

Foreword

This is the first time NHS Citizen has undertaken the production of information packs. They have been created to help everyone taking part in the NHS Citizen Assembly discussions on how the NHS can improve access to services; mental health services; gender identity services; young people's healthcare; and self-care and personalised services. NHS Citizen has commissioned NHS England to provide the content that has formed these documents and we would like to thank everyone who has been involved for going out of their way in a very short space of time to pull these packs together.

Headlines

Gender dysphoria describes the discomfort felt by people whose innate gender identity, the sense of being a boy/man or girl/woman, conflicts with their visible sex characteristics.

The main influences on gender identity are developed in the brain during early development and it is therefore not a lifestyle choice.

- It is estimated that 20 people per 100,000 are transgender.
- The current growth rate in the number of transgender people is 15% per year. Better social, medical and legislative provision for transgender people, as well as greater awareness, may be leading towards this increase.
- Demand for services for transgender people is increasing each year with relatively few specialised services to cope with demand with a small number of specially trained staff.
- Few younger people present for treatment despite the fact that most gender dysphoric adults report experiencing gender variance from a very young age. Social pressure, in the family and at school often prevent children from revealing their gender variance.
- When transgender people reveal their gender variance they are exposed to a risk of bullying, hate crime, and discrimination.

There are currently seven Gender Identity Clinics in England. They directly provide some services and co-ordinate the delivery of others within the 'care pathway' for individuals as part of a clinical network. Gender Identity Clinics receive referrals either from GPs and other medical specialists. They offer an initial assessment for people affected by gender concerns and advise them of the options available that might help address these concerns.

NHS England has a gender identity clinical reference group (CRG) To support the work of the CRG, NHS England has established a transgender network with over 100 members.



Overview

- What do we mean by transgender?
- Headline statistics
- Patient voices
- What services are provided?
- What is NHS England doing?

What do we mean by trans-gender?

Gender dysphoria describes the discomfort felt by people whose innate gender identity, the sense of being a boy/man or girl/woman, conflicts with their visible sex characteristics. The main influences on gender identity are developed in the brain during early development and it is therefore not a lifestyle choice.

The term transgender includes all those who experience some degree of gender variance, which often requires no medical treatment. A relatively small number of others experience transsexualism, which is the need or desire to transition to live permanently in the role that matches their natural gender identity, often with medical assistance.

Although terminology is not always used consistently by transgendered people, throughout this evidence pack we use the term “trans” to describe those who are undergoing or have undergone transition. An individual transitioning from male to female would thus be a trans woman, and one transitioning from female to male would be a trans man. After transition many of these individuals prefer to be, and therefore should be, regarded simply as men and women.

The term gender dysphoria is also commonly used to describe the discomfort or distress caused by a mismatch between a person’s gender identity and their biological sex assigned at birth.

What would you do if your 7 year old son told you that he wanted to be a girl? Or your 14 year old daughter told you that she feels that she really is a boy?

Some common misunderstandings - being trans is **not**:

- A lifestyle choice. Most trans people feel they have no choice at all about how they live. Many feel distressed about it and wish they could fit in as easily as other people.
- A mental illness. There is no psychiatric evidence that trans people are delusional, and careful mental health checks are carried out before anyone is allowed to undergo medical transition. Trans people do suffer higher than average rates of depression and stress related illness but this is probably due to prejudice and social exclusion.



What do we mean by trans-gender?

Being trans is **not**:

- A new phenomenon. Trans people have existed throughout history and some societies have developed special social roles for them.
- About sexuality. Trans people can be straight, gay or bisexual like anybody else. Sexual orientation and gender are separate things.
- About disguise. People who transition do so in order to let their bodies more accurately reflect the way they feel on the inside, not to pretend to be something they're not.
- Always obvious. Many trans people blend into society so that you would never notice they were different.



"I had to see hearing consultant as I'm deaf he decided appropriate to question me about all my trans notes on my medical file"

Headline statistics¹

- It is estimated that 20 people per 100,000 are transgender.
- 80% were assigned as boys at birth (and are now trans women), 20% were girls at birth (and now trans men). There is some evidence to suggest the gender balance may eventually become more equal.
- The current growth rate in the number of transgender people is 15% per year. Better social, medical and legislative provision for transgender people, as well as greater awareness, may be leading towards this increase.
- Demand for services for transgender people is increasing each year with relatively few specialised services to cope with demand with a small number of specially trained staff.
- Few younger people present for treatment despite the fact that most gender dysphoric adults report experiencing gender variance from a very young age. Social pressure, in the family and at school often prevent children from revealing their gender variance.
- At school, children or teenagers with a gender identity issue are often subjected to abuse. Bullying can take many forms; isolation and exclusion, insults and name-calling, and even physical attacks.
- Many young people and adults with gender dysphoria often also experience complex mental health needs that can arise from depression, anxiety, stress, isolation associated with the distress associated with gender dysphoria.
- Many adults with gender identity issues describe childhood difficulties. Often they complain of having been very unhappy children and teenagers, and that their suffering had not been recognised early enough by parents and professionals.

¹ Statistics sourced from a variety of reports; for details please refer to 'Further information' section at the end of this information pack



Headline statistics

- When transgender people reveal their gender variance they are exposed to a risk of bullying, hate crime, and discrimination.
- services being overloaded, because they do not agree with the processes used in Gender Identity Clinics, or just to avoid the social stigma.

Growing increase in access to young peoples trans services for some white middle class liberal background but others left out



- 10% of trans people have been physically threatened in public places.
- 73% have been harassed in public places, and 35% have attempted suicide at least once for reasons related to their gender identity. 45% have experienced family breakdown for reasons related to their gender identity.
- 64% of young trans men and 44% of trans women have been bullied at school, sometimes by teachers.
- Some people choose to self medicate, often using medication obtained via the web which may be unsafe, for a number of reasons such as NHS
- There is currently no national policy on access to gender specific screening (e.g. breast or cervical screening) for people that have undergone a gender transition.
- There is variation in GP prescribing practice across the country which leads to some patients being denied life-long medication post-surgery and discharge from a gender treatment pathway. This in turns leads to re-referral to Gender Identity Clinics purely for hormone treatment that could be prescribed in primary care. This in turn blocks access to Gender Identity Clinic capacity for other individuals.

What services are provided?

There are currently seven Gender Identity Clinics (GICs) in England. They directly provide some services and co-ordinate the delivery of others within the 'care pathway' for individuals as part of a "clinical network".

Gender Identity Clinics receive referrals either from GPs and other medical specialists. They offer an initial assessment for people affected by gender concerns and advise them of the options available that might help address these; this assessment is typically over 2-4 appointments with one or more health professionals with

expertise in gender identity from a medical/ counsellor/ psychotherapy/ psychology background. Gender Identity Clinics provide care for people with gender dysphoria, as described in the SGIS service specification and policy documents. The referrer of people who do not have gender dysphoria will be advised to re-refer to other appropriate services.

Gender Identity Clinics facilitate a variety of therapeutic practical, physical, medical and surgical interventions for people affected by gender dysphoria. The number and type of interventions



What services are provided?

provided, and the order in which these take place, will vary from person to person, according to need. Individuals may not need or desire some of these interventions.

In addition, Gender Identity Clinics provide patients with the opportunity to prepare for all aspects of their future life in a gender identity-congruent social role. This should include preparation for relationships, exploration of sexual identity and sexual expression, and the promotion and maintenance of optimal physical and mental health for the whole of life, from the present to the end of life. This requires cooperation and collaboration of the patient's GP.

A typical "clinical network" consists of one of the GICs working with other providers of surgery, epilation, voice and communication therapy and other services. The Clinic provides overall leadership for personalised treatment programmes for individual service users, and refers for, and co-ordinates, the interventions delivered by other providers within the clinical network.

Although there are some differences in the way that the seven clinics operate, all should offer patients access the care pathway in an equitable manner. GICs should operate in conformity with the *Good Practice Guidelines For The Assessment And Treatment Of Adults With Gender Dysphoria*.²

Educate more doctors so my trans friends don't exit consultations feeling worthless



²RCPsych Report CR181, October 2013

Patient voices

I have had my eight treatments from the NHS which never was going to be sufficient to remove my facial hair. I am currently living as a 'woman with a beard' as I am on benefits and cannot afford further treatment myself. The situation leaves me unable to be confident enough to go out, let alone have the confidence to apply for a job.

As a result I am socially isolated, depressed and confined to my home on limited income. My GP refuses to prescribe any creams and insists I go back to my GIC. The GIC informed me that the interim policy provides eight treatments and there is no way to complain or appeal.

I cannot understand why more choice of hair removal including electrolysis and laser is not more easily available via GPs? Also there should be an assessment of patient's needs; hair colouring, in relation to facial and other body hair and the number of sessions should be based on need not a number plucked out of the air.

What is magic about the number eight?





Patient voices



As a trans woman who has lived with this gender for over 15 years, I went for my routine flu jab at my GP practice. I was identified by my birth gender and called 'Mr' very loudly in the reception.

When I raised my concern about lack of confidentiality and legislation, I was told revealing my birth gender is important for the safety of the procedure!

There is such stigma and lack of dignity when you pluck up courage to attend, it is so unnecessary.

What is NHS England doing?

Specialised services are those provided in relatively few hospitals, accessed by comparatively small numbers of patients but with catchment populations of usually more than one million. These services tend to be located in specialised hospital trusts that can recruit a team of staff with the appropriate expertise and enable them to develop their skills. Gender identity clinics are one of the 75 specialised services commissioned by NHS England.

NHS England inherited a mixed system from various historical commissioning processes following the system reforms of 2013. Since becoming the sole commissioner of the specialised services, NHS England have endeavoured to bring these different approaches into a consistent approach for the benefit of patients across England.

- Firstly, an *Interim Gender Dysphoria Protocol and Service Guideline*³ was put in place.
- Secondly, a commitment was given to develop a new national service specification and policy. This is currently being developed in conjunction with clinicians,

commissioners and service users. It will shortly be reviewed by the Clinical Priorities Advisory Group.

- NHS England is also conducting a full review of adult gender identity services.

In the longer term, a forward strategy will be developed. This strategy will explore future demand for transgender service and seek to better understand how we can achieve excellent patient outcomes.

Development of Gender Identity Service Specifications

NHS England has a gender identity clinical reference group (CRG) which is part of the specialised services mental health programme of care. The Programme of Care covers all mental health services that are commissioned by NHS England. Members of the group come from all parts of the country and include clinical staff, patient and carer representation and professional bodies.

The CRG are responsible for providing NHS England with clinical advice regarding adult gender dysphoria and the development of commissioning

³ Interim Gender Dysphoria Protocol and Service Guideline 2013/14, <http://www.england.nhs.uk/wp-content/uploads/2013/10/int-gend-proto.pdf>



resources such as specifications, policy and clinical circulars. The CRG are accountable to the mental health programme of care, which, in turn is accountable to the Specialised Commissioning Oversight Group and Clinical Priorities Advisory Group.

NHS England establishes a transgender network

To support the work of the CRG, NHS England has established a transgender network with over 100 members. Traditionally trans people have constituted a group that has been 'hidden', without the opportunity to engage with commissioners and clinicians at a national level and so influence the development of NHS services. Attendance at the network meetings has been high with positive feedback received from attendees.

Three meetings have been held with the network since June 2013 with the next meeting planned for November 2014. The group is organised and facilitated by the NHS England Public Voice Team with support and contributions from colleagues in Specialised Commissioning and clinicians.

The workshops are designed to hear the views of people attending, provide updates, share information and work together to influence the strategic direction of services.

To continue to reach a wider audience a Twitter hash tag is used for the workshops and Twitter conversations are encouraged and discussed at the workshops. This ensures wider participation from beyond the people in the workshop and makes the event more inclusive, accessible and brings diverse input throughout the events.

In my experience, #NHSGenderID services don't know how to cope with those who aren't binary, aren't white and/or aren't monogamous



It is vital that current and future patients are involved in the development of gender identity services. This network group has influenced and made recommendations to:

- the clinical reference group who are responsible for advising NHS England about future services, and;
- the author of the overall review of gender services.

The group are also invited to a variety of engagement events arranged by NHS England e.g. Health and Care Innovation Expo, NHS Citizen.

"I would just like to say thank you for inviting me to such an enlightening and informative event. I thoroughly enjoyed it and will be able to give some positive feedback to our group members. It was lovely to be amongst likeminded people sharing and learning together."



Transgender network experiences

“I appreciated the positive ethos: the opportunity to make a fresh start and to put in places policies and structures that will achieve national consistency of treatment and care.”

“I’ve really appreciated the opportunity to engage with NHS England on their review of gender identity services. Being able to talk with patients, clinicians, senior managers and other stakeholders all together has been a refreshing approach to engagement.”

“As a member of this network group I feel respected, valued and heard by the NHS England Public Voice Team. This has helped to increase my confidence in sharing my views and gain a more positive view of the value of engaging with the NHS as a whole. Sometimes this is about my own care but at other times it’s about the care of other transgender people.”

Further information

Gender Identity Research and Education Service
www.gires.org.uk

Support for young people affected by gender dysphoria
www.mermaidsuk.org.uk

Royal College of Psychiatrists standards for the assessment and treatment of gender dysphoria
<http://www.rcpsych.ac.uk/files/pdfversion/CR181.pdf>

NHS England Interim Protocol for gender identity
<http://www.england.nhs.uk/wp-content/uploads/2013/10/int-gend-proto.pdf>

Scope of the gender identity Clinical Reference Group
<http://www.england.nhs.uk/ourwork/commissioning/spec-services/npc-crg/group-c/c05/>

Trans Media Watch
<http://www.transmediawatch.org/>

Costs involved
http://janefae.files.wordpress.com/2012/02/gid-paper_final_y.pdf

Good Practice Guidelines For The Assessment And Treatment Of Adults With Gender Dysphoria (RCPsych Report CR181, October 2013)



Views from Gather

The issues for this Assembly meeting were drawn from a public conversation online during August, which we used to test an early version of the NHS Citizen Gather process. Gather, is one of the elements that makes up NHS Citizen. NHS Citizen has three connected parts:

- **Discover** - find out what people are saying about the NHS
- **Gather** – have a discussion about what is important to you
- **Assembly** - work with others to make the NHS better

The 80 issues raised on the Gather site were used to define the five issues that the Assembly is now considering. Once the five issues had been identified, participants in the Gather test had an

opportunity to add to their previous points followed by a week of voting which was open to all - each participant who registered was able to vote on whether they agreed or disagreed on each issue.

It is critical to remember that this has been a short and stripped down test for crowdsourcing issues and comments, so the discussions were not as detailed as they would be in the final version of NHS Citizen. Importantly, the views expressed here are not representative of the public as a whole, just of those who took part.

The points raised for Gender Identity Services are shown below, in order of popularity, with the number of votes for and against shown alongside.

21 5



Developing and Funding Specialised Service.

I approach this issue with particular regard to gender identity services, for which demand is growing at 20% per annum for adults and 50% per annum for young people. This growth is likely to continue for the foreseeable future. About 650,000 people in the UK experience a significant degree of gender nonconformity, around 130,000 may seek medical care and, as yet, 25,000 have done so. The adult service is unable to cope with this growth.

14 13



Cap on Gender reassignment surgery.

My surgeon was advised that My surgery was funded on 25th April 2014. When I met with my surgeon for the Pre Op consultation (590 mile round trip at MY Expense) I was advised that NHS England had put a cap on Gender Reassignment surgery and I could not be given a date for surgery!

This is MOST Upsetting. I am now faced with total uncertainty as to whether I will ever get surgery. I am one voice for many who are in a similar position!