, education programmes and literature which are especially tailored to groups such as politicians and other policy makers, clinicians and other healthcare providers, the police, teachers, employers and journalists.
GnRH analogue	Gonadotrophin releasing hormones. In this context these drugs are used largely in adolescents or young people to suppress gonadal sex hormone production by the inhibition of pituitary gonadotrophin secretion and so block pubertal development.
GRS	Gender reassignment surgery (gender confirmation surgery)
HBIGDA	Harry Benjamin International Gender Dysphoria Association now known as WPATH.
Hormone therapy	A treatment in which birth sex characteristics are suppressed and corrected sex characteristics are encouraged through the introduction of hormones. For trans women this is oestrogen therapy and suppression of androgen secretion and action. For trans men this is androgen therapy.
LGBT	Lesbian, Gay, Bisexual and Transgender
MtF (trans woman)	Someone who is transitioning from living as a man to living as a woman.
SOGIAG	Sexual Orientation and Gender Identity Advisory Group. A sub group of the Equality and Human Rights Group at the Department of Health.
Transgender	In the UK transgender is used to describe those people who live all or part of their lives in their corrected gender role and may use hormonal treatments to further this and who may or may not seek to undergo gender reassignment surgeries. It is also used as an umbrella term in many parts of Europe and the USA.
Transsexual	A transsexual person is someone who seeks gender reassignment treatments including reconstructive surgery.
Trans	Primarily a UK term, trans may be used like 'transgender' as an umbrella term embracing a diverse community of people ranging from part time cross dressers to transsexual people who undergo gender confirmation treatments.
WPATH	World Professional Association for Transgender Health. An interdisciplinary, professional organisation working to further the understanding and treatment of gender identity disorders.

Definitions taken from:
Briefing 11: Trans people's health. Department of Health, 2007[1].
Good Practice Guidelines for the Assessment and Treatment of Gender Dysphoria. RCPsych, 2006 Draft[2].

1. Executive Summary

1.1 Introduction

As lead sector for gender reassignment services, North West London Local Specialised Commissioning Group held a seminar for commissioners in April 2006. From this it became evident that there was considerable unhappiness with some services provided by the NHS. In order to find out more it was felt that a patient satisfaction survey would provide useful information for commissioners. This study was developed and aimed to reach patients and service users all over the UK.

Transgender services are highly complex and the 'standard' NHS care pathway is in reality very rare. There appears to be a perception that NHS gender identity clinics (GIC) are inflexible, not based in reality and most importantly not patient focused. For this reason many patients take the private route to varying degrees from visiting private psychiatrists for hormone therapy prescriptions to attending private GICs and travelling outside of the UK for surgery.

In 2005 the Sexual Orientation and Gender Identity Advisory Group (SOGIAG) was established by the Department of Health under the Equality and Human Rights Group (EHRG). SOGIAG is working to develop and deliver a new strategy to promote equality and eliminate discrimination for Lesbian, Gay, Bisexual and Transgender (LGBT) people in health and social care. In order to do this SOGIAG agreed four work streams: better employment; inclusive services; Transgender and reducing health inequalities. Through these work streams SOGIAG gives an opportunity to LGBT people who both use and deliver health and social care services to use their experiences to inform service development.

The UK pathways are loosely based on the 'Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders'[3] (HBIGDA) which were developed in the USA in the 1970s and have been revised five times since then under the HBIGDA and under its new name of the World Professional Association for Transgender Health (WPATH) but there is no current guidance for treatment pathways for England or the UK. The Royal College of Psychiatrists is drafting guidelines[2], the consultation for which ended in February 2007. This guidance is expected to be published in summer 2008.

It is hoped that the findings of this study will aid in the development of enlightened, equitable and easy to access services.

1.2 Aim

The study aims to capture the patient experience of transgender services to assess positive and negative aspects and to inform future development of the service.

1.3 Potential Outputs

- Development of standards for treatment of transsexual people.
- Development of appropriate patient centred and flexible care pathways across all care providers.
- Development of an ongoing programme of audit/Patient Satisfaction Survey at each provider.

1.4 Method

The lead commissioner along with patient representatives scoped the survey and developed the questionnaires with the support of the AIAU. Members of SOGIAG were asked to comment on these. A small pilot was run in February 2007.

Three questionnaires were developed to be completed prospectively: the main questionnaire which was to be completed by all participants and two gender specific questionnaires. The questionnaires were designed to provide both qualitative and quantitative data (for proformas please see **Appendix B**).

As a previous study in this area had utilised a web based survey with great success it was decided to try this method as well as using traditional paper questionnaires. The online site was set up with costs being covered by a grant from the Gender Identity Research and Education Society (GIRES).

The survey was launched on 2nd July 2007 with publicity from SOGIAG and links from other sites such as Press for Change and the Gender Trust. Paper questionnaires were distributed by the FtM Network and the Gender Trust along with prepaid return envelopes and an information poster. Copies of the questionnaires along with prepaid envelopes were sent to the GICs.

1.5 Participation

The survey was open to all trans people no matter what stage of transition/treatment they were at and whether they were using or had used NHS or private treatment. Responses from outside the UK were accepted as the study wanted to identify what factors made up a good or bad total experience and it is likely that many lessons can be learned from other countries.

1.6 Timescale

Proforma development took place during spring 2007. The survey ran for six months from 2nd July until 31st December 2007 when the online site was closed. The deadline for paper copies was extended for two weeks to give every possible chance for their return.

1.7 Results

- A total of 647 responses were submitted over the six month survey period – 539 online and 108 on paper.
- The ratio of MtF:FtM was 4:1 which reflects results found in other studies.
- The age range of the population was 14 – 82 years with a median and mean age of 44 years. However there were differences between the MtF population where the average age was 46 and the FtM population where the average age was lower at 36.
- In total 98% of those who had surgery felt it was a positive or mainly positive experience and were happy with their outcomes.
- The largest proportion of respondents (26%) obtained a referral to a GIC through a psychiatrist in line with current commissioning practice in England. Other ways were self referral (15%) or through a GP (19%).
- Over half of the study population (50.5%) had attended a GIC or were waiting for a referral or their first appointment.
- The mean waiting time from specialist referral to first appointment at a GIC was 30 weeks and the median was 22 weeks. The range was same day to over six years. When looking only at those who attended a NHS GIC however the mean waiting time was 34 weeks and the median was 26 weeks.
- Just under half (49%) had any kind of health check and only 12% saw an endocrinologist before commencing hormone therapy.

- Almost two thirds of respondents (62%) felt that their GP addressed their needs appropriately but less than a fifth (19%) said their GP was knowledgeable about treatments and only 12% said their GP was able to explain to them what treatments were available.
- Over a third (36%) of those who attended a NHS GIC had to sign a formal patient agreement before they could commence treatment compared to only 20% of those who attended a private clinic.
- 20% of respondents who attended a NHS GIC felt that they had to keep aspects of their personal behaviour or lifestyle a secret compared to 10% of respondents who had private treatment.
- 39.5% of respondents were either totally happy with the care received at the GIC or felt it had more good than bad aspects. 16% of respondents felt negatively or very negatively about the care they received at the GIC.
- 35% felt that the care provided at their GP surgery could be improved and just under half (49%) felt that treatment for trans people at GICs could and should be improved.

1.8 Discussion

The complexity of the questionnaire means that, particularly with the online responses, there are some large gaps in the data. Although it is understood that the questionnaires were long and could be time consuming to complete it is unfortunate that a more comprehensive dataset could not be collected. Part of the learning experience of this survey has been that the availability of real time validation tools could have helped ensure better completeness.

The paper copies tended to be more complete than the online submissions with only 6% of the paper questionnaires lacking detail compared to 26% of the online submissions which gave little more than basic demographic information.

The age distribution data in the survey needs to be interpreted cautiously, particularly the trans man data. Among the explanations that have been discussed are: the small population size which may be more influenced by outliers; differences in psychosocial factors for trans man population; the historic backlog of cases and long waiting times for surgery.

1.8.1 Primary Care

The survey has raised multiple questions around the roles and responsibilities of primary care practitioners, not only for transgender patients but across the whole spectrum of gender variance, e.g. support for transvestites, as well as support for partners and families.

The study has shown that a large proportion of the transgender population has a historic mistrust of NHS services including a lack of belief in the ability of GPs to provide appropriate care. This has lead to movement back and forth between the NHS and the private sector which is not seen in any other service. Throughout the trans person's care pathway there is a need for holistic support, counselling and follow up care, for example, long term health needs such as screening, which the GP is ideally placed to provide. Indeed, GP behaviour is a crucial factor in the quality of the patient experience. It may not be well known among GPs that many relevant service and information tools are available for primary healthcare professionals to access both online and in printed form[4]. These tools are designed to help fill in the gaps in knowledge that many GPs are reported to have. These tools can also help GPs with managing the disappointment that many respondents related about the results of hormone and surgical treatment. Although support groups and peer networks exist some trans people may not be able to access them and GPs often remain authority figures with important influence on long term well being.

Although currently GPs tend to refer patients to a local psychiatrist in the first instance, new guidelines from the Department of Health, 'Guidance for GPs, other Clinicians and Health Professionals on the Care of Gender Variant People'[5] appear to be moving away from this process: the guidance highlights the central role the GP can play in determining, with a patient, the

most appropriate treatment pathway, initiating and continuing treatment if they feel competent to do so. This may mean arranging whatever multidisciplinary support is needed locally or referral to a specialist GIC. At present many GPs may not feel that they have appropriate and adequate knowledge and experience to accept this pivotal role but more widespread use of new tools and guidance, better awareness of trans issues and the anticipated increase in numbers of trans people presenting at their GP may lead to a fundamental change in the way these patients' care is managed.

1.8.2 Numbers and Outcomes

Although the study has not been able to derive per annum figures for surgery and/or treatment part of the background work has raised questions about follow up: estimated figures suggest 8-900 new cases are being seen each year by Charing Cross (approximately 500) and the major private clinic; there is a steady average rate of around 25 gender recognition applications per month (300pa); official statistics show only 101 NHS surgical procedures were carried out in 2005/6 (the last year for which data have been offered so far). It is likely that there are several possible interpretations of these data but they suggest that private surgical procedures probably outnumber NHS ones by 2:1 and that only a minority of people referred for assessment each year end their treatment in gender reassignment surgery (for more information see **Appendix A**).

As well as the steady rate of applications for the gender recognition certificate, it should be emphasised that the majority of respondents to this survey were happy with their outcomes (see **section 4.8.1**). This positive result, while welcome, should not overshadow the need for further work and improvements.

1.8.3 NHS/Private Interface

As mentioned above, this patient population is unusual in its practice of moving between NHS and private care throughout their care pathway. This leads to various considerations such as patients accessing private treatment abroad and then entering the NHS for follow up care e.g. for surgical complications. NHS GICs also must cope with the effects of self medication of hormones.

There is no discernable pattern of movement in this patient population between NHS and private services. It was clear that people moved between the two depending on constraints of time and finances and often followed a path other than that which they had originally intended.

1.8.4 Hormone Treatment

In general the study population were unhappy with the length of time they had to wait to be prescribed hormones leading to a small proportion of them (5%) self medicating at some stage. Although it is understood that there are many factors which may lead some to feel they have no other choice, this is recognised as a potentially dangerous practice for many reasons including: the unknown quality of the drugs; lack of consideration of side effects; lack of consideration of pre-existing health concerns or familial history. Anecdotal evidence suggests that following an ad hoc hormone regime can lead to poor outcomes in terms of physiological changes with the resulting need for further surgery: for example there is an anecdotal view that an inappropriate dosage of oestrogen may prematurely stop breast tissue development so that breast augmentation may be required. Just over a quarter (26%, n=167) of the total study population and almost half (46%) of the NHS population were unhappy with the time taken to be prescribed hormones although it was generally in line with current guidance.

There is an issue in that some GPs refuse to prescribe hormones when asked to by the GIC. As part of the ongoing holistic care of a trans person it is important that GPs are involved with the hormone regime as they are able to provide more local and personalised care.

1.8.5 Length of Time to First Appointment - 18 Week Wait

As mentioned in **section 4.2.3**, although the 18 week wait was not in force during the time of the survey, it is likely that the length of time to first GIC appointment will be measured from the GP referral. Currently, the GP will initially refer the patient to the local psychiatric service. A further referral is then needed from the local service to the GIC. It is clear that delays may arise in this two step referral process. As previously mentioned this process may begin to change but it is likely to take time and clarification is required in the short term. The role of the local psychiatric services may need to be clarified where there are co-existing mental health problems that may influence both the onward referral and patient pathway.

1.8.6 Discrimination

As was shown in **section 4.7.2**, trans people experience serious problems with discrimination: this is seen both in employment which contravenes the Sex Discrimination Act 1975 (Sex Discrimination (Gender Reassignment) Regulation 1999) and in health care. A recent amendment to the Sex Discrimination Act, the Sex Discrimination (Amendment of Legislation) Regulations 2008, has come into force which now extends the prohibition of discrimination on the grounds of gender reassignment to the provision of goods facilities and services including health care.

1.8.7 Service Improvements

It is clear that serious problems existed with NHS transgender services in the past which was a key reason for commissioning this survey. Equally, however, there is now evidence that steps have been taken to shorten waiting times and improve staffing levels in NHS GICs and that is supported by comments that have come out of this survey.

> "Recent experience of the Charing Cross clinic through friends who have had their ops in the last 8 months suggests that treatment (including post-op) for their NHS patients is now much improved and more user-friendly than before."

As mentioned before, it is important that this work continues and that development is monitored through ongoing audit programmes and patient and public involvement. Given that this survey and other recent studies have identified examples of a postcode lottery and discrimination in accessing healthcare it would appear that a national review of this service would be beneficial. This multidisciplinary review could encompass the development of a best practice model for commissioning which enables flexible, patient-centred, individual needs based care pathways incorporating local and specialised providers. It could also consider developing guidance on minimum standards of practice and behaviour for those providers. This may include the development of key performance indictors to increase transparency and accountability.

On a more general note, given the lack of knowledge evident in many areas of the NHS and cases of discrimination found, it may be that a more fundamental change is required with trans awareness being incorporated into general medical training for all doctors. This may raise awareness of not only the issues faced by this patient population but also the tools and resources available to health professionals. The Valuing Diversity Resource Guides[6] commissioned by the General Medical Council (GMC) address many issues around diversity and equal opportunities and it would seem a logical extension to cover trans issues in the same way.

1.9 Conclusions

The survey has provided important baseline data including the fact that, despite their journey, 98% of respondents were happy with their outcomes. This tallies with the recent pan-Europe survey 'Transgender Euro Study: Legal Survey and Focus on the Transgender Experience of Health Care'[7] which was carried out across 27 countries, in 14 languages and had over 2,500 responses.

The results of this study have not bought up any new areas of concern. On the contrary they have confirmed anecdotal accounts and therefore it is useful to have performed this survey. The results will enable commissioners and healthcare service providers to work on the areas of concern that have been identified and monitor future performance in a more focused manner.

The study has highlighted the importance of primary care practitioners providing more holistic care from initial contact, which is often a significant moment in the decision to transition and can impact on the entire treatment pathway, referral to tertiary services, prescription of hormone therapy and long term health monitoring. It is clear that often a lack of knowledge has inhibited this process and damaged perceptions of the service so the importance of better education for general practice surgeries and the use of available tools and information cannot be overstated.

The NHS must provide a service that is easy to access so that vulnerable patients do not feel forced to turn to DIY remedies such as buying drugs online with all the risks that entails. Patients must be able to access professional help and advice so that they can make informed decisions about their care, whether they wish to take the NHS or private route without putting their health and indeed their lives in danger.

This survey would not have been possible without a grant from SOGIAG which enabled the survey to be rolled out nationwide and a donation from GIRES to develop the online facility.

1.10 Recommendations

1.10.1 Primary Care

1. The Royal College of General Practitioners (RCGP) must work to raise awareness amongst its members of all aspects of gender variance through education and training for GPs and make use of all available facilities such as online tools.

2. It is understood that most GPs will see only a few cases of gender variance but they must aim to provide a full spectrum of care that allows open and frank discussion whatever the nature of the variance without fear of prejudice. This includes familiarisation for all primary care staff not just clinicians.

3. GPs should provide holistic care for transgender patients which includes: support for other family members; counselling and expectation management; long term health needs such as screening and hormone therapy prescription and monitoring.

1.10.2 Capturing Patient Numbers and Experience

4. More work needs to be done to validate the numbers of people coming through the service as this was not captured in this survey.

5. As this survey has captured so much data direction should be given by EHRG as to where to focus future audit work.

6. GICs currently carry out local audit as part of clinical governance arrangements but clinicians and commissioners need to work to widen the scope of this activity to encourage multi-centre audit, patient satisfaction surveys and PPI. This may also encompass the development of and measurement against key performance indicators.

1.10.3 Discrimination

7. Despite the work done by many parties including SOGIAG, the EHRG, patient and support groups and individuals it is clear that transphobic and discriminatory behaviour occurs. The Department of Health must work across all levels of the NHS and with Government to implement training of employers in the appropriate legislation.

8. To further this aim the GMC should work with other agencies such as the Postgraduate Medical Education Training Board (PMETB) and the RCGP to define minimum standards of best practice and eventually incorporate trans awareness into general medical training for all doctors.

1.10.4 Commissioning

9. A national level review should be initiated to develop appropriate best practice for commissioning of trans gender services to remove the postcode lottery that appears to exist for service users. This commissioning framework should be capable of procuring a diverse range of services (national and local, NHS and private sector as appropriate) to provide a flexible, patient centred, multi-disciplinary, individual needs based approach to care.

10. Specialised commissioners should work together with PCTs to eliminate the current postcode lottery in funding and create clear and equitable criteria for funding. They should investigate all avenues including, where appropriate, funding care through private clinics to reduce waiting times.

11. Specialised commissioners should continue to review and implement as appropriate how the 18 week referral to treatment target is applied for patients going through the gender confirmation process. If practicable a national definition should be developed with a clear definition of how the 18 week target applies to this service.

1.11 Action Plan

		Priority		
		High	Med	Low
1.	The survey report will be on the Department of Health EHRG web page and will be summarised in the Equality and Human Rights Bulletin. **Equality and Human Rights Group, AIAU**	✓		
2.	EHRG to link with the RCGP regarding development and distribution of education and training materials and tools. **Equality and Human Rights Group, RCGP**		✓	
3.	GICs to develop an ongoing programme of audit and Patient Satisfaction Survey. **GICs, Specialised Commissioners**	✓		
4.	The GMC to work with other agencies to develop minimum standards for best practice and eventually embed trans awareness in general medical training. **GMC, RCGP, PMETB**		✓	
5.	AIAU re-audit to be informed by EHRG. **Equality and Human Rights Group, Specialised Commissioners, AIAU**		✓	

2. Introduction and Background

As lead sector for gender reassignment services, North West London Local Specialised Commissioning Group held a seminar for commissioners in April 2006. From this it became evident that there was considerable unhappiness with some services provided by the NHS. In order to find out more it was felt that a patient satisfaction survey would provide useful information for commissioners. This study was developed and aimed to reach patients and service users all over the UK.

Transgender services are highly complex and the 'standard' NHS care pathway is in reality very rare. There appears to be a perception that NHS gender identity clinics (GIC) are inflexible, not based in reality and most importantly not patient focused. For this reason many patients take the private route to varying degrees from visiting private psychiatrists for hormone therapy prescriptions to attending private GICs and travelling outside of the UK for surgery.

Estimates of prevalence of transsexualism in the UK population vary: a recent GIRES paper[8] estimates the figure may be as high as 1 in 4000 within the general population whereas other studies have shown 1:12,225 in Scotland (Wilson et al., 1999[9]) and 1:21,186 in the Netherlands (Van Kesteren et al., 1996[10]). There have been relatively few studies in this area and it is easy to imagine that the numbers seen in any potential study could be influenced by the wishes of some members of the trans community to live in stealth. For more information on this please see **Appendix A**.

In 2005 the Sexual Orientation and Gender Identity Advisory Group (SOGIAG) was established by the Department of Health under the Equality and Human Rights Group. SOGIAG is working to develop and deliver a new strategy to promote equality and eliminate discrimination for Lesbian, Gay, Bisexual and Transgender (LGBT) people in health and social care. In order to do this SOGIAG agreed four work streams: better employment; inclusive services; Transgender and reducing health inequalities. Through these work streams SOGIAG gives an opportunity to LGBT people who both use and deliver health and social care services to use their experiences to inform service development.

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2.1 Aim

The study aims to capture the patient experience of transgender services to assess positive and negative aspects and to inform future development of the service.

2.2 Potential Outputs

- Development of standards for treatment of transsexual people.
- Development of appropriate patient centred and flexible care pathways across all care providers.
- Development of an ongoing programme of audit/Patient Satisfaction Survey at each provider.

2.3 Standards

There are no current UK guidelines or standards but the WPATH Standards are loosely followed and the Royal College of Psychiatrists has draft guidelines due for publication this summer.

- The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders, sixth version. February 2001[3].
- Good Practice Guidelines for the Assessment and Treatment of Gender Dysphoria. RCPsych 2006 Draft[2]

3. Methodology

The lead commissioner along with patient representatives scoped the survey and developed the questionnaires with the support of the AIAU. Members of SOGIAG were asked to comment on these. A small pilot was run in February 2007.

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3.1 Participation

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3.2 Timescale

Proforma development took place during spring 2007. The survey ran for six months from 2nd July until 31st December 2007 when the online site was closed. The deadline for paper copies was extended for two weeks to give every possible chance for their return.

4. Results

The online response was immediate with almost 200 submissions in the first 24 hours although this did drop off as expected.

At the end of the data collection period almost 600 responses had been submitted online and 108 paper copies received. The data were checked for uniqueness and validity using identifiers such as date of birth, gender and postcode as well as other information provided. This identified 36 instances of duplication. Another 4 responses were removed due to lack of information. This meant that 539 partial or complete online submissions and 108 paper copies were received giving a total of 647 responses over the six months. This makes this study one of the largest pieces of work of its kind carried out within the trans community.

The majority of respondents already thought of themselves as trans before they sought professional help to transition and a similar number already had a clear idea of the treatment they wanted.

Table 1 - How respondents identified themselves before starting treatment

	Yes (%)	No (%)	Not recorded (%)
Thought of self as trans	399 (62)	62 (9)	186 (29)
Knew treatment wanted	377 (58)	84 (13)	186 (29)

Of those who were unsure, many expressed feelings of emotional conflict, confusion or turmoil, depression and suicidal feelings. For most the priority was to get counselling or talk to a professional to get clarity on their condition before moving forward. Some had no idea that treatment was even possible and others wanted to shape their treatment and not get pushed down a 'standard' treatment pathway.

4.1 Demographics

The ratio of trans women:trans men was 4:1 which reflects proportions of service activity and expected incidence. Various studies carried out in western nations have had slightly different results but a ration of 4:1 or 3:1 is not uncommon (Weitze and Osburg 1998[11]; Whittle et al. 2007[12]; Pauly 1968[13]).

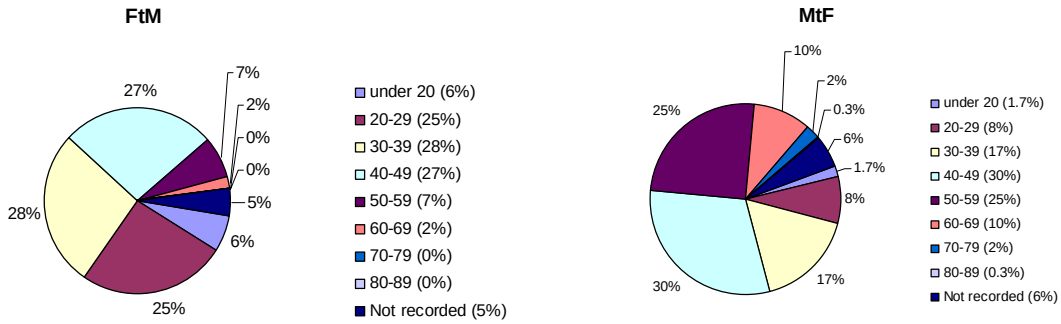
The age range of those completing the questionnaires was 14 – 82 years with a median and mean age of 44 years indicating a normal distribution with no outliers.

There appeared to be some differences between the trans woman and trans man populations: the average age (mean and median) of the trans woman group was 46. This is close to the averages for the whole survey population which is to be expected as they make up such a large proportion of the whole group. The mean and median for the trans man population however was much lower at 36 years of age. It is not known why this is but it is possible that the smaller numbers of trans men could be causing the data to be skewed or there could be societal differences which mean trans men are more certain of their gender identity and less hesitant about seeking treatment.

Table 2 - Average age and age range of survey population

	Lower quartile	Median	Upper quartile	Mean	Range
Trans men	28	36	44	36	16 – 63
Trans women	39	46	55	46	14 – 82
Whole survey pop.	36	44	53	44	14 - 82

Figure 1 - Breakdown of age of survey population



The age profile of the study population reflect that of the general population in that they are normally distributed however the relatively small size of the study population means that there is some variation.

Table 3 – Comparison of age of survey population to general population (%)

Age (years)	Survey population	General population*
Under 20	2.6	8
20 – 29	11	13
30 – 39	19	14
40 – 49	30	15
50 – 59	21	13
60 – 69	9	10
70 – 79	1.7	7
80 and over	0.2	4

* Figures based on United Kingdom mid 2006 population estimates.

4.1.1 Ethnic Origin

84% of the survey population were of white British origin and 7% were of another white origin. Only 4% (n=27) of the study population were of an ethnic origin other than white although another 5% (n=30) did not have their ethnic origin recorded. This does quite closely reflect the general population where 92.1% are of white origin and 7.9% belong to other ethnic groups. When looking at the study population however it must be noted that the very small numbers are likely to skew the results.

Figure 2 - Breakdown of ethnic origin of survey population (numbers of patients)

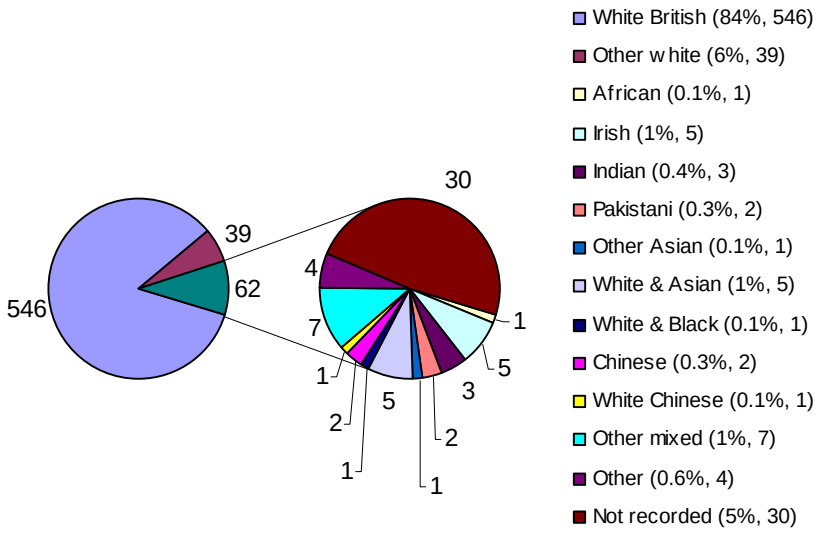


Table 4 - Comparison of ethnicity of survey population to general population

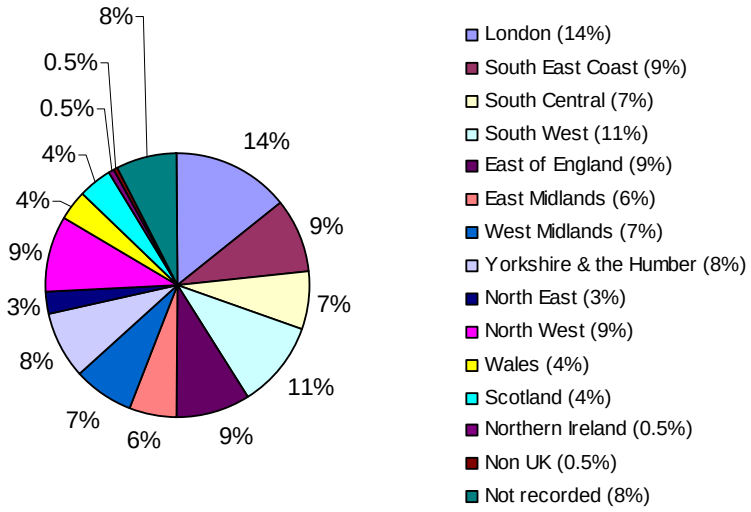
	Survey population	General population*
White British	84	85.7
White Irish	1	4
Other white	6	2.4
Total white	**91**	**92.1**
Indian	0.4	1.8
Pakistani	0.3	1.3
Other Asian	0.1	0.4
White & Asian	1	0.3
White & Black	0.1	0.5
Chinese	0.3	0.4
White & Chinese	0.1	
Other mixed	1	0.2
Other	0.6	0.4
Total non white	**9**	**7.9**

* Figures based on UK population: by ethnic group, 2001.

4.1.2 Geographic Spread

Although the largest single group of respondents was from London, responses were received from all ten Strategic Health Authorities in England as well as Wales, Scotland and Northern Ireland. Three responses were also received from outside of the UK: from Holland, Jersey and the USA.

Figure 3 - Breakdown of Strategic Health Authorities

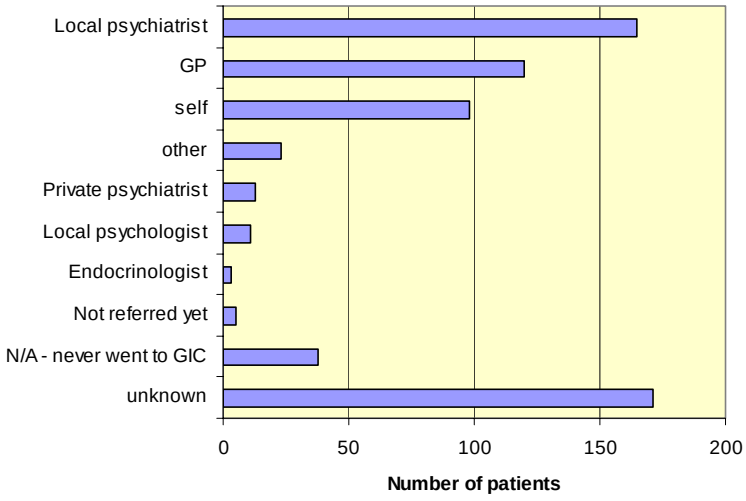


4.2 Referral, Assessment and Starting Treatment

4.2.1 Originator of Referral to GIC

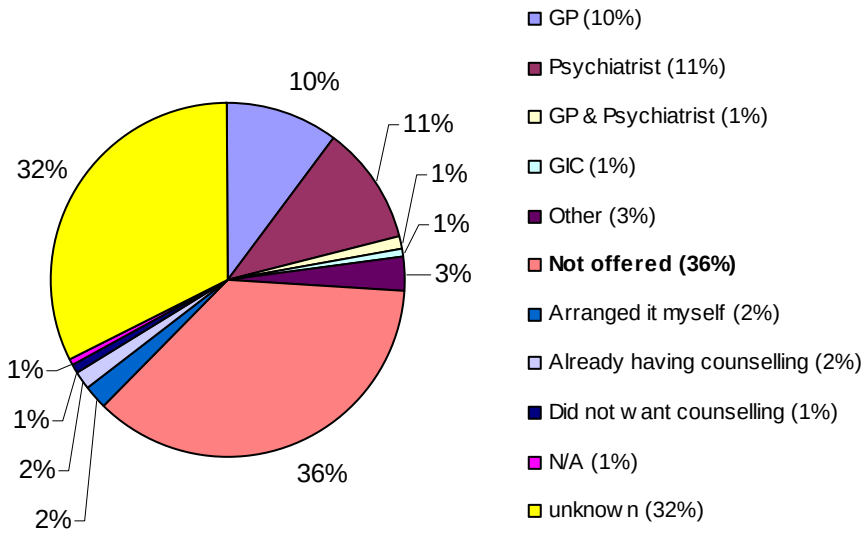
The most common way for a patient to obtain a referral to a GIC was through a psychiatrist (26%, n=165) which is in line with the WPATH Standards[3] and accepted commissioning practice in England. A number were self referrals (15%, n=98) which would be largely private although GICs in Scotland do allow patients to self refer. Almost a fifth of referrals (19%, n=120) were from a GP which is slightly surprising as many GICs do not accept direct GP referrals. As a tertiary service commissioners and some clinics prefer patients to first go to a psychiatrist, for both clinical and financial reasons. Anecdotal evidence suggests that some GICs also feel that patients who are seen by a psychiatrist before referral are better triaged as they can eliminate unrelated mental health conditions.

Figure 4 - Originator of referral to a GIC



Over a third of patients (36%, n=234) were not offered any counselling when they sought help to transition. 22% (n=143) were offered counselling by their GP or psychiatrist.

Figure 5 - Sources of offers of counselling

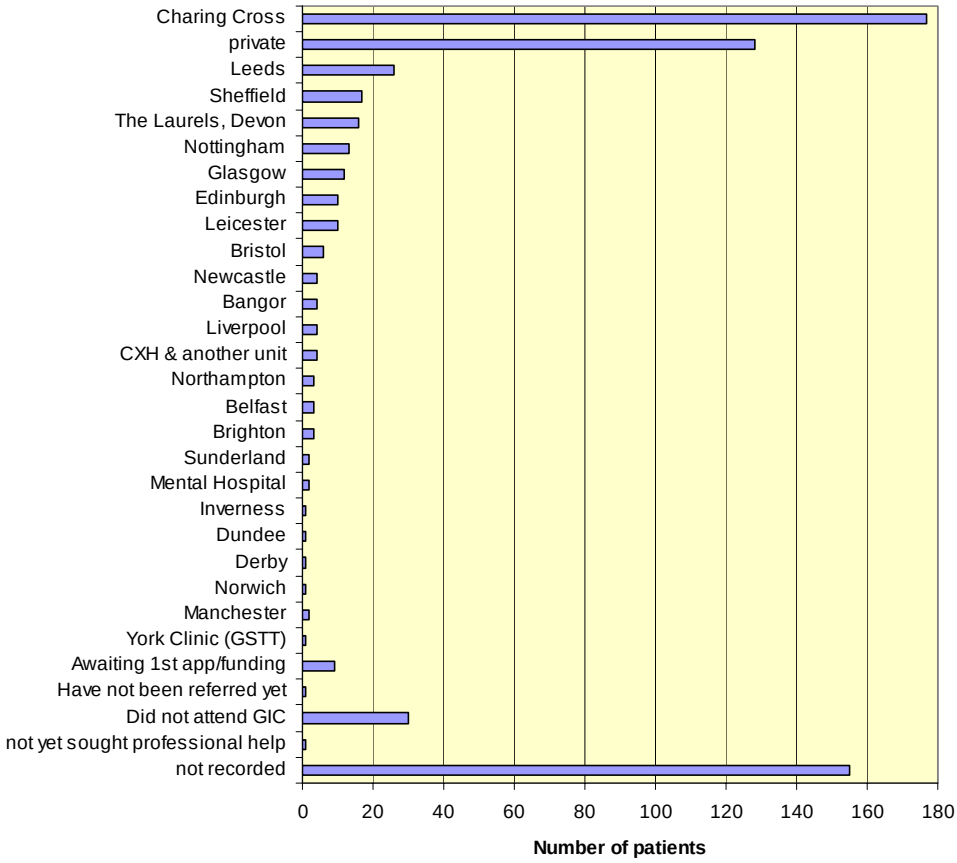


4.2.2 GIC Attended

Almost a third (28%, n=181) of all respondents attended Charing Cross Hospital although not all of these remained there for all of their treatment. Almost half of the study population (49%, n=318) attended a GIC and another 10 (1.5%) were awaiting referral or their first appointment. Other respondents attended private GICs and clinics across the UK.

The chart below shows the GIC attended if there was one. If more than one was attended then the response represents the GIC where the majority of treatment took place.

Figure 6 - Breakdown of GIC attended



4.2.2.1 Distance travelled

Anecdotal evidence has suggested that trans people often have to travel long distances for treatment and this survey supports this. Analysis was done using home postcodes given and that of the GIC attended to give approximate distances from one location to another. The distances are in miles and measured 'as the crow flies' so actual travelling distances using roads or public transport would be longer. The mean distance travelled for all respondents for whom there were data (n=405) was 69.9 miles but the median was much lower at 45.5 miles. The range was from one mile to 403.7 miles which shows how the outliers have skewed the dataset.

Just under a quarter of the survey population (23%, n=92) travelled between 20 and 49 miles to get to their GIC and in total just under half (45%, n=184) had to travel over 50 miles to access their treatment.

However when the results were split into respondents who attended an NHS GIC and those who went private they were surprising: although, as can be seen from the charts below, the proportions and patterns were similar for both groups, the NHS patients actually had lower average distances travelled (mean 65.5 miles for NHS against 82.1 miles for private, median 36.9 miles against 58.2 miles). Also the respondent who travelled furthest, 403.7 miles, was actually a private patient. It is not know why this was but it is possible that private patients have researched their options and made a choice to travel that distance to be treated by a specific person or organisation whereas NHS patients often have no option where there are sent. It must also be noted that these data are based only on postcodes given by respondents which relate to where they live now so, particularly for those who transitioned many years ago, they may not relate to where they were living whilst undergoing treatment.

Figure 7 - Distance travelled in miles by number of patients (NHS v private)

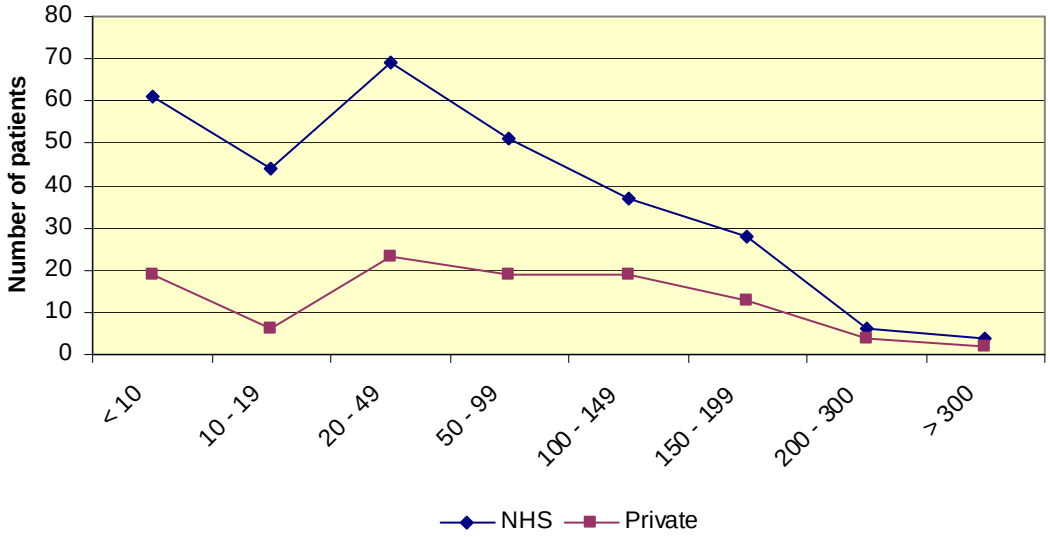
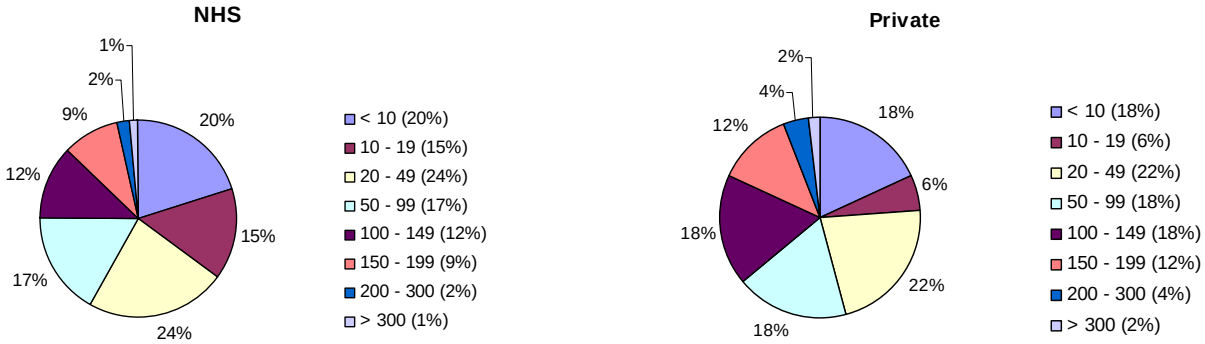


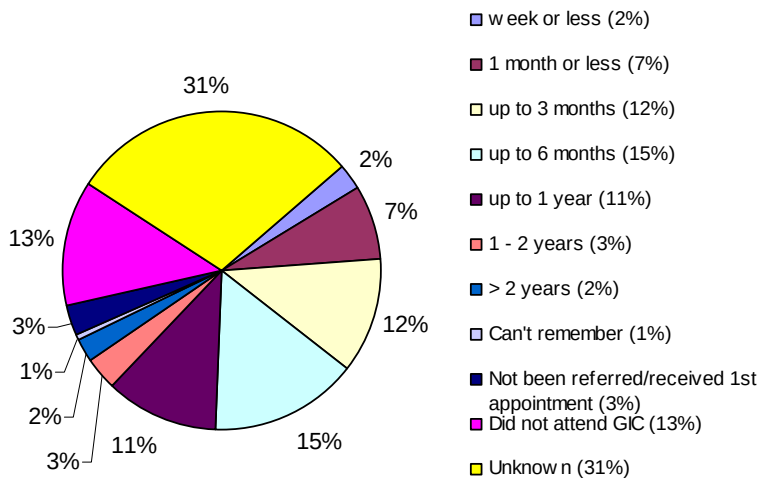
Figure 8 - Distance travelled from home to GIC in miles (NHS v private)



4.2.3 Time from Referral to First Appointment

Just under 10% of respondents (9%, n=64) had their first appointment at a GIC within a month and 37% (n=237) within 6 months. More worrying is the 5% (n=37) that waited over a year. The mean waiting time was 30 weeks or approximately seven months and the median was 22 weeks (approximately five months) showing how the mean is affected by outliers. The range was same day to over six years. These figures are based on the time from referral to a GIC (whomever it was made by – specialist, GP or self) to the first appointment at a GIC. They do not take into account when the first contact with health services was made (i.e. seeing a GP) or any waiting time whilst being referred to a psychiatrist or other specialist outside of a GIC.

Figure 9 - Time from referral to appointment (total survey population)

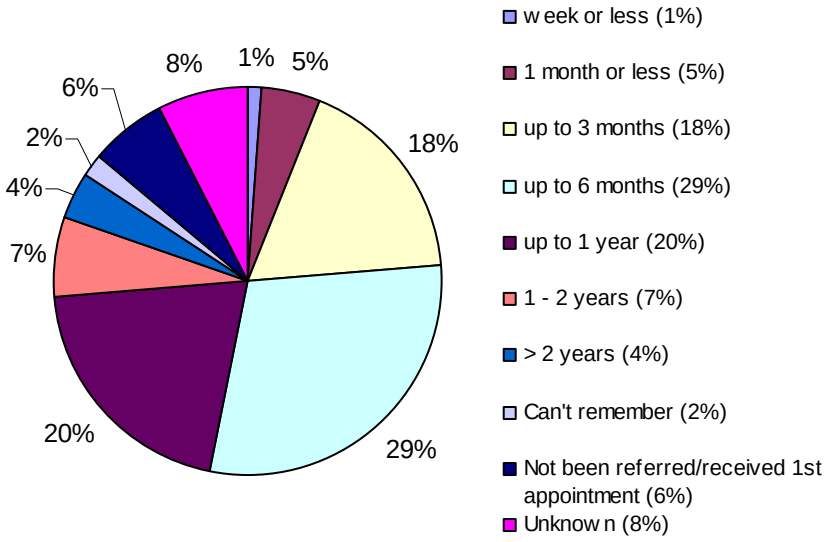


The above figures include the whole study population including those who went privately and were likely to have much shorter waiting times which may skew the data.

The chart below looks only at those patients who went to a NHS GIC and so gives a better picture of the current NHS service. The average waiting time for NHS patients was higher at 34 weeks and the median was 26 weeks again showing how the data are skewed by outliers. The range was same day to over six years, the same as for the whole survey population.

Although the survey did not cover the time when the 18 week rule applied, it is likely that for this service the 18 weeks would start with the GP referral. Looking only at those responses with data (n=304), 61% (n=184) would be in breach of the 18 week rule (from specialist referral to GIC to the first appointment). The picture would be even worse if counting started from the first GP referral.

Figure 10 - Time from referral to appointment (NHS only)



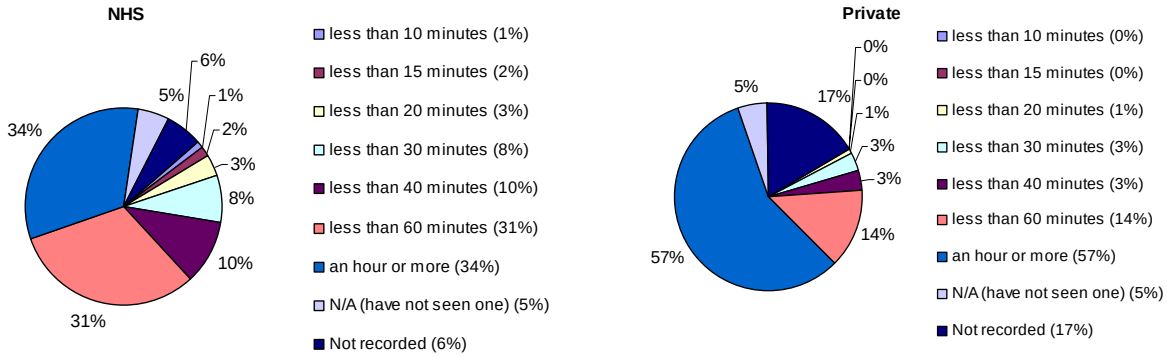
4.2.4 First Appointment with a Gender Specialist Psychiatrist

Almost a third of all the respondents (31%, n=198) spent an hour or more with a gender specialist psychiatrist at their first appointment and another fifth (19%, n=124) spent between forty and sixty minutes.

However, when this is broken down into NHS and private patients, two different pictures can be seen. The proportion of NHS patients spending an hour or more with a psychiatrist at their first appointment (34%, n=110) was much smaller than that of private patients (57%, n=88). No private patients spent less than 15 minutes and only one spent less than 20 minutes whereas 3% (n=9) of NHS patients spent less than 15 minutes at their first appointment and another 3% (n=11) spent 20 minutes or less.

Although this finding is not surprising this variation in practice is not acceptable. Although some of the respondents who spent less than 20 minutes on their first appointment transitioned some years ago when the attitudes of healthcare professionals may have been different, others had begun their treatment in the last couple of years.

Figure 11 – Length of 1st appointment (NHS v private)



4.2.5 Initial Assessment

Just under half of the respondents (49%, n=322) had some kind of health check before hormone treatment was commenced. This varied from a basic check with baseline hormone levels to full medical with bloods, lipids and organ function. Although this is positive, almost a fifth (18%, n=116) had no check and in another 28% (n=181) of cases this was not recorded. Potentially 46% (n=297) of respondents may have had no health check at all before starting this major treatment.

If this is then broken down into those who had NHS (n=321 with data) and private (n=145 with data) treatment, there is no difference between the two. Over two thirds of respondents (69%) who commenced hormone therapy on the NHS had a health check before doing so and it is the same figure for those who went private.

Only 12% (n=80) saw an endocrinologist prior to starting hormone treatment. Over half of respondents (56%, n=360) did not see an endocrinologist and in 28% of cases this was not recorded so it is possible that the majority of the study population (84%, n=538) could have started hormone therapy with no input from a hormone specialist.

Again if this is broken down into NHS (n=317 with data) and private (n=145 with data) then 22% of NHS patients saw an endocrinologist prior to starting hormone therapy. This figure was even worse for respondents who took the private route with only 7% seeing an endocrinologist.

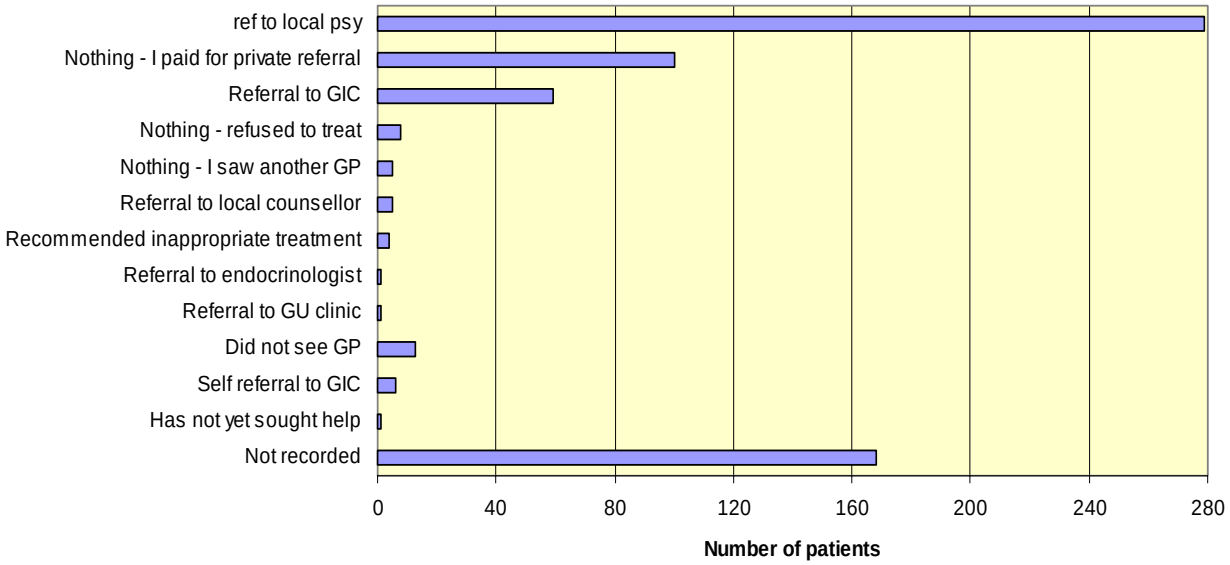
This worrying trend continues with less than a quarter (24%, n=154) of all respondents seeing an endocrinologist at least once after starting hormone treatment and of this group only 42% (n=66) were seeing one frequently.

4.3 Experiences with the GP

For most trans people their GP is their first point of contact: although the internet has opened up many opportunities for research and sources of information the perception of the GP as the entry point to any treatment is still strong. Even those following a private treatment pathway tended to visit their GP first.

As can be seen from the chart below the majority of patients (43%, n=279) were referred to a local psychiatrist. International guidelines were framed with the US healthcare system in mind, and indicate that a psychiatrist should be seen at some point in the patient care pathway. 9% (n=59) of respondents were referred directly to a GIC by their GP but these were not always successful as some GICs do not accept GP referrals. 15% (n=100) paid for a private referral as their GP would not or did not take any action and a further 3% (n=19) did not see their GP initially and/or self referred directly to a GIC. These figures reflect the results of other UK studies (Whittle et al., 2007[12]).

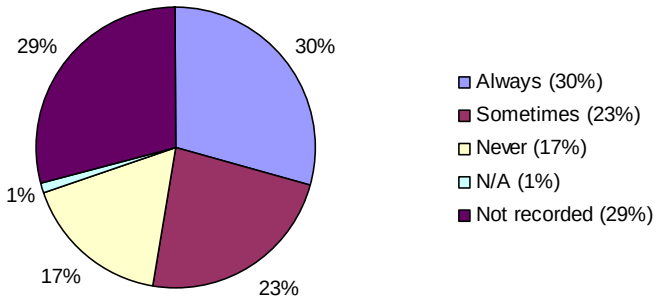
Figure 12 - Action taken by GP



4.3.1 Help, Support and Appropriateness of Action

The survey found that generally respondents had a positive experience as over half (53%, n=339) felt that their GP could always or sometimes help and support them adequately. 17% (n=111) had a negative experience as their GP was never able to help and support them.

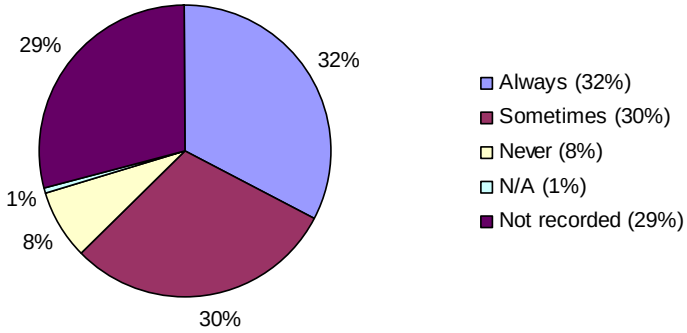
Figure 13 - Was your GP always adequately helpful and supportive in your decision to seek gender reassignment?



Of those that did not feel their GP was helpful and supportive just under half (47%, n=52) changed their GP and just over half (53%, n=59) did not. In total 77 respondents changed their GP including 25 people who were in the 'sometimes' group although some of these were for other reason such as a house move.

This positive picture continues as the majority of respondents (62%, n=404) felt that their GP always or sometimes addressed their needs appropriately. A smaller proportion (8%, n=50) felt that their GP never addressed their needs appropriately.

Figure 14 - Do you feel you GP addressed your needs appropriately?



4.3.2 GP Knowledge

Although the results show that generally the respondents felt their GPs were helpful, supportive and addressed their needs appropriately, it is clear that GPs' levels of knowledge are often not as high. Less than a fifth (19%) felt that their GP was knowledgeable about treatment and only 12% said their GP explained what treatments were available.

Follow up treatment appears to be better with 35% saying their GP encourages regular appointments, and 33% saying their GP ensures they are on appropriate screening programmes. 18% of respondents did not know the answer to this question which suggests that their GP does not.

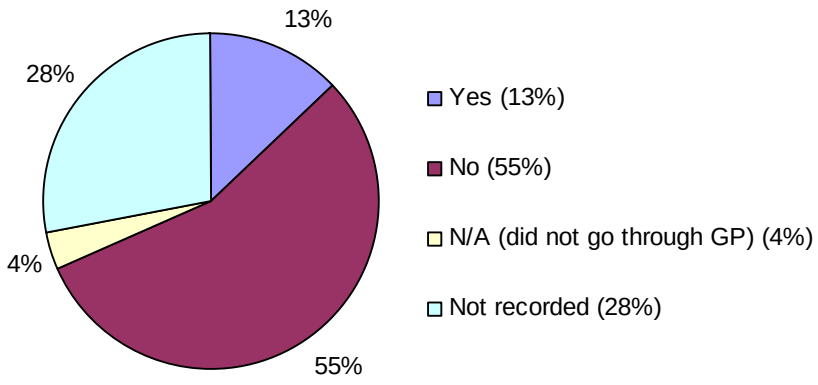
Table 5 - GP knowledge and follow up

Does your GP:	Yes (%)	No (%)	N/A (%)	Don't know (%)	Not recorded (%)
Have knowledge of treatment?	126 (19)	331 (51)	5 (1)	-	185 (29)
Explain available treatments?	77 (12)	379 (58)	5 (1)	-	186 (29)
Encourage further appointments?	225 (35)	229 (35)	5 (1)	-	188 (29)
Keep in touch with GIC?	155 (24)	277 (43)	16 (2)	6 (1)	193 (30)
Ensure you are on screening programmes?	211 (33)	113 (17)	17 (3)	116 (18)	190 (29)

4.3.3 Prescription of Hormone Treatment

Hormone therapy is usually initiated through an endocrinologist or psychiatrist with the ongoing prescriptions given by a GP. Although the majority (55%, n=358) did not experience any problems, 13% (n=84) of respondents said their GP refused to prescribe hormones despite the fact that the treatment had been recommended.

Figure 15 - GP refusal to prescribe hormones



4.4 Experiences with the GIC

As noted in **section 4.2.2** almost half of the study population attended a NHS GIC for at least part of their treatment.

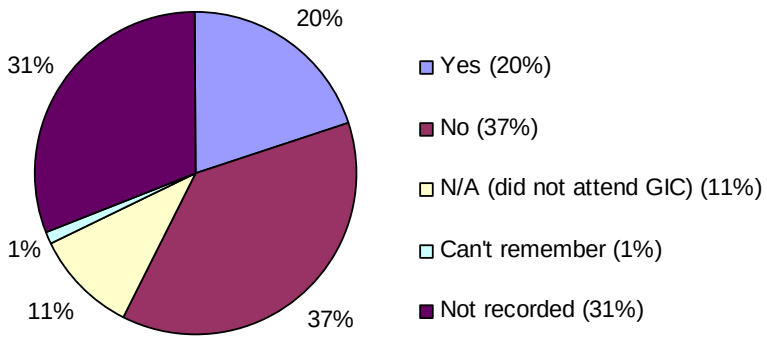
4.4.1 Written Agreements

There does not seem to be any UK protocol for admission to a GIC but many do require patients to sign a written agreement of terms under which treatment will be provided. This may encompass a code of behaviour that the patient must adhere to or other aspects.

The survey found that the largest proportion of respondents (37%, n=240) did not have to sign any agreement of terms but it is likely that this figure includes some who went to a private GIC. A small number (1%, n=7) cannot remember if they had to or not but most of these transitioned more than ten years ago.

A break down between NHS (n=284 with data) and private (n=145 with data) patients, shows a clear difference. Over a third (36%) of respondents who went to an NHS GIC did have to sign a written agreement whereas only 20% of those who attend a private clinic did.

Figure 16 - Required to sign a written agreement of terms (total survey population)

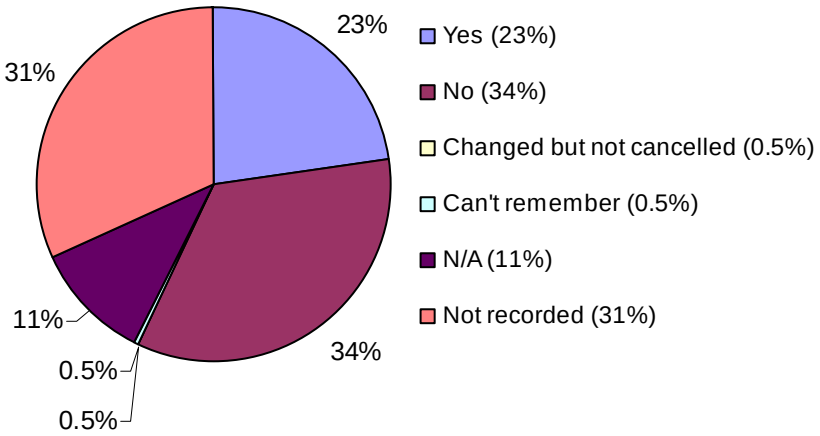


Of those that did have to sign an agreement (20%, n=130), the majority (70%, n=91) were not able to have a say in the content of this agreement so it could not reflect their individual circumstances. Just under a third (28%, n=37) felt they could contribute and influence the content of the agreement.

4.4.2 Visits to the GIC

As there are very few NHS GICs in England patients requiring treatment often have to travel very long distances for their appointments as has been shown in **section 4.2.3**. Anecdotal evidence suggests that appointments are cancelled by GICs without any prior notification causing significant inconvenience and expense to patients.

Figure 17 - Appointments cancelled by GIC

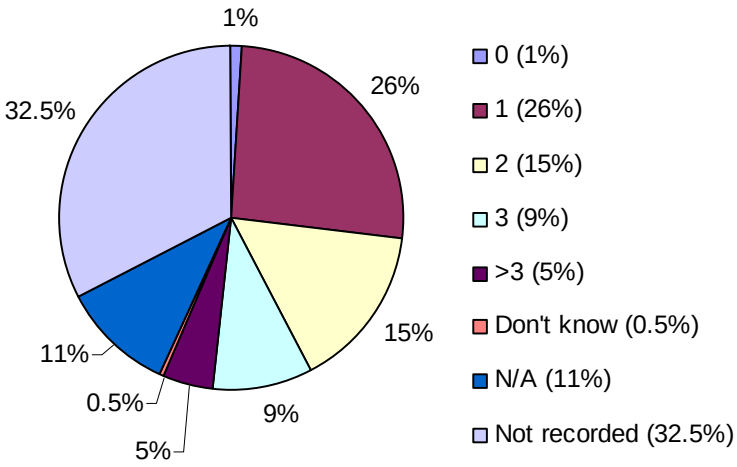


Although the majority of respondents (34%, n=220) did not have appointments cancelled by the GIC almost a quarter (23%, n=148) did. Of this group just under half (46%, n=69) were given insufficient or no notice of the cancellation with the result that they had made journeys and incurred expenses unnecessarily as well as potentially wasting holiday leave from work.

4.4.3 Seeing a Psychiatrist

Psychiatric consultations form the basis of GIC care. Psychiatrists are responsible for many aspects of a patient's treatment pathway from providing support during the Real Life Experience (RLE), deciding on hormone therapy and providing a referral to a surgeon for gender reassignment surgery. It is therefore vital that patients can build a relationship with their psychiatrist and be involved in and feel comfortable with all decisions taken.

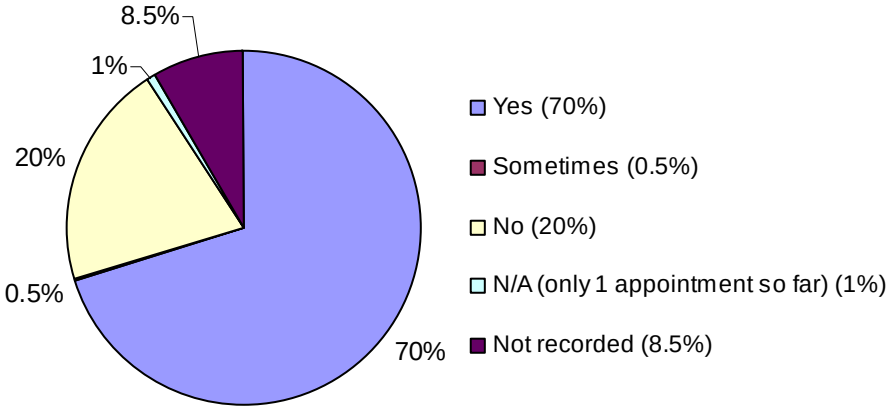
Figure 18 - Number of different psychiatrists seen at the GIC



As can be seen in the above chart just over a quarter of respondents (26%, n=166) saw only one psychiatrist at the GIC and slightly more (29%, n=191) saw more than one. 1% (n=8) have not seen a psychiatrist: there are several reasons for this including that they are still waiting for an appointment or that they saw a psychologist, psychotherapist or other counsellor. Although this is likely to be a reflection of current numbers of gender specialist psychiatrists and their workload it is more positive to see that the majority of respondents (47%, n=303) said they did have a lead psychiatrist even if they could not see them at every appointment. 9% of respondents (n=57) said they did not have a lead psychiatrist.

Of those that did have a lead psychiatrist over two thirds (70%, n=212) felt they were supportive and knowledgeable about their specific needs and a fifth (20%, n=62) felt they were not.

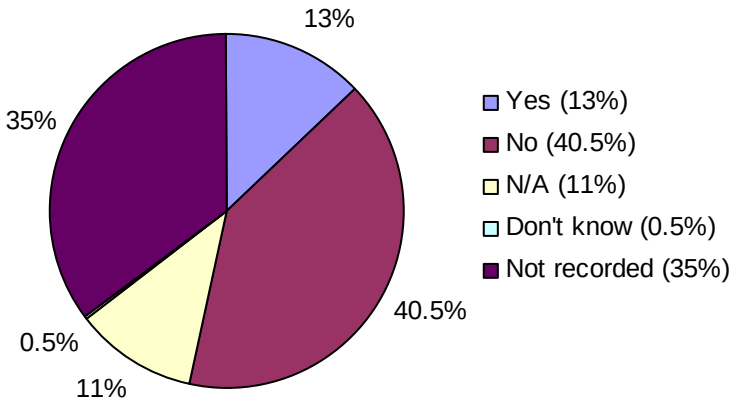
Figure 19 - Lead psychiatrist was supportive & knowledgeable



4.4.4 Treatment Options and Involvement in Decision Making

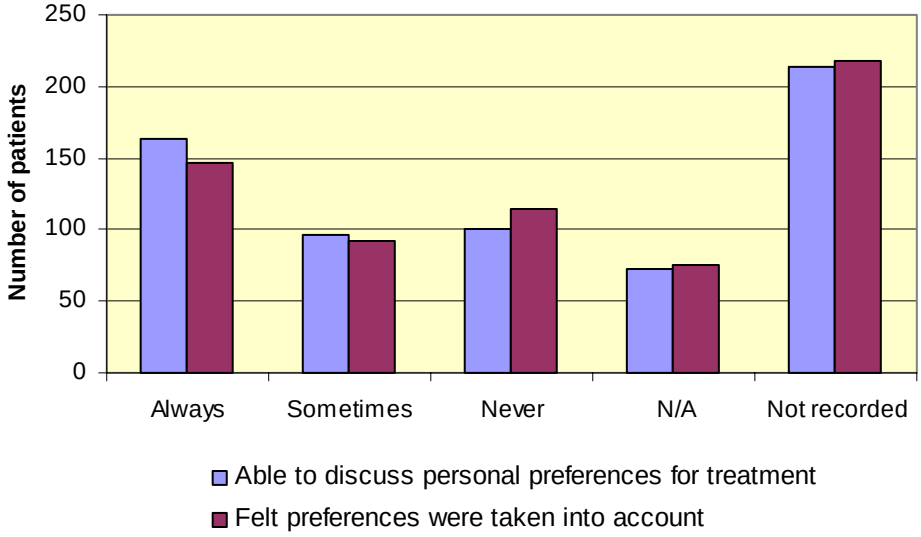
As can be seen below a large proportion of respondents (40.5%, n=260) felt that there were no medical, nursing or other staff at the GIC who were responsible for explaining possible treatment options. This is an important service as even if a patient had an idea of what treatment they wanted, they may not know exactly how it works and what the options are or even if it is an appropriate treatment for them. As this study has shown some patients did not know what treatment they wanted or even what services were available and would need appropriate support and guidance.

Figure 20 – Were staff responsible for explaining treatment options?



A large proportion of respondents felt they were given the opportunity to discuss their personal preferences for different treatments (25%, n=164) and that these preferences were taken into account by their psychiatrist when making decisions about their treatment plan (23%, n=147).

Figure 21 - Inclusion of personal preferences into treatment plan



Almost half of respondents (45%, n=289) felt that they had the power to make decisions about their treatment and could give informed consent because they understood the implications and risks

involved. Of the remaining group, 30% (n=196) did not answer this question and 10% (n=63) felt it was not applicable. It is of concern that 15% (n=99) felt disempowered.
If the data are broken down into respondents who used the NHS (n=310 with data) and the private route (n=140 with data) the difference is very clear: almost a third of NHS patients where there were data (31%) felt that they did not have any power to make decisions about their treatment compared to only 4% of respondents who had private treatment.

Almost half of respondents (49%, n=314) felt that they did not have to keep any aspect of their sexuality, personal behaviour or lifestyle secret because of fears that treatment would not start or may be stopped, which is reassuring. Often those that did feel they had to keep aspects of their life secret, of which many were to do with sexuality, perceived that there was pressure from the GIC to be heterosexual once transitioned. However, trans people may be hetero-, homo-, bi- or asexual in just the same way as the whole population and anecdotal accounts agree with this. Other aspects were around mental health issues such as depression or addiction or issues around (un)employment.

A clear difference could also be seen in responses to this question when comparing NHS patients (n=309 with data), of whom 20% felt they had to keep aspects of their lifestyle secret, to private patients (n=140 with data) of whom only 10% felt this need.

Table 6 - Involvement in & barriers to treatment at a GIC

	Yes (%)		No (%)		N/A (%)*	
	NHS	Private	NHS	Private	NHS	Private
Felt had power to make decisions about treatment	186 (60)	103 (73)	95 (31)	5 (4)	29 (9)	32 (23)
Felt had to keep aspects of life secret	63 (20)	14 (10)	219 (71)	95 (68)	27 (9)	31 (22)

* N/A – respondents did not attend a GIC, have not yet been referred or received 1st appointment date or have only had one appointment.

4.4.5 The Real Life Experience at the GIC

The majority of those patients who were already largely living in their corrected gender before their first appointment at the GIC (n=223) had this recognised by the GIC (74%, n=165). Similarly, for those respondents who were already permanently transitioned (n=190) this was accepted by the GIC as fulfilling some or all of the RLE in the majority of cases (68%, n=130).

Of those respondents who had not yet transitioned (n=151) the largest proportion (63%, n=95) felt that the GIC did everything it could to make the experience as positive and as simple as possible. Although this is a good proportion it is still the case that 56 patients (37% of this group and 9% of the total study population) felt that the GIC did not support them through the RLE and some respondents reported obstructive or confrontational behaviour. Other issues were: not being prescribed hormone therapy before undergoing RLE; a lack of advice and support when telling family, friends and employers; being told that being threatened 'came with the territory'.

Table 7 - Acceptance by GIC of previous time spent living in corrected gender

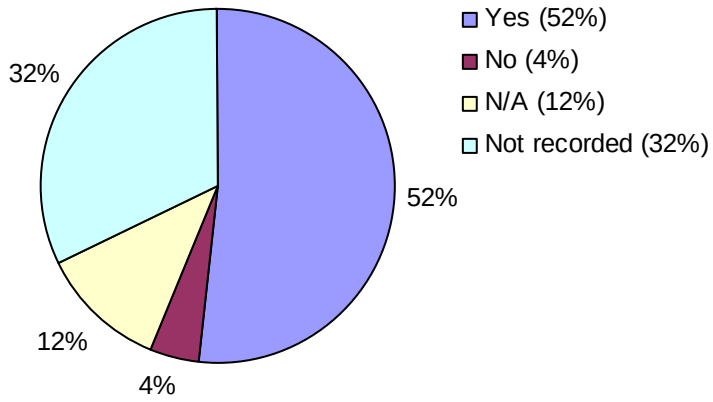
	Yes (%)	No (%)	N/A (%)
Largely living in corrected gender recognised by GIC	165 (38)	58 (13)	216 (49)
Permanently in corrected gender accepted as RLE by GIC	130 (30)	60 (14)	248 (56)
Not living in corrected gender helped & supported by GIC	95 (22)	56 (13)	286 (65)

Responses with no data were not included in the analysis. Figures are respectively: 208; 209;210.

4.4.6 Satisfaction with the GIC

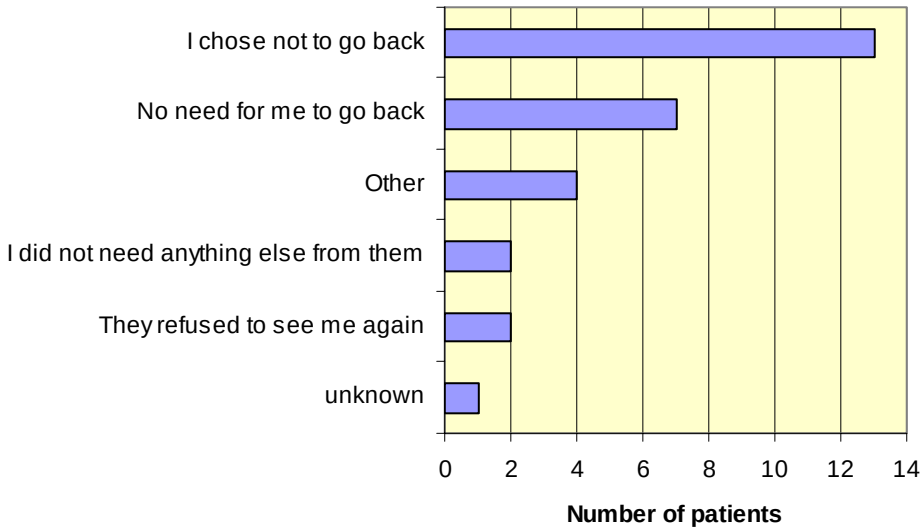
Over half of respondents (52%, n=334) continued with their treatment at a GIC with only 4% (n=29) not returning after the first visit.

Figure 22 - Continued treatment at a GIC after 1st appointment



Of those that did not continue treatment at a GIC the most common reason was that they chose not to go back either because they were unhappy with the GIC regime particularly with regards to staff attitudes, waiting times and delays in accessing hormone therapy or because they just decided that the private route was more appropriate for them.

Figure 23 - Reason for stopping treatment at the GIC



In total the largest proportion of respondents (39.5%, n=256) were either totally happy with the care they received at their GIC or felt it had more good than bad aspects. One person felt it was neither particularly good or particularly bad and 16% (n=105) viewed the care they received in a negative way.

> "All the staff at the GIC and Charing Cross Hospital have been extremely supportive and are very professional in all aspects."

> "I think the NHS route worked for me in terms of timescale and the quality of the Psychiatrist I had. However the idiosyncratic nature of service provision in the UK is a

problem due [to] the lack of consistency in assessment, funding and follow up. There is also a lack of good emotional support from the services as well as a lack of coordination at times in the patient's treatment pathway. Sometimes the patient may be on several different waiting lists for Psych/2nd opinion/speech therapy/hormones etc, this is not good and does not reflect "joined up thinking".

"NHS provision is woefully inadequate. Funding is patchy, a genuine postcode lottery. It is very hard to find out what the PCT policies are."

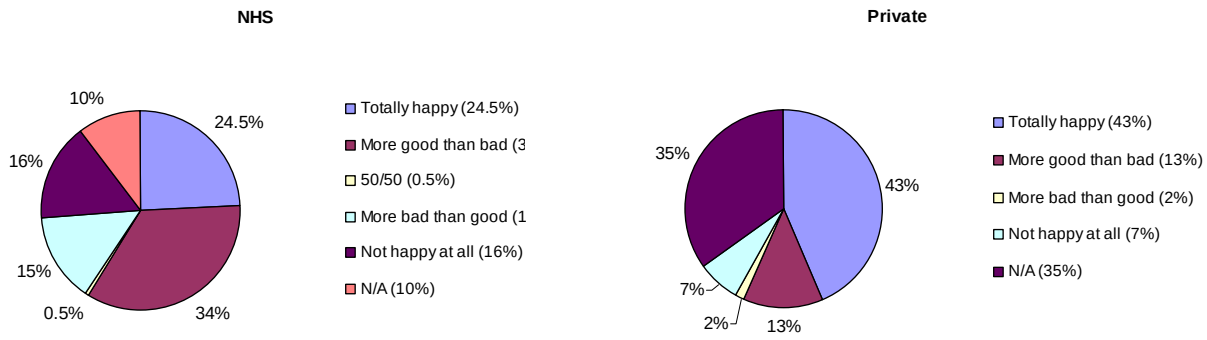
"I am thoroughly upset at the length of time I have had to wait so far - it has been almost 18 months since I first saw my GP and I am still waiting for hormones. I can fully understand why people choose to take the private route. At my rescheduled appointment, following my cancelled first appointment, I arrived in good time, only to find that the doctor I was supposed to be seeing had been told the previous day that he didn't have any appointments that day - and this was after I had been phoned to make sure I was still going to attend! I was told that he was on his way in, but that there was another person to see him before me. This would mean that I would miss my return coach to Manchester. After I had explained the situation, they managed to get one of the other psychs to see me. However, I personally feel that situations such as this are completely unnecessary and avoidable, and only serve to put the GIC in a worse light."

"There is too much expectation/pressure to follow a particular pathway."

"…in the 6 and a half years I attended [the] GIC I was subject to a lot of mental and verbal abuse and no treatment was ever facilitated.....False accusations made about origins of medication and medical file mix ups and blunders were the norm. Obviously none of the protocols or guidelines set up in the 'Harry Benjamin Standards of Care' have been complied with in the case of [the] GIC."

Although the largest proportion of respondents felt they had a positive experience at their GIC, once the data are broken down into those who followed the NHS or private routes the variance can be seen. Just under a quarter of NHS respondents (24.5%) were totally happy with the care and treatment they received compared to 43% of those who went private. Similarly 7% of those who took the private route were not at all happy with the service compared to more than twice that (15%) in those who went to a NHS GIC.

Figure 24 - Experience of GIC care (NHS v private)



* N/A– respondents did not attend a GIC, have not yet been referred or received 1st appointment date or have only had one appointment.

4.5 Hormone Therapy

Hormone therapy is usually the first step taken when transitioning before any decisions are made regarding gender confirmation surgery. Indeed for some trans people this will be as far as they will go and is particularly the case for people who transition later in life.

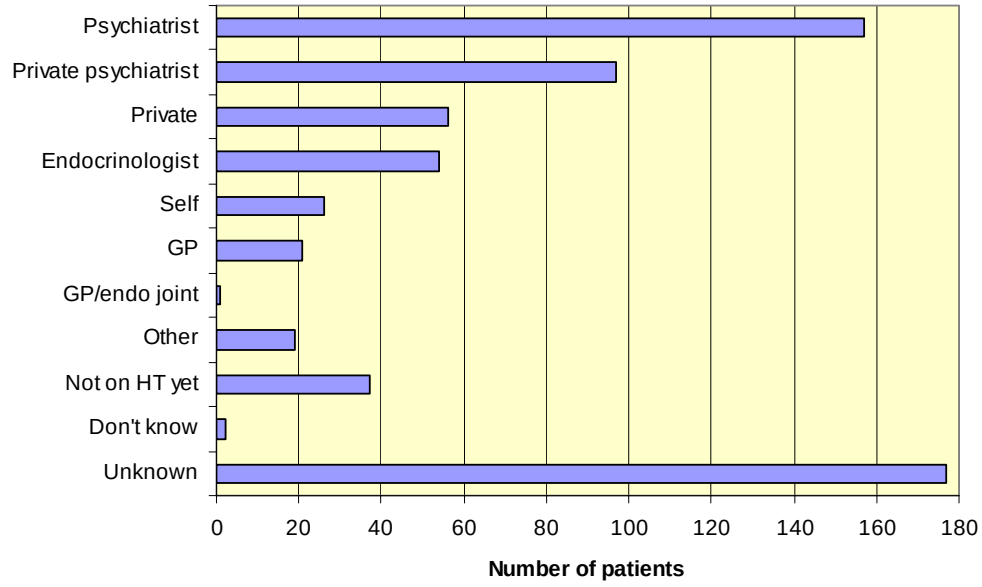
Although it varies, most NHS GICs require a patient to have lived in role (the 'real life test/experience' (RLE)) for a period of time before they will prescribe hormones and this can cause problems for some patients. For this reason patients often pay privately for hormone therapy before they begin treatment at a GIC which can cause conflict with the GIC. One patient who had been on hormones for two years privately whilst waiting for an appointment to a GIC had their prescription withdrawn at their first appointment and was told they had to start from scratch. This contradicts the WPATH guidelines which state that the RLE is not a diagnostic measure so the lack of a formal recorded RLE at a GIC is not a reason for withholding hormone therapy.

As can be seen from the charts below, the proportions of respondents who were required to gain a second psychiatric opinion before being prescribed hormones differed greatly depending on whether they were NHS or private patients: 40% of NHS respondents had to get a second psychiatric opinion compared to only 10% of private patients. It is interesting to note that although the WPATH guidelines[3] state that hormones should be 'prescribed by a physician and should not be administered without adequate psychological and medical assessment before and during treatment' there is actually no requirement to gain a second psychiatric opinion before hormones can be prescribed.

Figure 25 - Requirement to see a second psychiatrist before prescription of HT (NHS v private)

Although a psychiatrist was the most common healthcare professional to initially prescribe hormone therapy the chart below shows there are other avenues which may or may not be as appropriate. More worryingly 4% (n=26) started therapy by self medicating, mainly by buying hormones online where they have no way of checking the provenance of the drugs they are taking, ensuring that they are what they say or even that they would form an appropriate regime for that person.

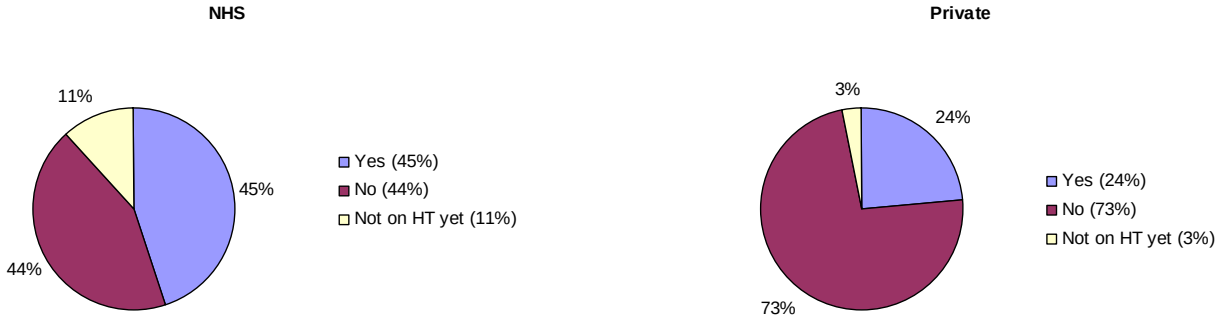
Figure 26 - Initial decider of HT & dose



Just over a quarter (26%, n=167) of all respondents felt that they should have been prescribed hormones sooner than they were including three who are still waiting to start hormone therapy and one as mentioned above who was on hormone therapy but has had it withdrawn and must now do the RLE before starting it again. The largest proportion (35%, n=227) felt the timing was appropriate and they should not have been prescribed it any earlier.

However, when this is broken down into those who followed the NHS route against those who had private treatment the picture looks very different as can be seen below in **figure 27**. Almost half of NHS respondents (45%) felt that they should have received hormone therapy earlier and a similar figure (44%) felt the timing was appropriate. Looking at those who had private treatment just under a quarter (24%) felt that they should have received hormone therapy earlier but almost three quarters (73%) felt that they had received their hormone therapy within a reasonable time.

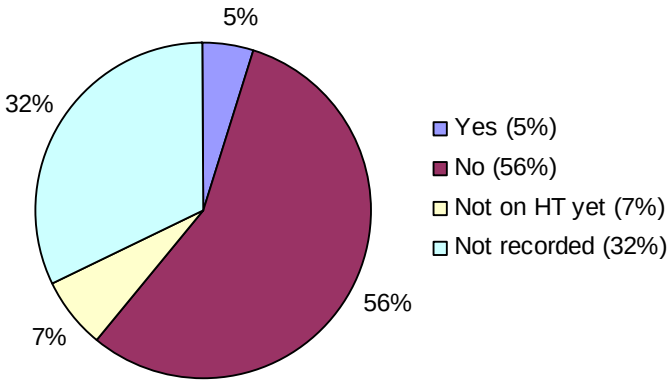
Figure 27 - Patients who felt they should have been prescribed HT sooner than they were



Four respondents who are not yet on HT feel they have been waiting too long.

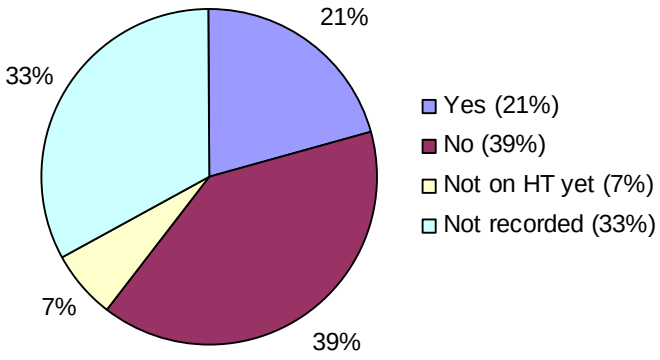
Only a small proportion of respondents (5%, n=33) have used gonadotrophin releasing hormone analogue (GnRHa). These drugs can be used in adolescents or young people to suppress gonadal sex hormone production by the inhibition of pituitary gonadotrophin secretion and so can block pubertal development. In the UK GnRH analogue is only available after puberty is complete. In other centres around the world the analogue is administered to young people, after careful screening, when puberty is under way but before substantial development of secondary sex characteristics. The timing of any intervention is crucial and must be in accordance with protocols that include exact measures of pubertal development, psychological stability in the young person and adequate familial/social support.
Of these respondents only one was a trans man, all the rest were trans women.

Figure 28 - Use of GnRH analogue



The majority of respondents (39%, n=256) have not experienced any problems of either a medical or other nature with their hormone regime. Just over a fifth (21%, n= 134) have had problems. The most common of which were: side effects such as high blood pressure, depression and mood swings, DVT, loss of libido, skin irritation from patches, 30% (n=40); dose too low or too high, 25% (n=34); no noticeable effect, 7% (n=10).

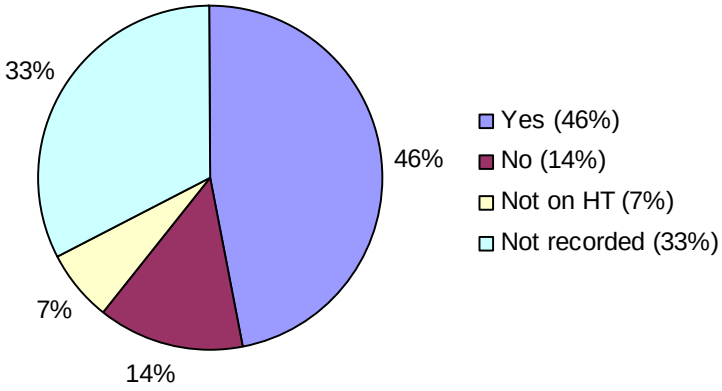
Figure 29 - Problems experienced on HT



Of those that did experience problems (21% of total study population, n=134) the majority (70%, n=94) were sorted out to the respondent's satisfaction and in one case this is ongoing. Just over a quarter (27%, n=37) feel their problems have not been satisfactorily resolved and in two cases this information was not given.

In general it appears that the respondents are happy with their hormone therapy management as almost half (46%, n=303) said they felt satisfied and healthy on their hormone regime. 14% (n=88) are not happy and the main reasons for this are: they would like to see an endocrinologist or get monitored/checked more regularly 16% (n=14); the dose is still too low 14% (n=12); the lack of feminisation/masculinisation 10% (n=9); they would like to change their HT or have more choice of type or method 10% (n=9).

Figure 30 – Do patients feel satisfied with & healthy on current HT regime?



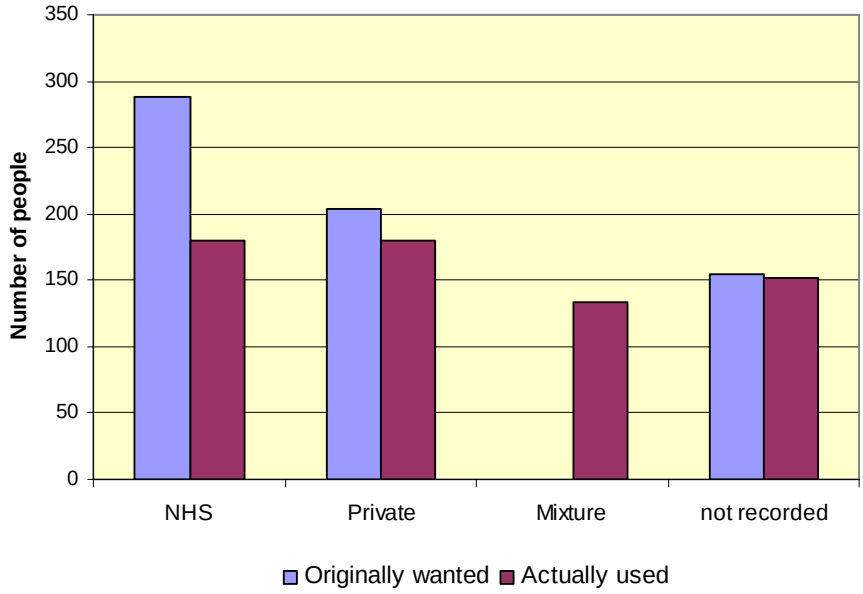
4.6 Funding

In many cases there appears to be a discrepancy between the respondents' original choice of provider, i.e. NHS or private and their eventual actual route. Although 45% (n=288) originally planned to use the NHS for their treatment the difficulties and delays encountered meant that a significant proportion (21%, n=134) ended up using a mixture of NHS and private services.

For those respondents who had planned to use the private route (n=204) the main reasons for this were: Delays in getting treatment on NHS, 30%, n=62; perception of NHS standard of treatment ('horror stories'), 29%, n=60; wish to have control over their treatment, 13%, n=26; difficulties in getting funding from local authorities, 8%, n=16.

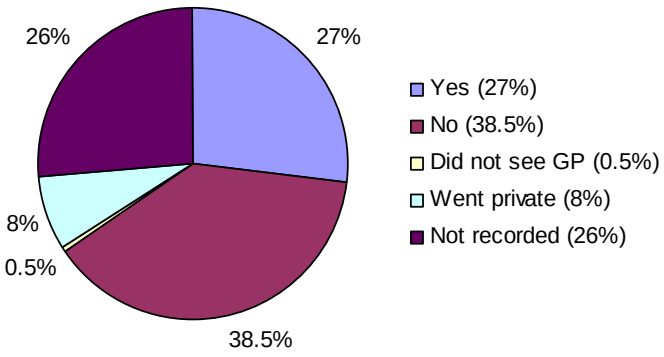
What is not clear from these figures but was seen in the raw data is that there were a small number of respondents (n=4) who had planned to go private but because of the costs actually used the NHS.

Figure 31 - NHS v private treatment



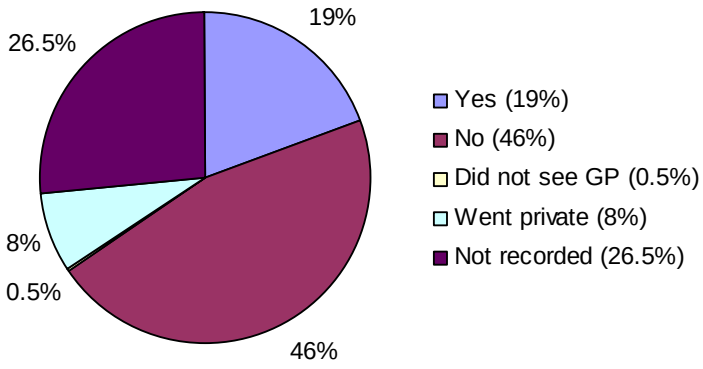
It is positive that the majority of respondents (38.5%, n=249) said that their GP did not raise any issues regarding funding for their treatment however it is possible that this is because they lacked the knowledge to know there might be a problem.

Figure 32 - Funding issue raised by GP



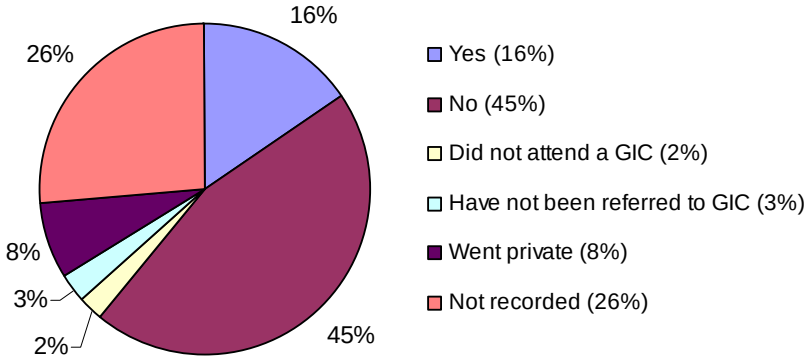
A similar picture is seen in the chart below: Almost half of the respondents (46%, n=297) said that their GP did not suggest that treatment could not be funded or that it might be against the PCT funding policy to provide treatment.

Figure 33 - GP suggested treatment could not be funded or was against local funding policy



A similar figure can be seen in the chart below as 45% (n=293) did not have any problems getting funding for their first GIC appointment.

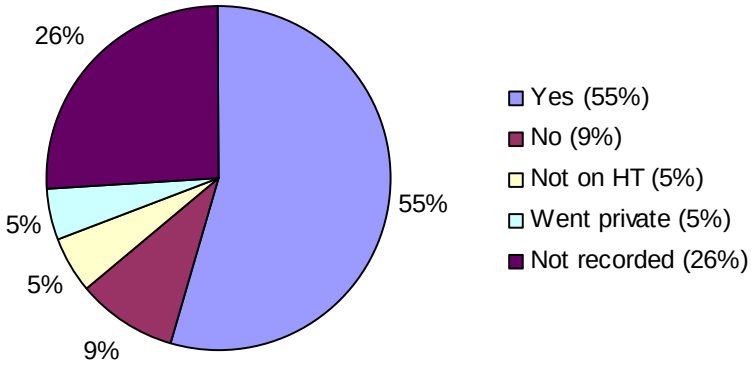
Figure 34 - Issues raised regarding funding for GIC appointment



The majority of respondents (55%, n=353) found that funding was readily available for hormone therapy with only 9% (n=60) having problems obtaining funding. Of this group one of the main obstacles seem to be with the GP surgeries refusing to prescribe. A number of patients only received funding for hormones after they had had gender reassignment surgery.

Some respondents were told that the money used for hormone therapy could be better spent elsewhere and some GPs stated that the healthcare needs of trans people were less 'real' than those of, for example, cancer patients. This is despite the fact that the cost to the NHS of generic oestradiol, a common, hormone therapy for trans women, is actually less than the prescription charge.

Figure 35 - Funding readily available for hormone therapy



Some respondents believed that blanket bans on funding treatment for Gender Dysphoria exist despite the Court of Appeal holding that it is unlawful (R v North West Lancashire Health Authority ex pA, D and G [2000] 1 WLR 977). However this is likely to be due to local policies which are assigning low priority to gender reassignment services.

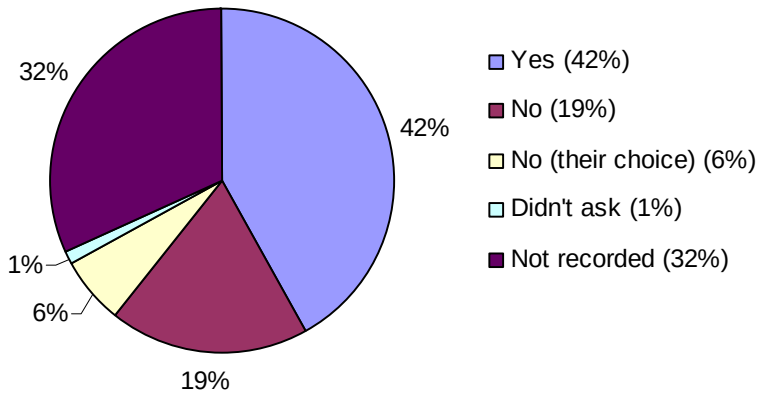
4.7 Patient Satisfaction

The majority of respondents (42%, n=273) are still going through transition and around a third (32%, n=204) are fully transitioned. For just under a third (26%, n=170) this information was not given. Of those going through transition the majority (54%) are awaiting surgery with another 24% waiting for further treatment or surgery. 11% have only just started their journey or are still waiting for their first appointment, either NHS or private.

Of those who have transitioned the majority (54%) completed treatment between 2 and 10 years ago, a fifth (20%) transitioned more than 10 years ago and a quarter (25%) transitioned less than 2 years ago.

The majority of patients (42%, n=272) felt they were able to have a family member or partner present during some aspect of their treatment.

Figure 36 - If patients felt they could have family member/partner present



Of those that did not feel they could have someone present with them or did not have it as much as they would have preferred (n=146) (i.e. with different healthcare providers – GP, GIC, psychiatrist, surgeon), 41% (n=60) would have liked to have someone with them. Over half (59%, n=86) were happy to have no one with them.

4.7.2 The Real Life Experience

Over half of all respondents (56%, n=363) have done some form of RLE and their experiences are a mixture of positive and negative. Across the board respondents appeared to have the best experiences with their GP and friends and the worst experiences with their families. Indeed a common theme of the survey has been the loss of personal relationships particularly with parents or children who often find the need to transition difficult to accept. Some have experienced bullying or abuse at work (including two responses from NHS workers) and have been effectively forced to change jobs. Such discriminatory behaviour is unlawful under the Sex Discrimination Act 1975 (Sex Discrimination (Gender Reassignment) Regulations 1999).

Others have been surprised by the understanding and acceptance shown in the workplace or in their communities.

Table 8 - RLE ratings (Number of patients)

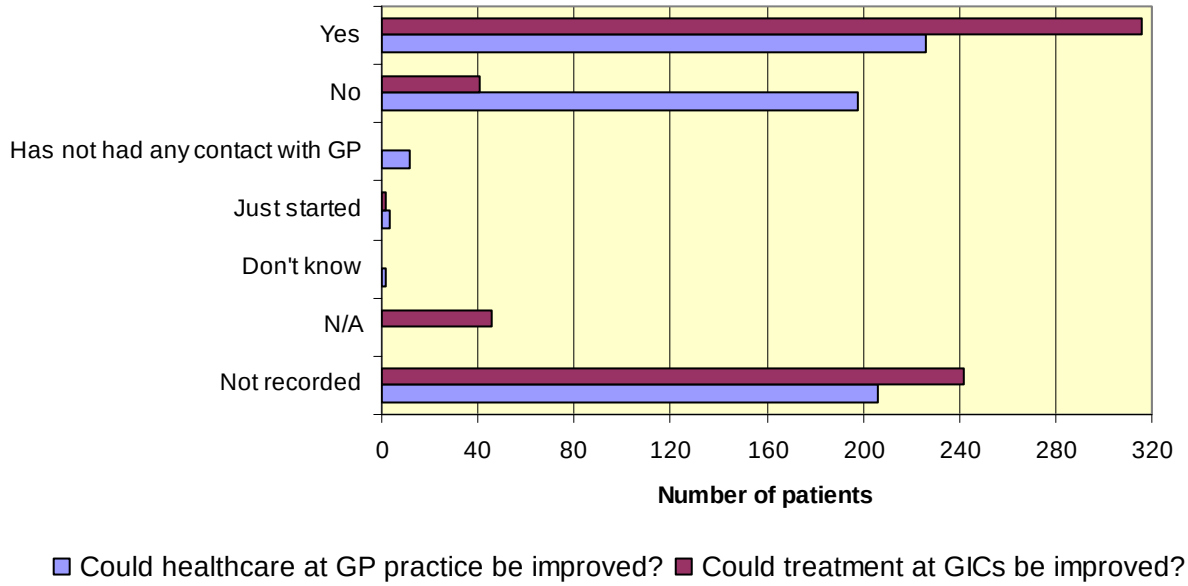
	Grading from 1 – 10 where 1 = very bad, 10 = excellent											Did not do a recognised RLE	Did not do RLE	Has not done full RLE yet	Not recorded
	1	2	3	4	5	6	7	8	9	10	N/A				
Work	26	11	17	15	26	16	26	51	45	108	23	16	10	40	217
Public	9	8	15	20	25	25	33	56	77	95	0	16	10	39	219
Family	46	21	23	15	38	29	33	42	31	80	4	16	10	40	219
Friends	13	9	15	9	22	21	27	48	66	131	3	16	10	39	218
GP	29	7	6	9	27	15	34	39	52	141	3	16	10	40	219

As can be seen in **figure 37** below, although many people had positive experience with their GP it is clear that there is still a way to go. Over a third of respondents (35%, n=226) feel that the healthcare at their GP surgery could be improved. The most common theme is that of knowledge and understanding. GPs generally see very few cases of gender variance (e.g. transsexualism) and most are simply not aware of the care pathway and treatment options. On the other hand, just under a third (31%, n=198) of respondents do not feel that the service provided by their GP could be improved.

The difference when looking at care provided by GICs is starker: just under half (49%, n=316) think that treatment for trans people at GIC could be improved compared to just 6% (n=41) who feel that no improvements are needed.

Issues with GICs include: the rigidity of the NHS system; lack of understanding and empathy; lack of patient focus; ‘one size fits all’ approach – does not look at individual needs/choices.

Figure 37 - Improvements possible in healthcare services (general practice and GIC)

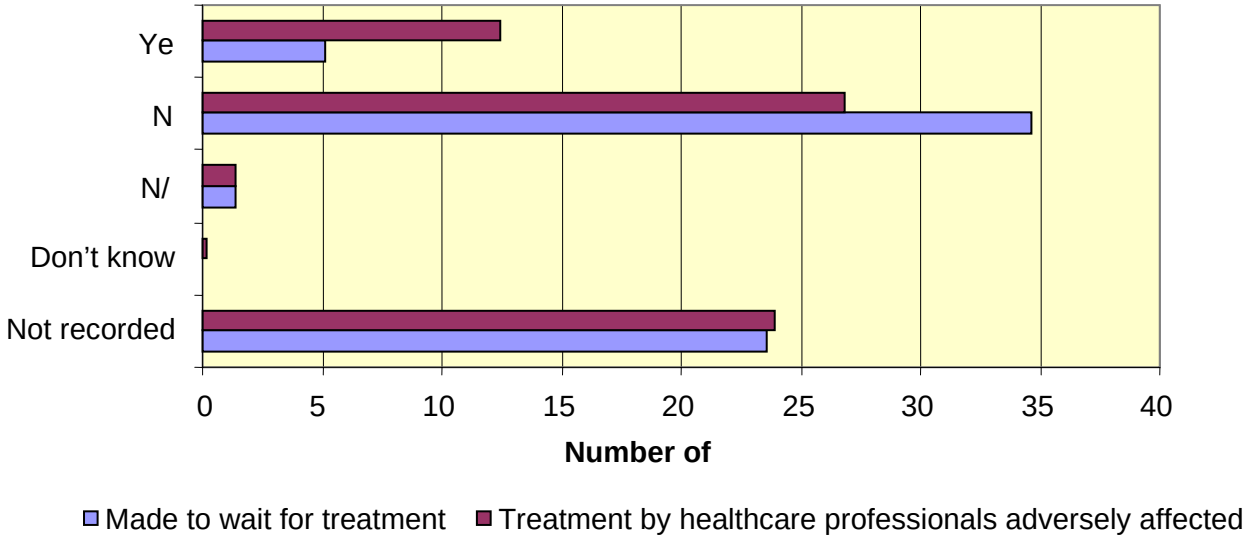


* N/A– respondents did not attend a GIC, will not attend a GIC or are waiting for 1st appointment.

Over half of the respondents (53%, n=346) did not feel that they had ever been made to wait or refused treatment relating to another medical condition (other than being trans) because a doctor, nurse or other healthcare professional did not approve of gender reassignment. However 8% (n=51) felt they had, which is of concern. A further 2% (n=14) had not fully transitioned yet so had no experience of this. These results reflect those seen by Whittle et al., 2007[12].

Similarly 41% (n=268) of respondents did not think that being trans had adversely affected the way they had been treated by doctors, nurses and other healthcare professionals. However, almost a fifth (19%, n=124) did believe this was the case which is very worrying; again this is reflected in the results from other studies (Whittle et al., 2007[12]). Not only do such outdated attitudes and prejudices have no place in healthcare provision but they run counter to current legislation.

Figure 38 - Treatment adversely affected by trans status



It is evident that this highly complex treatment pathway can take many years and has many challenges. Most respondents felt that it had affected their general life (49%, n=313) and personal relationships (46%, n=299). Many also felt their finances were affected as, even if they did not take the private route, many procedures such as hair removal, which can be ongoing, breast augmentation and facial feminisation surgery are not available on the NHS.

Unexpectedly, although a large proportion of respondents (41%, n=167) their life had been affected, work was the lowest on the list. Some found that employers and colleagues were supportive and accepting although the number of N/As was largest in this group as a number of respondents reported that they have been unable to work due to medical conditions either directly or indirectly linked to being trans.

Table 9 - Has the time taken by the transitioning process affected aspects of life

	Yes (%)	No (%)	N/A * (%)	Not recorded (%)
General life	313 (49)	87 (13)	11 (2)	236 (36)
Finances	292 (45)	109 (17)	11 (2)	235 (36)
Personal relationships	299 (46)	99 (15)	11 (2)	238 (37)
Work	267 (41)	125 (19)	17 (3)	238 (37)

* N/A – Respondents have not transitioned yet or have only just started or do not work/are retired.

4.8 Experiences of Surgery

The second part of the survey was the gender specific questionnaires and these focused largely on experiences of gender reassignment surgery. 44% (n=286) of the study population have had some kind of gender reassignment surgery (this includes chest reconstruction for trans men but does not include breast augmentation or facial feminisation surgery for trans women) and of this group 88% (n=251) completed the relevant questionnaire. If this is broken down further into trans men and women then 90% (n=60) of the trans man survey population and 87% (n=191) of the trans woman survey population who have had surgery completed the questionnaire.

Some people who have not yet had any GRS also answered these sections so in total 327 questionnaires were partially or completely answered which represents 51% of the total study population.

4.8.1 Overall Experience

Almost two thirds of respondents (63%, n=204) felt they were well prepared for their surgery although the proportion was slightly higher in the trans woman group. The proportion of patients who did not feel well prepared for surgery was the same for both groups at 10%.

Table 10 - Felt well prepared for surgery

	Yes (%)	No (%)	N/A (%)	Not recorded (%)	Total
Trans man	43 (54)	8 (10)	19 (24)	9 (11)	**79**
Trans woman	161 (65)	26 (10)	50 (20)	11 (5)	**248**
Total	**204 (63)**	**34 (10)**	**69 (21)**	**20 (6)**	**327**

The majority of respondents (47%, n=154) described their experience of genital surgery as all or mostly positive although the proportion was higher among trans women. This is explained by the larger proportion of trans men (75%) who have not had any genital surgery who appear to be deterred from this by the difficulties of the operations and poor outcomes.

Table 11 - Overall experience of genital surgery

	All positive (%)	Mostly positive (%)	Mixture of positive & negative (%)	Mostly negative (%)	All negative (%)	N/A (%)	Not recorded (%)	Total
Trans man	-	8 (10)	9 (11)	-	1 (1)	59 (75)*	2 (3)	**79**
Trans woman	89 (36)	57 (23)	25 (10)	4 (2)	3 (1)	57 (23)	13 (5)	**248**
Total	**89 (27)**	**65 (20)**	**34 (10)**	**4 (1)**	**4 (1)**	**116 (36)**	**15 (5)**	**327**

* This figure is high as many trans men do not go on to have genital surgery because of the risks and poor outcomes.

When looking only at those patients who have had surgery where data are available (n=244), the decision to have surgery is overall a positive one with 64% (n=155) saying it was the 'best thing I ever did'; 14% (n=34) feeling it was either a happy event or a positive experience and a further 20% (n=49) who, despite experiencing problems, felt it was 'overall the right decision' for them. In total 98% (n=238) of this population felt it was a positive or mainly positive experience and only 2% (n=6) felt it was a negative one.

In these areas the proportions of trans men and women were fairly similar but looking at the more negative descriptions differences can be seen. Only one trans man wished he could go back and this referred to his experiences of genital surgery where seven years of procedures had left him with a catalogue of medical problems and a phallus which was not realistic either in appearance or function. Of the two trans women who wish to go back, one feels that they were totally misdiagnosed by their psychiatrist and was encouraged to go down a particular path without serious consideration on their part or a second opinion.

Table 12 - Feelings regarding decision to have surgery and its affects on life

	FtM (%)	MtF (%)	Total
Best thing I ever did	29 (37)	126 (51)	155 (47)
A happy event	4 (5)	17 (7)	21 (6)
A positive experience	3 (4)	10 (4)	13 (4)
Overall the right decision	17 (22)	32 (13)	49 (15)
Uncertain – could have got by without it	-	1 (0.5)	1 (0.5)
Probably the wrong decision for me	-	-	-
It left me in constant pain/disabled	-	1 (0.5)	1 (0.5)
I wish I'd never done it	-	1 (0.5)	1 (0.5)
I wish I could go back	1(1)*	2 (1)	3 (1)
N/A	16 (20)	49 (19)	65 (20)
Not recorded	9 (11)	9 (3.5)	18 (5.5)
Total	79	248	327[+]

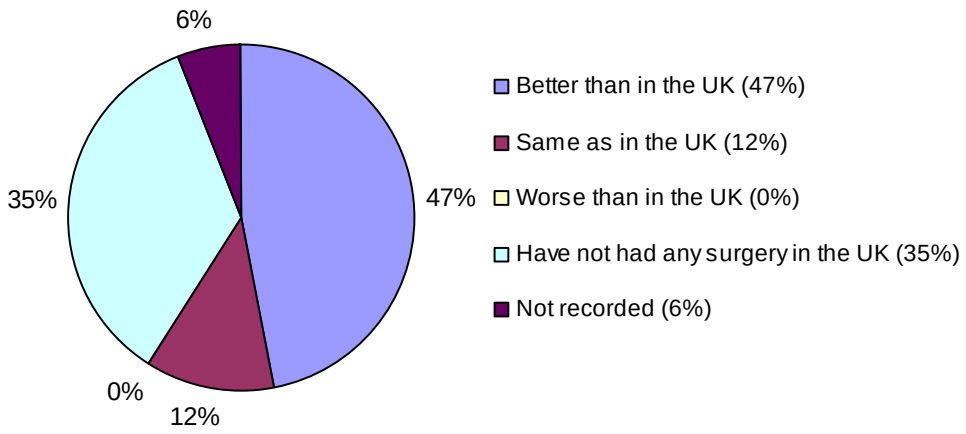
* Does not refer to the decision to transition but the experience of genital surgery.
[+] Includes 76 respondents who have not had surgery yet.

4.8.2 Surgery Abroad

The majority of respondents who have had surgery have undertaken this in the UK whether by going through the NHS or by paying privately. The most common reasons for this seem to be that there are no problems with language (for instance in the case of complications) and that traveling is, in most cases, kept to a minimum.
However there does appear to be a growing number of trans people who are choosing to go abroad for the full range of surgery from breast augmentation to the most complex genital surgeries such as phalloplasty. The survey found that 51 respondents had had surgery outside of the UK which is

18% of those who have had some gender reassignment surgery. Of this group two were trans men who both had genital surgery and the rest were trans women. The largest proportion (47%, n=24) felt that the treatment they received was better than that which they had received in the UK and 12% (n=6) felt it was the same.

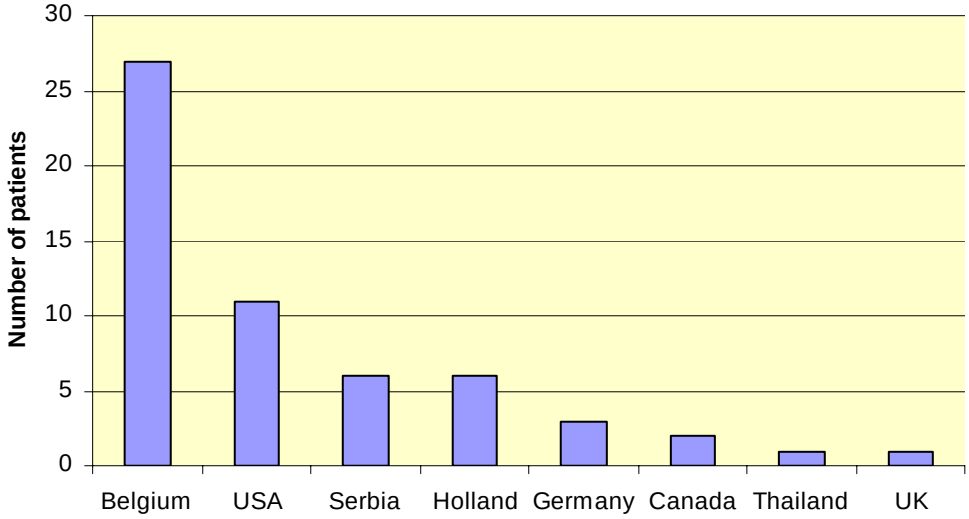
Figure 39 - Experiences of surgery outside of the UK



4.8.2.1 Most popular places for surgery

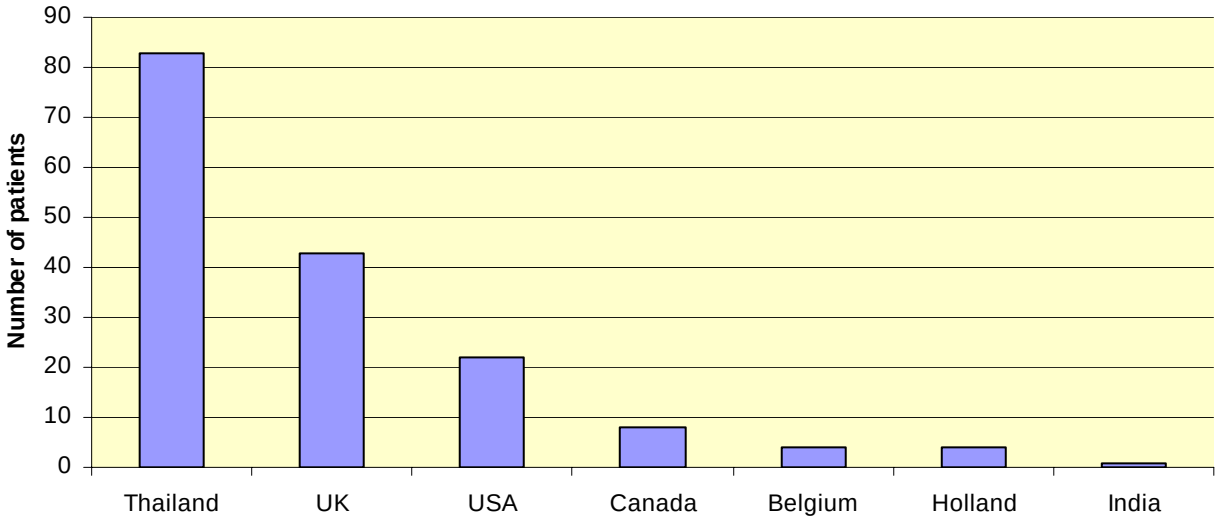
The most popular place for surgery for trans men according to those who completed the questionnaire was Belgium with 34% (n=27) of respondents mentioning it. It was felt to give the best outcomes for phalloplasty in terms of technique, appearance and functionality. Serbia was felt by 8% (n=6) to give particularly good results for metoidioplasty.

Figure 40 - Best places for FtM surgery



The most popular place for trans women was Thailand by a large margin with 33% (n=83) of those who completed the questionnaire mentioning it. The second most popular location was, surprisingly, the UK with respondents noting the quality of (mainly private) surgeons, access to aftercare and no requirement to travel across borders.

Figure 41 - Best places for MtF surgery



5. Discussion

The complexity of the questionnaire means that, particularly with the online responses, there are some large gaps in the data. Although it is understood that the questionnaires were long and could be time consuming to complete it is unfortunate that a more comprehensive dataset could not be collected. Part of the learning experience of this survey has been that the availability of real time validation tools could have helped ensure better completeness.

The paper copies tended to be more complete than the online submissions with only 6% of the paper questionnaires lacking detail compared to 26% of the online submissions which gave little more than basic demographic information.

The age distribution data in the survey needs to be interpreted cautiously, particularly the trans man data. Among the explanations that have been discussed are: the small population size which may be more influenced by outliers; differences in psychosocial factors for trans man population; the historic backlog of cases and long waiting times for surgery.

5.1 Primary Care

The survey has raised multiple questions around the roles and responsibilities of primary care practitioners, not only for transgender patients but across the whole spectrum of gender variance, e.g. support for transvestites, as well as support for partners and families.

The study has shown that a large proportion of the transgender population has a historic mistrust of NHS services including a lack of belief in the ability of GPs to provide appropriate care. This has lead to movement back and forth between the NHS and the private sector which is not seen in any other service. Throughout the trans person's care pathway there is a need for holistic support, counselling and follow up care, for example, long term health needs such as screening, which the GP is ideally placed to provide. Indeed, GP behaviour is a crucial factor in the quality of the patient experience. It may not be well known among GPs that many relevant service and information tools are available for primary healthcare professionals to access both online and in printed form[4]. These tools are designed to help fill in the gaps in knowledge that many GPs are reported to have. These tools can also help GPs with managing the disappointment that many respondents related about the results of hormone and surgical treatment. Although support groups and peer networks exist some trans people may not be able to access them and GPs often remain authority figures with important influence on long term well being.

Although currently GPs tend to refer patients to a local psychiatrist in the first instance, new guidelines from the Department of Health, 'Guidance for GPs, other Clinicians and Health Professionals on the Care of Gender Variant People'[5] appear to be moving away from this process: the guidance highlights the central role the GP can play in determining, with a patient, the most appropriate treatment pathway, initiating and continuing treatment if they feel competent to do so. This may mean arranging whatever multidisciplinary support is needed locally or referral to a specialist GIC. At present many GPs may not feel that they have appropriate and adequate knowledge and experience to accept this pivotal role but more widespread use of new tools and guidance, better awareness of trans issues and the anticipated increase in numbers of trans people presenting at their GP may lead to a fundamental change in the way these patients' care is managed.

5.2 Numbers and Outcomes

Although the study has not been able to derive per annum figures for surgery and/or treatment part of the background work has raised questions about follow up: estimated figures suggest 8-900 new cases are being seen each year by Charing Cross (approximately 500) and the major private clinic; there is a steady average rate of around 25 gender recognition applications per month (300pa);

official statistics show only 101 NHS surgical procedures were carried out in 2005/6 (the last year for which data have been offered so far). It is likely that there are several possible interpretations of these data but they suggest that private surgical procedures probably outnumber NHS ones by 2:1 and that only a minority of people referred for assessment each year end their treatment in gender reassignment surgery (for more information see **Appendix A**).

As well as the steady rate of applications for the gender recognition certificate, it should be emphasised that the majority of respondents to this survey were happy with their outcomes (see **section 4.8.1**). This positive result, while welcome, should not overshadow the need for further work and improvements.

5.3 NHS/Private Interface

As mentioned above, this patient population is unusual in its practice of moving between NHS and private care throughout their care pathway. This leads to various considerations such as patients accessing private treatment abroad and then entering the NHS for follow up care e.g. for surgical complications. NHS GICs also must cope with the effects of self medication of hormones.

There is no discernable pattern of movement in this patient population between NHS and private services. It was clear that people moved between the two depending on constraints of time and finances and often followed a path other than that which they had originally intended.

5.4 Hormone Treatment

In general the study population were unhappy with the length of time they had to wait to be prescribed hormones leading to a small proportion of them (5%) self medicating at some stage. Although it is understood that there are many factors which may lead some to feel they have no other choice, this is recognised as a potentially dangerous practice for many reasons including: the unknown quality of the drugs; lack of consideration of side effects; lack of consideration of pre-existing health concerns or familial history. Anecdotal evidence suggests that following an ad hoc hormone regime can lead to poor outcomes in terms of physiological changes with the resulting need for further surgery: for example there is an aneacdotal view that an inappropriate dosage of oestrogen may prematurely stop breast tissue development so that breast augmentation may be required. Just over a quarter (26%, n=167) of the total study population and almost half (46%) of the NHS population were unhappy with the time taken to be prescribed hormones although it was generally in line with current guidance.

There is an issue in that some GPs refuse to prescribe hormones when asked to by the GIC. As part of the ongoing holistic care of a trans person it is important that GPs are involved with the hormone regime as they are able to provide more local and personalised care.

5.5 Length of Time to First Appointment - 18 Week Wait

As mentioned in **section 4.2.3**, although the 18 week wait was not in force during the time of the survey, it is likely that the length of time to first GIC appointment will be measured from the GP referral. Currently, the GP will initially refer the patient to the local psychiatric service. A further referral is then needed from the local service to the GIC. It is clear that delays may arise in this two step referral process. As previously mentioned this process may begin to change but it is likely to take time and clarification is required in the short term. The role of the local psychiatric services may need to be clarified where there are co-existing mental health problems that may influence both the onward referral and patient pathway.

5.6 Discrimination

As was shown in **section 4.7.2**, trans people experience serious problems with discrimination: this is seen both in employment which contravenes the Sex Discrimination Act 1975 (Sex Discrimination (Gender Reassignment) Regulation 1999) and in health care. A recent amendment to the Sex Discrimination Act, the Sex Discrimination (Amendment of Legislation) Regulations 2008, has come into force which now extends the prohibition of discrimination on the grounds of gender reassignment to the provision of goods facilities and services including health care.

5.7 Service Improvements

It is clear that serious problems existed with NHS transgender services in the past which was a key reason for commissioning this survey. Equally, however, there is now evidence that steps have been taken to shorten waiting times and improve staffing levels in NHS GICs and that is supported by comments that have come out of this survey.

> "Recent experience of the Charing Cross clinic through friends who have had their ops in the last 8 months suggests that treatment (including post-op) for their NHS patients is now much improved and more user-friendly than before."

As mentioned before, it is important that this work continues and that development is monitored through ongoing audit programmes and patient and public involvement. Given that this survey and other recent studies have identified examples of a postcode lottery and discrimination in accessing healthcare it would appear that a national review of this service would be beneficial. This multidisciplinary review could encompass the development of a best practice model for commissioning which enables flexible, patient-centred, individual needs based care pathways incorporating local and specialised providers. It could also consider developing guidance on minimum standards of practice and behaviour for those providers. This may include the development of key performance indictors to increase transparency and accountability.

On a more general note, given the lack of knowledge evident in many areas of the NHS and cases of discrimination found, it may be that a more fundamental change is required with trans awareness being incorporated into general medical training for all doctors. This may raise awareness of not only the issues faced by this patient population but also the tools and resources available to health professionals. The Valuing Diversity Resource Guides[6] commissioned by the General Medical Council (GMC) address many issues around diversity and equal opportunities and it would seem a logical extension to cover trans issues in the same way.

6. Conclusions

The survey has provided important baseline data including the fact that, despite their journey, 98% of respondents were happy with their outcomes. This tallies with the recent pan-Europe survey 'Transgender Euro Study: Legal Survey and Focus on the Transgender Experience of Health Care'[7] which was carried out across 27 countries, in 14 languages and had over 2,500 responses.

The results of this survey have not bought up any new areas of concern. On the contrary they have confirmed anecdotal accounts and therefore it is useful to have performed this survey. The results will enable commissioners and healthcare service providers to work on the areas of concern that have been identified and monitor future performance in a more focused manner.

The study has highlighted the importance of primary care practitioners providing more holistic care from initial contact, which is often a significant moment in the decision to transition and can impact on the entire treatment pathway, referral to tertiary services, prescription of hormone therapy and long term health monitoring. It is clear that often a lack of knowledge has inhibited this process and damaged perceptions of the service so the importance of better education for general practice surgeries and the use of available tools and information cannot be overstated.

The NHS must provide a service that is easy to access so that vulnerable patients do not feel forced to turn to DIY remedies such as buying drugs online with all the risks that entails. Patients must be able to access professional help and advice so that they can make informed decisions about their care, whether they wish to take the NHS or private route without putting their health and indeed their lives in danger.

This survey would not have been possible without a grant from SOGIAG which enabled the survey to be rolled out nationwide and a donation from GIRES to develop the online facility.

7. Recommendations

7.1 Primary care

1. The Royal College of General Practitioners (RCGP) must work to raise awareness amongst its members of all aspects of gender variance through education and training for GPs and make use of all available facilities such as online tools.

2. It is understood that most GPs will see only a few cases of gender variance but they must aim to provide a full spectrum of care that allows open and frank discussion whatever the nature of the variance without fear of prejudice. This includes familiarisation for all primary care staff not just clinicians.

3. GPs should provide holistic care for transgender patients which includes: support for other family members; counselling and expectation management; long term health needs such as screening and hormone therapy prescription and monitoring.

7.2 Capturing Patients Numbers and Experience

4. More work needs to be done to validate the numbers of people coming through the service as this was not captured in this survey.

5. As this survey has captured so much data direction should be given by EHRG as to where to focus future audit work.

6. GICs currently carry out local audit as part of clinical governance arrangements but clinicians and commissioners need to work to widen the scope of this activity to encourage multi-centre audit, patient satisfaction surveys and PPI. This may also encompass the development of and measurement against key performance indicators.

7.3 Discrimination

7. Despite the work done by many parties including SOGIAG, the EHRG, patient and support groups and individuals it is clear that transphobic and discriminatory behaviour occurs. The Department of Health must work across all levels of the NHS and with Government to implement training of employers in the appropriate legislation.

8. To further this aim the GMC should work with other agencies such as the Postgraduate Medical Education Training Board (PMETB) and the RCGP to define minimum standards of best practice and eventually incorporate trans awareness into general medical training for all doctors.

7.4 Commissioning

9. A national level review should be initiated to develop appropriate best practice for commissioning of trans gender services to remove the postcode lottery that appears to exist for service users. This commissioning framework should be capable of procuring a diverse range of services (national and local, NHS and private sector as appropriate) to provide a flexible, patient centred, multi-disciplinary, individual needs based approach to care.

10. Specialised commissioners should work together with PCTs to eliminate the current postcode lottery in funding and create clear and equitable criteria for funding. They should investigate all avenues including, where appropriate, funding care through private clinics to reduce waiting times.

11. Specialised commissioners should continue to review and implement as appropriate how the 18 week referral to treatment target is applied for patients going through the gender confirmation process. If practicable a national definition should be developed with a clear definition of how the 18 week target applies to this service.

8. Action Plan

		Priority		
		High	Med	Low
1.	The survey report will be on the Department of EHRG web page and will be summarised in the Equality and Human Rights Bulletin. **Equality and Human Rights Group, AIAU**	✓		
2.	EHRG to link with the RCGP regarding development and distribution of education and training materials and tools. **Equality and Human Rights Group, RCGP**		✓	
3.	GICs to develop an ongoing programme of audit and Patient Satisfaction Survey. **GICs, Specialised Commissioners**	✓		
4.	The GMC to work with other agencies to develop minimum standards for best practice and eventually embed trans awareness in general medical training. **GMC, RCGP, PMETB**		✓	
5.	AIAU re-audit to be informed by EHRG. **Equality and Human Rights Group, Specialised Commissioners, AIAU**		✓	

9. Dissemination

This report will be disseminated within London, Kent, Surrey, Sussex, Essex, Bedfordshire and Hertfordshire unless other wise stated:

A Full report to: SOGIAG members; GIC Leads; Royal College of Psychiatry; Royal College of General Practitioners; The General Medical Council; GIRES; Press for Change; The Gender Trust; FtM Network; NSG Leads; Julia Stallibrass, Head of Specialised Commissioning, NSCG; Acute Trust Medical Directors, Clinical Governance Leads and Clinical Audit Managers; PCT Chief Executives; SCG Directors of Public Health; SHA Directors of Public Health and any other persons who have expressed an interest in this report.

An Executive Summary to: Strategic Health Authority and Acute Trust Chief Executives.

Recipients of this report are encouraged to disseminate the report more widely.

The full report will be available on the NHS web site: http://nww.esussexaiau.nhs.uk

10. References

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Appendix A

Population Levels and Service Demand

Population levels and service demand – Christine Burns

Population estimates for transsexual people are based on published research in The Netherlands[1] and Scotland[2] over the last decade, combined with available data from Government agencies that deal with changes of name and gender (e.g. DWP, Passport Agency, DVLA). There are no corresponding reliable estimates for the number of people who consider themselves transgender, since their existence as a group has only recently begun to be appreciated.

In 2005 the former Women and Equality Unit indicated that there are an estimated 5,000 transsexual people in the UK[3] – although it should be noted that this includes those who (statistically) are predicted to seek help in the future, those who are already undergoing treatment and those who have completed treatment for their gender issues.

In other words, this should not be confused as either the number who have already undergone reassignment or the number who are going to present for treatment. It is merely an estimate of the total population.

The Charing Cross Gender Identity Clinic reports that it receives around 500 new referrals every year and has 2,000 patients on its books at any point in time. The principal private clinic dealing in gender identity issues also reports seeing an average of 300-350 new patients each year. Overall, this suggests a total volume of new cases annually amounting to around 8-900 per year.

However, ministers have also confirmed to Parliament that only 99 NHS gender reassignment surgeries were carried out in the last year for which statistics are available[4].

[1] Van Kesteren PJ, Gooren LJ, Megans JA, *An epidemiological and demographic study of transsexuals in The Netherlands*, Arc Sex Behav. 1996 Dec;25(6):589-600. This research provides the longstanding statistic that gender identity disorder affects 1 in 11,900 of the adult population (rounded in some accounts to 1 in 11,500)

[2] Wilson P, Sharp C, Carr S, *The prevalence of gender dysphoria in Scotland: a primary care study*, Br J Gen Pract. 1999Dec:49(449):991-2. This broadly supports the Dutch figure with a population estimate of 1 in 12,500 of the adult population

[3] *Gender Reassignment – A Guide for Employers*; Women & Equality Unit (DTI); January 2005; Page 5

[4] Hansard 27th Feb 2006 Col 446W. "Jane Kennedy: In 2004–05, there were 99 combined operations for transformation from male to female and zero combined operations for transformation from female to male.

The Gender Recognition Panel (GRP), which administers applications for legal recognition under the Gender Recognition Act, reports that over 2350 requests had been received since the enabling legislation came into force in April 2005[5]. Of these, 97% of applications are successful, including many from people who, at the time, are still waiting for NHS surgery[6]. The GRP also reports that an average of 25 fresh applications are received every month now that the initial backlog has been dealt with. This appears to indicate that the overall number of people completing care by permanent gender role change is around 300 each year. Contrasting that number with the official figures for NHS surgeries would suggest that a disproportionate number of patients obtain surgery by private means, regardless of whether they started NHS care or not.
All these statistics need to be interpreted according to the appropriate circumstances:

- The prevalence ratio of around 1 in 11,500 of the general population provides a crude means of estimating the likely numbers of pre and post-operative transsexual people within the adult population.

- The population estimate of 5,000 people is relevant when considering the level of the trans community need for health and social care services. The number also provides an indication of the numbers of people likely to have a transsexual relative. In other words, the number of parents, aunts, uncles, sisters, brothers and children with a trans person in their life is likely to run into several tens of thousands.

- The 500 pa figure for Charing Cross gender clinic referrals and the level of 25 gender recognition applications per month are both indicative of the numbers who are likely to present for and complete NHS care in England and Wales each year. In practice it means that the average PCT is likely to see few new cases annually. In turn this means that timely and clinically appropriate provision for the needs of such patients is never going to have a significant impact on budgeting. Savings are far more likely to be found through creative approaches to commissioning – especially with a view to making greater use of local resources to cover care needs. Remember that innovation of this kind is positively encouraged as part of World Class Commissioning (using strategies to deal with the market and meet demand).

[5] The figure from the GRP as at 18th Mar 2008 was 2366 applications. Only 72 of these had been refused (3%).
[6] Genital reassignment surgery is not an absolute pre-requisite for legal recognition, although it is generally expected that most applicants will have undergone such treatment unless medically contraindicated. The Gender Recognition Panel has accepted several applications where surgery has been agreed but delayed for funding reasons. It is reasoned that NHS delays are beyond the applicant's control and that they do not constitute a reason for delaying access to the important rights conferred to transsexual people by legal recognition.

Appendix B

Audit Proformas

Audit Questionnaire - Both Genders

Thank you for participating in this questionnaire. There are 6 sections, which may take up to 30 minutes. Please answer this questionnaire first and then go on to the gender specific questionnaire.

Please use an extra sheet at any point in the questionnaire where you wish to answer more fully

Section 1: Your Details

1. What is your date of birth? .....

2. Which sex was recorded on your birth certificate?

   Male ☐ Female ☐

3. What is your post code? .....

4. What is your ethnic origin? (Please tick one only.)

White British	☐	Indian	☐	Caribbean	☐	Chinese	☐
Irish	☐	Pakistani	☐	African	☐		
		Bangladeshi	☐				
Other white background			☐	White & Black Caribbean			☐
Other Asian Background			☐	White & Black African			☐
Other Black background			☐	White & Asian			☐
Other mixed background			☐				
Other Ethnic Group			☐				

Section 2: Referral, Assessment and Starting Treatment

5. What was the date of your first GP appointment in relation to your gender identity concerns (dd/mm/yy if known)?

   .....

6. Before being referred to the clinic you are currently using, were you initially referred to a local psychiatrist/psychologist about your gender identity concerns?

   Yes ☐ No ☐

   If no please explain why below:

7. If yes, on what date did you see the local psychologist/psychiatrist (dd/mm/yy if known)? .....

8. If you were not referred to a local psychologist/psychiatrist , were you referred by your GP, initially, to a specialist Gender Clinic (GIC)?

   Yes ☐ No ☐

9. If you were not referred to a local psychologist or psychiatrist or a GIC what action did your GP take? (Please tick all that apply.)

Nothing – GP refused to treat me. ☐
Nothing – I ended up seeing another GP to refer me to a local psychiatrist / psychologist or specialist GIC. ☐
Nothing – I paid for a private referral instead. ☐
Referred me to a local counsellor. ☐
Recommended inappropriate treatment (i.e. antidepressants). ☐

10. If your GP did not refer you, who did refer you to a GIC?

.....

11. Whoever referred you, how many times did you see this person before they referred you to a GIC?

.....

12. Which GIC did you attend?

Charing Cross	☐	Leeds	☐
Sheffield	☐	Bristol	☐
Leicester	☐	Brighton	☐
Nottingham	☐		

Other (please state): .....

13. On what date did you first attend this clinic (dd/mm/yy if known)?

.....

14. How long from being referred to the GIC did you wait for your first appointment?

.....

15. How long did your first appointment with a Gender specialist psychiatrist last? (Please tick one.)

Less than 10 mins	☐	Less than 15 mins	☐	Less than 20 mins	☐
Less than 30 mins	☐	Less than 40 mins	☐	Less than an hour	☐
More than an hour	☐				

16. How many times did you see someone at the GIC before you were provided with hormone therapy?

Once ☐ Twice ☐ Three times ☐ Four times ☐

17. Did any of the following offer you a referral for counselling?

GP ☐ Psychiatrist ☐ Not offered counselling ☐

Other (please state): .....

18. Before hormone treatment was started was any form of health check carried out and did this include baseline hormone levels or other blood tests?

Health Check:		Yes ☐	No ☐	
Baseline Hormone levels tested:	Yes ☐	No ☐		
Other Blood Test/s:	Yes ☐	No ☐		

Other, please state: .....

19. Did you see an endocrinologist (a specialist in hormones) prior to starting hormone treatment?

Yes ☐ No ☐

20. After starting hormone treatment did you see the endocrinologist again?

Frequently ☐ Rarely ☐ At least once ☐ Never ☐

21. On what date did you transition to live permanently in the gender opposite to that stated on your original birth certificate (dd/mm/yy)?

.....

22. How many transgender related surgeries have you had? Please tick all that apply and give approximate dates.

Male to female trans woman	Date
Breast augmentation	☐
Orchidectomy (to remove the testicles)	☐
Penectomy (to remove the penis)	☐
Vaginoplasty (to create a vagina)	☐
Full vaginoplasty (all of the above - orchidectomy, penectomy and vaginoplasty - in one surgical procedure)	☐
Other operation (please describe):	☐
Female to male trans man	☐
Bilateral mastectomy (to remove the breasts and to sculpt a masculine chest)	☐
Other operation (please describe):	☐

23. Are you still seeing a Gender specialist psychiatrist on a regular basis?

Monthly	☐	Every 3 months	☐	Every 6 months	☐
Yearly	☐	No	☐		

24. Is this your choice?

Yes ☐ No ☐

25. Notwithstanding any future gender related surgery you may need (eg phalloplasty, vaginoplasty) do you consider your need for psychiatric monitoring to be finished?

Yes ☐ No ☐

26. Do you still attend a specialist Gender clinic on a regular basis?

Yes ☐ No ☐

Please comment further below:

27. At any stage in your treatment were you given the opportunity to have a family member/partner present? (Please tick all that apply.)

With the GP ☐ At the GIC ☐ With the hormone specialist ☐
With the surgeon ☐ Never ☐

28. If you did not have this opportunity would you have liked to have been able to involve a family member/partner in your treatment?

Yes ☐ No ☐

Section 3: Your GP

29. Did/do you feel your GP was able to adequately support and help you in your decision to seek gender reassignment?

Always ☐ Sometimes ☐ Never ☐

30. If no, did you change your GP because of this?

Yes ☐ No ☐

Please explain below and state whether or not you changed your GP more than once:

31. When you saw your GP did/do you feel they address/ed your needs appropriately?

Always ☐ Sometimes ☐ Never ☐

If no please explain why below:

32. When you first went to your GP did you already think of yourself as transsexual?

Yes ☐ No ☐

33. Did you have a clear idea of what treatment you wanted?

Yes ☐ No ☐
Please explain below:

34. Was/is your GP knowledgeable of treatment for trans people?

Yes ☐ No ☐

35. Did your GP explain what treatments were available?

Yes ☐ No ☐

36. Did/does your GP accept the information you provide concerning appropriate treatments and/or operations?

Yes ☐ No ☐

37. Did/does your GP understand that you will require hormone supplementation for life?

Yes ☐ No ☐

38. How many appointments, relating to being trans, did you have to have with your GP before a referral was made to a psychologist/psychiatrist?

One ☐ Two ☐ Three ☐ Four ☐

39. Did your GP talk to you to see whether you had any other immediate health care needs arising from your gender issues? (e.g.: depression or anxiety)

Yes ☐ No ☐

40. Did/does your GP maintain and/or encourage regular further appointments with him/her?

Yes ☐ No ☐

41. Did/does your GP regularly keep in touch with the specialist GIC care providers?

Yes ☐ No ☐

42. Relating to your gender identity, what was your worst experience with your GP?
Please describe:

43. Relating to your gender identity, what was your best experience with your GP?
Please describe:

44. Did your GP at any stage refuse to prescribe you hormones even though the psychiatrist/psychologist had said they were in favour of prescribing them?

Yes ☐ No ☐

45. If yes, what reason was given? (Please tick any that apply):

A question over your mental state ☐
A question over your physical state ☐
A question of another illness ☐

Other reason given (please state): .....

46. Do you feel your GP has ever been reticent in supporting your need for reconstructive genital surgery?

Yes ☐ No ☐ N/A ☐

47. Did you move home before you had obtained your desired final surgery, so that your new GP came under another Healthcare Trust?

Yes ☐ No ☐

48. If yes, did you experience any difficulties continuing your treatment after this change of GP?

Yes ☐ No ☐ N/A ☐

If yes please describe below:

49. Does your GP ensure you are on relevant health screening programmes?

Yes ☐ No ☐

If no, do you know why? Please comment:

Section 4: Your experience at a Gender Identity Clinic

50. Did you have to sign any written agreement of terms under which treatment would be provided?

Yes ☐ No ☐

51. If yes, were you able to contribute and say what should be in the agreement so that you felt that the agreement took notice of your individual circumstances?

Yes ☐ No ☐ N/A ☐

52. If you did not sign any such agreement that was put before you, were you still able to progress with your treatment under that clinic?

Yes ☐ No ☐ N/A ☐

53. Other than psychiatric appointments, what other services did the gender clinic offer? (Please tick all that apply.)

Voice therapy	☐	Electrolysis or laser hair removal	☐
Dress and deportment classes	☐	Blood tests	☐
Counselling	☐	Group therapy	☐
Support group meeting	☐	None	☐

Other (please describe):

54. Approximately how many times in total did you attend a psychiatric session during your treatment at the gender clinic?

55. Were any appointments ever cancelled by the gender clinic?

Yes ☐ No ☐

56. Were you given sufficient notice if this happened?

Yes ☐ No ☐

If no please give details below:

57. When making the appointment were your personal circumstances taken into account e.g. travel times to the clinic, if you have a disability and so may experience difficulties with public transport or if you would have to arrange an overnight stay?

Yes ☐ No ☐

58. During your visits to the clinic, how many different psychiatrists did you see?

One ☐ Two ☐ Three ☐ More than three ☐

59. Did/do you have a lead psychiatrist in charge of your case?

Yes ☐ No ☐

60. If yes, did/do you feel that your regular psychiatrist was supportive and knowledgeable about your specific needs?

Yes ☐ No ☐ I do/did not have a regular psychiatrist ☐

61. Were there any medical, nursing or other staff at the GIC whose responsibility it was to explain all your treatment options to you?

Yes ☐ No ☐

62. At the GIC, were you given an opportunity to discuss your personal preferences for different treatments you wished to undertake?

Always ☐ Sometimes ☐ Never ☐

Please give details below:

63. Did you feel your preferences for different treatments were taken into account when the psychiatrist reached their decision as to what hormones you might have or which surgeon you would be referred to?

Always ☐ Sometimes ☐ Never ☐

Please give details below:

64. Did the GIC require you to see a second psychiatrist for his/her opinion before you would be prescribed hormone treatment?

Yes ☐ No ☐

If yes, how long was it between seeing the first and the second psychiatrist?

65. Who initially decided what hormones and dose you could have? Please tick one box:

GP ☐ Psychiatrist ☐ Endocrinologist ☐

Other (please state):

66. Did the GIC insist you have separate counselling sessions?

Yes ☐ No ☐

67. Did you receive separate counselling and if so from whom? (Please tick all that apply.)

No counselling ☐ Other gender specialist ☐
Psychiatrist ☐ Non specialist counsellor ☐

68. At the GIC, were you told of any meetings or forums for service users or patient groups within the clinic?

Yes ☐ No ☐

If yes, were you given the opportunity to find out more and get involved in this group or forum?

Yes ☐ No ☐

69. Did the psychiatrist at the GIC give you enough support (e.g. by writing regularly to your GP, writing a letter so you could change your name or writing letters confirming treatment for your workplace)?

Always ☐ Sometimes ☐ Never ☐

70. If you had already largely started living in your preferred gender role before your first appointment at the GIC was this recognised by the clinic?

Yes ☐ No ☐ N/A ☐

Please give details below:

71. If you had already started living permanently in your new gender role (transitioned) before your first appointment at the GIC was this accepted as satisfying some or all of the Real Life (test) Experience?

Yes ☐ No ☐ N/A ☐

Please give details below:

72. If you had not started living permanently in your new gender role (transitioned) before your first appointment at the GIC do you feel the GIC did everything it could to make the experience as positive and simple as possible?

Yes ☐ No ☐ N/A ☐

Please give details below:

73. Did/do you feel you had/have the power to make decisions about your treatment so long as you understood the implications and the risks involved? (i.e.: that you were able to give informed consent to treatments, for example you knew the risks of hormone therapy whilst smoking.)

Yes ☐ No ☐

74. Did/do you ever feel that you had/have to keep any part of your sexuality, personal behaviour(s) or lifestyle secret because if known, it would result in either treatment not starting or being stopped?

Yes ☐ No ☐

If yes please explain why below:

75. How do you feel about the psychiatric sessions you underwent? (Please tick whichever option best describes your opinion.)

Really helpful ☐ Obstacle to overcome ☐
Necessary ☐ Both good and bad aspects ☐

76. At your first appointment at the GIC, did someone explain to you the criteria that would be applied before they would refer you for any gender reassignment (GR) surgery?

Yes ☐ No ☐

If yes, later on, did you feel that the criteria as explained were applied?

Yes ☐ No ☐

77. Did you have to ask for a surgical referral for your first operation?

Yes, had to ask ☐ No, was offered without me having to ask ☐

78. Were you offered a choice of surgeons for the type of surgery being considered?

Yes ☐ No ☐

79. Please tick any operations where you were offered a choice of surgeon:

Male to female - trans woman

Breast augmentation ☐
Orchidectomy (to remove the testicles) ☐
Penectomy (to remove the penis) ☐
Vaginoplasty (to create a vagina) ☐
Full Vaginoplasty (the above; orchidectomy, penectomy and vaginoplasty in one surgical procedure) ☐

Other operation: .....

Female to male - trans man

Bilateral mastectomy (to remove the breasts and to sculpt a masculine chest) ☐
Vaginectomy (to remove the vagina) ☐
Phalloplasty (to create a penis) ☐

Other operation: .....

Please give details of hospital used and any choices you were given:

80. Did your psychiatrist at the GIC refer you to the surgeon, or did you have to ask your GP to refer you onwards to the surgeon?

Referred direct from GIC ☐ Had to go back to GP ☐
Other (please state):

.....

81. If you can, please list the length of time between the first and second referral for the different surgery/ies? (Please give approximate waiting time and date of operation(s).)

Male to female trans woman	Length of time between referrals (months)
Breast augmentation	
Orchidectomy (to remove the testicles)	
Penectomy (to remove the penis)	
Vaginoplasty (to create a vagina)	
Full Vaginoplasty (all of the above - orchidectomy, penectomy and vaginoplasty - in one surgical procedure)	
Other operation (please describe):	
Female to male trans man	

Bilateral mastectomy (to remove the breasts and to sculpt a masculine chest)
Vaginectomy (to remove the vagina)

Phalloplasty (to create a penis)

Other operation (please describe):

82. At the GIC, did anyone discuss with you the potential problems associated with surgery including surgical and psychological outcomes?

Yes ☐ No ☐

83. At the GIC, did anyone discuss with you and explain to you what the effects of genital surgery on your sex life may be?

Yes ☐ No ☐

84. After your first visit to the GIC did you go back for any more appointments to continue with your treatment /transition?

Yes ☐ No ☐

85. If no, why not? (Please tick one only.)

They refused to see me again. ☐
I chose not to go back as I did not like it there. ☐
I decided I did not want to continue treatment. ☐

Other (please explain): .....

86. Overall, were you happy with the service you received at the GIC?

Yes, totally ☐ Yes, there was more good than bad ☐
No, there was more bad than good ☐ No, not at all ☐

Section 5: Hormone Therapy

87. On what date did you first receive hormones? .....

88. Do you feel you should have been prescribed hormones sooner than you were?

Yes ☐ No ☐

89. Please give details of your hormone regime (please list drugs taken and dosage):

90. Have you used GnRH analogue?

Yes ☐ No ☐

91. Have you had any medical or other problems of any kind associated with your hormone therapy?

Yes ☐ No ☐

If yes, please explain exactly what the problem was and what the hormone concerned is known as (e.g. peaking on Sustanon, polycythemia, or too low a dose of Oestradiol for change to occur etc):

92. Was this problem with your hormone therapy sorted out to your satisfaction?

Yes ☐ No ☐

93. Do you feel satisfied and healthy with respect to your hormone regime?

Yes ☐ No ☐

If no, why not and how do you think this could be improved? Please explain:

Section 6: Funding

94. Was the question of funding ever raised by your GP?

Yes ☐ No ☐

95. Did your GP ever suggest treatment could not be funded or that it was against local funding policy to provide treatment?

Yes ☐ No ☐

96. When you were first referred to a GIC, were any issues raised regarding funding being available for this appointment?

Yes ☐ No ☐

If yes please explain what reasons were given for funding not being available:

97. Was funding readily available for hormone treatment?

Yes ☐ No ☐

If no please explain why below:

98. When you were told you would be referred for surgery, were you told the waiting list times for surgery/ies?

Yes ☐ No ☐

99. If yes, what were the waiting list time(s)?

Male to female trans woman	Waiting times
Breast augmentation	
Orchidectomy (to remove the testicles)	
Penectomy (to remove the penis)	
Vaginoplasty (to create a vagina)	
Full Vaginoplasty (all of the above - orchidectomy, penectomy and vaginoplasty - in one surgical procedure)	
Other operation (please describe):	
Female to male trans man	
Bilateral mastectomy (to remove the breasts and to sculpt a masculine chest)	
Vaginectomy (to remove the vagina)	
Phalloplasty (to create a penis)	
Other operation (please describe):	

100. If you have had NHS surgery(ies) how long did you actually have to wait after referral?

Male to female trans woman	Actual time waited
Breast augmentation	
Orchidectomy (to remove the testicles)	
Penectomy (to remove the penis)	
Vaginoplasty (to create a vagina)	
Full Vaginoplasty (all of the above - orchidectomy, penectomy and vaginoplasty - in one surgical procedure)	
Other operation (please describe):	
Female to male trans man	
Bilateral mastectomy (to remove the breasts and to sculpt a masculine chest)	
Vaginectomy (to remove the vagina)	
Phalloplasty (to create a penis)	
Other operation (please describe):	

101. From the beginning, did you choose to use private treatment rather than NHS treatment?

Yes ☐ No ☐

If yes please explain why you chose to go privately rather than go through the NHS?

102. If you originally intended to use the NHS for your gender reassignment (GR) treatments, did you ever have to pay to see a GP and/or psychiatrist, counsellor or any other health professional privately in order to either obtain or progress your GR treatments? (Please tick all that apply.)

No ☐ First referral ☐ Second referral ☐ Surgical consultation ☐

Please give more details of who you saw and why:

103. When you were referred for surgery at any point were you told that funding was not available for:

The surgery itself?	Yes	☐	No	☐
The surgeon you had chosen to go to?	Yes	☐	No	☐

If yes to either, was funding agreed after an appeal?

Yes ☐ No ☐

Please give details below:

104. Did you pay to have any of your operations privately? (Please tick all that apply.)

Male to female trans woman

Breast augmentation	☐
Orchidectomy (to remove the testicles)	☐
Penectomy (to remove the penis)	☐
Vaginoplasty (to create a vagina)	☐
Full Vaginoplasty (all of the above - orchidectomy, penectomy and vaginoplasty - in one surgical procedure)	☐
Other operation (please describe):	☐

Female to male trans man

Bilateral mastectomy (to remove the breasts and to sculpt a masculine chest)	☐
Vaginectomy (to remove the vagina)	☐
Phalloplasty (to create a penis)	☐
Other operation (please describe):	☐

If yes please explain why below:

Section 7: Patient Satisfaction

105. How long was the period of time between the first day of your transition to the date of your first gender reassignment surgery?

.....

106. Please rate your experiences of the Real Life 9test) Experience (RLE) on a scale of 1 to 10, where 1=very bad, 10=excellent.

	1	2	3	4	5	6	7	8	9	10
Your RLE in work	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Your RLE in public	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Your RLE with your family	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Your RLE with your friends	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Your RLE with your GP	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

107. Please use the box below to make any comments you would like to regarding your Real Life Experience.

108. Do you think your healthcare at your GP surgery could be improved?

Yes ☐ No ☐

Please comment below:

109. Do you think treatment for trans people at GICs could be improved?

Yes ☐ No ☐

Please comment below:

110. What was your worst transitioning experience? Please describe:

111. What was your best transitioning experience? Please describe:

112. Have you ever been ever made to wait for or refused treatment relating to another medical condition (other than being trans) because a doctor, nurse or other health care professional did not approve of gender reassignment?

Yes ☐ No ☐

If yes, please give details below, explaining when and where this happened and what was said or done:

113. Do you think that being trans has adversely affected the way you have been treated by doctors, nurses or other healthcare professionals?

Yes ☐ No ☐

If yes, please explain in what way being trans has adversely affected the way you have been treated by a doctor, nurse or other healthcare professional:

114. Would you describe yourself as currently being a healthy person?

Yes ☐ No ☐

If no, do you think any of your ill health is attributable to any part of your transition or new gender role medical treatment? (E.g. you may now have depression, having not suffered previously or your surgery has caused specific problems.)

115. How many years were there between first informing your GP of your gender problems until the final operation or point of closure when you felt your gender identity problems had been resolved to your satisfaction? (Please explain closure or end point for you.) If you are still undergoing treatment please go to Q116.

116. If you are still receiving treatment or waiting for further treatment or surgery(ies) and have yet to reach a point of closure please give number of years between first informing your GP of your gender identity problems and the present day. If possible please also estimate the time remaining until resolution of these problems and why they are currently unresolved.

117. Do you think that the time taken by the transitioning process has affected your life, finances, personal relationships, and work?

General life:	Yes	☐	No	☐
Finances:	Yes	☐	No	☐
Personal relationships:	Yes	☐	No	☐
Work:	Yes	☐	No	☐

If yes, please explain below:

Thank you for participating in this Audit Project. Please now complete the gender specific (MtF/FtM) questionnaire.

You may complete the gender specific questionnaire at a different time but please send them both back to us together.

Audit Questionnaire - Trans Man (FtM)

This questionnaire contains 6 sections. Not all may be applicable. Please answer all that are relevant to you and allow approx 30 mins to complete.

Please use an extra sheet at any point in the questionnaire where you wish to answer more fully.

Section 1: Your first consultation with a surgeon

1. When you saw the surgeon did he discuss each of the following with you:

   a) Surgical complications? Yes ☐ No ☐ Don't Know ☐

   b) Possible effects upon sexual function post-operatively? Yes ☐ No ☐ Don't Know ☐

   c) Possible options for types of surgery (eg phalloplasty v metoidoplasty)? Yes ☐ No ☐ Don't Know ☐

   d) The structure and function of your post-operative genitalia and possible trade-offs which might improve one aspect (eg appearance) at the cost of others (eg function)? Yes ☐ No ☐ Don't Know ☐

2. Did you feel that you fully understood the surgery prior to it being done and that you were in control of the decisions taken?

   Yes ☐ No ☐ To a degree ☐

   Please explain below any aspects about which you were unclear or of which you did not feel in control:

3. Prior to the surgery did your GP discuss your post-operative support needs with you?

   Yes ☐ No ☐

Section 2: Your experience of hospital and surgery

4. On admission to hospital did you feel you were treated throughout with dignity and respect?

   Yes ☐ No ☐

5. Did staff at the hospital make your condition widely known among other staff or patients?

   Yes ☐ No ☐

Please make any comment you feel would clarify your responses to Q4 and Q5:

6. Immediately following your surgery, during recovery from the anaesthetic, do you feel you were supported enough in terms of:

Being kept informed of what was happening?	Yes	☐	No	☐
Being informed of how surgery had gone?	Yes	☐	No	☐
Being allowed to sleep?	Yes	☐	No	☐
Being given appropriate pain control?	Yes	☐	No	☐

Please explain by noting any good points or bad points in the immediate recovery process below:

7. How many nights did you spend in hospital after surgery?

.....

8. Do you feel that you were given suitable pain control in the days following surgery?

Yes ☐ No ☐

Please explain giving medication names if known, how pain was controlled during these first few days:

9. Did you experience any complications while you were in hospital?

Yes ☐ No ☐

If yes, please explain below:

10. Do you feel that any complications that arose were dealt with efficiently and promptly?

Yes ☐ No ☐ N/A ☐

11. Did you have sufficient time after surgery to discuss with your surgeon the outcome and possible future consultations?

Yes ☐ No ☐

12. Before discharge from hospital were you given a contact point of someone who could advise if complications developed while you were at home?

Yes ☐ No ☐ Told to contact GP ☐

Section 3: Surgery you underwent

13. Have you had chest reconstruction surgery?

    Yes ☐ Am planning to ☐ No/will not be ☐

    If yes, how long did you have to wait for this surgery? .....

14. Do you feel this was too long?

    Yes ☐ No ☐ N/A ☐

15. If yes, did the delay in having this operation cause you problems when trying to transition?

    Yes ☐ No ☐

    Please explain below:

16. If you have had chest reconstruction surgery, were you pleased with the results?

    Yes ☐ No ☐ N/A ☐

    If no please explain why below:

17. If you needed scar revision were you offered it?

    Yes ☐ No ☐ N/A ☐

    If no please explain why below:

18. Have you had a hysterectomy or oophorectomy (to remove the womb or ovaries)?

    Yes ☐ Am planning to ☐ No/will not be ☐

19. If you have had a hysterectomy was the surgeon aware of what veins, skin tissue etc needed to be preserved for later use by an urologist or specialist phalloplasty surgeon to give you the option of penis construction at a future date?

    Yes ☐ No ☐ N/A ☐

20. Were these options above (Q19) discussed with you?

    Yes ☐ No ☐ N/A ☐

21. If you have had a hysterectomy, were the problems and issues involved should you then go on and have genital surgery explained to you?

Yes ☐ No ☐ N/A ☐

22. If you have not had a hysterectomy or oophorectomy, was the possible risk of ovarian, endometrial or cervical cancer, should you decide not to have them removed, explained to you?

Yes ☐ No ☐ N/A ☐

23. Have you discussed penis construction with your surgeon?

Yes ☐ No ☐

If yes, How far into your treatment was it before the possibility of phalloplasty was mentioned?

24. Did/do you feel deterred from phalloplasty or similar genital surgery?

Yes ☐ No ☐

If yes please explain why below:

Genital Construction Surgery (Not including Hysterectomy or Oophorectomy)
If you have not had any kind of genital construction please go to Question 65:

25. Have you had a phalloplasty (operation to create a penis)?

Yes ☐ Am planning to ☐ No/will not be ☐

If not, please could you give your reasons below:

26. If you have had a phalloplasty at which hospital was it carried out?

.....

27. What kind of phalloplasty did you have?

Abdominal flap ☐ Forearm flap ☐

Other (please state): .....

28. Prior to surgery was hair removal from donor site advised?

Yes ☐ No ☐ N/A ☐

29. Did you have the opportunity to see more than one phalloplasty or urology specialist surgeon before reaching your decision to have a phalloplasty or metoidoplasty (operation to create a micropenis)?

    Yes ☐ No ☐

30. What factors influenced your decision concerning the type of phalloplasty or metoidoplasty you had?

    Specialism of particular surgeon ☐
    Recommendation from clinician ☐
    Recommendation from other trans man ☐
    Potential outcome ☐
    Risks involved ☐
    Healing time ☐
    Other (please state): _____

31. How many surgeons were you referred to for phalloplasty?

    .....

32. Have you had a metoidoplasty?

    Yes ☐ Am planning to ☐ No/will not be ☐

33. If yes, what was the main reason you preferred a metoidoplasty to a phalloplasty?

34. If you have had any kind of genital surgery (i.e phalloplasty or metoidoplasty), how long including all procedures, revisions, stages and post operative remedial work was it before you had a functional penis that you are satisfied with?

    .....

35. Did you experience any complications during surgery or afterwards?

    Yes ☐ No ☐

    If yes please explain below:

36. Are you satisfied with your phalloplasty or other genital surgery?

    Yes ☐ No ☐

    If no, please explain why below:

37. Have you had a vaginectomy (to remove the vagina)?

Yes ☐ Am planning to ☐ No/will not be ☐

38. Was this your choice?

Yes ☐ No ☐

If no please explain why below:

39. If you have had a vaginectomy, are you satisfied with the result?

Yes ☐ No ☐ N/A ☐

If no please explain why below:

40. If you have had an erection device implanted are you satisfied with its functionality?

Yes ☐ No ☐ N/A ☐

If no please explain why below:

41. If you have had genital surgery can you urinate whilst standing?

Yes ☐ No ☐

If no please explain why below:

42. If no, are you content not to stand in order to urinate?

Yes ☐ No ☐

If no please explain any difficulties you may be experiencing:

Scrotoplasty and Testicle Implant
If you have not had this surgery, please go to Question 65:

43. Have you had a testicular prosthesis?

Yes ☐ Am planning to ☐ No/will not be ☐

44. If yes, how many silicon testicles do you have?

One ☐ Two ☐

45. If one, are you satisfied with the appearance of your genitals?

Yes ☐ No ☐ N/A ☐

46. If you have had a scrotoplasty are you satisfied with the surgical outcome?

Yes ☐ No ☐ N/A ☐

Section 4: Post surgery

47. Were you able to have access to your surgeon whenever you needed him/her?

Always ☐ Sometimes ☐ Never ☐

48. Were you forced by circumstances to travel in great discomfort at any time post-operatively?

Yes ☐ No ☐

49. Did you have any choice of surgeon for any of your genital operations?

Yes ☐ No ☐

If yes, which operations:

50. Would you have liked to have had the option of consulting other surgeons even if this meant travelling abroad?

Yes ☐ No ☐

51. Have you had any surgery outside of the UK?

Yes ☐ No ☐

If yes, how did your experience compare to your experience of surgery in the UK?

Better than the UK	☐	Worse than the UK	☐
Same as the UK	☐	Have not had any surgery in the UK	☐
N/A	☐		

Please note which countries you have had surgery in:

52. After the surgery when you had returned home did you feel that support was available from your GP and their practice colleagues (e.g. nurses)?

Yes ☐ No ☐

53. If yes, were you satisfied with the level of support received from your GP's practice?

Yes ☐ No ☐

Please explain below what support was provided and how well it met or did not meet your needs:

54. How long has it been since your genital surgery?

55. How long after surgery was it before you returned to your previous normal daily routine (e.g. work)?

Less than 4 weeks	☐	4 to 8 weeks	☐	9 to 12 weeks	☐
13 to 16 weeks	☐	4 to 6 months	☐	7 to 12 months	☐
13 to 24 months	☐	Over 24 months	☐	Never able to return to previous routines	☐

Please comment as appropriate below:

56. Following your genital surgery do you have a satisfactory sex life?

Yes ☐ No ☐ N/A ☐

If no, please explain why if possible:

57. Following your genital surgery do you still have sexual sensation in your micro penis (clitoris)?

Yes ☐ No ☐ N/A ☐

If no please explain why below:

58. Can you achieve climax with your penis?

Yes ☐ No ☐ N/A ☐

If no please explain why below:

59. Do you like the appearance of your penis?

Yes ☐ No ☐ N/A ☐

60. If you use public male spaces such as showers or changing rooms are you inhibited from revealing your penis due to its appearance?

Yes ☐ No ☐ N/A ☐

61. Have you had any long term complications with the outcome of your surgery?

Yes ☐ No ☐ Minor Issues ☐

Please explain any issues or complications arising from your surgery:

62. Have you needed any subsequent corrective surgery?

Yes ☐ No ☐ Anticipate/waiting for corrective surgery ☐

Please give details below:

63. Have you been/will you be able to obtain any corrective surgery you need on the NHS?

Yes ☐ No ☐ Don't know ☐

64. Did you need to have another psychiatric evaluation in order to obtain access to corrective surgery?

Yes ☐ No ☐ Had to explain that it was not appropriate ☐

Section 5: General experiences

65. Relating to your post operative care did you experience any problems whilst in hospital (this may be related to the surgery, staff or any aspect of your care)?

Yes ☐ No ☐

If yes, please give details below:

66. If you did experience problems, how do you think these issues can be overcome? Please explain below:

67. If you have not had genital surgery, how do you find sexual relationships?

No problem ☐ Difficult ☐ Avoided ☐

Impossible ☐ N/A ☐

68. Presuming distance and money are not an issue; where in the world, including the UK, do you feel is the best country to go to have genital reconstruction surgery/phalloplasty because of the excellent and speedy results that are obtained? Please explain your reasons for this choice.

69. Phalloplasty in the UK is currently carried out using multiple stages and can take up to five years or more to complete if the patient has a urinary hook up due to complications and other factors. If you are aware of the methods used in Europe, America or elsewhere and this could be made available to you would you prefer to have a phalloplasty that could produce the same results but with less down time, recovery and being off work, carried out by surgeons from those countries, if the surgeon/s from abroad were brought over to the UK?

Yes ☐ No ☐

Please explain why below and give details:

Section 6: Final Feelings

70. In hindsight, would you say that you felt you were well prepared for your surgery?

Yes ☐ No ☐

If no, please comment on your preparedness and how it might have been improved:

71 Overall, how would you describe your experience of genital surgery?

All positive	☐	Mostly positive	☐
A mixture of positive and negative			☐
Mostly negative	☐	All negative	☐

72. Finally, how would you regard your decision to have surgery and the effects of surgery in your life (please tick one box only):

Best thing I ever did	☐	A happy event	☐	A positive experience	☐
Overall the right decision	☐	Uncertain – could have got by without it	☐	Probably the wrong decision for me	☐
It left me in constant pain or disabled	☐	I wish I'd never done it	☐	I wish I could go back	☐

This concludes the audit questionnaire. Thank you very much for your time and effort you have given in participating in

Audit Questionnaire – Trans Woman (MtF)

This questionnaire contains 6 sections. Not all may be applicable. Please answer all that are relevant for you and allow approx 20 mins to complete.

Please use an extra sheet at any point in the questionnaire where you wish to answer more fully

Section 1: Your first consultation with a surgeon

1. When you saw the surgeon did he discuss each of the following with you:

   a) Surgical complications? Yes ☐ No ☐ Don't Know ☐

   b) Possible effects upon sexual function post-operatively? Yes ☐ No ☐ Don't Know ☐

   c) Possible options for types of surgery (eg peno-scrotal inversion v colo-vaginoplasty)? Yes ☐ No ☐ Don't Know ☐

   d) The structure and function of your post-operative genitalia and possible trade-offs which might improve one aspect (eg appearance) at the cost of others (eg function)? Yes ☐ No ☐ Don't Know ☐

2. Did you feel that you fully understood the surgery prior to it being done and that you were in control of the decisions taken?

   Yes ☐ No ☐ To a degree ☐

   Please explain below any aspects about which you were unclear or of which you did not feel in control:

3. Prior to the surgery did your GP discuss your post-operative support needs with you?

   Yes ☐ No ☐

Section 2: Your first experience of hospital and surgery

4. On admission to hospital did you feel you were treated throughout with dignity and respect?

   Yes ☐ No ☐

5. Did staff at the hospital make your condition widely known among other staff or patients?

   Yes ☐ No ☐

   Please make any comment you feel would clarify your responses to Q4 and Q5:

6. Immediately following your surgery, during recovery from the anaesthetic, do you feel you were supported enough in terms of:

Being kept informed of what was happening?	Yes	☐	No	☐
Being informed of how surgery had gone?	Yes	☐	No	☐
Being allowed to sleep?	Yes	☐	No	☐
Being given appropriate pain control?	Yes	☐	No	☐

Please explain by noting any good points or bad points in the immediate recovery process below:

7. How many nights did you spend in hospital after surgery?

8. Do you feel that you were given suitable pain control in the days following surgery?

Yes ☐ No ☐

Please explain, giving medication names if known, how pain was controlled during these first few days:

9. Did you experience any complications while you were in hospital?

Yes ☐ No ☐

If yes, please explain below:

10. Do you feel that any complications that arose were dealt with efficiently and promptly?

Yes ☐ No ☐ N/A ☐

11. Did you have sufficient time after surgery to discuss with your surgeon the outcome and possible future consultations?

Yes ☐ No ☐

12. Before discharge from hospital were you given a contact point of someone who could advise if complications developed while you were at home?

Yes ☐ No ☐ Told to contact GP ☐

Section 3: Surgery you underwent

13. Have you had a vaginoplasty (an operation to create a vagina)?

Yes ☐ Am planning to ☐ No/will not be ☐

14. If yes, was hair removal from donor site advised prior to surgery?

Yes ☐ No ☐ N/A ☐

15. If you have had a vaginoplasty, were you given sufficient instruction in how to dilate your vagina?

Yes ☐ No ☐ N/A ☐

16. Was your dilation regime and possible options for changes explained to you in sufficient detail prior to discharge from hospital?

Yes ☐ No ☐ N/A ☐

Please comment on any good or bad experiences relating to your responses to Q15 and Q16:

17. Was your first dilation conducted in suitably private surroundings such that your comments, instructions from staff and your reactions could not be overheard?

Yes ☐ No ☐

If no, Please explain any improvements you would have wished or problems which you felt limited your learning from that first dilation below:

18. Did you experience any complications during surgery or afterwards?

Yes ☐ No ☐

If yes please explain below:

19. Are you satisfied with your genital reconstruction surgery?

Yes ☐ No ☐

Please explain further below:

Section 4: Post surgery

20. Were you able to have access to your surgeon whenever you needed him/her?

Always ☐ Sometimes ☐ Never ☐

21. Were you forced by circumstances to travel in great discomfort at any time post operatively?

Yes ☐ No ☐

22. Did you have any choice of surgeon for any of your genital operations?

Yes ☐ No ☐

If yes, which operations:

23. Would you have liked to have had the option of consulting other surgeons even if this meant travelling abroad?

Yes ☐ No ☐

24. Have you had any surgery outside of the UK?

Yes ☐ No ☐

25. If yes, how did your experience compare to your experience of surgery in the UK?

Better than the UK	☐	Worse than the UK	☐
Same as the UK	☐	Have not had any surgery in the UK	☐
N/A	☐		

26. After the surgery when you had returned home did you feel that support was available from your GP and their practice colleagues (e. g. nurses)?

Yes ☐ No ☐

27. If yes, were you satisfied with the level of support received from your GP practice?

Yes ☐ No ☐

Please explain below what support was provided and how well it met or did not meet your needs:

28. How long has it been since your genital surgery?

.....

29. How long after surgery was it before you returned to your previous normal daily routine (eg. work)?

Less than 4 weeks	☐	4 to 8 weeks	☐	9 to 12 weeks	☐
13 to 16 weeks	☐	4 to 6 months	☐	7 to 12 months	☐
13 to 24 months	☐	Over 24 months	☐	Never able to return to previous routines	☐

Please comment as appropriate below:

30. Following your genital surgery do you have a satisfactory sex life?

Yes ☐ No ☐ N/A ☐

If no please explain why if possible:

31. Following your genital surgery do you still have sexual sensation in your clitoris?

Yes ☐ No ☐

If no, please explain why below:

32. Do you experience pain during intercourse?

Yes ☐ No ☐

33. Have you had any long term complications with the outcome of your surgery?

Yes ☐ No ☐ Minor Issues ☐

Please explain any issues or complications arising from your surgery:

34. Have you needed any subsequent corrective surgery?

Yes ☐ No ☐ Anticipate/waiting for corrective surgery ☐

Please explain:

35. Have you been/will you be able to obtain any corrective surgery you need on the NHS?

Yes ☐ No ☐ Don't know ☐

36. Did you need to have another psychiatric evaluation in order to obtain access to corrective surgery?

Yes ☐ No ☐ Had to explain that it was not appropriate ☐

Section 5: General Experiences

37. Relating to your post operative care did you experience any problems whilst in hospital (this may be related to the surgery, staff or any aspect of your care)?

Yes ☐ No ☐

If yes, please give details below:

38. If you did experience problems, how do you think these issues can be overcome? Please explain below:

39. If you have not had genital surgery, how do you find sexual relationships?

No problem ☐ Difficult ☐ Avoided ☐
Impossible ☐ N/A ☐

40. Presuming distance and money are not an issue; where in the world, including the UK, do you feel is the best country to go to have genital reconstruction surgery because of the excellent and speedy results that are obtained? Please explain your reasons for this choice.

Section 6: Final Feelings

41. In hindsight, would you say that you felt you were well prepared for your surgery?

Yes ☐ No ☐

If no, please comment on your preparedness and how it might have been improved:

42. Overall, how would you describe your experience of genital surgery?

All positive ☐ Mostly positive ☐
A mixture of positive and negative ☐
Mostly negative ☐ All negative ☐

43. Finally, how would you regard your decision to have surgery and the effects of surgery in your life (please tick one box only):

Best thing I ever did ☐ A happy event ☐ A positive experience ☐

Overall the right decision ☐ Uncertain – could have got by without it ☐ Probably the wrong decision for me ☐

It left me in constant pain or disabled ☐ I wish I'd never done it ☐ I wish I could go back ☐

This concludes the audit questionnaire. Thank you very much for your time and effort you have given in participating in this audit.