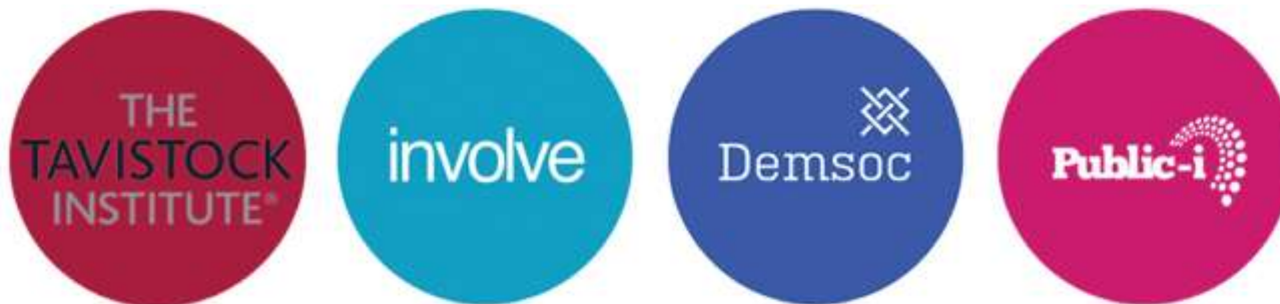
NHS Citizen Assembly Stocktake (March 2015)

Gender Identity Services

Version 1



Gender Identity Services

Background

NHS England has heard through various routes (individual complaints; the Transgender Network; Healthwatch England; NHS Citizen) of the inequalities facing trans-people in accessing healthcare, most notably long waiting times, poor patient experience and, in some cases, discrimination.

Across 2013 and 2014 our focus was on the implementation of an interim commissioning policy, and on the development of a new service specification and commissioning policy for gender identity services under the leadership of the Clinic Reference Group for Gender Identity Services. The new commissioning policy aims for a more equitable approach to commissioning, and was due to be considered by the Clinical Priorities Advisory Group in December 2014.

We established a task & finish group for gender identity services in September 2014, comprising senior commissioning leads, the chair of the clinical reference group for Gender Identity Services, the chair of the Patient and Public Voice Assurance Group, and communications and patient engagement leads. The group was chaired by the Director of Commissioning (Corporate) up to 30 November 2014, and by the Regional Director of Specialised Commissioning (London) from February 2015.

The task & finish group has focussed on:

- Addressing long waiting times for assessment and surgery
- Inequitable access to services, and variability along the pathway
- Services for children and young people
- Poor patient experience, and inequalities experienced by trans people
- Communication and information

The task & finish group was well placed to take the lead on developing responses to two formal letters of escalation that were received from Healthwatch England in September and December 2014, setting out concerns around long waiting times for genital reconstruction surgery and inequalities in accessing care. Our responses were submitted in October 2014 and January 2015.

Table: Area teams with commissioning responsibility

Area Team	Gender Identity Clinic and / or surgical unit
Cumbria, Northumberland, Tyne & Wear	Northern Region Gender Dysphoria Service, Newcastle
South Yorkshire & Bassetlaw	Porterbrook Gender Identity Clinic, Sheffield Leeds Gender Identity Clinic
Leicestershire and Lincolnshire	Gender Identity Clinic, Northampton Nottingham Gender Identity Clinic
Bristol, North Somerset and South Gloucestershire	Laurels Gender Identity Clinic, Exeter
Surrey and Sussex	Nuffield Health, Brighton (male to female surgery)
London	Gender Identity Clinic, West London Mental Health NHS Trust Charing Cross Hospital (male to female surgery) Andrology Centre (female to male surgery)

Bold text highlights actual or planned engagement with people who use gender identity services or their representatives

	Concerns that we heard	Action that we took	Future work that is planned	Key risks and mitigations
1	NHS England has not accepted that under the NHS Constitution transgender people have a right to be seen within 18 weeks of referral to gender identity services.	Previous fragmented commissioning arrangements across PCTs, and lack of clarity around interpretation of DH guidance, frustrated a consistent application of the 18-week standard to gender identity services. In January 2015 the task & finish group proposed to the Specialised Commissioning Oversight Group that NHS England should publicly confirm the applicability of the 18-week Referral to Treatment standard to gender identity services. This was agreed, and NHS England confirmed this in its response to *Healthwatch England* in January 2015; this has been publicised by LGBT media outlets and on social media.	A formal statement on the applicability of the 18 week RTT standard will be part of the communications plan that we intend to implement in March 2015 (see 10 below). The work that is planned to bring waiting times on the gender identity pathways to below 18 weeks is described at (3) below.	Risk: Awareness of the applicability of the 18 week standard will raise un-realistic expectations about our ability to increase capacity in the system, and how quickly this can be achieved. Mitigation: As part of our communications plan we will explain the work that we are doing to bring waiting times below 18 weeks by March 2017 (see (3) below) but setting out very clearly why it is unlikely that we can achieve this goal earlier (increasing referral rate; scarce expertise; time needed to identify, recruit and train new professionals in the context of international shortage; a need to develop infrastructure).
2	There is no transparency around waiting times for genital reconstruction	In November 2014 we convened a meeting of the providers of genital reconstruction surgery and senior commissioning leads. As an outcome of this meeting we were able, for the	We will continue to publish updated waiting time data each quarter, reflecting the monitoring information we require from our providers.	As at (1) above

	surgery.	first time, to publish waiting time data in January 2015.		
3	Waiting times for male-to-female genital reconstruction surgery are too long; there needs to be additional surgical capacity to address the problem.	NHS England deployed additional resource to increase surgical capacity at Nuffield Hospital in 2014/15, and this has begun to reduce the number of patients waiting for male-to-female surgery. As an outcome of the provider / commissioner meeting in November 2014 we have profiled the additional investment that will be needed to reduce waiting times for all male-to-female surgery to under 18 weeks by March 2017. Current waiting times for new referrals are around 22 months. We estimate that without additional capacity waiting times for new referrals will increase to 42 months by March 2017.The immediate waiting time pressures relate to male-to-female genital reconstruction surgery, for which there 4has been an increase in referrals of around 45% in the past two years. As of 1 October 2014 there were 323 patients who had waited at least 18 weeks for a surgical appointment and who meet the clinical criteria of readiness to proceed to surgery.	The forecast long-term increase in referrals and the known lead-in time for proposed mitigations (such as training of new surgeons) suggests that even with enhanced capacity through immediate additional investment, an 18 week best practice standard for new referrals will not be achieved until March 2017. Initial costing models suggest that a recurrent increase in funding of £4.4m is needed in 2015/16, rising to £5.6m by 2017/18, to meet projected recurrent demand for surgical services. In addition, a further £3.2m is required non-recurrently across 2015/16 and 2016/17 to reduce current waiting list backlog to 18 weeks by March 2017. Area teams are testing activity and financial assumptions with providers.	Risk: The financial resource to increase capacity may not be available to NHS England, particularly given the continuing increase in referrals. Mitigation: NHS England expects to make difficult decisions about how funding for specialised services is prioritised in 2015/16. However, we are committed to deploying additional funding in 2015/16 and subsequent years to reduce waiting times for genital reconstruction surgery to below 18 weeks by March 2017 subject to a consideration of other priority areas in 2015/16, and to the outcome of price negotiation with the providers.

		In January 2015 the Specialised Commissioning Oversight Group considered a paper on the issue, and agreed that area teams will start discussions with providers as a matter of urgency about potential options to expand capacity.	The London team is meeting Imperial Healthcare NHS Trust and Aspen Healthcare on 11 March to work through the capacity management plan for 15/16. Both providers have outlined the number of additional cases that they can undertake in 14/15 and 15/16. Discussions with Imperial Healthcare NHS Trust will focus on the creation of additional capacity by the employment of two additional consultant surgeons and additional theatre time, and possibly earlier reductions in waiting times through a sub-contracting model with the independent sector.	
4	There are also long waiting times for accessing gender identity clinics	The Task & Finish Group has focused on understanding better where pressures in the pathway currently reside, the reason for waiting time pressures and potential solutions. Our initial investigation of high level data indicates that only two of the gender identity clinics in England are operating within the 18 week wait for first referral and that queues are likely to grow significantly over the next few years.	An NHS England team comprising commissioning leads and a senior analyst will visit each of the gender identity clinics by the end of March 2015. **Where possible the visits will include talking to users of the services.** Meetings were held in Exeter on 19 February and Leeds on 24 February.	Risk: As with (3) above Mitigation: As with (3) above

		We need to understand the problem in more detail, and we are arranging for a small team to meet with each of the gender identity clinics. Specifically, we need some insight in to possible causes for problems with patient flow, and quantify what resource it might take to increase flow and so reduce the wait for first referral.	Future meetings: Sheffield on 13 March, Newcastle on 17 March and London on 19 March. Northampton and Nottingham to be confirmed. We will conclude the visits with a multi-provider workshop on 16 April as a “wash up” session for this work. We will use the outcome of this work to identify the reasons for bottlenecks in the pathways, and quantify the resource needed to reduce waiting times for non-surgical services to below 18 weeks.	
5	There are inconsistent protocols and procedures across the gender identity clinics	We have begun to address the inconsistent approach to delivery of services through the implementation of the interim commissioning policy in 2013 and development of the new commissioning policy and service specification in 2014 (which was due to be considered by CPAG in December 2014).	We will use the outcome of the work described in (4) above to identify solutions. The task & finish group is overseeing a programme of work to investigate the variability in access to specialised psychological	

		We have used the programme of work described in (4) above to establish a process for investigating further the concerns around variability across the different pathways and networks. We gave a commitment in our response to *Healthwatch England* in January 2015 for area teams to investigate the variability in access to specialist psychological support.	support; the North of England Specialised Commissioning Team is scoping a proposal to bring to the task & finish group in April; **this will include a proposal for a process of engagement with people who use gender identity services.**	
6	Availability of records to new healthcare professionals (so that a patient does not have to repeatedly explain their medical history)	We have used the programme of work described in (4) above to establish a process for addressing these concerns.	We will use the outcome of the work described in (4) above to identify solutions (April 2014).	
7	It can be difficult for children and young people to access gender identity development services.	We have met with the clinical lead of the sole provider of gender identity development services for children and young people (Tavistock and Portman NHS Foundation Trust). The Task & Finish Group has agreed to encompass the young people's service in the scope of its work.	We have agreed a programme of work with the Trust that will, between April – May 2015, focus on: • Increase in the number of referrals to the young people's service • Delays in transition to adult services	Risk: This programme of work is likely to provoke a heated debate amongst stakeholders about relaxing the current approach for prescribing cross sex hormones to young people who have decided upon gender reassignment. Mitigation: We acknowledge that

		• Communication with adult networks • Poor patient experience This work will include a refresh of the existing service specification, **informed by the views of people who use this service**	this is a legitimate debate, and we put in place a framework for a proper and transparent debate to be had in such a way to inform the work around the refresh of the service specification as appropriate. We are looking at how the CRG for GI Services (adult services) can provide clinical leadership on this issue – this may involve the formation of a sub-group with input from paediatric mental health and paediatric endocrinology experts.
8	Transgender people experience discrimination and other inequalities when trying to access healthcare, particularly in primary care; there is a lack of information and support from NHS professionals	We have scoped the potential remit of a programme of work to address these concerns, including legal advice on the responsibilities on NHS England under the equalities legislation as commissioners of primary care services. We have concluded that these concerns cannot be addressed by NHS England alone. They require a coordinated, system-wide approach from a number of organisations with statutory accountability for regulation, leadership and standards.	We will establish a plan of action with NHS England colleagues in the context of our role as commissioners of primary care services by May 2015. This will include defining the responsibilities of CCGs and how we work with them on this issue.	Risk: We do not know whether other organisations will accept the invitation; we may raise expectations amongst stakeholders that are not for us to deliver. Mitigation: We will embark upon some informal engagement before the letters of invitation are sent.

9	A lack of training and accreditation opportunities for medical professionals, both for specialists and GPs; there is no credible workforce or succession plan in place for professionals working in gender identity services	Since December 2014 the chairman of the clinical reference group for gender identity services has, through the *British Association of Gender Identity Specialists*, begun to define what knowledge, skills and behaviours are required of specialists in this field.	NHS England will engage other organisations in this work, particularly Health Education England the relevant royal colleges of medicine. Workforce and training will be one of the key areas for discussion at the symposium in June 2015 (see above).	Risk: Responsibility for workforce issues does not rest primarily with NHS England, which means that stakeholders may have unrealistic expectations about our ability to deliver change. Mitigation: Strong engagement with Health Education England and the various royal colleges of medicine and professional associations; we need to achieve synergy across NHS England commissioning plans and HEE workforce and training plans.
10	NHS England has not communicated what work it is doing to address the concerns of trans people	**The Transgender Network that we have established** continues to provide a dialogue with trans-gender people and their representatives, to support and inform us in the development of a new approach for commissioning gender identity services. The fourth Transgender Network workshop was held in November 2014**; it was planned in collaboration with people who use gender identity services and their representatives**. The event enabled remote participation through live streaming on the internet. The chair of the Task & Finish Group presented the work of the group to participants. We have posted highlights	We intend to implement a communications plan from March 2015 subject to approval from the Chief Executive's Office. We will offer engagement activities in April and May 2015 **specifically for trans people as part of the current consultation on the framework for prioritisation of specialised services.** The fifth Transgender Network	Risk: We have made repeated promises to deliver a more transparent and consistent approach to communications, so a further delay in delivering on our commitment will be damaging. Mitigation: Task & Finish Group to agree, implement and publish our communications plan; we need support from the Chief Executive's office to publish.

		of the November workshop on the internet, and we have shared an event report with people who attended on the day. We have also shared with delegates the Healthwatch England escalation letter (December 2014) and our response. In January 2015 we made a public commitment to: • Publish terms of reference and membership for the task & finish group, and publish regular updates on the work of the group • Provide regular opportunity for interaction with NHS England on our work to improve gender identity services via social media • Publish details of what patients can expect from gender identity services and how they can make a complaint if necessary We have not yet delivered on this commitment.	workshop will be held on 28 May 2015. **Planning for the day will be in collaboration with people who use gender identity services and their representatives.**	

Authored by Jeremy Glyde, Head of Strategic Change Management (Specialised)

Signed off by Will Huxter, Regional Director of Specialised Commissioning (London)
6 March 2015