

## **Interim Review Gender Identity Services [Adults] – Information covered in the presentation given on the 20<sup>th</sup> March 2014**

Maggie Morgan Cooke and Ian Snelling presented a quick 'snapshot' of where the team were with the review. Maggie apologised that there was no draft written document to give out at the meeting but there were a number of information gaps which would be shared during the session and further help from the audience at the workshop would be sought to add to the information already gathered. The areas where particular help was sought included:-

Areas of good practice or patient experience. Some patients during the review period have commented that they had had good experiences and thought this should be referenced in the review. People present were asked to let the team have any such good practice or experience in the form of a written e mail or other source at the earliest opportunity.

Rationale for recommending a separate review of children and younger people gender identity services. Maggie said that it was not appropriate to review children's services as part of the adult review also time was a constraint. However there was strong feeling from service users and some NHS staff that if outcomes were to be improved in the longer term and issues such as increasing referrals were to be addressed, a separate review is required. Maggie suggested the session in the afternoon about children and young people's services could provide information which would strengthen this argument within the review document.

Ideas and approaches that could be applied to address culture and attitudes of staff in the NHS through better awareness training and education. Also it was recognised that there was no established bespoke career pathway for medical and clinical staff to follow for this specialty. Any commentary that could be captured during the day that would enrich the review document in these areas would be appreciated.

Any additional suggestions of research or useful resources for the companion document would also be welcome.

Data, lots of challenges in this area including the quality of data available, willingness of NHS providers and local commissioners to share their data in a timely way. Overcoming issues of governance even though the data requested was anonymised and fairly basic with NHS staff. There were also issues relating to validation of the data, variation between local areas on how data was used and collected. The review team were on their fourth attempt to obtain this basic data from all the local areas. However Ian was going to share some data but a plea was made to treat it with caution as further data quality checks were to be made so the team could be more certain of its accuracy. More on data is outlined below.

At the present time, the team were working on three components to the review.

These are:-

The interim review report on Adult services which would need to go through a sequence of processes before it is made available not least because there were changes at the senior level in NHS England and it is important that this review document reaches and gains the support of senior management within NHS as well as the main gender identity clinic providers. The review also needs to be linked to

the timeframes and consultation processes envisaged for the service specification which is well under development by colleagues on the Clinical Reference Group.

A 'companion' document which would contain more detailed information and useful references which may be particularly useful to local area teams in the NHS or NHS staff who are new to this specialty to increase their understanding as appropriate. Jo Wasley researcher was leading the development of this piece of work which was about 90% complete.

The third and final component was the data element, one part of which was a series of 'interactive maps'. The idea was to show the audience with a small sample of data and some specialist analytical support in the form of Ian in this case who is a member of the review team, what the potential could be in showing anonymised data. Ian used a series of slide shots. For example using postcodes across NHS England, we could begin to show how many patients from the Trans community might be in each clinical commissioning group area and also how far they might be travelling to a clinic or place of treatment.

### **Data and Interactive maps - see slides provided**

Ian Snelling [review analyst] outlined the data collection for this interim review was challenging, with varying quality of data held by the commissioning hubs in local area teams and a lack of consistency in what data could be supplied by the NHS Clinical Commissioning Groups (CCGs) or Commissioning Support Units (CSUs). The situation was made more complex by changes in the structure of the NHS in the past year or so and current information governance concerns within the NHS about the collection of patient level data by CCGs. Whilst governance and confidentiality are important areas there seemed to be a variance in the interpretation of policies in the local teams. Some central guidance around information governance may be useful.

The Clinical Reference Group for Gender Identity Services has been tasked to develop at least 2 service specific measures in 2014/2015. The CRG also has ambitions for a more wide set of measures going forward which are focussed on better patient outcomes. More about this from John Dean was shared later during the day.

Data was requested from the 10 NHS England Commissioning Hubs. Basic data was received from 5 hubs, 4 hubs did not reply to the request, and one hub have their all their patients contracted to another hub. The review team were still attempting to get the outstanding data.

Using the only available data provided from the 5 NHS England Commissioning Hubs, the review revealed 3,745 active patients across the seven GICs. 70% of these patients were attending the London GIC.

### **CCG level variations in numbers of active GIC patients resident in their area**

The map, based on the data received from the 5 NHS England Commissioning Hubs, illustrates the number of active patients in each CCG per 100k population (aged 18-90). The average number of active patients per CCG is 18, or 9.13 patients per 100k population (aged 18-90). However, it should be noted that at least 12 CCGs have over 40 active patients, and some 68 CCGs have less than 10 active patients. There are therefore large local variations in the number of active patients.

We identified comparatively high levels of active patients for some CCGs. For example, Sheffield CCG (home of Sheffield GIC) has 90 active patients, Brighton and Hove CCG has 84 active patients, as compared to Halton CCG with 1 patient, and Devon and Torbay CCG with 7 patients.

Data from commissioners of gender identity services in England was used to explore where patients live in relation to the hub which funded their treatment (the assumption being that they were attending a GIC in that hub area and we can therefore get a sense of where the demand for each clinic is coming from and gain some indication of how far individuals might be travelling to access a GIC.

For example, the data illustrates that people are accessing services in London from all over the country, even where that means travelling past a GIC which is closer to where they live. A similar picture emerges for Nottingham. Other GICs (e.g. Leeds and Northampton) seem to have a much more localised patient base.

More work is needed to understand where demand is likely to be highest, and why. Commissioners and frontline staff in these areas in particular may require additional support in planning Gender Dysphoria services.

One area of specific concern is the perception by the trans community that there is a lack of transparency of accurate waiting times for patients and GP's. This is a constant and understandable source of frustration and complaints from service users.

From data supplied by 3 of the GICs, average waiting times range from 3 months to 9 months for new referrals. One patient has waited 51 months (as at Jan 2014) whilst waiting for funding arrangements to be agreed. Clinics suggest that the long waits are because of funding arrangements.

More exploration of the data needs to occur the review team concluded to really understand that the data is both robust and what it is telling us about the services.

According to the limited data supplied, referrals have shown a steady increase over the last 5 years, averaging around a 15% year on year increase. More work needed to be undertaken to better understand referrals and patterns of referral and this would be an area for further work recommended by the review.

This brief 10 minute session was then opened up for questions from the audience about what they had heard and also suggestions of points that could help 'fill the gaps' so this could be added into the review information already collated.