

**Gender Identity and Non-
binary Workshop**
28th May 2015
Coin Street



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1 Introduction

This paper outlines the process and outcomes from a Gender Identity Workshop held in London on 28th May 2015. The workshop was arranged and facilitated by the Patient and Public Voice Team, NHS England with support and contributions from colleagues in Specialised Commissioning, NHS Clinicians, patients and service users and members of the voluntary sector.

2 Context and Background

2.1 This was the fifth meeting of the transgender network. This meeting aimed to update people on the various work which is currently being undertaken around the gender identity services and the commissioning of those services. (See appendix A for outline of the day)

2.2 Participants on the day

Participants included: -

- Transgender men and women and non-binary people.
- Voluntary sector organisations
- Clinicians from the majority of the Gender Identity Clinics in England
- The majority of lead Commissioners for Gender Identity Services
- A number of invited clinicians
- Other colleagues from NHS England, Specialised Commissioning

Many of the above had attended previous workshops but there were some new people to the network group which was really welcomed. Over the last two years more people and organisations have become involved, however, it is acknowledged that we need to continue to work with people to ensure that this is an inclusive network.

2.3 Aims of the workshop

- NHS England to lead in bringing together different stakeholders to work in partnership and continue a conversation on a national level with trans and non-binary people and communities, the organisations that support them, commissioners of services and clinicians from gender identity clinics about NHS services
- To discuss progress made from the last meeting
- To provide an update on the work of the Clinical Reference Group including feedback on the consultation on the specification and policy
- To share information from the work being undertaken in the Gender Identity Services Task and Finish Group
- To share and develop areas of good practice

- Discuss and share views on future developments of gender identity services and the commissioning of these services
- To continue to build the foundations for partnership working in the future

3 Engaging people beyond the workshop venue

The workshop was designed to hear the views of people attending, provide updates, share information and work together (See appendix A for the agenda for the day).

To continue to ensure we have a wider reach this workshop was webcast. You can access the webcast at:

<http://www.nhs.uk/public-i.tv/core/portal/trans-non-binary>

People also used twitter hashtag #NHSGenderID for the workshop and they were displayed on a twitter wall in the room. This ensured wider participation from beyond invited guests and made the event more inclusive, accessible and brought diverse input throughout the day.

The purpose and background information was tweeted before the event.

@NHSEngland led the twitter input and encouraged people to join in the debate though the hashtag #NHSGenderID.

4 Outline of the day

Olivia Butterworth, Head of Public Participation, NHS England opened the day, welcomed everyone and explained who was in the room. There was also an apology from Will Huxter, Regional Director Specialised Commissioning (London) Senior Responsible Officer for the Taskforce who although was committed to attending was unable to attend on the day due to personal reasons.

This was followed by the presentations:

- Update on the work of the Task Force - Jeremy Glyde - Head of Clinical Effectiveness Team, Specialised Services , NHS England

In his presentation Jeremy also outlined the proposed Symposium to take place on the 30th June, who was invited and the purpose of the event. The Symposium aimed to pull together other organisations and professional bodies needed to progress this agenda. He also invited people from the network to register their interest in attending the event, a form would then be sent to those people to fill in outlining the added value they could bring to the event. The planning panel for the symposium chose people based on the information they had supplied to ensure a good cross representation of people and organisations.

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- Specifications and policies - Themes arising from Consultation - Dr John Dean - Chair of Clinical Reference Group and Steve Hamer - Deputy Mental Health, Programme of Care and High Secure Lead, North West Hub

All the presentations can be found on the micro site

<http://www.nhs.uk/public-i.tv/core/portal/trans-non-binary>

After each presentation people had the opportunity to feed in their comments or raise questions. There was also opportunity to raise and post questions on the sticky walls in the room. (see Appendix B for questions posted)

Afternoon session

Following lunch we split into four workshop groups:

Group 1 - Needs of people who identify as non-binary and the response of services

Group 2 - Developing a communication Strategy

Group 3 - Providing information that empowers trans and non-binary users of health services, including e-learning, toolkits and factsheets

Group 4 - Harnessing the value of partnership with the voluntary sector in developing and delivering patient pathways

Plenary feedback

All of the groups gave an overview of the discussion in their group including action points to take the agenda forward. (See appendix C for workshop notes)

5 Next Steps

- Send out the workshop report
- Hold another workshop later in the Autumn/Winter
- A workshop is being held to focus on Children and Young people's services – people in the network can make expressions of interest to attend. People were advised that they would be sent out a form to complete giving details of how their particular expertise would be relevant at this meeting as places are limited.

**Patient and Public Participation Team
Patients and Information Directorate, NHS England
August 2015**

6 Appendices

6.1 Appendix A

Trans and non-binary Workshop Programme
Thursday 28th May 2015, Coin Street Neighbourhood Centre, London
With the exception of the start and finish - all timings are flexible and shown as an indication only

10.30	Coffee on arrival and registration
11.00	Welcome, introductions, aims of the day - Olivia Butterworth Terms of engagement and description of the network
11:30	Update on the work of the Task Force Will Huxter - Regional Director Specialised Commissioning (London) Senior Responsible Officer for the Taskforce Jeremy Glyde - Head of Clinical Effectiveness Team, Specialised Services , NHS England
12:30	Specifications and policies - Themes arising from Consultation Dr John Dean - Chair of Clinical Reference Group Steve Hamer - Deputy Mental Health, Programme of Care and High Secure Lead, North West Hub
13.00	Lunch
13.45	Small workshops including <ol style="list-style-type: none"> 1. Needs of people who identify as non-binary and the response of services 2. Developing a communication Strategy 3. Providing information that empowers trans and non-binary users of health services, including e-learning, toolkits and factsheets 4. Harnessing the value of partnership with the voluntary sector in developing and delivering patient pathways
15:15	Plenary feedback
15:45	Summing up the day and next steps - Olivia Butterworth
16.00	Close

6.2 Appendix B – Questions posted

These are questions which were stuck on the stick walls. These questions will go to the Gender Identity Task and Finish Group which will co-ordinate a response and bring back to the next workshop later in the year

	Question
1	Epilation – could NHS England produce a list of approved practitioners?
2	According to the NHS England service spec – Direct referral from GP to GIC is now protocol (No local referral) Is this consistent throughout all NHS England and CCGs?
3	Leeds GIC appointments close together and charring Cross far apart why?
4	Concerned that Public Health England is putting out ignorant information about trans. How can that happen?
5	Improving GIC services will require equitable funding processes and significant investment service specifications will not otherwise be met. When will such structures and resources be implemented?
6	Why are few referrals for female GRS being directed to Parkside, despite available surgical expertise?
7	18 week waits do not apply to NHS services throughout the NHS including mental health services. It only applies to consultant led services. GICs are not all consultant led so why will GICs be treated differently to other NHS services?
8	18 week RTT is actually 80 week RTT – ‘time to effective treatment’ Does any other area of NHS healthcare suffer grotesquely long waits?
9	Should G.Ps be encouraged/trained to prescribe ‘bridging hormones’?
10	Who is responsible for delivering standardised funding from NHS England to GICs? When will this happen
11	18 weeks is to treatment not first appointment
12	Why do some GICs expire referrals at 12 months? Wastes appointments renewing
13	What are the protocols for complaints of GPs unwilling to see trans patients with mental health issues?
14	Why do some GICs manage to assess some individuals in an average of two visits when other clinics take an average of four or five?
15	What is the non-binary pathway
16	Would persuading the UK passport office to accept ‘MX’ or non-gender binary titles allow some/many individuals a space to live with comfort and perhaps reduce need/demand for transition?
17	How will NHS England ensure that it is not being ‘held hostage’ by a number of service providers?
18	Why has FFS been excluded as a clinical option?
19	On what moral basis would an informed consent model not be considered for trans health care?
20	How will 3 rd sector organisations be provided with financial and other resources to deliver meaningful support to trans people?
21	What steps will commissioners take to ensure representative patient feedback on services is procured in a timely manner?
22	Engagement with CCGs and primary care – how?

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23	Prescribing issues GP/GIC
24	Need clarity on prescribing and roles
25	Who is responsible for allowing multiple revisions and reviews of specialised services to bring about such a growth of waiting lists and a stagnation of service delivery – Please name a single senior individual who is specifically responsible?
26	Current GIC staff (especially at Charing Cross) are bad at non-binary people. Will there be training to fix this?
27	How will the NHS ensure organisational memory on trans issues?
28	Number of facial epilations – How many treatments?
29	When will there be parity of esteem of the GIC delivered aspects of care (e.g. psychological hormonal) with surgical aspects?
30	Why has there been no recognition that the service specification will result in inflationary costs for GIC provision, due to increased frequency, increased throughput- separate from 18 week wait?
31	More money to target 18 RTT for surgery ££££ for facial hair removal requests - £3M may be More money to reduce regional inequalities of service More money for GIC's to bring down waiting lists for 1 st and 2 nd apps What is the answer?
32	Hair growth blocking cream VANQA is very useful but prescribing is being blocked as “not permanent ” even if patient is happy to pay
33	There is a gap on long-term post – SRS problems, where RCOG wash hands and only option is local funding for referral to Charing Cross
34	Last two years - budgets need to be looked at nationally in areas with financial problems (i.e. the North) This has resulted in funding reduction in the GIC's effectively national services but funded as part of 'regional' allocation
35	How will NHS England reach out to those people who are not internet connected?
36	Reports that some GICs refuse to provide hormones to full time carers??? Will service standards address this
37	Standardisation of services. What is the standard matrix
38	Raising complaints safely without fear
39	To who and where do patients address their fears
40	To who and where do patients address their complaints?
41	Engaging regulators – where do people go to?
42	Voluntary sector – devolution of responsibility but not power – we need ££££
43	What is the role of the G.P in prescribing
44	Far better training and understanding in the CAMHs service for young trans/gender variant
45	Training for the CCG staff on Trans procedures?
46	What are the protocols for complaints of GPs unwilling to see trans patients with mental health issues?

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6.3 Appendix C – Workshop notes

6.3.1 Workshop 1 feedback – Needs of non-binary people and the response of services

This workshop was webcast so you can see the full discussion in the afternoon at <http://www.nhsengland.public-i.tv/core/portal/trans-non-binary>

The workshop was an opportunity to hear the voice of non-binary people and from services who offer gender identity services to understand how services work with non-binary people and non-binary people's experience of these services. The workshop also identified some next steps which need to be taken.

Concerns:

- Health professionals having a lack of knowledge about issues affecting non-binary people
- Unsure of what treatment is available
- Fear – not being able to say what it is we want
- Judgemental attitudes
- Cost of traveling to and from clinics
- Sometimes it is easier to present yourself in a binary way as you might get access to treatment quicker
- Lack of acceptance of being non-binary, this can lead to Mental health issues
- Gender Recognition Certificate - until officials recognise non-binary it will always be an issue
- Sometimes it is better to not mention any of your mental health problems to speed up treatment

From a clinical perspective

- There is a lack of confidence because little is known about non-binary, there is not enough evidence base and research
- Clinicians need to be brave and take calculated risks but need to be backed by their organisations and the wider health and care community

Other points

- Terminology can sometimes be confusing
- There is a time lag between social norms, values, cultures, acceptance and then medical world

Actions

- Training for health professionals delivered by non-binary people
- On the ground difference of training/advice given to staff
- Clear understanding of terminology
- NHS England - we need to simply and quickly understand what we can do and are trying to achieve
- Informed consent model to be discussed at the symposium

- GIC's need to tell us need to be clear and tell non-binary people what their options are
- Professionals needs organisational backup and support to give them to confidence to provide better services
- Support required in finding academic research into NB people and their need

6.3.2 Workshop 2 feedback - Developing a communication Strategy

Jo Stringer began the workshop by reflecting on the level of communication in the past and acknowledged that this needed to be improved. This will be addressed by the development of a specific communications strategy for Gender Identity Services and the Gender Identity Network which will be produced in partnership with users of the service. The plan is for the draft communications strategy to be a working document that will be shared on a wider level with members of the Gender Identity Network.

The following issues and comments were raised by participants:

- There are two sets of communications issues. Firstly NHS England's communication as the commissioner of gender identity services and secondly communication from providers which was felt to be poor. It was acknowledged that some communication was in NHS England's direct control whilst provider communication would need to be encouraged and supported. NHS England is not responsible for the communication that comes from provider organisations but can address issues on behalf of users of the service if they arise.
- Communication with the Gender Identity Network has improved recently but there is still a feeling that a lot of NHS England's work around this area takes place in secrecy and there is little communication and feedback apart from the Network meetings where a lot of information is shared. Questions have been asked about the role and remit of the Task and Finish Group and contact details for the membership. Members of the Network would like to know more about how to get involved and how to influence the work of the Task and Finish Group. Individual participants reported positive experiences of communication with local commissioners but this was not consistent.

Jo Stringer clarified the current process for approving documents and information for publication and acknowledged that this presented a challenge. Participants felt that it would be useful to have a list of key contacts in NHS England and their contact details.

A wider discussion took place around participants experience of the complaints system particularly in terms of services provided by Gender Identity Clinics. Some participants felt that they were labelled as troublemakers if they raised issues and concerns. Discussion took place around how patient experience was currently being captured and how this might usefully fit into the commissioning cycle. The opportunity to meet with Commissioners on a regular basis was also suggested as a means of improving communication. Jo Stringer agreed to raise this with the lead Commissioner, Steve Hamer.

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The issue of representation on the Clinical Reference Group (CRG) was raised and it was felt that the language in the policies and service specifications could be seen as inaccessible for some members of the community.

There appears to be limited communication between patients and providers apart from appointment letters and no contact between NHS England commissioners and members of the community apart from Network events.

Jo Stringer clarified that the proposed communications strategy will be a high level document.

A range of information that could be produced was discussed. The possibility of providing useful information to GP's was raised. A link to the NHS Choices website was also raised as a possible action. It was noted that work is currently being undertaken on developing the NHS England website so that the current pages around the Gender identity CRG will be updated. Additionally work is also being undertaken to refresh the current stakeholder list as this is a means of communication which may be out of date. The process for registering on the stakeholder list will be circulated to members of the Network.

Participants felt that any communications strategy would also need to consider relationships between the press and media.

Participants also raised the issue that some members of the community did not have access to the internet or social media and this will need to be incorporated into the communications strategy.

Agreed Actions:

- A discussion to take place with Steve Hamer about ways in which members of the Network can communicate on a regular basis with commissioners.
- Key contact details to be shared with the wider Network.
- Communication to be developed on a wider whole system approach rather than just the specialised services part of the Gender Identity pathway.
- An update of the NHS England website is currently taking place so suggestions around the CRG, stakeholder list and links to other websites will be considered.

6.3.3 Workshop 3 feedback - Providing information that empowers Trans and non-binary users of health services, including e-learning, toolkits and factsheets

Key issues raised:

If you were one of the 100,000 people looking for information what would have been useful to you?

- Information to help me manage the increasing pressure I faced whilst trying to decide the best way forward for me.
- It is important to get the right and full information early in order to make the right choices
- Information for GPS who need to be educated in this area e.g. fact sheets
- A fact sheet on what a GP may or may not do
- Any information provided needs to be endorsed/branded by NHS England as then the doctors will take notice of it. I could also use the information in my consultations as it would lay out what action should be taken.
- Information should go via CCGs as they also need to understand responsibilities and ensure that these are being adhered to
- If there is information people need to know where to look for it.
- Information is required between your visits to Gender Identity Clinic
- I need to know how the system works – a clear NHS document
- I need to know what treatment and care I can expect to receive locally and nationally
- Families and carers require information as well
- The rating of GPS re their knowledge of trans care and issues but you would have to be very careful re this.
- Better to highlight the good GPS than the bad
- People who are transgender don't just need care in relation to being trans. They may need other services for example mental health services and staff in these units also need to understand trans issues
- Rights re what ward a person is put on male or female – this can cause great anxiety
- Could we ensure that all the 257 groups nationally that exist to support trans people have the links to information that Mermaids and GIRES do? Care as that this may go out of date.
- Sign post these links on the NHS Choices website
- Good practice makes things sound optional. Things should be policy not just good practice that way they will start happening
- Important to provide the information in different ways – not everyone can access internet.

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- People need information at different levels and not everyone needs or wants the basic level please don't assume that they do.
- NHS Choices need all the groups that are on transwicki

Other information

- Bernard and Terry from Gires shared information they have produced with the group (links to this) – if you spot anything that is missing please contact Bernard at BernardGI@aol.com
- It is important that the correct information is provided across the board so that people can access it.
- If you have problems you can approach your local Healthwatch and their advocates will represent you with your NHS provider and deal with complaints or queries you have – It's important that all Healthwatch staff offering this service have received training in Transcare and issues
- Film and leaflet produced by Healthwatch Hampshire

Men's Health

- Modelled on the Haines Carr manuals. Guide for transmen for Transmen.
- As inclusive as possible.
- Aimed at age 16 plus.
- Useful for trans masculine and non – binary, first draft will be ready by the end of June and then go to the advisory board.
- NHS England will send to their network for comments.
- If you are interested in contributing please contact transhealthguide@hotmail.com

6.3.4 Workshop 4 feedback - Harnessing the value of partnership with the voluntary sector in developing and delivering patient pathways

Key issues raised:

- Few trans specific organisations (many small grass roots groups)
- TUC 2014 : LGBT VCS = 0.04% of VCS income
- There is a lack of Trans and non-binary competence in these organisations
- Piece meal funding – lack of continuity, skills and consistency
- Patchy geography

Potential Funders

- NHS England, CCGs, Grants and Trusts

Making the case

- Evidence and research
- Joint Strategic Needs Agreement (JSNA)

Discussion

- Need a community development approach
- VCS services should complement medical services e.g. signpost and advocacy (the NHS can be reluctant to refer to these services)
- Trans issues often not represented in the JSNA
- VCS OFTEN UNFUNDED SO IT CAN BE DIFFICULT TO CONTROL THE QUALITY OF SERVICES
- VCS does not mean free
- Risk that VCS could be used as an additional gateway – would not want this to deter people from accessing the services that they need.

What could be more appropriately provided in the voluntary sector?

- Peer support
- Independent support
- Transition from youth to adult
- Older people
- A social model of care could be used to compliment the medical pathway

Action Plan

- To pilot centres of excellence providing social pathway alongside the medical
- Need voluntary sector directories – GIRES hold some of these. Clinics have a wide geography and so information wider required for the clinics
- Identify gaps in the pathway
- Is there a proportionate quality measure that could be used – what training and qualifications can be used for people to do different roles
- Use appropriate voluntary sector venues as satellite gender identity clinics
- Voluntary sector needs to provide support for Trans people and health professionals
- Also think about support for families and carers