



Response to 'Escalation of Advice' from Healthwatch England Gender Identity Services

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1 Introduction

This report is a response to the 'Escalation of Advice' from Healthwatch England in respect of lack of access to gender identity services. This escalation requires NHS England to instigate an initial investigation into the issues raised and to identify whether further investigation is necessary.

The investigation has been carried out by the Director of Commissioning (Corporate) this has included:

- A review of NHS England work to date on gender identity services
- An assessment of the current issues
- A meeting with representatives of Healthwatch England to further understand the issues raised
- A summary of next steps

2 Background

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.

- It is estimated that 20 people in 100,000 are transgender in England
- The current growth rate in the number of transgender people is increasing. 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 specialist 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 at a very young age
- When transgender people reveal their gender variance they are often exposed to bullying, hate crime and discrimination

(Source – NHS Citizen Assembly Information Pack 18 September 2014)

3 Gender Identity Services

Specialist Gender Identity Services (SGIS) provide assessment, care and treatment for people affected by concerns regarding gender identity, role and/or expressions that differ from the cultural norm for their birth assigned sex.

These services are delivered through a variety of providers on pathways of care designed to assist people with gender dysphoria to explore their gender identity, find a gender role that is comfortable for them and provide therapeutic interventions. The process of treatment aims to achieve an improved quality of life. As such, all

interventions, including surgery, should be viewed as possible components of a personalised package of care specific to the needs of each service user.

Personalised treatment programmes may or may not involve a change in gender expression or body modifications. Services also ensure that the right checks and balances are in place prior to people undergoing irreversible treatments and possible surgical interventions.

In April 2013 Gender Identity Services became the commissioning responsibility of NHS England. Prior to this point gender identity services were commissioned by Primary Care Trusts either directly for their local population or through Specialised Commissioning Groups. There was no consistent approach to commissioning or understanding the complete picture of services and access to these services in England.

4 Existing Service Provision

Once an individual patient has been referred by their GP there are currently 7 Gender Identity Clinics (GIC) commissioned by NHS England.

No.	Name	Location
1	The Laurels Gender Identity and Sexual Health Centre	Devon
2	West London Mental Health Trust Gender Identity Clinic	London
3	Northamptonshire Healthcare FT Specialist Gender service	Northampton
4	Nottingham Gender Clinic	Nottingham
5	Sheffield Health and Social Care NHS FT Sexual and Relationship, Sexual Medicine and Transgender Services	Sheffield
6	Leeds Gender Identity Clinic	Leeds
7	Northern Region Gender dysphoria Service	Newcastle

Gender identity clinics will:

- accept referrals for patients registered with GPs anywhere in England.
- follow operational policies consistent with UK intercollegiate "Good Practice Guidelines" for the assessment and treatment of adults with gender dysphoria (UKGPG).
- comply with UKGPG in the delivery of care for their patients; departures in clinical practice from UKGPG, which may occur as a consequence of the exercise of clinical judgment, must be justifiable and the rationale must be explained to the patient.
- Once the patient has been seen at a GIC the patient pathway for gender identity services is dependent on the patients' individual need.

• The patient pathway is provided below, this can be found in the interim protocol and service guidelines 2013/14 published on the NHS England website. http://www.england.nhs.uk/2013/10/28/gender-protocol/

This complex pathway indicates some services that are the commissioning responsibility of NHS England and some of which are those of Clinical Commissioning Groups (CCGs).

5 Protocol Flow Chart

"When implementing the protocol the patient should be a full participant in decisions about their health care and wellbeing and be given any information or support that they need in order to do so"

Should patients be referred for genital surgery there are currently 3 NHS England commissioned services in England:

No.	Provider Name	Location
1	Imperial College Healthcare NHS Trust	London
	(Charing Cross Hospital)	
	Provider of Male to female surgery	
2	St Peters Andrology Centre	London
	Provider of female to male surgery	
3	Nuffield Health Hospitals	Brighton
	Provider of Male to female surgery	

There is also one NHS England commissioned service for child and adolescent gender identity services, Tavistock and Portman NHS Foundation Trust

6 Work to Date

The section below outlines the work that has been carried out by NHS England since April 2013 in conjunction with clinicians, patients, carers, friends and relatives.

- A Gender Identity Clinical Reference Group (CRG) was established in 2013 this includes clinical staff, patients, carers and representatives of professional bodies. http://www.england.nhs.uk/ourwork/commissioning/spec-services/npccrg/group-c/c05/
- In June 2013 the CRG embarked on the development of a new service specification and clinical commissioning policy.
- To support the CRG in this work the Transgender Network was established and now has over 100 members. The network has held three meetings since June 2013. It is designed to hear the views of people and to influence the strategic direction of services. It is organised and facilitated by the NHS England Patient and Public Voice Team.

http://www.england.nhs.uk/ourwork/patients/public-voice/identity/

- Eight network engagement sessions have been held, which can be accessed at https://storify.com/NHSEngland/nhs-england-gender-identity-services-review
- The CRG work has embraced the principles of the UK Inter-Collegiate "Good Practice Guidelines for The Assessment and Treatment of Adults with Gender Dysphoria" published in October 2013.
- Also supporting this work was a study commissioned by the then NHS England lead Deputy National Medical Director (Health Inequalities). As part of this research, Equality and Heath Inequalities team members' supported and attended the trans* health matters conference that took place in Birmingham on 1st May 2014 and the eight network engagement events.
- In recognition of the time required to develop the new service specification an Interim Protocol was adopted in July 2013 and became operational across England in October. This was based on the NHS Scotland "Gender Reassignment Protocol" 2012. http://www.england.nhs.uk/wpcontent/uploads/2013/10/int-gend-proto.pdf
 - At the NHS England AGM on 18 September 2014 improving gender identity services was one of five topics for in depth discussion. This had the active participation of Executive and Non-Executive Board Members.

7 Areas for improvement

Healthwatch England and a number of local Healthwatch have provided information on the current experiences of transgender people. These stories concur with the experiences communicated by the Transgender Network, recognised by the CRG in the new service specification and highlighted at the recent AGM including;

- A need for a patient/individual centred approach to care
- A lack of information for patients about their treatment
- Variation in Services with inconsistent protocols and procedures
- Ensuring GPs have the right information to offer appropriate support
- Long waiting times for assessment and treatment
- Variable quality of communication with and between healthcare professionals
- Ensuring good integration between the pathway for children and young people and the pathway for adults
- Treating transgender people with dignity and respect

8 Next Steps

• The new service specification and clinical commissioning policy will be received by the NHS England Clinical Priorities Advisory Group in October 2014 for consideration and submission to the prioritisation process in

December. It has been recommended, if approved, that the specification and policy should be submitted for full public consultation.

- Assuming successful consultation and adoption by NHS England of the specification and clinical commissioning policy, it will be ready for implementation during 2015/16.
- Reinforcing the importance of this work the NHS England Commissioning Intentions 2015/16 for Prescribed Specialised Services published in October 2014 state at paragraph 104 "A review of gender pathways, including access to treatment, will be undertaken to identify how existing pathways can be strengthened and improve services for patients"
- On 1 September the Specialised Services Turnaround Director asked that a Gender Identity task and finish group should be established as part of Workstream 1.
- This is designed to carry out an assessment of the current work and to recommend short, medium and longer terms actions required. This work has the active involvement of the chair of the Patient and Public Voice Group
- An immediate short term priority of the task and finish group is to undertake an assessment of demand for services.
- This includes the numbers waiting for assessment by the GICs, the number of people on the care pathway, the number of people waiting for surgery, the current capacity of providers, the potential capacity available and current and future resource implications.
- This work has commenced and an initial assessment will be complete by the end of November.
- This next meeting of the Transgender Network will be held on 27th November 2014

Any changes to Gender Identity services will then need to be considered with other services as part of business planning for 2015/16.

9 Patient Complaints

Patients wishing to raise a complaint about Gender Identity services should direct their complaint to the NHS England customer contact centre either by post, telephone or email:

Write to: NHS England PO Box 16738 Redditch B97 9PT Telephone: 0300 311 22 33 (Monday to Friday 8am to 6pm, excluding English Bank Holidays).

Email: england.contactus@nhs.net

Staff in the customer contact centre will then direct individual patient complaints to the most appropriate person in NHS England for a response.

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9th October 2014