

A guide to trans service users' rights

Transgender wellbeing and healthcare



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About this publication

This publication explains your rights as a trans person when you access services in the NHS. It includes relevant law, regulations and good practice guidance relating to your care. It explains funding processes and waiting times, how to appeal against funding decisions and how to make appeals or complaints if you need to. It also suggests ways in which you can have a voice in your healthcare system.

Factors such as your family, social and work situations and the law relating to these areas of your life, impact on your general wellbeing and are therefore relevant to your medical care. These are also covered in this publication.

The information in this publication is mainly for trans people but it also includes advice for those providing care for trans people – doctors, nurses, receptionists, hospital managers, commissioners and other staff in the NHS setting. Much of this information is helpful for other non-medical agencies such as citizens advice bureaux and social services.

The publication is written by the Gender Identity Research and Education Society's team that includes doctors and trans people. All the team members have specialist knowledge and experience in the transgender field.

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Section 1 Legal aspects

1.1 Do I have the right to be treated on the NHS?

You have the right to all the treatments available to everyone else including, for instance, fertility treatments. In addition, case law in the:

North West Lancashire Health Authority v A, D and G, Court of Appeal, 1999).

confirms that the NHS should provide **treatments that include hormones and, where necessary, surgery**. These are deemed to be valid and appropriate treatments for gender variant conditions, whereas extended psychotherapy is not, on its own, a sufficient treatment.

In its judgment, the Court of Appeal acknowledged that the authorities (Primary Care Trusts) who make decisions about funding have the right to accord this treatment 'low priority'.¹ However, it would be unlawful for them to use this power in such a way as to deny gender confirmation treatment to transsexual people altogether.

For a recommended approach for commissioners of treatment, please see Parliamentary Forum on Gender Identity (2008): *for Health organisations commissioning treatment services for trans people*, available at www.gires.org.uk/genderdev.php

1.2 What is the "Duty of Care"?

Under common law the NHS is obliged to take such care towards an individual as is reasonable in all the circumstances, to avoid injury to that individual or his property.

NHS organisations are also liable for clinical negligence and for any other harm negligently caused to service users or visitors, say in a hospital setting. This means that if they do not look after you properly, either because they have done something wrong or because they have failed to do something and as a result you suffer 'harm or loss', that could be regarded as a breach of their duty towards you.

For advice regarding the 'duty of care' in all clinical circumstances, see UNISON Duty of Care Handbook: stock number 2135 (tel: 0845 355 0845) (£5 to non UNISON members) www.unison.org.uk/healthcare/pages_view.asp?did=1183 and www.unison.org.uk/healthcare/dutyofcare/index.asp

For information regarding indemnity arrangements within primary care, see: www.rdforum.nhs.uk/workgroups/primary/indemnity_arrangements.doc

¹ R v North West Lancashire Health Authority v A, D, and G (2000) 1 WLR 977

1.3 Would having a Gender Recognition Certificate make any difference to my treatment?

If you have made a successful application to the gender recognition panel (GRP) you will be granted a gender recognition certificate (GRC) under the Gender Recognition Act (GRA 2004). The number of people who have successfully applied is now (in 2008) more than 2,000.² 75% of cases are dealt with within 20 weeks of receiving an application.³ If your birth was registered in the UK you are automatically entitled to a new birth certificate. The GRC gives you the right to be treated “*for all purposes*” according to the gender role in which you now live permanently, whether or not you have had genital surgery. This may make staff more aware of using correct names and titles and more willing to give you appropriate accommodation in a hospital ward. It entitles you to special protection against information about your trans status or history being passed on to others (see *Privacy versus disclosure* at section 1.4) but it should not make any difference to your **medical** treatment.

n.b. In medical terms you, as a trans service user, may well have mixed sex characteristics. Your ongoing medical care must be provided in accordance with these, REGARDLESS of your **legal** gender status, e.g. trans women may still need prostate gland checks, while trans men do not. Both trans men and trans women may benefit from breast checks as they get older.

But, even if you do not have a Gender Recognition Certificate, it is still GOOD PRACTICE for medical and non-medical staff working in hospitals, surgeries and clinics to show the same respect for your privacy and to behave towards you as if you did have a GRC. This means that if you have changed your role permanently you should be cared for according to your ‘new’ role. (For the impact of GRCs on Genuine Occupational Qualifications in employment situations, see paragraph 1.9 below)

The Equal Opportunities Commission (now absorbed into the Equality and Human Rights Commission) also recommended that, as good practice, public authorities (and that includes the NHS) apply any provisions for transsexual people in their equality duty to people who define as transgender as well.⁴

² June 2008: up to this date there have been a total of 2373 applications (of which 21 were withdrawn). Therefore 2352 people regard themselves as having transitioned for life, although not all of these have (yet) been granted full GRCs; of the total: 95 were interim GRCs (66 were initially refused and 77 are pending).

³ Tribunals Service (2008) Business Plan for 2008–2009. Crown Copyright available at www.tribunals.gov.uk

⁴ Equal Opportunities Commission: Meeting the gender duty for transsexual staff – guidance for GB public authorities, February 2007. Available at www.equalityhumanrights.com/en/Pages/default.aspx

So, names and titles used should be in accordance with your presentation and your wishes, regardless of legal status. If there is any question about which ward you should be in, it is for the staff to discuss this with you, discreetly, and to try to reach an agreement about where you will stay. It may be that compromise will be necessary on both sides.

1.4 Privacy versus disclosure?

What doctors and medical staff need to know

Everyone is entitled to privacy as a human right.

Confidentiality and discretion are always required when caring for any service user. However, as mentioned in section 1.3, the law provides extra privacy protection under the Gender Recognition Act for those transsexual people who are applying for, or who already have, a Gender Recognition Certificate. If you are in this position, doctors, or any other members of staff working in a hospital or clinic, who pass on such information to others without your permission, risk committing a criminal offence. This is because the information is protected under the Gender Recognition Act and has been acquired in an 'official capacity'. Some limited level of privacy protection continues even if the application for a Gender Recognition Certificate is not initially successful and, as stated above, it constitutes good practice for health professionals to safeguard your privacy in all circumstances, even if you do not have a GRC.

If you have applied for, or have obtained, a GRC, medical staff are only allowed to break the privacy rule in very particular circumstances. There is no exemption 'in the public interest'.

The Gender Recognition Act's rules about 'disclosure' in the healthcare setting are as follows:

- It is not an offence under section 22 of the Act to disclose protected information if:
 - the disclosure is made to a health professional;
 - the disclosure is made **for medical purposes**; and
 - the person making the disclosure reasonably believes that the subject has given consent to the disclosure or cannot give such consent.
- 'Medical purposes' includes the purposes of preventative medicine, medical diagnosis and the provision of care and treatment.
- 'Health professional' means any of the following:

- a registered medical practitioner;
- a registered dentist within the meaning of section 53 of the Dentists Act 1984;
- a registered pharmaceutical chemist within the meaning of section 24(1) of the Pharmacy Act 1954 or a registered person within the meaning of article 2(2) of the Pharmacy (Northern Ireland) Order 1976;
- a registered nurse;
- a person who is registered under the Health Professions Order 2001 as a paramedic or operating department practitioner;
- a person working lawfully in a trainee capacity in any of the professions specified in this paragraph.

However, these exemptions should not be regarded as a licence to pass on information freely about your trans medical history.

So, whether you have a GRC or not, if doctors need to pass on your details to other doctors or medical staff, they should first ask themselves:

- Is the information regarding your present or past gender status or gender treatment relevant in the circumstances?
- What would be the *purpose* of passing on such information – is it *medically* relevant?
- Is there a way of providing information that is relevant, without necessarily referring to your trans identity or history?
- Have names and pronouns been chosen so that you are not inadvertently 'outed'?

If, for instance, you are a trans woman whose GP is referring you for carpal tunnel syndrome to another medical professional, the covering letter does not need to include the information that, as well as having a sore arm, you 'used to be a man', or 'used to be known as...', or that you 'have been treated for two years for transsexualism', yet doctors often do this.

Trans people frequently complain that letters of referral have a whole page covering the issue of gender treatment. The sore arm seems almost an afterthought.

There will be occasions where it is necessary for a doctor to indicate that you are having particular hormone treatment; however, this still does not require any specific mention of your change of gender status or transsexualism. It may well be that the hormone

information alone will indicate to the doctor receiving the letter that you are trans, but at least the essential information will have been presented in a way that is relevant to the circumstances and preserves your dignity.

It is bad practice for doctors to insist upon legal name change as a condition for providing any stage of medical treatment. Once you are living according to the new role, letters and envelopes should be addressed in accordance with your new role (unless you request otherwise).



Any disclosure that publicly indicates your change of gender status is also unacceptable. The information given in the window of this envelope is a real life example of unwarranted disclosure (the name and address have been changed). As it happens, the person to whom this envelope was actually addressed is the holder of a Gender Recognition Certificate and this public announcement broke the law.

Names and titles on medical records may also be changed at the point that you change gender role permanently, or sooner, if you request this and you are able to provide some evidence of the intended permanency of the change (see 1.5 below). Medical records may be kept electronically, or on paper, or a mix of both. Clinicians may agree to change your name and title on your electronic or paper folder or Lloyd George envelope, retrospectively, but individual notes contained within any of these may not be changed because this may put your health at risk.

(Disclosure of unwanted personal details will also be a concern of trans people, when and if the new HealthSpace electronic system is introduced. See Section 1 – Appendix 1 for details.)

[A trans man's story](#)

The date for my hysterectomy and oophorectomy had just been confirmed. I was worried that this operation, which would usually be done only on women, could cause me to be treated as a woman by hospital staff. I don't have a GRC and, in

any case, I decided that protecting my privacy now was less important than avoiding embarrassment later when I arrived at the hospital. With my agreement my GP wrote the following:

I write on behalf of my patient, Mr Phil Miles. Mr Miles is a 28 year old man. He transitioned to live as a man three years ago, and has been having hormone therapy (testosterone) for about three and a half years. His appearance and demeanour are that of a man. He has undergone chest reconstruction, and has marked facial and body hair. He does not have a Gender Recognition Certificate as he is still in a legal marriage. His husband is his next-of-kin.

He is due to undergo hysterectomy and oophorectomy on (date...) at your hospital. Mr Miles is aware that this is an unusual situation and he is concerned about his accommodation and treatment. He would obviously find it very embarrassing to be put in a completely female ward, and other patients might also be uncomfortable with his presence there.

He would be grateful if staff on the relevant ward could be made aware of the situation. I rely on your discretion and ask that this information is used on a 'need to know' basis only.

When I arrived at the hospital, I was directed, as I feared, to an all female ward, but as I arrived, a nurse came out of the ward and asked, 'Mr Miles?' Good start, I thought, Mr Miles.

The nurse allocated to me explained that the ward staff had all been made aware of my situation. I couldn't be looked after on a men's or a mixed ward because I required specialist nursing that was only available on the 'gynaecology' ward and no side rooms were available immediately. She talked about the 'intimate nature' of the surgery that I and the other patients were undergoing and how this could be awkward for all of us, including me. Between us we decided on a form of words to explain my presence in the ward that was essentially true, without 'outing' me.

The other patients were told that I was being put in the same ward because my surgery (unspecified) would be done by the same surgeon, and he preferred to have all his patients together. They were told that I would be put into a side room as soon as one was available.

On the second day, I was moved into the side-room but, to be honest, the ward experience wasn't that bad. One good thing about being on the women's ward was that nobody made the mistake of trying to get me to pee into a bottle. There were no bottles! Curtains were always drawn for intimate stuff, including when the surgeon came round with students in tow. He was actually very careful not to say

anything that gave the game away. He never mentioned gender issues; he used the right name and pronouns and didn't mention the reason for the surgery.

One of the nurses (a man), who had apparently missed the original briefing, said he didn't want to have anything to do with my aftercare as 'it' was against his religion. My special nurse told me later that the hospital manager had made it very clear that not caring for a patient was not an option and that his personal views were irrelevant and he'd better get on with it!

Generally, I felt pleased with my treatment. I was consulted, so even though the arrangements were not perfect, I was able to accept the compromise. I knew they were putting my medical care first. Correct names and titles were used whereas I know other trans people who have been wrongly addressed by medical staff. My partner was welcomed as my next-of-kin. I was impressed with the hospital management's response to the nurse who had refused to treat me.

1.5 How do I change my name?

Changing your name in the UK does not normally need any legal process. It can be done simply by adopting and using a new name (see www.communitylegaladvice.org.uk/en/legalhelp/leaflet31_1.jsp). A doctor may do this for you as far as the NHS is concerned. However, it is often a practical necessity to do this legally, so that you can manage bank accounts, driving licences etc. It will also be necessary when applying for a GRC; legal change of name may be achieved privately and inexpensively through a Statutory Declaration before a solicitor or in a Magistrates Court, or through Deed Poll. The only route for those under 16 to change their name is through Deed Poll with the agreement of those with Parental Responsibility (see footnote 11) (www.deedpoll.org.uk).

1.6 If I am applying for a Gender Recognition Certificate or for time off work, what kind of letters do I need from my doctor?

And what doctors need to know about letter-writing for trans service users

If you want to obtain a Gender Recognition Certificate (GRC) you will need letters from two gender specialists, one of whom must be a medical doctor.

The Panel needs evidence that you:

- are experiencing or have experienced gender dysphoria;
- have transitioned to live in the opposite gender role for at least two years prior to making the application; and
- intend to live for the rest of your life in the gender role in which you now live.

In addition to the 'diagnosis', the Panel needs details about your hormone treatment (including dates when you started, if available); any psychological treatment/support that you have had. Surgery is not a requirement, but where it **has** taken place, your doctor/surgeon must itemise surgical procedures giving dates where possible. The Panel will also require evidence of your continuous change of gender role (see: www.gires.org.uk/grpex.php).

If you are applying for an Interim Gender Recognition Certificate (see below), you will need exactly the same information from your doctor as for the full GRC.

Letters from doctors or chartered psychologists should include details of their qualifications and GMC/BPS/RCP registration number, and should indicate if they are gender specialist, and if they appear on the list of such specialists recognised by the GRP.

You or your doctor may find the following contacts useful:

The Gender Recognition Panel contact:

E-mail: grpinquiries@dca.gsi.gov.uk

Tel: 0845 355 5155; mail: GRP, PO Box 6987, LE1 6ZX

Advice for clinicians on providing letters for trans service users is available at:

www.grp.gov.uk/formsguidanceinformationformedicalpractitioners.htm

www.grp.gov.uk/documents/guide_med_prac_standard.pdf

The proforma provided on these sites may not provide enough space to include all the details, but they do give an indication of what is required.

If you need a letter from your doctor for time off work, explain to him or her that the paperwork needs to be written in consultation with you, so that no unnecessary and unwanted disclosure occurs. For instance, if you have already transitioned and nobody at work knows of your trans background, then your doctor should not refer specifically to the kind of surgery you are planning to undergo and should be careful about names and titles. If you need time off work for medical treatment that is not related to your gender treatment, your doctor should not refer to any gender issues. If you have transitioned full time, whether you have a Gender Recognition Certificate or not, your 'new' name and appropriate pronouns should be used, unless you stipulate otherwise.

1.7 What effect does the Gender Recognition Certificate have on marriage and civil partnerships?

Your doctor should be aware that the breakdown of close relationships is one of the greatest psychological barriers to good outcomes following transition. Professional help to work through relationship issues may be a vital ingredient of your treatment. If you are in a legal marriage contracted before the GRA was enacted, the law allows you to remain married to the same person. However, you will not be entitled to a full Gender Recognition Certificate unless you bring your marriage to an end.⁵ If you are in this situation, you may be experiencing a great deal of distress. As you work through this with your partner, you may need to explain this to your doctor and ask for some professional counselling and support. It was vitally important to all the people shown in these photographs to sustain their relationships, and they have done so, but not without pain.

⁵ A Civil Partnership would also have to be brought to an end if one party wished to obtain a GRC.



These two women are legally married. As they do not wish to annul their marriage, the woman with a transsexual history is unable to obtain a Gender Recognition Certificate.

Interim Gender Recognition Certificate

You may be considering a different solution that is just as distressing. You may obtain an interim GRC, which lasts six months, during which time you can use this certificate as grounds for ending your marriage. You may then enter into a Civil Partnership with the same person to whom you were married.



Lin and Emma are still together but, reluctantly, they annulled their marriage so that Emma could obtain a Gender Recognition Certificate giving her full legal rights. Since the annulment they have obtained a Civil Partnership.

For annulment of a Civil Partnership see

www.adviceguide.org.uk/index/family_parent/family/ending_a_civil_partnership.htm

1.8 How does employment law affect trans people as service users in medical situations and as employees in the workplace (including the NHS)?

You are likely to be expected to commit to living full-time according to the new gender role for a period of time (sometimes still referred to as the 'real life experience') before you are referred for irreversible genital surgeries.

It is therefore right that doctors should be, at the very least, aware of the difficulties that arise in the work situation. These can make it hard or even impossible for you to change your role.

The study *Engendered Penalties*⁶ found that 42% of respondents to the on-line survey complained that they felt unable to transition full-time because this might threaten their employment status. In theory, you should not be harassed or otherwise discriminated against at work. In reality, the transition period is the time when you are most at risk of verbal and even physical abuse. Even trans people working in the NHS itself are sometimes discriminated against by co-workers.

A nurse's story:

While still living as a man, I worked for five years as an SRN in a large NHS hospital that included a medical school. Before I transitioned, I started hormone treatment and had electrolysis for removal of facial hair. Some nine months later, after discussions with my hospital managers about the timing of transition and change of uniform, I transitioned from John to Joan.

I experienced difficulties on the ward where I was then working: medical students on ward rounds made jokes about me in the hearing of patients; some other nurses refused to work with me and their attitude rubbed off on the patients. One nurse actually cornered me in the linen cupboard and was threatening and abusive. I tried reporting this but the nurse concerned said I was lying, and although the managers didn't really believe her, they took a 'what do you expect' kind of attitude towards me.

I became seriously depressed and started making mistakes. I was given to understand that if I didn't resign I would be fired. I left.

The Sex Discrimination Act (Gender Reassignment) Regulations 1999

The Sex Discrimination Act 1975 had already been interpreted to provide some protection for transsexual people in the workplace,⁷ but it was updated in 1999 by the introduction of Gender Reassignment Regulations to clarify that protection for transsexual people in employment and vocational training. At the same time, the existing Genuine Occupational Qualifications (GOQs) in relation to all men and women, were extended to create some employment barriers to transsexual people. These were later amended, and those that remain are interpreted differently depending on whether or not you have a GRC (see below, page 16).

In all other circumstances, the 1999 regulations make it unlawful for an employer to discriminate against an individual on the grounds that he or she:

⁶ Whittle, S, Turner, L, Al-Alami, M (2007) *Engendered penalties: transgender and transsexual people's experiences of inequality and discrimination*. p15

Available at www.pfc.org.uk/files/EngenderedPenalties.pdf

⁷ Chessington World of Adventures v R (1997) IRLR 556 EAT

- intends to undergo;
- is undergoing; or
- has undergone gender reassignment.

An employee who is currently undergoing transition at work is, therefore, protected in the same way as a person who transitioned in the past, maybe even years before. However, the SDA does not protect other transgender people such as those who cross-dress occasionally.

The Gender Reassignment Regulations (1999) apply to employees, contract workers and those undertaking vocational training.

The regulations give protection:

- at recruitment;
- during employment; and
- when ending a job, regardless of length of service or hours worked.

Employers, including the NHS, must not treat transsexual people (as described under the 1999 regulations) less favourably than their work colleagues. Employers may be liable for the behaviour of other employees if they have not taken adequate measures to prevent discrimination, harassment or victimisation of these transsexual people.

If you are employed by the NHS and you intend to transition at work, preliminary discussions with you should include drawing up a 'memorandum of understanding' covering all issues such as: when and how co-workers are to be informed of your change of status; the timing of your transition; organising new uniform; use of changing and toilet facilities; name change; any alteration in duties; time off work and so on. The memorandum should remain open for reconsideration, as some aspects of treatment and timing may not be known, or may change. It is good practice for employers to provide diversity training that includes trans issues **for all staff** in accordance with the Gender Equality Duty (see below). Staff should be warned that any discriminatory behaviour towards trans people will not be tolerated. Unfortunately, as in Joan's case, prejudice sometimes starts at the top of an organisation. Theoretically, she was protected by the Sex Discrimination Act but, in practice she, like many trans people, felt too disempowered to pursue her situation at an Employment Tribunal.

If you are a transsexual person who has been victimised, harassed and/or unfairly dismissed, and you wish to pursue the matter through an Employment Tribunal, you will need to be realistic about the financial implications and the emotional impact on you. The process can take several years. This step should not be undertaken lightly; professional legal advice is highly recommended.

On April 6th 2008, legal protection for transsexual people was extended to include the provision of “*goods, facilities and services and premises*” under the *Sex Discrimination (Amendment to Legislation) Regulations*.⁸ This means that you must not be treated less favourably than other people when, say, looking for a room in an hotel, or being served in a shop. In hospitals and care homes, however, there is an exemption that can be brought into play as long as the discrimination is proportionate and its aim is legitimate. In the case of Phil Miles (section 1.4 above) it could be regarded as proportionate to put him in the women’s ward (moving him as soon as possible to a side room) because the aim, in his case, was to provide expert nursing that was unique to that ward. However, it would have been improper for the hospital staff to assign **all** transsexual people automatically to single-sex wards on the basis of the sex on their birth certificates.⁹

Genuine Occupational Qualifications

An employer is able to discriminate if a ‘genuine occupational qualification’ (GOQ) applies to particular tasks undertaken by any employees. For example ‘single sex’ GOQs may be invoked in cases where:

- ‘searches’, such as the police routinely undertake, are part of the job and must be done by a person ‘of the same sex’ as the person being searched; or
- intimate care is provided in a care home situation.

If you are already employed in a job that involves a GOQ and you then transition to the opposite gender role, you are entitled to be redeployed if that is deemed necessary. If an accommodation cannot be reached between you and your employer, you may be dismissed but **only** as a last resort when all other avenues have been tried.

In all these cases, including at recruitment, the employer may not use the GOQ argument to discriminate against a transsexual person where there are other employees available to do the task.

A Gender Recognition Certificate does protect you in these circumstances. For example, if you already have a Gender Recognition Certificate as a woman, then you are a woman ‘for all purposes’. This means that your employer must regard you as a woman for the purposes of establishing a genuine occupational requirement.

⁸ This update of the SDA should have occurred on 21 December 2007. Trans people who believe they have been discriminated against in terms of ‘goods, facilities and services, and premises’ after this date, but before the introduction of the amendment on April 6th may be able to take legal action. For advice contact the Equality and Human Rights Commission at www.equalityhumanrights.com/en/Pages/default.aspx

⁹ Department of Health advice on accommodating trans people in single-sex accommodation situations. Available at www.dh.gov.uk/en/Healthcare/Samesexaccommodation/SSAinpractice/DH_099088

If you do *not* have a Gender Recognition Certificate even though you may be living full-time as a woman (and possibly had gender confirmation surgery), you may be regarded as having the gender status of a man for the purposes of a genuine occupational qualification. However, this will clearly not always be appropriate or necessary, and common-sense should prevail.

The Gender Equality Duty (GED) requires all public authorities to have a Gender Equality Scheme (GES) in place (April 2007). They must also ensure that those organisations contracted to provide services for them, meet the same standards of equality as the public authority itself. The GES protects all men and women, including trans people. The Department of Health's publication on the Single Equality Scheme 2006 – 2009 includes the intention to "*develop an action plan to address discrimination against transgender people*". The scheme also includes the following:

"The Department of Health is committed to tackling gender inequalities within the healthcare sector by recognising the specific health needs of men, women and transgender people....The Department's commitment to create a patient-centred service which extends choice and is responsive to all patients and users, especially with regards to the gender perspective, will ensure that any gender differences in treatment and access are eliminated".

Email: dh@prolog.uk.com; website: www.dh.gov.uk/publications

Individual NHS Trusts are required to have their own schemes in place which they may model on that described in the Department of Health document.

1.9 What is the impact of the General Medical Council's guidance?

The General Medical Council's (GMC) guidance (in force from 2 June 2008), *Consent: patients and doctors making decisions together*, puts great emphasis on information-sharing, discussion of treatment options, tailoring information to the needs and wishes of the individual service user and the involvement of carers and families. Your doctor should have received a copy of this booklet in May 2008. The publication will also be available on the website: www.gmc-uk.org/guidance/ethical_guidance/consent_guidance/recording_decisions.asp

If you would like a copy, email the GMC at standards@gmc-uk.org

1.10 How does the Human Rights Act (HRA, 1998) protect me?

The Human Rights Act brings the Articles of the European Convention on Human Rights into UK law. The government intended that public service providers would have regard to the principles of equality and fairness embodied in the Act, when delivering those

services. The principles of human rights can also be used by individuals when seeking to improve services from public service providers.

“The language and ideas of human rights can be used to secure changes to policies, procedures and individual decisions.”

“Human rights principles can help decision-makers and others see seemingly intractable problems in a new light.”

“Human rights offer a more ambitious vision of equality beyond anti-discrimination and can help people in situations where everyone is being treated equally badly.”¹⁰

A human rights’ argument could be used, for instance, where a trans woman who has transitioned and is living permanently as a woman (without a GRC) is refused access to the ‘ladies’ toilets in a Gender Identity Clinic. Trans people who are not disabled, are often obliged to use the toilets for the disabled which singles them out as ‘different’. This offends against the principles of dignity, respect and fairness.

The Department of Health has its own publication *Human Rights in Healthcare – A Framework for Local Action*¹¹ that outlines some ‘key benefits’:

- The quality of health services will improve so that patients’ experiences reflect principles of dignity, equality, respect, fairness and autonomy.
- Uncomfortable or complex issues involving people’s rights are handled more effectively and with greater patient satisfaction.
- There will be more meaningful engagement of patients and their carers and families in the development of policy and practice.

The following two Articles of the European Convention on Human Rights are particularly relevant to trans people and they underpin the aims of the Gender Recognition Act:

- Article 8 states that everyone is entitled to “*respect for private and family life, home and correspondence*”.
- Article 12 protects the “*right to marry and to found a family, according to national laws governing the exercise of this right*”.

Article 14 can only be used in conjunction with other Articles; it ensures that all convention rights, including the two mentioned here, are “*secured without discrimination*”

¹⁰ Sceats, S (2007) The Human Rights Act – changing lives. *The British Institute of Human Rights*. Sponsored by Garden Court Chambers, London. Available at www.wlga.gov.uk/english/equalities-social-justice/new-bihr-report-the-human-rights-act-changing-lives

¹¹ *Human Rights in Healthcare – A Framework for Local Action* is available at www.dh.gov.uk/publications and you can place an order via email to dh@prolog.uk.com

on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.”

Further information is available at:

www.opsi.gov.uk/ACTS/acts1998/ukpga_19980042_en_1

1.11 How does the Data Protection Act (DPA 1998) protect me?

The Data Protection Act took effect from March 2000. It requires confidentiality of patient information processed on the internet, via e-mail and conveyed by telephone or post. It embodies the same principles as the 1984 Act. You have a right to inspect data used to identify you: names, addresses and photos, for instance, and to correct, block, remove or destroy personal details if they are inaccurate. You can ask for your data not to be processed if it causes you ‘unwarranted and substantial damage or distress’.

The Department of Health guidance on the impact of data protection in relation to medical notes, patients’ rights of access to notes and an entitlement to copies of letters between doctors, can be found at:

www.ico.gov.uk/Home/for_organisations/data_protection_guide.aspx

1.12 What does the Health and Social Care Act (HSCA 2001) mean for me?

The Health and Social Care Act means that the NHS (usually via a subcontractor) must provide an independent advocate for you, if you wish to make a complaint. This service may be especially useful for people with learning disabilities or whose language and culture differences make it hard for them to act on their own behalf. For further information on making a complaint see section 3 of this document.

Further information is also available at:

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_5133261

1.13 What are the legal limitations on treatment of children and young people in the UK?

It is usual for children and young people under the age of sixteen, to have the consent of an adult having Parental Responsibility (PR)¹² for them, for every stage of treatment.

¹² A person with Parental Responsibility (PR) will include: the natural mother automatically; the natural father, if married to the mother at the time of child’s birth or having subsequently married her, or having a section 4, 1a Order or 4,1b agreement (Children Act CA 1989); anyone with a Residence Order, s8 and s12, CA 89 or a Care Order, s31, s33(3) CA 89; anyone with a Special Guardianship Order, s14A, CA 89, an Adoption Order; or a Placement Order (s22 Adoption and Children Act 2002). Under a Placement Order the Local Authority and prospective adopters share PR, alongside any parents who have PR. The local authority determines the extent to which the PR of parents and prospective adopters is to be restricted (s25 Adoption and Children Act 2002). An Adoption Order will extinguish all PR held by anyone other than the

However, in some cases, the consent of any adult(s) having Parental Responsibility is not necessary if the young person under sixteen is deemed, by the doctor, to be 'Gillick' competent¹³ according to the Fraser guidelines.



Trans parents with their daughter. The father in this case, is also the natural mother and therefore automatically has parental responsibility for their daughter.

Fraser guidelines:

These guidelines were written in respect of contraception for young girls but they may be applied to other situations as well, including gender variant young people who seek medical intervention in the early stages of puberty. The following inferences are relevant:

- the young person understands the advice being given: benefits, risks, potential side effects and the effects of non-treatment;
- the young person will begin or continue accessing hormones (often from the internet) in an unregulated way; and
- without treatment the young person's physical or mental health (or both) is likely to suffer.

adopters. Where step-parents adopt their partners' children, partners who are the natural parent retain PR (s46 3b, Adoption and Children Act 2002).

In relation to births registered from 1 December 2003, a natural father who is not married to the mother of the child but whose name was entered on the relevant child's birth certificate will automatically have Parental Responsibility. Step parents may acquire PR under s4A (CA 89). Where step-parents adopt their partners' children, the partner who is the natural parent PR (s46 3b, Adoption and Children Act 2002).

In respect of children born before 1 December 2003, a natural father may now obtain PR by being entered on the relevant child's birth certificate at a later date, with the agreement of the mother.

¹³ 'Fraser guidelines' and 'Gillick competence' derive from a court case, *Gillick v West Norfolk and Wisbech Area Health Authority* (1986) AC112. In order for those under the age of 16 to be regarded as competent they must have, not merely an ability to understand the nature of the proposed treatment, but a full understanding and appreciation of the consequences of both the treatment in terms of intended and possible side-effects and, equally important, the anticipated consequences of failure to treat. This might apply where there is disagreement regarding treatment between the child and the parent, or other person having Parental Responsibility.

It is **extremely** unlikely that the issue of medical intervention for a young trans person would be undertaken without the consent of someone with parental responsibility. If this were to be an issue, the Fraser guidelines state that treatment may be given where:

- the young person cannot be convinced to involve parents/carers or allow the medical practitioner to do so on their behalf, and
- the young person's best interests require that treatment be undertaken without parental consent.

Gillick competence means that the young person must understand the issues, and retain the information long enough to:

- consider the information appropriately; and
- make a decision based on the information received.

After the sixteenth birthday, a young person is deemed to be competent (Family Law Reform Act, 1969, section 8). A discussion about the issue of the legal competence of young people is available at

www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1115457

The **Children Act 1989**¹⁴ introduced the concept of 'the ascertainable wishes and feelings of the child concerned (considered in the light of his or her age and understanding)' into the 'welfare checklist'; the checklist must be used in any case affecting the child's upbringing. The act also requires consideration of 'any harm which the child has suffered or is at risk of suffering.' The withholding of medical intervention for Gillick competent young trans people (under 16) who wish to have hormone-blocking treatment to interrupt physical pubertal changes, will inevitably allow the development of alien secondary sex characteristics. This causes lifelong disadvantage and, therefore, 'harm'.

The United Nations Convention on the Rights of the Child (1989) states that children have rights to: 'self-determination, dignity, respect, non-interference and to make informed personal decisions'.

1.14 [What about contact with my children after transition?](#)

Trans parents are sometimes denied contact with their children. This can have a devastating effect on service users and their ability to transition successfully.

¹⁴ The Children Act 1989 is available at:
www.opsi.gov.uk/Acts/acts1989/Ukpga_19890041_en_1.htm

If you are a trans parent who has Parental Responsibility (PR) for your child (see section 1.13 above), you do not lose this as a result of changing your gender role, having gender confirmation treatment or obtaining a Gender Recognition Certificate.

However, angry and hurt spouses and partners sometimes use the 'trans' situation to try to prevent the trans parent having a relationship with a child. Social services may intervene because they believe that a trans person should not be looking after children. In either of these circumstances, you (the trans parent) may find that you become involved in a court situation. If you are the primary carer for your child you may seek a Residence Order (under the Children Act 1989) to stabilise your situation and that of your child.

If you are not the primary carer, and you are separated from your family, then the issue may be one of contact with your children. You may need to go to court for a Contact Order (under the Children Act 1989).

Guidance relating to the Family Proceedings Court (in the County Court or the Magistrates Court) can be found at: www.gires.org.uk/courtinfo.php

Independent Cafcass officers may be asked to report to the court. Cafcass stands for *Children and family court advisory and support service*. Cafcass provides advice and support for children and their families. Its officers also provide independent advice to family courts. You can find out more about them at www.cafcass.gov.uk/



This Dad had to fight through the courts for a Contact Order, so that she could see her children

If you are a parent in this situation you may find the following article by Professor Richard Green helpful when talking to your solicitor. It shows that –

*“transsexual parents can remain effective parents and that children understand and empathise with their transsexual parent. Gender identity confusion does not occur.”*¹⁵

Dr David Freedman and colleagues have also published an article that demonstrates that –

¹⁵ Green, R (1998) Transsexuals' Children, 1998, *International Journal of Transgenderism*, 2(4). Available at www.symposion.com/ijt/ijtc0601.htm

*“children of transsexual parents are not themselves likely to develop features of gender dysphoria, nor do they experience mental health problems associated with gender identity disorder.”*¹⁶

Similarly, the long term evidence of children raised by same-sex couples demonstrates that quality of parenting is far more significant for children's psychological well-being than whether they are being raised in one type of family or another. (Golombok, S, 2000).¹⁷

Trans people have the same rights as any other individual to adopt or foster a child.

¹⁶ Freedman, D, Tasker, F, Di Ceglie, D (2002) Children and adolescents with transsexual parents referred to a specialist gender identity development service: a brief report of key developmental features *Clinical Child Psychology and Psychiatry* 7(3):423-432. SAGE Publications.

¹⁷ Golombok, S (2000) *Parenting: what really counts?* Routledge, London.

Section 1 – Appendix 1: HealthSpace

Will the proposed New NHS Care Records Service (Electronic) take away my privacy?

The possibility of electronic recording of patients' health notes on a central *HealthSpace* 'spine' has raised some concerns. However, because most doctors' surgeries depend a great deal on IT systems, service users' health details may already be available to several doctors in the same practice and, perhaps, to others in nearby practices and hospitals where such arrangements have been made by doctors themselves and their staff.

The notion of having all service users' notes available anywhere in the country is intended to make life safer. A person registered with a GP in Penzance could have a car accident in Manchester and be treated at the local Accident and Emergency, with a full knowledge of the injured person's medication, allergies and any other possible contra-indications to emergency treatment.

Key features of the proposed system are:

- The manner of rolling out this system

This system will start with Summary Care Records in limited areas but, ultimately, the process will have to be repeated to cover the entire population. You will be told when it comes to your area. Later on, detailed records will be added. It is anticipated that the programme will take several years to complete.

- How the information is recorded

Many conditions and treatments will be coded, using standard codes that are already in daily use, such as DVT (deep vein thrombosis) or PE (pulmonary embolism). Where new codes are agreed for standard common conditions service users will require a key to them so that they can understand their notes. However, these notes will still include some text to describe details of conditions and treatment and all of these data will have to be entered into the new system.

- Access to notes

You will be able to see your notes on line. If you want hard copy you should apply, in writing, to your GP or PCT (there will be a small fee)

- How will service users correct notes where errors have been recorded?

You cannot change your electronic record yourself. If you see an error you must apply to your GP.

- Is it going to be an opt-in (you choose to be on the 'spine') or an opt-out system (you will be automatically entered on the 'spine' unless you stipulate otherwise)?

It appears that the second option is preferred - you can opt out - but you are warned that this may affect your quality of care.

- Access to sensitive information

You can require that access to 'sensitive information' is blocked so that it is limited to the organisation that created the record. That information will then only be accessed with your permission or in emergencies. You cannot prevent a healthcare professional including in your records something he or she deems relevant. There will be role-based access so that receptionists, for example, will not be able to access the same level of information that a doctor could.

Your right to privacy is spelled out in the NHS leaflet *The Care Records Guarantee*, also available at:

www.connectingforhealth.nhs.uk/crdb/boardpapers/docs/crs_guarantee_2.pdf

Further information regarding the proposed HealthSpace system can be found at:

www.nhscarerecords.nhs.uk/patients/what-is-the-nhs-crs; and

www.nhscarerecords.nhs.uk/patients/frequently-asked-questions

Section 2 NHS funding processes and waiting times for trans service users

2.1 Introduction

This section describes the complexities of the funding system and provides you with guidance on how to navigate it, with minimum delay. It answers some of the questions that are typically asked by service users.

Many trans people find that they have difficulty in obtaining funding for treatment for their gender discomfort, even when they have been referred to a gender specialist. Some Primary Care Trusts (PCTs) are reluctant to pay for this treatment promptly, or even at all. If you are in this situation, it is important that you understand how the NHS funding processes work. You need to know what treatments are likely to be covered in your area (this is very variable); you need to know the factors that may delay the approval of your treatment, and what you can do to speed up the process.

2.2 What is the role of Specialised Commissioning Groups (SCGs)?

Specialised Commissioning Groups have been recently introduced, and play a significant role in deciding on policies related to the funding of treatment for unusual conditions such as gender variance (dysphoria).¹⁸ One SCG is located within each Strategic Health Authority (SHA, see Appendix 1 for populations and contact details). The role of these Groups is to develop common policies on behalf of the PCTs within the boundary of each SHA.

The SCGs enter into contracts with the providers of specialist health services (tertiary referrals). In respect of gender variance these may include the Gender Identity Clinics (probably one designated Clinic) or other gender specialists in the independent sector, as well as the units that provide surgery. These service providers have to submit tenders for the work. The contracts will state the specifications for the treatment to be provided. After the contract is awarded, the designated providers will apply for funding in respect of each referral, unless a blanket funding scheme covering all referred service users has been agreed. SCGs are permitted to award contracts, not only to private providers, but also overseas, as long as these meet contemporaneous UK standards.

¹⁸ Gender dysphoria refers to the personal experience of discomfort of a trans person. It is still the term in use by many doctors and it is also the language of the Gender Recognition Act 2004. Many trans people prefer the term 'gender variance' which just describes a gender experience and/ or presentation that is not stereotypical. Both terms are used in this document to describe those seeking, or undergoing, medical treatment, but in the broad range of gender variant experience there are trans people who do not need medical treatment.

'World Class Commissioning' should impact on SCGs in several ways. Those making decisions should be selected for their competencies that include relevant 'knowledge, skills, behaviours and characteristics'. The aims of commissioners should include long-term improved health outcomes, through good practice and a development of internal resources, as well as buying in external expertise. There is also an emphasis on 'practice-based commissioning'.

www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/index.htm

The SCG system should result in more consistent funding policies but should not be expected to increase the amount of money made available to pay for treatment since this depends on the sum allocated by the PCT.

This does not tie you absolutely to the designated service provider. If you can show reasonable grounds for choosing an alternative provider, you should put your situation, in writing, to the lead commissioner for the Transgender service within the SCG.

2.3 What is the role of the Strategic Health Authorities in funding?

There are 10 Strategic Health Authorities (SHAs) in England. They are responsible for high-level policies in the regions that they cover. They do not control the PCTs' or the SCGs' decisions regarding the treatment of any condition. An SHA may have a view that might be highly influential, but it is not binding on the PCTs.

At Appendix 2 at the end of section 2 there is a chart that summarises the process for approving, funding and providing treatment.

2.4 On what grounds could the Primary Care Trust delay or refuse funding for my treatment?

The NHS is legally required to fund treatment but PCTs are allowed to take into account reasonable local priorities. This gives rise to wide differences in local funding policies, in that there are substantial local differences in the types of treatment that are covered and the speed at which funding is approved.

In England, the Department of Health (DH) allocates the money for funding the treatment of all conditions to the 152 PCTs. The decision of the court in the North West Lancashire Health Authority case established the right to treatment for transsexualism but PCTs are still allowed to make different decisions about how they prioritise funding, provided that this is done on rational grounds.¹⁹ For instance, some Trusts have said that they are according very low priority to certain conditions because they need to cut funding in order to avoid being in deficit; and some have

¹⁹ North West Lancashire Health Authority v A, D, and G (2000) 1 WLR 977

argued that there is no evidence that the treatment is successful. You may wish to dispute this if you are appealing against a PCT decision (see Section 3).

So, in practice, the process of allocating money for treatment, as well as the actual amounts of money made available, varies. Consequently, some PCTs will fund many treatments for trans people readily but others accord all the treatments a very low priority.

N.b. Doctors are required to treat trans people for their gender variant condition but if they feel unable to do so in a sympathetic and supportive manner, then they should immediately find an alternative doctor who can.

2.5 How do the PCTs decide which treatments they will fund?

Each PCT has its own internal committee that sets priorities for spending the money that it receives from the Department of Health. Priorities are based on what the committee sees to be the most urgent needs of the local population and what is best for service users. It considers the cost of each type of treatment and examines the research evidence that demonstrates its benefits.

Because the trans population is relatively small and it is hard to predict the numbers seeking treatment for the first time each year, PCTs will not usually set a fixed budget for treating gender variant people. Instead, it will limit its spending by establishing a policy that defines the types of treatment and the maximum number of cases per year that it will treat. If this is the case with your PCT, you are entitled to see the document and to challenge it if you think it is unfair.

Generally, specialist psychiatric assessment and hormonal medication will be funded. Some PCTs are willing to fund some hair removal, especially on skin from a donor site that is to be used in later surgery; and speech therapy where it is included in the package of care provided by a Gender Identity Clinic (GIC) or a private gender specialist.

Funding for surgery is likely to be limited to what the PCT regards as 'core procedures'. This may exclude anything that the PCT deems to be 'cosmetic' or 'aesthetic' such as facial feminising surgery or, in some cases, breast augmentation for trans women, even though these procedures may help to make transition to the new gender role more successful. You may not like the terms 'core/non-core procedure' and 'cosmetic' because they imply that some treatments are more important than others, rather than considering what is important in your case and responding to that in a flexible way. However, the reality is that PCTs may insist on excluding certain surgeries. The local protocol on breast surgery, for instance, may exclude some non-trans people as well as trans people and be applied equally to both. In any case, even core procedures are likely to be limited by each PCT's

annual budget limit. Occasionally, a PCT will agree to fund private, or even overseas, surgery if the treatment matches its quality and cost standards.

2.6 The 'linear' approach versus the flexible approach to treatment

Historically, where PCTs have funded treatment, it has been according to a set 'linear' pathway that includes:

- **primary care** provided by the GP (this will be ongoing in the provision of hormone therapy and monitoring whether or not surgery is undertaken);
- **secondary care** provided by a local psychiatrist (this is a specialised mental health service) who will refer the service user to –
- **tertiary care** providing specialised care for gender variant people. This may be provided either by a Gender Identity Clinic or by an independent gender specialist approved by the PCT); and
- **tertiary care** for surgery following referral by the GIC, or independent gender specialist, to a surgical unit. Surgery may occasionally be private and even overseas; the surgical unit will require the referral to be backed by 2 opinions (for genital surgery), one of which must be from a medical doctor.

However, although elements of this approach to treatment will undoubtedly remain, the guidance in the draft *Good practice guidelines for the assessment and treatment of gender dysphoria (2006)* advocates a much more flexible approach. The Chair of the working group responsible for writing this guidance, Professor Kevan Wylie, said in the preamble:

*“We herald a new approach to care which has evolved from a linear progressive sequence to multiple pathways of care which recognise the great diversity of clinical and presentation needs”.*²⁰

This means that you may be able to obtain funding from the PCT for treatments that are:

- provided locally
- organised through your GP, who may:

²⁰ Wylie, K (2007) Preface to draft *Good Practice Guidelines for the Assessment and Treatment of Gender Dysphoria*. p6. Available at www.rcpsych.ac.uk/pdf/Standards%20of%20Care%20Draft%20v8%203b%20final.pdf

- initiate treatment (following a diagnosis) if confident to do so. The cornerstone of treatment for gender variant people is hormone therapy. This is straightforward and not costly.
- refer a service user directly to a local gender specialist; and
- make other local referrals, say for psychological support²¹ and/speech and language therapy, within the local area.

The PCT may be persuaded of the benefits of this approach because:

- it is likely to be economic because it limits the need for costly appointments at the GICs;
- it will shorten waiting lists generally and, therefore, avoid delay for individual trans service users;
- it will help to develop the expertise of GPs and other health professionals around the country; and
- it is in line with world class commissioning.

And from the perspective of you, the service user, in addition to speedier access to treatment:

- It makes a holistic approach to your treatment more likely as your GP will be familiar with you, your other health needs and your family circumstances.
- It may give you more control over your treatment by enabling you to:
 - have more choice among the different elements of treatment;
 - have more flexibility in the timing of your treatment; and
- it will eliminate the need for long and expensive journeys.

However, this localised approach might not be suitable for all service users, especially those with complex medical needs. Also, many GPs do not feel sufficiently experienced to take responsibility for treating trans people. For those doctors who are considering taking a more active role in the care of trans people,

²¹ The need for local support for many trans people cannot be overestimated. “Those who identify as trans were twice as likely to have serious thoughts of suicide, more than three times as likely to have attempted suicide in the past five years and over five times as likely to have attempted suicide in the past twelve months, than non-trans people.” Browne, K, Lim, J (2008) *Count me in too – additional findings report: mental health*, Spectrum, available at www.countmeintoo.co.uk

the DH publication *Guidance for GPs, other clinicians and health professionals on the care of gender variant people* is available in hard copy and on line at www.gires.org.uk/dohpublications.php

It may take a while for PCTs to adopt this more flexible approach and for local practitioners to build up their confidence and expertise in this field.

2.7 How do the Primary Care Trusts' funding decisions impact on waiting times?

The GIC or private gender specialist will not usually offer you an appointment until the PCT has agreed to fund it.

The PCT's decision-making process may include consideration of each individual funding application by a committee. This process may result in a delay of several months before the GIC or private gender specialist, or the surgical unit, will be able to offer an appointment.

If your PCT has a block contract with a GIC or private specialist, that contract will automatically cover the payments for appointments provided that they have been made via the local psychiatrist. If you are thought to have particular health concerns requiring an appointment with an endocrinologist, the PCT will usually fund this as part of your 'package'.

The PCT's agreement to any surgery must also be obtained before the surgical unit will offer an appointment.

Again, this may be returned to the PCT 'committee' for consideration, even though you have fulfilled the 'readiness and eligibility'²² criteria for surgery. This can cause further delay in the process.

The DH publishes a helpful guide to the way that the PCTs work on its website: www.dh.gov.uk/en/AdvanceSearchResult/index.htm?searchTerms=Primary+care+Trusts.

2.8 What effect does the 18 week target waiting time have?

The 18 week NHS target is expected to apply to treatments for gender variant conditions from December 2008. The target applies from when service users are

²² 'Readiness and eligibility' are concepts which appear in the *Harry Benjamin International Gender Dysphoria Association's The standards of care – sixth version p28,29* (2001) (recently renamed World Professional Association of Transgender Health). These criteria include: legal age; usually, a requirement of continuous hormone therapy; a substantial period of living continuously in the new gender role and reasonable mental stability.

referred by their GP, to when they receive specialist treatment.²³ This may be a direct referral to a local specialist service, or to an out-of-area provider. In the latter case, an initial local psychiatric assessment may be required, but this should also be encompassed within the 18 weeks without delaying the referral to the specialist provider.

In any event, until December 2008 the wait may continue to be at least six months for the first and then each follow-up appointment at a GIC. As mentioned above, a large part of the delay in getting a first appointment is owing to the time taken by the PCT to agree funding.

The GICs are under great pressure to meet the 18 week target for treatment so it should bring about a major improvement in waiting times. Where clinics have insufficient gender specialists to comply with the new target time they will need to engage more staff. The GIC at Charing Cross Hospital in London has already increased staffing in order to reduce its waiting times.

The waiting time for a hormone prescription varies considerably. Some gender specialists will start hormones immediately upon making a diagnosis (usually health tests are ordered ahead of, or simultaneously with, the prescription for hormones); a few gender specialists still insist that you change your gender role and live in that role (sometimes still referred to as the real life experience) for an unspecified length of time – usually until the next appointment that is sometimes several months away – before they will offer hormone therapy. If you have started self-medicating you should be brought into a monitored hormone regime in view of the uncertainty of the quality of off-prescription products as well as the need to regulate dosage and to monitor your health (see the NHS publication *A guide to hormone therapy for trans people*).

Surgery is already covered by the NHS waiting time target. You should expect any surgery within 18 weeks from the date that the GIC or private gender specialist refers you to the surgical unit.

²³ This information came directly from the National Specialised Commissioning Team (July 31 2008). However, there remains a certain amount of confusion among GICs and PCTs about how the 18 weeks is to be interpreted in relation to treatment at a Gender Identity Clinic where a preliminary assessment by a local psychiatrist is required.

2.9 What happens if I want to get *some* of my treatment from a private doctor?

The British Medical Association has issued clear guidance:

- Patients who are entitled to NHS funded treatment may opt into or out of NHS care at any stage.
- Patients who have had a private consultation for investigations and diagnosis may transfer to the NHS for any subsequent treatment.
- They should be placed directly onto the NHS waiting list at the same position as if their original consultation had been within the NHS.

Available at www.bma.org.uk/ap.nsf/Content/NHSprivate

All service users are entitled to come back to the NHS. There is not a firm policy bar on mixing NHS and private care. For example, as with any other condition, you could pay for a private out-patient appointment, for the sake of speed, but then opt for a NHS procedure. However, in the case of complex care packages involving a number of different clinicians or gender specialists, it can get more complicated.

You may find resistance from PCTs to providing further funding if you have had private treatment.

- The PCT may be reluctant to provide funding for you if you are seen to be jumping the queue. If, for example, you have paid for hormone medication privately and/or you are considered to be suitable for surgery by a private gender specialist (whether or not employed in a unit that is under contract to a SCG), but do not meet the PCT's '*readiness and eligibility*' criteria, you may be asked to undergo the usual NHS process to demonstrate suitability (this might, for instance, entail living in role for a longer period).
- The PCT would not share funding on a combination of NHS and private surgery in a single episode. For instance, if the PCT had been persuaded to fund an operation to reduce the Adam's apple (thyroid chondroplasty), this could not be combined with a self-funded reshaping of the nose (rhinoplasty).
- If you are attending a GIC, the tertiary level NHS gender specialist may disapprove of your obtaining some of the treatments elsewhere unless you have prior approval. However, if this specialist approves your choice of surgeon and believes you are ready for surgery, and you have this 'opinion' plus a second one confirming your readiness, then you may be accepted back into the NHS GIC after surgery.

Quite a few trans people have surgery abroad, sometimes without the approval of a gender specialist at a GIC. If you choose to do this, you may have some difficulty in obtaining any corrective procedure that may be necessary, from within the NHS, unless it is an emergency. For example, in a case where breast implants have become infected, there is no doubt that the NHS would remove the implants and treat the infection; however, it might not fund replacements.

If you think you may wish to use private services you should investigate the policy of your local PCT and also check the views of the gender specialists whose services you may need to access after surgery.

2.10 What can I do to speed up the process and get approval to fund my treatment?

If you are intending to have treatment within the NHS, it is a good idea to find out as soon as possible about the policy adopted by your PCT, and to identify those who will be involved in making decisions. Contact details for each PCT can be obtained via the search facility provided by the NHS at www.nhs.uk/ServiceDirectories/Pages/PrimaryCareTrustListing.aspx

You can contact your PCT by telephone and ask to speak to the people within the organisation who are involved in the process of approving treatment; or you can write explaining your situation and asking for advice. This should alert you to any funding difficulties or other reasons that might indicate the likelihood of delay.

Following notification of an appointment date at the GIC or other gender specialist, it may help if you contact the staff who make appointments. You may be able to fill a slot that someone else has cancelled.

If you need to change an appointment, you should explain your reasons in writing to avoid any misunderstanding that might jeopardise your treatment. An unexplained change might be taken as a sign that you are uncertain about starting, or continuing, your treatment. Even if you have spoken to someone on the phone and have been allocated a further appointment, it is still worthwhile writing a letter to confirm this. Keep a copy of it in case it is needed during the next visit to the GIC. For example, the letter might state:

Further to my conversation with Ms Jolly on June 3rd 2008, regarding my next appointment at the GIC that was originally scheduled for September 6th 2008, I am writing to confirm that this date conflicted with an important training course that my employer wishes me to attend. As this is vital to my career, I was obliged to cancel my appointment. It has now been rescheduled for October 1st 2007.

If you change an appointment for surgery, it is **not** necessary to wait a further 18 weeks. The time already spent waiting must be taken into account.

Delay is also caused because service users sometimes cancel appointments at the very last minute, or they simply fail to turn up. One GIC found that over the period of a single month 25% of

Section 2 – Appendix 1: Strategic Health Authorities – populations and contact details

Source: Office of National Statistics 2006 mid-year population estimates (2001 census based). UK total population: 60,587,500

N.b. Specialised Commissioning Groups are co-terminus with SHAs, but they are not necessarily under the same roof. Names and addresses of those involved in the SCGs may change.

- 1 **North East SHA** (2,555,700)
Riverside House, Goldcrest Way,
Newcastle upon Tyne NE15 8NY
Tel: 0191 210 6400
Email: enquiries@northeast.nhs.uk
Website: www.northeast.nhs.uk

SCG

Rebecca Eadie
NHS North of Tyne
Centre for Advanced Industry
Coble Dene, North Shields
North Tyneside, NE29 6DE
Tel 0191-2196016
Email: Rebecca.Eadie@newcastle-pct.nhs.uk
Tel: 0191 219 6000

- 2 **North West SHA** (6,886,600)
Gateway House, Piccadilly South,
Manchester M60 7LP
Tel: 0845 050 0194
Email: website@northwest.nhs.uk
Website: www.northwest.nhs.uk

SCG

Jon Develing
North West SCG
Quayside, Wilderspool Park, Greenalls Avenue,
Stockton Heath, Warrington WA4 6HL
Email: Jon.Develing@nwsct.nhs.uk
Tel: 01925 406125
Jenny Scott
Email: Jenny.Scott@nwsct.nhs.uk
Tel: 01925 406023

- 3 **Yorkshire and the Humber SHA** (5,140,000)
Blenheim House, West One, Duncombe Street,
Leeds LS1 4PL.
Tel: 0113 295 2000
Tel: 0114 226 4401 (Sheffield)
Email: sha.enquiries@yorksandhumber.nhs.uk
Website: www.yorksandhumber.nhs.uk

SCG

Cathy Edwards
Director of Yorkshire and the Humber SCG
c/o Barnsley PCT
Hillder House, 49/51 Gawber Road
Barnsley S75 2PY
Tel: 01226 433 742
Email: Cathy.Edwards@barnsleypct.nhs.uk
Tel: 01226 433742

- 4 **East Midlands SHA** (4,333,200)
Octavia House, Bostocks Lane, Sandiacre,
Nottingham NG10 5QG
Tel: 0115 968 4444
Email: communications@eastmidlands.nhs.uk
Website: www.eastmidlands.nhs.uk/

SCG

Kate Caston
Lakeside House, 4 Smith Way, Grove Park
Leicester LE19 1SS
Email: Kate.Caston@lcrpct.nhs.uk
Tel: 0116 295 7635

- 5 **West Midlands SHA** (5,366,700)
St. Chad's Court, 213 Hagley Road, Edgbaston,
Birmingham B16 9RG
Tel: 0845 155 1022
Email: eamonn.kelly@westmidlands.nhs.uk
Website: www.westmidlands.nhs.uk

SCG

Karen Helliwell
St. Chad's Court, 213 Hagley Road
Edgbaston, Birmingham B16 9RG
Email: Karen.Helliwell@wmssc.nhs.uk
Tel: 0121 695 2288; 0121 695 2369

- 6 **East of England SHA** (5,606,600)
Victoria House, Capital Park, Fulbourn,
Cambridge CB21 5XB
Tel: 01223 597500;
Email: webmaster@eoe.nhs.uk
Website: www.eoe.nhs.uk

SCG

Carole Theobald
Associate Director - Specialised Mental Health and Learning Disabilities
East of England SCG
The Old Mill, Haslers Lane, Great Dunmow
Essex CM6 1XS
Louise Littlefair, MH/LD Secretary/Business Support
Email: Louise.Littlefair@eoescg.nhs.uk
Tel: 01371 877260
Tel: 01371 877240

- 7 **London SHA** (7,512,400)
Southside, 105 Victoria Street,
London SW1E 6QT
Tel: 020 7932 3700
Email: enquiries@london.nhs.uk
Website: www.london.nhs.uk/

SCG

David Kemsley
Head of Specialised Commissioning
NW London LSCG
Hillingdon Primary Care Trust
Kirk House, 97-109 High Street
Yiewsley, West Drayton
Middlesex UB7 7HJ
Email: David.Kemsley@hillingdon.nhs.uk
Sue McLellen
Email: Sue.McLellen@londonscg.nhs.uk
Tel: 020 3049 4183

- 8 **South East Coast SHA** (4,236,500)
York House, 18-20 Massetts Road, Horley,
Surrey RH6 7DE
Tel: 01293 778899
Email: info@southeastcoast.nhs.uk
Website: www.southeastcoast.nhs.uk/

SCG

Stephanie Newman
South East Coast SCG
The Causeway, Goring by Sea
Worthing BN12 6BT
Email: Stephanie.Newman@secscg.nhs.uk
Tel: 01903 708478 / 708414

- 9 **South Central SHA** (3,995,400)
Rivergate House, Newbury Business Park,
London Road, Newbury,
Berkshire RG14 2PZ
Tel: 01635 275500
Email: corporateoffice@southcentral.nhs.uk
Website: www.southcentral.nhs.uk/page.php?area_id=12

SCG

Simon Jupp
South Central SCG
Omega House, 112 Southampton Road, Eastleigh
Hants SO50 5PB
Email: Simon.Jupp@hampshirepct.nhs.uk
Tel: 023 8062 7464

- 10 **South West SHA** (5,130,000)
NHS South West, Wellsprings Road, Taunton,
Somerset TA2 7PQ
Tel: 01823 333491
Email: go@southwest.nhs.uk
Website: www.southwest.nhs.uk/

SCG

Louise Tranmer
South West SCG
Hampton House, Top of St Michael's Hill, Cotham
Bristol BS6 6AU
Email: Louise.Tranmer@nhs.net
Tel: 0117 330 2633 / 2640

England total (population rounded up: 50,763,000)

Contact information for Wales

Health Commission Wales (2,965,900)

Specialist Services, Unit 3a, Caerphilly Business Park, Caerphilly CF83 3ED

Email: hcw.enquiries@wales.gsi.gov.uk

Website: www.wales.gov.uk/healthcommission

Complaints: hcwcomplaints@wales.gsi.gov.uk

For help to make a complaint: Complaints manager, Ground Floor Front, Park House, Greyfriars Road, Cardiff CF10 3AF

SCG

Stuart Davies

Specialised Commissioning,

Health Commission Wales

Unit 3A Caerphilly Business Park, Van Road

Caerphilly, CF83 3ED.

Email: Stuart.Davies1@wales.gsi.gov.uk

Tel: 02920 807577

Andy Williams, Associate Director

Email: Andy.Williams@Wales.GSI.Gov.UK

Susan Thompson, Lead Commissioner

Email: Susan.Thompson@wales.gsi.gov.uk

Contact information for Scotland

Health Scotland (5,116,900)

Woodburn House, Canaan Lane, Edinburgh EH10 4SG

Tel: 0131 536 5500

Health Scotland, Clifton House, Clifton Place, Glasgow G3 7LS

Tel: 0141 300 1010

Email: general_enquiries@health.scot.nhs.uk

Website: <http://www.healthscotland.com/contact/index.aspx>

SCG

Deidre Evans

Director, National services Division,

Room 063, Gyle Square,

1 South Gyle Crescent,

Edinburgh EH12 9EB

Email: Deirdre@nsd.csa.scot.nhs.uk

Tel: 0131 275 6000

Alex Robertson

Email: alex.robertson@nsd.csa.scot.nhs.uk

Tel: 0131 275 7563

Contact information for Northern Ireland

Northern Ireland (1,741,600)

Eastern Health and Social Services Board

12-22 Linenhall Street, Belfast BT2 8BS

Tel: (0)28 9032 1313

Email: pr@ehssb.n-i.nhs.uk; FOI@ehssb.n-i.nhs.uk

Website: www.ehssb.n-i.nhs.uk/EBWEB.NSF/Homepage?OpenPage

Northern Health and Social Services Board

County Hall, 182 Galgorm Road,

Ballymena BT42 1QB

Tel: (028) 2531 1000

Email: webinfo@nhssb.n-i.nhs.uk

Website: www.nhssb.n-i.nhs.uk/

Southern Health and Social Services Board,

Tower Hill, Armagh BT61 9DR

Tel: (028) 3741 0041

Email: info@shssb.n-i.nhs.uk

Website: www.shssb.org/

Western Health and Social Services Board

15 Gransha Park, Clooney Road,

Londonderry BT47 6FN

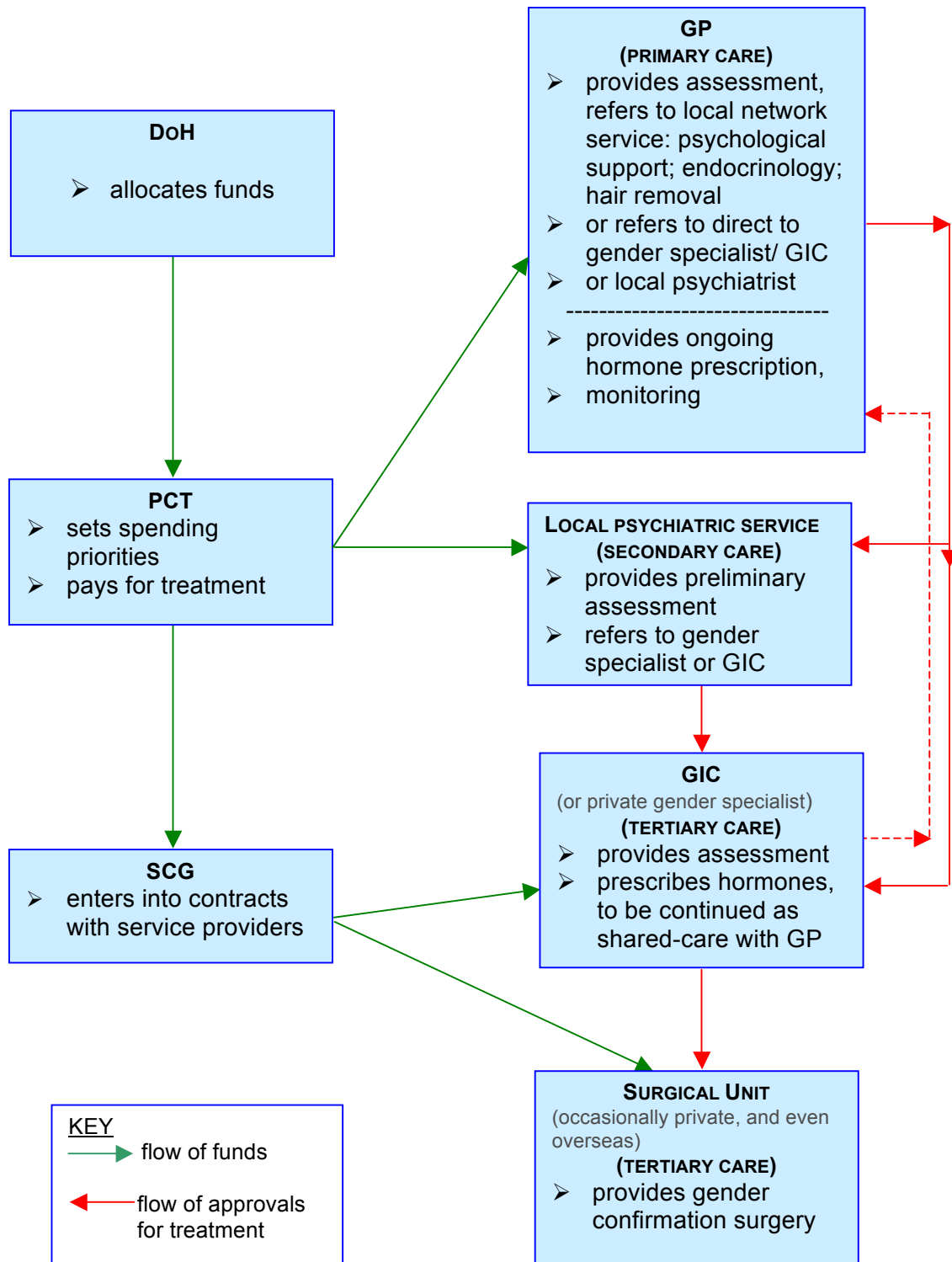
Tel: (028) 7186 0086

Email: info@whssb.n-i.nhs.uk

Website: www.whssb.n-i.nhs.uk/

Section 2 – Appendix 2

The process of approving, funding and providing treatment for gender dysphoria under the SCGs; the current possible arrangements (August 2009)



Section 3 Pursuing appeals and complaints

Introduction

All those accessing NHS or other medical services have the right to appeal against restrictions to their treatment, and to lodge complaints about any aspect of treatment they have undergone, whether for gender related issues or unrelated health matters. You may also wish to raise an issue about how medical and other NHS staff have behaved towards when you have, for instance, attended a clinic with a relative or partner, or you have visited someone in hospital.

Raising complaints can seem daunting; you may not know how to set about it, and you may feel nervous that making a complaint will have repercussions which could make doctors hostile towards you and jeopardise your treatment. This section gives advice about how to access the complaints procedures, and how to write letters to the relevant people.

3.1 What should I do if my treatment is denied or unreasonably delayed?

It is always open to you to put your case to the PCT and/or the more recently established Specialised Commissioning Groups that have now become responsible for certain aspects of the commissioning process for the treatment of trans people. You will probably need to progress through different stages, starting with an appeal, rather than a complaint.

Your initial contact should be through the Patient Appeals and Liaison Service (PALS). Usually you will find leaflets or information in the waiting area, or you can ask the receptionist for information about PALS.

Each PCT, is required to operate a:

- Patient Advice and Liaison Service. PALS may be used for minor matters that can be resolved quickly without a formal enquiry or the need to take the matter further.²⁴ If that does not work, you will receive help from PALS to transfer to the –
- PCT's formal complaints process. The PCT has to respond within 25 days after receiving your complaint. If the PCT wants more time, it has to obtain your consent. The PCT is expected to apologise where its service has failed and

²⁴ N.b. The Department of Health has published its intention to arrange a new process enabling service users to obtain help from an independent body that will examine the complaint and judge whether it has been handled correctly. This appears in its policy document *Making experiences count – the proposed new arrangements for handling health and social care complaints*, but will not come into effect until 2009
www.dh.gov.uk/en/Consultations/Liveconsultations/DH_075652

then make every effort to improve the service as a result of the complaint. If you are still dissatisfied, the complaint can be referred to the –

- PCT's internal mediation service. This would result in a complaints mediation meeting to hear your account of events personally, to sort out any misunderstandings, to make sure that all the facts have been considered and, if possible to resolve the difficulty.

The mediation service presents you with a decision that is not independent, but is made by the organisation against which you are complaining. If that does not produce what you think is an acceptable result, you can complain via other means, as described below.

If you wish to contact your PCT direct, contact details can be obtained from:

www.nhs.uk/servicedirectories/Pages/PrimaryCareTrustListing.aspx

N.b. PCTs may now choose to rename themselves using the NHS brand.

For instance Oxfordshire PCT would become known as NHS Oxfordshire.

The [Healthcare Commission](#) is responsible for reviewing complaints about the NHS or independent healthcare services (see below) in England that have not been resolved locally. If you wish the Healthcare Commission to review your case, you can do so via:

www.healthcarecommission.org.uk/db/documents/Independent_review_request_form.pdf

Further information is available at:

www.healthcarecommission.org.uk/aboutus/complaints.cfm

3.2 [What can my doctor do to help me obtain funding?](#)

Your GP's support for funding is vital in the initial stage of your treatment. If your GP is unfamiliar with the treatment of trans people the DH publication *Guidance for GPs, other clinicians and health professionals on the care of gender variant people* will assist. (Available at www.gires.org.uk/dohpublications.php)

At a later stage, if ongoing funding is not provided for surgery, both your GP and/or your gender specialist (if these are 2 different people) may write to the PCT on your behalf, explaining your need for treatment and the benefits to your health of having such treatment, versus the detrimental effect of withholding treatment or delaying it unreasonably.

Your case, having been prepared by your GP and/or gender specialist will be considered by a 'case review panel'.

You may also write to the Chair of the PCT review panel.

3.3 Writing a letter to the PCT – what should I say?

In addition to supportive letters from your doctor(s), you might write to your PCT including some or all of the following information:

- your legal right to be treated (see sections 1.1 for North West Lancashire Health Authority v A, D and G, Court of Appeal, 1999; and section 1.10 for Human Rights Act);
- ways in which you have complied with your gender specialist's readiness criteria (see footnote 20 under paragraph 2.7); including
- information about the time you have already waited;
- additional information regarding the impact that non-treatment is having on your life and the resultant stress (see sample letter below);
- evidence that the treatment proposed is appropriate for you, and that there is a track record of successful outcomes over many years of treating trans people in this way (see *Is treatment successful* at section 3.11); and
- you may wish to emphasise that the condition is not a life-style choice and your treatment is medically necessary.

Letter to the Chair of the PCT

Dear Dr Lloyd,

I am a trans woman. I have been living as a woman continuously for 18 months, and I have been on hormones for two and a half years, so my appearance is considerably feminised. Up until recently, I have had good relationships with my family and my employers. I intend living as a woman for the rest of my life.

My gender specialist and my GP have both referred me for gender confirmation surgery to make my genital appearance that of a woman. I have no health problems that could make surgery risky.

Despite all these factors, I understand that the PCT Panel has made a decision that my surgery cannot be funded at this time. I have not been told why this decision has been taken or how long I will have to wait before it is reviewed. Without this surgery I am living in limbo as I cannot achieve a sense of personal wholeness while I still have male genitalia. This has a huge impact on my daily life. I continue to feel great stress about the 'wrongness' of my body, and I am always

fearful that someone will find out that I am not as I appear on the outside.

I travel as part of my job. Recently, I was searched by a security guard at an airport. She didn't notice anything, but she might have done, and this possibility makes me extremely stressed. Searches happen frequently now so travelling is a constant problem and I live in fear of being discovered. Using toilet facilities is a nightmare. I am scared to use facilities in airports, stations, shops, theatres, cinemas, leisure or sports centres in case I am challenged. Of course, any venue that involves communal changing is just impossible. Even if I had a gender recognition certificate, I would still feel that fear because of my male genitalia.

The legal obligation to treat this medical condition comes from the case of North West Lancashire Health Authority v A, D, and G. In the Judges' decision, they made it clear that commissioning authorities may not use their prioritisation policies to effectively create a 'blanket ban'. Yet it appears that this is what has happened to me. I believe you might also find it useful to see the 'Guidelines for organisations commissioning treatment for trans people', prepared by the Parliamentary Forum on Gender Identity.²⁵

Please can you take account of the fact that cost of treatment of trans people is a fraction of the overall PCT budget. Moreover, you have received a letter from the XXXXXXXX Support Group, that explains why other interventions, such as psychiatric treatment, do not work because this is an innate biological condition.

With proper treatment, I know I can continue to live as a stable, fully-functioning person, making a meaningful contribution to society. Deprived of treatment, my mental health is deteriorating and this is affecting my relationships with my family; I am functioning less well at work and I dread losing my job and becoming a burden on everyone. I have fought so hard to achieve my transition this far and have complied with everything that has been required of me. This denial of funding for my surgery has made me have suicidal thoughts. I do not want to become an ongoing liability to NHS mental health services.

²⁵ This document is available at www.gires.org.uk/mps.php

It would help me if I could understand what criteria are being used to judge whether or not funding for surgery will be approved promptly. I request that the PCT provides me with detailed reasons for refusing to fund surgery, and that its Panel reviews my situation urgently.

Regards

Jane Carter (Ms)

Copies to: MP/ GP/ Support group

You may find it helpful to involve your Member of Parliament (MP) in order to add weight to your arguments with the PCTs. The MP may be willing to write a supportive letter to the Chair of the PCT. The MP may also write to the Chair of the SHA, who may be able to influence the PCT's decision. Press for Change publishes information on each MP at: www.pfc.org.uk/node/1485

Your MP may wish to see the document prepared specifically for MPs, *Transsexualism – the inside story*, and the *Guidelines for health organisations commissioning treatment services for trans people* prepared by the Parliamentary Forum on Gender Identity. Both these documents can be found at: www.gires.org.uk/mps.php

If you are denied treatment despite your best efforts and those of your GP, MP and the support groups, and if you have exhausted the complaints process described below, you may resort to legal action. That is likely to be a lengthy, expensive and uncertain process, although it is possible that the PCT may decide that funding the treatment is a better use of public money than engaging in costly litigation.

3.4 How can I pursue a complaint regarding the 'attitudes' of health professionals?

In general terms, many trans people are satisfied with the health services they receive. However, in addition to delay or denial of funding many trans people complain that the attitudes of those providing the treatment are sometimes disrespectful and make service users feel humiliated.

In fact, one of the biggest causes of complaints made by trans people against medical professionals in the NHS is their 'attitude'. If doctors are rude and dismissive, this can have a knock-on effect on receptionists and other non-medical staff. This almost certainly applies to only a minority of professional medical staff. Sometimes, this is caused by prejudice but often it is simply an unawareness (and lack of training) regarding the appropriate way to behave. Intentional or not, it makes a big impact on the lives of those who are looking to the medical profession to provide them with help.

Even those trans people who are themselves medically trained: doctors, nurses and others are sometimes faced with discriminatory attitudes and behaviour in their workplace – a hospital or clinic for instance – from their colleagues and co-workers (see Joan’s story under section 1.8).

3.5 Some real life experiences

Service user A

I was still living as a man when I attended the GIC for my first appointment; I was really nervous. It had taken me all my courage to get this far. While I was sitting in the waiting area along with other patients who were not attending the GIC, the receptionist called out across the room “you will need this map for your next visit because the gender clinic is moving to a new address”. As I got up to go and take the map from her, all eyes were on me. Everyone now knew things about me that I would have wanted to keep private. I wished the floor could have opened up.

What should I do?

Speak to PALS to find out, if possible, the name of the complaints manager of the clinic. Address him or her directly and tell your story just as it is here. You should receive a letter back, apologising for the distress caused, indicating that the reception staff have been told of the incident and are now aware that they must all be more careful. Events like these are often unintentional and will not recur once it has been pointed out to the staff concerned. Training of staff should be done so that such mistakes are not made in the first place. If something similar happens again, go back to PALS and ask advice about the complaints process.

Service user B

I had been living as a woman full time for 6 months. I had a job that involved meeting the public so it was quite stressful. Some of my colleagues had been okay with me because they had been warned that they had to be, but many weren't. They would say nasty things in a stage whisper behind my back, knowing I could hear them. The atmosphere was strained.

I felt I had done well to cope with it. When I went in for my appointment with the psychiatrist, instead of asking me how I was getting on, he showed no interest in me at all. I was expecting to be able to share my difficulties at work and have a pat on the back for surviving. He barely acknowledged me and then said "you're just a transvestite aren't you?"

I was determined not to let him see that I was upset because I was afraid he would think I was too weak to go through with the treatment. I dreaded every visit after that and I never felt I could tell him how I was really feeling.

What should I do?

This is a chronic problem where you are under pressure to be a 'success' in your new role. This, understandably, makes you afraid to show any signs of weakness. However, it is worth challenging the doctor in a polite letter (see below) but you may also consider copying it to your PCT (PALS) or use the complaints procedure for your GIC.

Dear Dr Regen,

At my recent Clinic appointment, you said "You are just a transvestite, aren't you?" in an extremely challenging manner. I am not a cross-dresser, but if I were, I would have felt unable to acknowledge it when confronted in that way. This made me very uncomfortable with discussing any difficulties I may have.

Yours.....

Cc XXX Health Trust/PCT

Service user C

My GP was supportive and helped me to get treatment. I had to go to a local psychiatrist to get a referral to a GIC. I started attending the GIC and then I moved to live in a nearby town just a couple of miles away, but I came under a different PCT.

My funding stopped abruptly but nobody warned me, so I went to my next appointment at the GIC and then was told that they couldn't continue to see me because there was no funding. I contacted my new PCT and explained the situation but they insisted that I have *another* referral to yet *another* local psychiatrist for *another* diagnosis! All this took months; I wrote letters which they lost, I made lots of telephone calls, some of which led nowhere and people were always saying they would talk to a colleague and call back. They never did. I was terrified of being dropped altogether. My own GP wasn't sure what her position should be because the prescriptions she was giving me for hormones were based on the GIC's original prescription and I was no longer being treated there – apparently. It was all a mess. I had sleepless nights and felt suicidal and started self-harming.

Eventually, I did get an appointment with a local psychiatrist under my new PCT; she knew absolutely nothing about gender variance or transsexualism but was honest enough to say so. She was very kind and referred me for further treatment on the basis that it would be cruel and unreasonable to stop treatment that had already been started. Not exactly a clinical decision, and certainly one that could have been taken months before which would have caused me much less anxiety.

What works!

Of course, this shouldn't happen but, if you intend to move house, you may need to take some measures yourself to prevent disruption of your treatment. So **before moving house**, you should check with your GP whether this will involve a new PCT and SCG. If it does, then contact both your current PCT and the new PCT and SCG, and alert them to your expected change of address. Take advice from them about the steps that will be necessary to ensure that your treatment is not interrupted. Your new PCT will become liable for funding your treatment at the clinic and the SCG, if different from your original one, may use different providers. Also, you could request that your GP liaise with a GP in the new area who might be willing to take over your treatment and organise hormone prescriptions and monitoring.

The service user in this case, did exactly what had to be done: phone calls, letters and persistence. It worked, eventually, but it took months. If she had known this situation might arise, she could perhaps have avoided it.

Service user D

My SCG had decided that all chest reconstructions should be undertaken by a particular local surgeon who had experience in doing mastectomies on women, but had never operated on a trans man. I wasn't happy about this.
Letter to lead commissioner for transgender services (all names fictional)

Dear Mr Arthur,

I have been given your name as the lead commissioner on transgender health in my area.

I am a trans man and have been told that I may have chest reconstruction surgery on the NHS. I am grateful for that, however, I would like to address you regarding the surgeon, Miss Evans, to whom I have been allocated.

I hear excellent reports of the work of this surgeon, but my enquiries revealed that she has only done mastectomies on women. I really need to be sure that the person undertaking my chest reconstruction has experience in achieving the appearance of a male chest. This is emphasised in the 'Department of Health Publication, 'Guidance for GPs, other clinicians and health professionals on the care of gender variant people' (p17).

“Although many surgeons are familiar with mastectomy, few have experience in creating the appearance of a male chest. It may be best that any referral made by the GP or other clinician should be to a surgeon who has experience in undertaking chest reconstruction in trans men.”^{26,27}

I would like you to consider engaging the services of Mr Mitchell who is based at Thurwell Hospital. I appreciate that this referral is to an independent provider and would take me out of area, however, I have looked into the cost and it is if anything slightly less expensive to the NHS than going to Miss Evans.

The advantage from my point of view is that Mr Mitchell has done chest reconstruction on a reasonable number of trans men, and has also corrected gynaecomastia in men. He has the experience necessary to make a really good job of my surgery. I am sure you will appreciate that the appearance of a trans man's chest is crucial to his ability to be comfortable in changing room and sports situations.

I hope you find my request reasonable and I look forward to your response.

Regards,

²⁶ *Chest reconstruction for female to male trans people* (2002) FtM London, published in conjunction with consultant surgeon Mr Dai Davies. This booklet gives comprehensive advice on all aspects of chest surgery. For further information contact info@ftmlondon.org.uk or contact Mr Davies at enquiries@plasticsurgerypart.org.uk or via the website at www.cosmeticsurgeryuk.com

²⁷ Bowman, C, Goldberg, JM. (2006) Care of the patient undergoing sex reassignment surgery. *International Journal of Transgenderism* 9(3/4):135–165.

3.6 What do I do if I am unhappy about an individual doctor?

Lodging a complaint at any level is stressful for you. This is especially so if the matter escalates and involves other agencies. Usually, matters can be resolved or improved at local level and in a low key way. This is much the better pathway for your mental wellbeing if it is possible. That does not mean that you should put up with behaviour from a health professional that makes you feel miserable and angry.

Scenario 1

Your GP seems reluctant to treat you at all or to refer you on to a gender specialist. Remember that you are entitled to treatment for your gender discomfort (see section 1.1) and your doctor is not entitled to refuse to treat you. Even if an unwilling doctor could be pushed into providing treatment for you, you may be more comfortable transferring to another doctor. You have the right to be allocated to a different doctor and your GP should organise this for you. If you believe your GP is not willing to treat you but has not said so outright, you can put it to him or her:

“are you unwilling to treat me for my gender difficulties because, if so, please will you refer me to another GP as soon as possible?”

If you are not comfortable saying this, you could put it in writing. If you do not succeed in obtaining treatment then you should complain to the PCT.

Scenario 2

If you are unhappy about the way you have been treated in a face-to-face situation with a gender specialist and you do not feel able to say so at the time, the best way to react, initially, is to write a polite letter to the individual concerned.

Dear Dr Tarbret,

I had my second appointment with you last week and it left me feeling very shaky and depressed.

I have been living as a woman for several months. I haven't changed my name legally, but I now use the name Mary Stead. My family and friends have all started to call me Mary, even though they slip up sometimes.

You repeatedly referred to me as Mr Stead. I found this very undermining.

I really need your support and it would help me a great deal if you could respect my identity as a woman by calling me Mary or Ms Stead.

***Regards,
Mary Stead.***

The **best** outcome in this case would be a short reply from the doctor, apologising for having been so thoughtless and promising to do better on your next visit. An **acceptable** outcome may be that the doctor uses your correct name title on the next occasion.

If neither of these outcomes is achieved you may take it further by complaining to the Gender Identity Clinic complaints manager (at the Foundation Trust if applicable, see below).

If you have a serious complaint about your doctor, possibly even involving malpractice, you will certainly have to take the matter to the PCT. Remember that you have to lodge your complaint within 12 months after the incident about which you are complaining.

You may need to take it further, in which case you could contact the *General Medical Council (GMC)* which ultimately has the power to stop doctors practising, either temporarily or permanently. The GMC publishes a booklet *How to Complain About a Doctor*. However, if you do take matters to the GMC, this will immediately stop any complaints procedure that you have initiated with the PCT. The local complaint procedure will resume when the GMC has dealt with the complaint.

Further information is available at

www.gmc-uk.org/concerns/making_a_complaint/a_patients_guide.asp

Telephone: 0845 357 8001.

3.7 How can I lodge a complaint against a gender identity clinic?

Making a complaint against the GIC (rather than an individual doctor within it) involves a similar process to that outlined above for the PCT. You should start by approaching the complaints manager and if that does not produce a satisfactory result, then you should talk to PALS, and work through the formal complaints procedure if necessary. So, the process would be much as described above.

However, if the GIC you are attending is a 'foundation trust' it may not have this two track complaint procedure. So, in such cases you will need to contact the complaints manager who is within the Mental Health Trust that is responsible for the GIC you are attending. The Trust's complaints procedure should be on display.

3.8 What avenues are there for making complaints against doctors in private practice?

Complaints against doctors in private practice can initially be made in the same way as with any doctor. As shown above in the sample letters, you can start by writing to the doctor explaining the problem as you see it. However, if it is a matter that you need to take further, you can make your complaint to the Healthcare Commission and the General Medical Council (contact details below). The Healthcare Commission also pursues complaints against private hospitals. Private providers of health services are required to register with the Commission. More information about its role in the private sector and making a complaint via the Commission is available at:

www.healthcarecommission.org.uk/db/documents/Let_us_know_if_you_are_concerned_about_an_independent_healthcare_service.pdf

3.9 How do I obtain support from the Independent Complaints Advocacy Service?

You may find it helpful to obtain the support of the Independent Complaints Advocacy Service (ICAS). ICAS will support you in making a complaint and will advise on further avenues for pursuing the matter if it has not been satisfactorily settled at local level. You will be assigned a dedicated advocate who will assist you with letter writing, form filling and attendance at meetings.

www.carersfederation.co.uk/what-we-do/icas/

This organisation is regionally based:

North East 0845 120 3732
Yorkshire and Humberside 0845 120 3734
North West 0845 120 3735
West Midlands 0845 120 3748
South West 0845 120 3782
London 0845 120 3784
Bedfordshire and Hertfordshire 0845 456 1082
Essex 0845 456 1083
Cambridge, Norfolk and Suffolk 0845 456 1084
South East 0845 600 8616
East Midlands 0845 650 0088

3.10 Are there any other avenues for pursuing a complaint?

Typically, the other avenues for pursuing a complaint involve a lengthy process that may take several years to complete. They include:

- *Healthcare Commission*: as mentioned above the Commission is responsible for the independent review of local decisions about complaints:

www.healthcarecommission.org.uk/contactus/complaints.cfm

- *Parliamentary and Health Service Ombudsman*: carries out independent investigations into complaints about poor treatment or service provided through the NHS in England. This includes private health providers if the treatment was funded by the NHS.
www.ombudsman.org.uk/make_a_complaint/health/index.html
- *National Institute for Health and Clinical Excellence*: reviews clinical practice with regard to specific conditions.
www.nice.org.uk/aboutnice/whoweare/policiesandprocedures/complaints_policy_and_procedure_april_2006.jsp
- The professional bodies issue guidance on clinical practice, although they do not regulate individual clinicians, for example:
 - *Royal College of Psychiatrists*
www.rcpsych.ac.uk/mentalhealthinformation/treatments/howtogethelp.aspx
 - *Royal College of General Practice*
www.rcgp.org.uk/patient_information.aspx
see also: www.nhs.uk/Conditions/GPs/Pages/Complaints.aspx
 - The BBC: it also publishes advice on making a complain in the NHS
www.bbc.co.uk/health/talking_to_your_doctor/gp_complaints.shtml

3.11 Is treatment successful?

PCTs will sometimes take the view that there is no evidence that hormone treatments and surgery are successful in alleviating gender dysphoria, therefore they accord it very low priority on the grounds that public money should not be spent in that way. Sometimes, those making decisions about funding are not well informed about conditions of severe gender variance and they believe that manifesting an opposite gender expression is a lifestyle choice. Some still believe that it is a psychiatric disorder and should be treated as such, that is, with no physical medical interventions. If you are seeking to contradict such views, there are some suggested sources below to which you might refer.

Variations of the current approach to medical treatment – a combination of hormone therapy, usually surgical correction and, for most, a change of gender role as well as some psychological support – have been practised for 60 years or more. A properly prescribed regimen by qualified practitioners is described, in the Harry Benjamin standards of care, as “*medically indicated and medically necessary*”. Gender confirmation treatment is –

*“not ‘experimental’, ‘elective’, ‘cosmetic’, or ‘optional’ in any meaningful sense”.*²⁸

There is little research in the field of medical care for severe and continuous gender discomfort. No prospective, long-term studies have been done. There are retrospective studies that are necessarily small, given the rarity of gender variance to a degree that requires medical intervention.

It is also the case that these studies have taken ‘surgery’ as the end point of treatment, so satisfaction has historically only been measured in those people who have had gender confirmation surgery. The surgical outcome, which is not always entirely satisfactory, is often one of the factors about which service users complain. This does not mean that their decision to undergo such surgery was inappropriate and very few express regrets for having taken that decision. A recent UK survey showed that 98% of those who had undergone genital gender confirmation surgery were satisfied with the outcome.²⁹

Medical practice in this field is beginning to take account of the fact that some trans people do not have such surgery. In any case, genital surgery for trans men has been quite unusual, although numbers having this surgery are now rising.

²⁸ Harry Benjamin International Gender Dysphoria Association’s The standards of care, sixth version (2000) Symposium, Düsseldorf. p26.

²⁹ Schonfield, S, (2008) Audit, Information and Analysis Unit: Audit of patient satisfaction with transgender services (2008). Project co-ordinator Mrs Carrie Gardner.

Other surveys indicating a high success rate include:

- Landén, M, Wålinder, J, Hambert, G, Lundström, B (1999) Factors predictive of regret in sex reassignment. *Acta Psychiatrica Scandinavica* 97(4):284–289.

- Landén found that only 3.8% of trans people had regrets after surgery. The main predictors of regret were found to be lack of family support and dissatisfaction with surgical results.



- Smith, YLS, Van Goozen, SHM, Kuiper, AJ, Cohen-Kettenis, PT (2005). Sex reassignment: outcomes and predictors of treatment for adolescent and adult transsexuals. *Psychological Medicine* 35:88–99.

- This study found that regrets were few. No patient was actually dissatisfied; 91.6% were satisfied with their overall appearance and the remaining 8.4% were neutral.



- Meyer, WJ, Bockting, WO, Cohen-Kettenis, PT, Coleman, E, Di Ceglie, D, Devor, H, Gooren, L, Hage, JJ, Kirk, S, Kuiper, B, Laub, D, Lawrence, A, Menard, Y, Patton, J, Shaefer, L, Webb, A, Christine, C, Monstrey, S (2001). The standards of care for gender identity disorders, sixth version. *Journal of Psychology and Human Sexuality*, 13:1– 30.

- There are no demonstrable, successful conversions of transsexual people via psychotherapy.

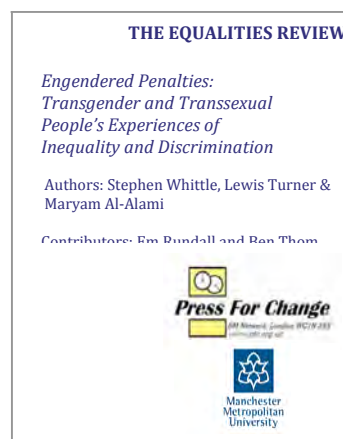
- Meyer *et al* (2001) Harry Benjamin International Gender Dysphoria Association's Standards of Care (2001) Symposium, Düsseldorf.

- Psychotherapy is not intended to cure the gender identity disorder



- Whittle, S, Turner, L, Al-Alami, M (2007) *Engendered penalties: transgender and transsexual people's experiences of inequality and discrimination*, p78
www.pfc.org.uk/files/EngenderedPenalties.pdf

- It is also understood that suicidality is relatively common in trans people. Many report that they were at their most vulnerable around the time that they finally sought treatment because they realised that they could not continue as they were. The *Engendered penalties* study found that 34.4% of trans people had seriously considered, or actually attempted, suicide, some of them more than once. So those making decisions about funding and providing treatment need to take account of the impact on mental health if treatment is denied or unreasonably delayed.



3.12 Is transition a life-style choice?

There is a considerable weight of evidence that those who are experiencing severe gender discomfort, sufficient to require medical intervention, have an innate biological condition. The change of gender role is not undertaken lightly as it puts the individual at risk of damaging relationships, losing employment and being in actual danger on the streets. Nobody 'chooses' to be transsexual.

- GIRES (2006) Besser, M, Carr, S, Cohen-Kettenis, PT, Connolly, P, De Sutter, P, Diamond, M, (Chair) Di Ceglie, M (Ch and Adolescent section only), Higashi, Y, Jones, L, Kruijver, FPM, Martin, J, Playdon, Z-J, Ralph, D., Reed, T, Reid, R, Reiner, WG, Swaab, D, Terry, T, Wilson, P, Wylie K.

Atypical gender development – a review,
International Journal of Transgenderism 9(1):
29-44. Available at

www.gires.org.uk/genderdev.php



- This Review brings together the scientific evidence regarding the various factors potentially involved in the development of a gender identity that is not consistent with the sex appearance. It is sometimes useful to refer to the biological etiology of severe gender variance so

that commissioners understand that undergoing transition and seeking medical treatment is not a 'lifestyle' choice. See also the Parliamentary Forum's *Guidelines for health organisations commissioning treatment services for trans people*.³⁰

- Those providing funding also need to understand that as gender variance is not a psychiatric disorder, treatments that focus on psychiatric interventions alone will not be successful. Psychological support (rather than psychiatric intervention) is very helpful when provided in conjunction with hormone therapy and, in many instances, surgery. As the surveys mentioned above indicate, this approach to treatment for trans people has a long record of success.

See also the NHS publication: *Guidance for GPs, other clinicians and health professionals, on the treatment of gender variant people*.

(2008) Curtis, R, Levy, A, Martin, J, Playdon, Z-J, Reed, B, Reed, T, Wylie, K.

- Annex A of this publication offers a brief overview of the science up to the time of publication. Further studies have been done since it was written and articles are in preparation, available at www.gires.org.uk/dohpublications.php



³⁰ Parliamentary Forum on Gender Identity (2005) *Guidance for health organisations commissioning treatment for trans people* (currently being updated – 2008). Available at www.gires.org.uk/mps.php

Part 4 Service user involvement in the NHS

4.1 Will health providers listen to my views?

This section gives you an introduction to the avenues through which you can get involved in improving the services that the NHS offers. This is worthwhile not only for you but also for other trans people who will need help from the NHS in the future.

The *Health and Social Care Act 2012* placed a legal duty on NHS trusts, PCTs and SHAs to make arrangements to involve and consult patients and the public in service planning and operations. A later amendment to the Act established *Patient and Public Involvement (PPI) Forums*. In 2007 a further amendment resulted in the Forums being replaced with *Local Involvement Networks*, known as LINKs.

LINKs covers all the Trusts and Social Services within each local authority area. The Department of Health also provides information about the development of LINKs.

The *NHS Centre for Involvement* is developing a set of guidelines to help you become involved in your *Local Involvement Network*. If you have any questions about these documents, you can email info@links.nhs.uk or call on 024 7615 0705.

The following six documents are available at www.nhscentreforinvolvement.nhs.uk/

- Guide No. 1 – Summary: Local Government and Public Involvement in Health Act 2007;
- Guide No. 2 – What LINKs mean for Health and Social Care Commissioners and Managers;
- Guide No. 3 – What LINKs mean for local authorities;
- Guide No. 4 – What LINKs mean for people and communities;
- Guide No. 5 – Procuring a host to support LINKs;

4.2 What is the first step to becoming involved?

You can start by attending Board meetings and annual general meetings of your Trust. These are open to the public and enable you, as a service user, to meet the directors and convey information about the standard of service that the Trust provides. Some Boards allow members of the public to comment at the end of their meetings on items of business that have been discussed. Such comments should be recorded in the minutes of the meeting. For instance, as a result of such

a comment, the Board minutes of the West London Mental Health Trust now contain information about the waiting times experienced by people attending its Gender Identity Clinic and the action it is taking to reduce them.

The annual general meetings also offer an opportunity for you to make comments and ask questions. Information about the Trust's meetings can be obtained from the Board Secretary at its headquarters.

The West London Mental Health Trust, which is responsible for the Gender Identity Clinic affiliated to the Charing Cross Hospital, has provided the following examples of the ways it has involved service users:

- taking part in the recruitment process for trust staff;
- attending a clinical audit group to decide on audit priorities and influence;
- action planning;
- facilitating a session in staff training on service user and carer involvement; and
- co-facilitating training programmes, for example, clinical audit open to staff, carers and service users.

4.3 How can I get involved at national level?

Organisations outside the NHS are involved in scrutinising its work. This provides you with opportunities to become involved, directly or indirectly, so that you can have your say and perhaps influence decisions.

- The *Health Oversight and Scrutiny Committee* within each local authority usually publishes its work on the local authority's website. You can speak to your local councillor who will communicate your views to the Committee.
- There are a number of *Arms Length Bodies* established by the Department of Health to scrutinise the work of health services in areas that are relevant to trans people. These Bodies operate service user involvement processes. Three that are particularly worth contacting are:
 - the National Institute of Health and Clinical Excellence;
www.nice.org.uk/getinvolved/patientandpublicinvolvement/patientandpublicinvolvementpolicy/patient_and_public_involvement_policy.jsp
 - the Healthcare Commission;
www.healthcarecommission.org.uk/contactus/getinvolved.cfm
Email: feedback@healthcarecommission.org.uk

- the British Medical Association, which represents doctors in the UK, has a patient liaison group.
www.bma.org.uk/ap.nsf/Content/Hubpatientliaisongroup

Following appropriate treatment, trans people lead successful lives, making a valuable contribution to society.



We hope you have found this publication useful. If you need further advice, the following list of contacts may be able to provide additional help and support.

Information and support

The following national organisations offer trans people and their families a wide range of expertise. They may also be able to provide details of local support organisations.

a:gender

Tel: 020 7035 4253

Email: agender@homeoffice.gsi.gov.uk;

Website: www.agender.org.uk

Support for staff in government department/agencies who have changed, or who need to change permanently their perceived gender, or who identify as intersex.

DEPEND

BM Depend, London WC1N 3XX

Email: info@depend.org.uk;

Website: www.depend.org.uk

Free, confidential, non-judgemental advice, information and support to family members, partners, spouses and friends of transsexual people.

FTM Network

BM FTM.org.uk, London, WC1N 3XX.

Tel: 0161 432 1915 (Wed, 8–10.30pm)

Website: www.ftm.org.uk

Advice and support for female to male transsexual and transgender people, and to families and professionals; 'buddying' scheme; newsletter – Boys Own; annual national meeting.

Gendered Intelligence

Email: jay@genderedintelligence.co.uk; catherine@genderedintelligence.co.uk

Website: www.genderedintelligence.co.uk/index.html

Company offering arts programmes, creative workshops and trans awareness training, particularly for young trans people.

GENDYS Network

BM GENDYS, London WC1N 3XX

Email: gendys@gender.org.uk

Website: www.gender.org.uk/gendys

Network for all who encounter gender problems personally or as family members, lovers or friends, and for those who provide care; quarterly journal; biennial conferences.

GIRES

Gender Identity Research and Education Society
Milverley, The Warren, Ashtead, Surrey KT21 2SP

Tel: 01372 801554

Email: info@gires.org.uk;

Website: www.gires.org.uk

Promotes and communicates research; provides information and education to help those affected by gender identity and intersex conditions. Offers range of literature, e.g. to help families deal with 'transition'. GIRES will adjust these to a family's circumstances on application.

Mermaids

BM Mermaids, London WC1N 3XX

Tel: 07020 935066

Email: mermaids@freeuk.com;

Website: www.mermaids.freeuk.com

Support and information for children and teenagers who are trying to cope with gender identity issues, and for their families and carers. Please send SAE for further information.

Press for Change

BM Network, London WC1N 3XX.

Tel: 0161 432 1915 (emergencies only)

Website: www.pfc.org.uk

Campaigns for civil rights for trans people. Provides legal help and advice for individuals, information and training; newsletter and publications. Please send SAE for further details.

The Beaumont Society

27 Old Gloucester Street, London WC1N 3XX

Tel: 01582 412220

Email: enquiries@beaumontsociety.org.uk

Website: www.beaumontsociety.org.uk

For those who feel the desire or compulsion to express the feminine side of their personality by dressing or living as women.

The Beaumont Trust

27 Old Gloucester Street, London WC1N 3XX

Telephone helpline: (Tuesday and Thursday 7-11pm) 07000 287878

Email: bmonttrust@aol.com

Website: www.beaumont-trust.org.uk/

Assists those troubled by gender dysphoria and involved in their care.

The Gender Trust

PO Box 3192, Brighton, Sussex BN1 3WR

Tel: 01273 234024 (office hours)

Helpline: 0845 213 0505 (10am–10pm Monday to Friday; and 1pm–10pm Saturday and Sunday).

Email: info@gendertrust.org.uk;

Website: www.gendertrust.org.uk

Advice and support for transsexual and transgender people, and for partners, families, carers and allied professionals and employers; has a membership society; produces magazine – ‘GT News’.

The Sibyls

BM Sibyls, London WC1N 3XX

Website: www.sibyls.co.uk

Christian Spirituality Group for transgender people.

WOBS

Women of the Beaumont Society

BM WOBS, London WC1N 3XX

Tel: 01223 441246, 01684 578281

Email: wobsmatters@aol.com

Website: www.gender.org.uk/WOBSmatters

Operated by and for wives, partners, family

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