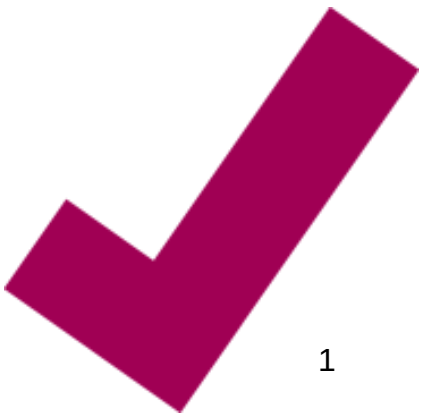
NHS England

Experiences of people from, and working with, transgender communities within the NHS- summary of findings, 2013/14



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Experiences of people from, and working with, transgender communities within the NHS- A summary of findings, 2013/14

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Contents

1 Foreword

1. This paper summarises what we heard about the experiences in the NHS of people within the transgender communities, through a listening exercise conducted by NHS England in 2013/14. Communications were opened up both online (through Twitter Clubs) and face-to-face (through one-to-one interviews, telephone interviews and workshops). Additionally, a listening exercise was also conducted with NHS staff.

2. In April 2013 Gender Identity Services became the commissioning responsibility of NHS England, inherited from primary care trusts and specialised commissioning groups. This work began because the services inherited were recognised to be inequitable and fragmented with regards to access. NHS England believed the first steps to improving this situation was to listen to, and engage with, the transgender community. This is extremely important to improving services because finding out about patient's experiences will play a significant part in forming actions for change.

2 Introduction

3. This document has been produced by NHS England to summarise findings from a listening exercise in 2013/14 that sought views from people within transgender communities around their experience of using the NHS. The original brief was to actively engage and strengthen the voice of people with gender dysphoria through their inclusion in a national listening exercise.

4. In this document, 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.

5. Although terminology is not always used consistently by transgender people, throughout this document the term "trans" is used 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.

6. This document is important because it reflects the views of the transgender communities which will help us to improve the way the NHS provides services and will help to tackle the historical inequalities that the NHS acknowledges exist.

3 What we did

7. The 2013/14 listening exercise with the transgender community was steered in a number of different ways to give a voice to as many people as possible. NHS England used the social media platform Twitter as the main form of communication. Additionally, one to one interviews, focus groups and group workshops were conducted to listen to the rest of the community. NHS staff were also given an opportunity to attend workshops as well as participate in one to one interviews to share their views.

3.1 Online communications

8. Service users had suggested that Twitter was a good way to engage the online community- specifically in the form of a Twitter Club. A Twitter Club in this context is defined as a series of themed live online discussions held on pre-agreed days which are widely advertised amongst people who have registered their interest in advance and allows others to join in through 'retweets'. A total of seven Twitter Clubs took place focusing on different groups within the trans communities:

    - Trans women
    - Trans men
    - Non binary trans people
    - Older trans people
    - Children and young trans people
    - Diversities with the trans communities
    - A wrap-up session for people who missed the previous sessions.

9. The NHS England communications team hosted the sessions via the Twitter account. To facilitate the discussion, the following four open questions were used at all sessions:

    - What works well in the gender identity services?
    - What are the gaps? How can they be addressed?
    - What does good look like?
    - How can we make a difference to people's lives?

10. The hashtag #nhsgenderid was used to collate the relevant tweets. A storify board was produced after each session to capture all tweets (available online at http://storify.com/michBS3). As of January 16, 2014, a total of 2,266 tweets with over 3.3 million impressions have used the #nhsgenderid hashtag.

11. The feedback received about the process of engagement through Twitter was positive.

3.2 Face-to-face communications

12. Interviewees were recruited through the promotion of the listening exercise- in particular this was from interested parties that attended the gender identity services workshop in November 2013. Additionally there were a number of people who had seen the promotion of the Twitter Club on Twitter and Facebook who preferred to take a face-to-face route to convey their views.

13. Interviews and feedback were sought from a variety of different people, including patients, community representatives and colleagues from gender identity clinics. In these interviews, the same questions used in the Twitter Clubs were used to guide the conversation; however due to the much smaller numbers of interviewees it was not possible to split the interviews into the Twitter Club transgender communities.

14. Clinical staff generally welcomed the review and were very willing to share their ideas and thoughts on the current service and how to improve it. Several gender identity clinics were represented at the service user and staff workshops held between June and November 2013. A further workshop took place on 20 March 2014.

4 What we heard

15. The following sections will be split into themes which summarise what we heard in 2013/14 from the trans communities and staff.

4.1 From the transgender communities

16. These stories represent just a sample of experiences shared; however the review found that these were the main areas of dissatisfaction amongst patients.

17. Patients who contributed to this review were not always readily willing to share their particular views or experiences of primary care. Some of the views that were captured in the Twitter and patient workshops feedback proved difficult at times to obtain. A few patients were anxious not to disclose their primary care experiences as they recognised the importance of the relationship with their GP and did not wish to risk that relationship even where it was less than satisfactory.

4.1.1 Stigma and its impact

18. The trans community felt there needed to be more recognition of the stigma they face and the impact it has on them as individuals. One trans woman said "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

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.
Twitter Club

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." Stigma can lead to a range of mental health problems including depression and anxiety, which has an effect on both the personal and professional lives of those affected.

4.1.2 Best care - true partnerships between NHS services and patient

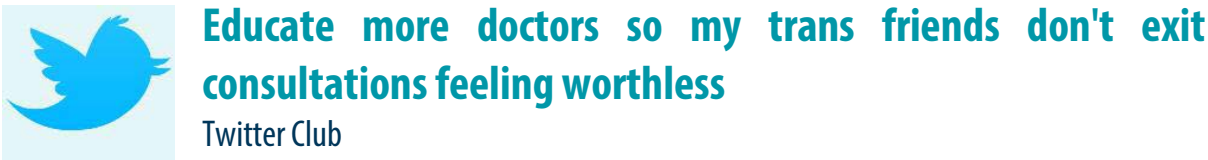
19. Feedback suggested that the trans community felt that the best care would come from a true partnership between the service and themselves. Where patients empowered with information were not a threat. This would also enable a better care pathway for private or self-medicating patients, achieving a greater equity of service.

20. Additionally good partnerships are linked with communication and engagement and one patient from the South West commented that there were some good examples of engagement of the local trans community through the local practice patient forum. Furthermore, a focus group in Sheffield also highlighted some good communication and ways of working between the GIC and primary care which they believed could be replicated elsewhere if local services were willing to work with their patients to achieve this.

4.1.3 Primary care knowledge critical

21. The trans communities told us that knowledge and input can be poor in primary care around gatekeeping, lack of protocol awareness, access to pre-referral counselling and post treatment follow up (hormone prescribing, blood tests – they are generic interventions rather than specialist/trans one).

22. Additionally, some patients told us that it was extremely difficult to find a GP who actually recognised their gender variance and this was a huge barrier to overcome in order to access services. At least one patient said they had physically moved house to be able to access a more 'sympathetic GP'. Two patients told us that they had ongoing complaints against their primary care services because of issues of attitudes from primary care staff and in one case a perceived breach of confidentiality around the patient's information.



23. Specific areas of concern were around the relationships between Gender Identity Clinics and the local GP which did not always work well in the interests of good patient care. Access to ongoing prescribing, particularly hormone therapies and access to facial hair removal were also areas of difficulty where GPs were often resistant to take on these responsibilities for their patients.

24. Several patients who were willing to share their experiences also recognised that where they had a GP who had good awareness of their condition and the local service provision from the GICs, then their experience was much improved. Patients commented that specific training for primary care staff could be very helpful in educating them about gender variance and perhaps reducing barriers and changing attitudes so that patients could benefit from the expertise that clearly exists already within primary care but is difficult to access at times.

4.1.4 Gender identity services - psychiatry?

25. The trans community felt that the gender identity service should not be a psychiatry monopoly. Currently people referred for treatment fall under the umbrella of psychiatry and people tweeted that psychologists have too much power around decisions of people within the trans community, both medically and legally. Older trans gender people also wrote that their mistreatment in the past, creating ongoing fears is embodied in psychologists. The trans communities felt that they were being held under a power of mental health, with some being treated as having a likely psychosis or autism. The community felt that hormones for transgender purposes should be available through sexual health clinics without the psychiatry element.

26. Additionally, because people are having to go through psychiatrists they said they felt like they had to act a certain way in order to get the treatment they need. Furthermore they felt that psychologists seem to control which trans diversities the NHS serves and mentions on its NHS Choices website. Within this, the community also said that there is no clear evidence that gender identity services should be within psychiatry and to look into alternative models of care. Finally they said they would also like recognition that gender distress is not a psychiatric disorder but is socially derived stress cause by notions of binary gender.

4.1.5 Blurred boundaries - gender identity is not sexuality

27. The trans communities felt that professionals had a tendency to blur boundaries between gender identity and sexuality, leading to expectations around lifestyle choices i.e. sexuality of partner, choice of clothes and pronoun preferences. They said, why does this place any bearing or business on medical or psychological teams? They also said they often do not talk about their sexuality because it can be used as a barrier to receiving treatment and services.

4.1.6 Everyone is different

28. The trans communities wanted the NHS to recognise that gender identity is not a one size fits all situation. This particularly reflects on the needs of non-binary trans people and other diversities within the community. Anecdotal information suggests that parallels may be drawn with regards to disabled trans people and assumptions about their gender identity. Discussion in the communities and the #NHSGenderID Twitter Clubs indicates that some disabled trans people experience being constructed as either genderless beings, or of being incapable of fully embodying their 'chosen' gender identity. This has the potential to create very real barriers to medical transition and support services when it is NHS staff that hold these assumptions.

29. As well as creating barriers to gender identity services, disabled trans people may also experience a lack of appropriate care, lack of respect or unnecessary questioning when accessing services that are not gender related.

30. Also discussed in the #NHSGenderID sessions was the inability of gender identity clinics (and psychiatry in general) to adequately support the experiences of Black, Asian and Minority Ethnic people. Patient experiences suggest that clinicians struggle to understand gender identity in a non-white context.

31. Furthermore, both the Twitter Clubs and the workshop sessions have highlighted a need for the NHS to make specific efforts to understand and engage with the trans communities in a way that is representative of all trans people living in the UK. To date, public/patient engagement has involved mostly white, non-disabled members of the trans communities.

4.1.7 Gender identity services

32. There were many comments about the gender identity services themselves, often specifically around treatment issues, including hair removal, binding/ reducing chest, voice surgery, lower/genital surgery. In particular one patient said with regards to hair removal: "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 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?"

33. Furthermore another patient commented on speech therapy: "Access to speech therapy or voice coaching is very scarce, yet very beneficial. I had to make a complaint and seek legal advice before I obtained a referral. The whole process took over two years for a referral. It was very difficult for me to function as a trans woman without it. The voice coaching I received made a big difference and changed my life it should be easier to receive without so many barriers in the NHS."

34. In addition to dissatisfaction with the treatments themselves patients felt people felt that administration could be improved and consideration could be placed on travel costs as due to the specialised nature of gender identity services, patients often have to travel a long way.

35. Finally, they felt that the length of wait for an appointment was unacceptable: "If eventually you find the courage to approach the NHS, you spend most of your time waiting for a referral, an appointment, and treatment. Along the way there are cancellations, poor communication, lost notes, travel over long distances and expense, breaches in your human rights, it is not a journey for the faint hearted. Mine took over four years, more than half this time was waiting."

4.2 From NHS staff

4.2.1 Loss of corporate memory

36. With the restructure of the NHS in 2013/14, some staff perceived a 'loss of corporate memory' along with the loss of some established data flows which made contract monitoring for gender identity services more difficult. Staff recognised the challenges around data and welcomed more guidance and consistency of data collection across the local teams so as to allow for greater transparency and the opportunity to compare and contrast performance for improvement. Many staff recognised the variance in practice amongst local contract arrangements affected patient services and in some cases could increase inequalities in services at the local level.

4.2.2 Lack of career pathway

37. Staff were concerned that there was not a defined career pathway for this speciality and general development opportunities for clinical staff were patchy. This was an area that staff considered needed to be explored given the changes in referrals and potentially service delivery for the future.

4.2.3 Cooperation between GPs and GICs

38. The majority of ‘frustrations’ with the NHS system at the present time, related to what was perceived as poor cooperation between GP and the GICs which included:

- Attitudes and unhelpfulness of practice staff with trans patients raising issues about lack of dignity and privacy

- Reluctance to prescribe hormone treatments or other medication by GPs for example which led to patients returning to GICs for them to supply the medication

- Lack of awareness of trans gender issues amongst primary care workforce particularly GP

39. They were frustrated that GPs seemed reluctant to play their part in the management of the overall pathway and specifically the management of the patient in relation to treatment such as endocrine therapy. It was acknowledged that some GPs might lack knowledge in this field and be seeking additional support to manage these patients and their care more effectively. However many staff from the GICs reported relationships with the GPs were deteriorating and that this was having an adverse effect on patients seeking treatment and care closer to home where their condition was well managed and it was appropriate for the GP to take the lead in their care.

4.2.4 Resource constraints

40. Staff felt frustrated by the constraints in the system on resources in 2013/14 particularly financial savings that needed to be made across the NHS which were dictated nationally. Several reported that waiting lists were increasing and in some cases quality standards were reduced as a direct result of these constraints. Staff reported that they perceived there were more complaints coming into their organisations as a result of waiting times increasing and other delays.

4.2.5 Waiting times

41. Waiting lists for surgery were a particular concern to patients and staff alike. Staff reported that there were particular issues in London services where the majority of patients are referred to for surgery as part of their transition. Lack of financial resources and clinical capacity to undertake the specialist surgery was resulting in increased challenges around new referrals and longer waiting times for patients already on waiting lists.

4.2.6 Planning

42. Staff said they would welcome greater participation and involvement in the planning processes of NHS England and the opportunity to work more closely with patients as part of the work through the CRG providing the timescales were realistic.

4.2.7 Communication

43. Some staff acknowledged that communication and relationships between all the GICs was not as good as it could be. Several staff commented that they would appreciate the opportunity to learn and share together if some 'headroom' could be created for the GICs to meet maybe twice a year. Staff said they were making efforts to gain feedback from patients on their services; however they would welcome opportunities to gain further improvement skills and knowledge as part of a career learning programme.

5 Steps taken

44. Throughout 2014 there was ongoing work in reaction to the listening exercise conducted. A proposed commissioning policy and service specification was developed by the Clinical Reference Group for Gender Identity Services, which aimed for a more consistent and equitable approach to commissioning these services.

45. In early November 2014, senior commissioning managers from area teams along with representatives from the three providers of genital reconstruction surgery met to explore issues around demand and capacity in depth.

46. Furthermore, our 'Patient and Public Voice' team held the fourth Transgender Workshop in November 2014 and this was attended by around 50 people, and enabled contributions from people across the country via the internet and social media. Many powerful views and ideas expressed on the day provided valuable insight for shaping our future work.

47. In December 2014, Healthwatch England escalated concern regarding around gender identity services and NHS England subsequently responded in January 2015 and this correspondence can be found at http://uktrans.info/18-week-confirmation.

48. Just prior to the end of 2014, the Specialised Commissioning Oversight Group met and agreed the applicability of the 18 week Referral to Treatment standard for referrals into gender identity services.

49. Lastly, gender identity and access to gender reassignment services was flagged as one of the five issues for discussion at the first NHS Citizen Assembly held in September 2014. More information about this including the evidence pack, webcasts of the workshop and subsequent discussions with the Board of NHS England can be found here http://www.nhscitizen.org.uk/assembly-meeting/. Progress on this issue was then reviewed as part of the NHS Citizen Assembly review and stocktake meeting held on the 25th March 2015. More information about that discussion and the update report is available here http://www.nhscitizen.org.uk/assembly-review-and-stock-take/

6 Next steps

50. NHS England is committed to acting upon the information in this report and in addition to the work already going on, we will propose some next steps for consideration:

- We will establish a work programme that will continue to improve the experiences of the trans communities within the NHS. We would propose that the work programme works with the Gender Identity Clinical Reference Group (GICRG) who currently already provides clinical advice to NHS England and supports the already established stakeholder engagement process and the network of services, providing a link for clinical staff.

- We will convene a multi-agency symposium in the summer of 2015 to agree how the various organisations that are responsible for regulation, clinical leadership and setting standards can work together to address the poor experience of trans people in accessing healthcare services.

- We will confirm the applicability of the 18 week Referral to Treatment Standard to people accessing gender identity services, and we are currently in discussions with the providers of male-to-female genital reconstruction surgery about how to increase surgical capacity in 2015/16.

- We (through the Gender Identity Services Task Group already established in NHS England) are going to establish governance arrangements for a Gender Identity Services Commissioning Group that will oversee implementation of NHS England's plans for improving gender identity services in the longer term; and identify resources that will be needed to support the work of this group.

- We (through the Gender Identity Services Task Group) will oversee a process for the development of a standard operating model for specialised gender identity networks, for implementation in April 2015 (with reference to either the interim commissioning policy or, if agreed by Specialised Commissioning Oversight Group following a recommendation from the Clinical Priorities Advisory Group, to the proposed new commissioning policy). This will improve equality of access to services, a standardisation and consistency of protocols and procedures and a partnership-orientated approach to care.

- We (through the Gender Identity Services Task Group) will establish a process for modelling the workforce implications of implementation of the interim / new commissioning policy; this will require a baseline assessment of current workforce and an assessment of future training needs (this will be a joint piece of work with Health Education England). This will ensure we have enough staff to meet the demands of the trans communities clinically (reducing waiting times for assessment and treatment) as well as providing training and information for staff throughout the NHS to help tackle some of the issues faced by the trans communities. This type of training would help to overcome stigma, build relationships between the service and the patient and provide a more personalised service.

- We will publish the communications strategy to support these next steps in May 2015.

The NHS is good at listening but when will services feel better for me?
Twitter Quib