NHS England

Treatment and support of transgender and non-binary people across the health and care sector: Symposium report

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1 Introduction

1. Since its establishment in April 2013, NHS England has learned of widespread problems concerning the treatment of transgender and non-binary people across the health and care sector, including reports of unaddressed health inequalities, discrimination and reduced access to health services.

2. NHS England's Board made a public commitment at the NHS Citizen Assembly in 2014[1] to address problems experienced by the transgender and non-binary communities within the NHS, and has started to make progress in a number of areas. The development of the Transgender and Non-Binary Network has been a key marker of progress, as has the work of the Gender Identity Services Task & Finish Group, which has recently completed a series of visits to gender identity clinics as part of its work to address waiting time issues, and which is also responsible for looking at training and workforce requirements across the GIS workforce.

3. However, it is clear that, due to the complexity and long-standing nature of many of the issues concerned, NHS England cannot solve all of the problems alone, and involvement from other organisations is required in order to make the kind of changes that will have real impact, and make a tangible difference, in improving the experience of transgender and non-binary people when using health and care services.

4. The first step was to engage with transgender and non-binary people, in order to identify the kind of issues faced by people accessing, or trying to access, healthcare services. The development of the Transgender and Non-Binary Network, and the continuing dialogue with members of the trans and non-binary communities, has been an important move in providing this patient community with a forum in which to raise concerns at a national level.

5. One of the key issues emerging from Network discussions was the treatment of transgender and non-binary people in the wider NHS system, outside of specific gender identity services. This led to a commitment from NHS England to facilitate exploring the responsibilities of those organisations with a statutory and/or professional role in the regulation and monitoring of how health and care services are delivered, as well as professional leadership and setting of standards, and to begin to identify where those organisations could make a difference.

6. To this end, a number of statutory organisations and professional associations were invited to a Symposium, to meet with a number of invited transgender and non-binary people, some of whom attended in a personal capacity, while others represented larger transgender and non-binary organisations.

7. The aim of the event was to bring these organisations into a single forum to discuss – for the first time collectively – the problems experienced by transgender and non-binary people. The objectives were for all attendees to

[1] http://www.nhscitizen.org.uk/assembly-meeting/

work collaboratively, and to agree a collective ambition to address, and improve, the experience of transgender and non-binary people in their use of health and care services, with a view to defining where responsibilities lie, and ensuring that responsible organisations take action to effect improvement.

The health service has to be one place where people are treated as individuals, and with dignity and respect. (Dame Barbara Hakin, National Director, Commissioning Operations, NHS England

2 Background

8. The Symposium took place at Coin Street Neighbourhood Centre, South Bank, London, on Tuesday 30 June 2015.

9. Attendees were:

   British Psychological Society; Care Quality Commission; CliniQ; Department of Health; Equality and Human Rights Commission; General Medical Council; Gender Identity Research and Education Society; Government Equalities Office; Healthwatch England; Health & Social Care Information Centre; Mermaids; Public Health England; Race Equality Foundation; Royal College of Psychiatrists; Royal College of Nursing; Royal College of General Practitioners; Royal College of Physicians; Royal College of Speech and Language Therapists; Stonewall; Trans Youth Hull; TPSG Hull (service user group); TransForum Manchester; Trans Healthcare Training; Transgender Information; UK Trans Info; Unique Transgender Network.

10. Other organisations invited to attend were: British Medical Association; Health Education England; Royal College of Surgeons of England.

11. The Symposium was webcast live at: http://www.nhsengland.public-i.tv/core/portal/webcast_interactive/181468 All slides presented on the day can be found here.

12. The Twitter hashtag #nhsgenderid[2] was in use throughout.

13. The format of the event was based on a mix of presentations; personal reflections; workshops and Q&A sessions, finishing up with a plenary session on next steps.

[2] http://www.symplur.com/healthcare-hashtags/NHSGenderID/analytics/?hashtag=NHSGenderID&fdate=07%2F01%2F2014&shour=00&smin=00&tdate=07%2F23%2F2015&thour=00&tmin=00

3 The story so far

14. Dame Barbara Hakin, NHS England's National Director for Commissioning Operations, opened the event.

15. She described how NHS England had done its best, after a shaky start, to engage with, and listen to, the views and concerns of people in the transgender and non-binary communities[3], but that NHS England as a commissioner was limited in terms of what could be achieved by commissioning alone.

16. Dame Barbara outlined a number of issues which had been raised with NHS England, including culture and attitudes; people wanting to be treated with dignity and respect; timely access to specialist services; capacity in the relevant sections of the workforce, not just in surgery – it's not just about more money, but the need to train more professionals with appropriate skills; and access to GPs who have enough knowledge to be able to support people and advise them appropriately.

> ***There is an issue with GPs not knowing enough to even start the conversation, or not wanting to have the conversation in the first place. This is a very significant cultural issue and long-term change is needed to get the right approach and attitude. (Dame Barbara Hakin)***

17. Professor Zoe Playdon, Emeritus Professor of Medical Humanities, University of London, gave the first talk of the day, with a presentation of what she sees as the cultural and societal journey of transgender and non-binary people so far. (Slides available via webcast at http://www.nhsengland.public-i.tv/core/portal/webcast_interactive/181468).

18. Professor Playdon talked about gender identity services as "an increasingly leaky ship" which had been patched up again and again, and which needed to start anew and be rebuilt. Her presentation also initiated discussion around a couple of topics which were revisited throughout the event – the need to remove psychiatrists as the "gatekeepers" to gender identity services, and the concept of the "narrative", and the idea that transgender and non-binary people have to tell a certain story in order to access services.

> ***I have no idea how many people have been forced from binary female to binary male because that is what the narrative said. (Professor Zoe Playdon)***

19. Dr John Dean, Chair of NHS England's Clinical Reference Group for Gender Identity Services, a former GP, and Clinical Director of a gender identity clinic,

[3] NHS Citizen Assembly (www.nhscitizen.org.uk)

followed up on the concept of stories, and talked about how the narrative is changing.

20. He said that an estimated 500,000 people in England had some degree of gender variance, but that not all of them would seek, or need, help from medicine or from elsewhere.

21. Dr Dean talked about current gender identity services, and some of the workforce and training issues that have such a significant impact on waiting times. He particularly highlighted the fact that specialist gender identity clinics had developed without any central planning, which had led to an uneven distribution of clinics around the country; the lack of a career path for professionals working in these services; and the variability in attitude and approach of clinical, managerial and support staff working in the healthcare sector. In his own experience, Dr Dean observed this ranging from the accepting, empathetic and supportive, to the unhelpful, dismissive and hostile. He described the training needs right along the care pathway. (Slides available via the webcast at http://www.nhsengland.public-i.tv/core/portal/webcast_interactive/181468)

> ***Trans people just want to get on with their lives, and go unnoticed. After transition, their healthcare needs are generally similar to those of the rest of the community. They want improved psychological and social wellbeing, and they want to live productive lives. (Dr John Dean)***

4 Personal stories

22. As part of the planning for the Symposium, NHS England invited a number of people to submit their personal stories and experiences of being a trans man or woman, or non-binary, in order to highlight particular issues faced by transgender and non-binary people accessing services and care across the NHS.

23. Due to time constraints, it was impossible to use all of the stories submitted, but each of the four narratives chosen were powerful, and thought-provoking in different ways. The next section highlights just some of what each of the speakers relayed to the room. Full coverage of each presentation can be viewed via the webcast at http://www.nhsengland.public-i.tv/core/portal/webcast_interactive/181468

4.1 Jude

24. Jude spoke in a personal capacity about the issue of informed choice.

25. He described his gender identity as being "in flux", with his self-knowledge "constantly evolving".

26. Jude talked about the desire to have top surgery, and his referral to a gender identity clinic. He said: "I did what a lot of trans people feel they need to do – I played a part".

27. He described his interview with the psychiatrist who found inconsistencies in his narrative and therefore referred him to a gender specialist when "all of the horror stories I had heard came true". Once again, the concept of "the narrative" was raised, with Jude describing how the use of real life experiences was a "cruel and unnecessary" part of the assessment process.

> ***A lot of us feel that we have to conform to the 'trapped in the wrong body' narrative, but there are people who CHOOSE to be trans, who don't hate themselves, or hate their bodies…All real life experience does is force people to adapt to outdated labels of 'trans men', 'trans women' or 'non-binary'. This is dangerous and it kills people…All we are asking is that people are given the information they need about the different procedures and treatments available so that they can make decisions about their bodies. Respect us as human beings and we might actually trust you. (Jude)***

4.2 Susan

28. Susan talked about the research she has done exploring the development of identity, and talked movingly about her own journey which was driven, initially, by a desire to change her physical appearance (something she tried to fight and suppress), and which resulted in "near collapse" at the age of 29, when she realised that she had to make some choices.

29. She talked about how the binary nature of the current service, and current social perceptions, pushes people into binary choices that they may not otherwise have chosen. A full set of slides can be found via the webcast page, where you can find out more about the research Susan has conducted into the complex issue of developing a personality. She now lives in a way that encompasses both gender roles.

> ***Simple acceptance is not enough…if you move towards transition, you have to accept that you may be replacing one set of conflicts with another. (Susan)***

4.3 Helen and Felix

30. Married couple Helen and Felix talked openly about their two very different experiences of transition.

31. Helen's experience was "very negative". She started out with a very good GP who provided really good care, but experienced insults directed both at herself, and at her ex-wife, when she met with a sexual health specialist. She was referred to a gender identity clinic where she described an experience of bullying and harassment, The process of transition was very long, and "tremendously stressful", at a time when there were no peer support groups to offer a helping hand.

> ***Putting people through that should never happen. I came out of the NHS traumatised by my experience. (Helen)***

32. In contrast, the couple refer to Felix's transition as being "charmed". Felix met his now wife after being referred to her, as an advocate for the trans community, by his GP. This was all part of Felix's care pathway. He was seen by a local psychiatrist within three months for a first assessment; and waited less than 18 weeks for surgery. Everything happened on time, every time, he said.

> ***The most important aspect of my transition was that I had the support of the voluntary sector, and the internet. Lots of people supporting me. These were informed people, who had lived the pathway, and who could help other people. (Felix)***

33. Felix, who works alongside Helen, running a service user group in Hull, talked about the importance of the voluntary sector which provides a "safety net" for many people. He made the point that clinicians cannot do everything, and that there is an awful lot of good work taking place amongst the many voluntary organisations, which desperately need some funding to enable them to better work together, and support clinical services.

4.4 Nick

34. The personal stories were finished off with a powerful presentation from Nick, who described his own experience of transition as joyous and life affirming but that negotiating the NHS gender identity system had been "debilitating", affecting every facet of his life.

35. He described the years of waiting for access to gender identity services; the failures to address inequalities for trans people; the fact that he had to write a letter every time he needed to reschedule an appointment at the clinic because patients were not trusted to use the telephone – waiting years to receive hormone treatment; being bullied into changing his name; poor administrative systems in clinics, and a process of manipulative gatekeeping by the clinics that compromises genuine therapeutic alliances between clinicians and patients.

Transition was the most joyous, life-affirming thing I have ever done, but the NHS almost broke me. I was a second-class citizen. The rules that govern fair access to the NHS do not apply to me because I am transgender. (Nick)

36. Nick talked about the experiences of others – "the pain, suffering, emotional turmoil, lives blighted and destroyed" as a result of NHS failures. Many people stay quiet and do not complain because they are fearful that the NHS will withdraw treatment if they make a fuss or they are so beaten down by transphobia, exclusion and internalised shame that they don't believe they deserve better.

37. He concluded by saying that he did find hope, in the shape of two clinicians who treated him as the expert he is on his own life and transition, and in the commissioner, who "went in to bat for me, but with one hand tied behind his back".

38. Nick called on NHS England to take the lead in finding a collaborative way forward in ensuring that organisations face up to their responsibilities towards transgender and non-binary people, and take accountability for their actions and failures to act. He said the system must be adequately funded and robustly commissioned, and have trans people at the heart of its transformation.

We need revolution, not evolution. We need profound long-term change: a Five Year Forward View for gender identity services". (Nick)

5 Group discussions

39. The Symposium continued with a number of small workshops, each of which contained one of the speakers, or topic leads; a facilitator, plus support from NHS England.

40. The purpose of the workshops was to explore, in more detail, some of the key issues which had been raised during the personal stories, and to ask of each group the following three questions:

> What is our responsibility?
>
> Where can we make a difference?
>
> What actions can we take?

41. Participants were asked to return to the main room after their workshop and highlight some of the key messages from their discussions. The following section attempts to capture some of those messages. Please note that only

one of the workshops was captured on the webcast, and that the sound quality of this workshop was impaired, as a result of technical issues.

5.1 Workshop 1: NHS and care services workforce

42. This workshop, led by Dr John Dean, was asked to look at issues relating to capacity and capability across the clinical, administrative and managerial sectors; professional pathways; and awareness and understanding e.g. use of pronouns.

43. Dr Dean delivered a short presentation on workforce and training issues at the start of the session.

44. Key issues raised:

- One area of concern is that of young professionals, who tend not to regard this specialty as an attractive career prospect. This needs urgent attention given the age profile of the current cohort of professionals working in this service.
- Concern re: recruitment and retention of staff in these services as well as succession planning; the need for a clear career pathway; career progression, and academic Continuing Professional Development (CPD) accreditation;
- Dr James Barrett described the ambition of the British Association of Gender Identity Specialists for an accredited training programme for each of the disciplines involved in the care of transgender and non-binary people. There are some examples of good practice – the Royal College of Psychiatrists and British Psychological Society has gender identity on their curriculums, and the Royal College of Nursing is developing a learning resource for healthcare assistants;
- However, there is no consistent multi-professional approach (an example given was the variation in undergraduate and post-graduate nurse training, where there is variation in the curricula across higher education institutions;
- An accredited multi-disciplinary qualification would be desirable with three different levels of knowledge. All staff should have a basic awareness of trans issues (level one), whether working in the NHS or independent sector, and whether new, or existing, staff. Level two would apply to all those delivering care to trans and non-binary people, where the level of knowledge and understanding should be good, and level three would be a more specialist requirement, for those delivering more specialised care. There are training needs for all professions and across all clinical disciplines, not just for medical practitioners. Everyone working in the NHS, including managers, administrative and support staff, has training needs.
- Vicky Osgood, of the General Medical Council (GMC), talked about the work the GMC is doing on 'credentialing', which is "…a process which

provides formal accreditation of attainment of competencies (which include knowledge, skills and performance) in a defined area of practice, at a level that provides confidence that the individual is fit to practise in that area in the context of effective clinical governance and supervision as appropriate to the credentialed level of practice". The GMC website describes it as "particularly relevant for doctors who work in areas of medical practice that are not covered by our existing standards for training, and in new and emerging areas of medical practice". The GMC is conducting a consultation (http://www.gmc-uk.org/education/continuing_professional_development/27258.asp) on credentialing, which closes on 4 October 2015;

- The GMC will also be consulting on a generic skill set which, it will be proposed, should be core for medical professionals;
- There was enthusiasm amongst the group for some collegiate work to explore options. The British Association of Gender Identity Specialists is well placed to facilitate this work. The following organisations gave a commitment to be involved – British Association of Gender Identity Specialists; British Psychological Society; General Medical Council; Royal College of Nursing; Royal College of Physicians; Royal College of Speech and Language Therapists.
- Other organisations not present for the discussion will be invited to join. In particular, the involvement of Health Education England will be critical.
- It was noted that a good way to engage with the Royal Colleges collectively is via the Academy of Royal Colleges.
- As a first step, Dr James Barrett will write to each of the organisations involved in the Symposium discussions, explaining the ambitions of the British Association of Gender Identity Specialists in this regard, and asking for a formal commitment to working on these issues. A meeting will be planned for the autumn. Dr John Dean will formally describe for James the work of the Clinical Reference Group around workforce and training, including links with Health Education England.
- Other issues that were discussed were the importance of voluntary organisations in providing a valuable resource for providing training to NHS staff, and the possibility of engaging with NHS Education for Scotland, which may prove helpful.

*Please note that the Gender Identity Research and Education Society (GIRES) has developed an e-learning package for GPs which can be accessed here: http://elearning.rcgp.org.uk/gendervariance

45. In the plenary session following the workshop, the concept of three levels of training was highlighted, as was the need for Health Education England to be a key driver in much of the work needed to progress this agenda. It was also acknowledged that a considerable level of patient engagement would be needed in developing some of the training and awareness-raising tools needed, as a lot of the educating would fall to the patient support groups and voluntary organisations.

> ***What has been made very clear to me is the power of the patient story…They are all very individual stories, but it is important that they are heard, by people in training in particular. Only then can they understand the extent of how people are feeling. (Vicky Osgood, Director for Education and Standards, General Medical Council)***

5.2 Workshop 2 – Service offer

46. This workshop, led by Felix and Helen Fenlon, was designed to focus on a number of areas, including networks and pathways, local services, and support and provision outside gender identity clinics.

47. Key areas for discussion were:

- Terminology

– Some voluntary sector trans organisations refer to themselves as a 'trans group'. This term was perceived by some as potentially reducing the validity of the services offered by voluntary organisations;
– Gender identity services are often described as a 'specialist service'. It was felt by some in the group that this was sometimes unhelpful as people may automatically expect that they would need to wait longer for specialist provision and therefore not challenge long waits.

- Funding for voluntary sector organisations

- This is different in different areas of the country so one organisation's experience is not necessarily the same as the other's;
- Funding often follows clinical outcomes, rather than looking at a person's well-being;
- There is a lot of added value that voluntary sector organisations can provide;
- Clinicians often perceive the work of voluntary organisations as being 'free' but they all incur costs associated with the services they provide, which are not currently funded in many areas.

- Engagement and trust

- Clinicians are often not aware of the services provided in a local area and therefore do not refer onwards;
- There is often a lack of recognition that transgender and non-binary people are experts in their field, and can offer 'niche' services, not available on the NHS';
- There is a perception of 'them and us'.

- Demonstrating value

- The NHS may not be aware of what is on offer and may not be sure what the outcomes of referring to voluntary sector organisations might be;
- There may be issues regarding quality assurance. NHS staff who refer to voluntary sector organisations need to know they are referring to a quality service.

48. Actions arising from this workshop were:

Possible action suggested	Organisation potentially responsible
NHS staff visits – an open offer to NHS staff to come and see what we do	Voluntary sector organisations/NHS England/Clinical Commissioning Groups
Further education to create a cultural shift amongst NHS staff	Health Education England
A move towards gender identity services becoming more user-led	Gender identity services/NHS England
Look to programmes such as Building Health Partnerships to identify how to better demonstrate outcomes	Voluntary sector organisations/NHS England/Clinical Commissioning Groups
Create a quality assurance framework for voluntary sector organisations – looking at what constitutes good in peer support, and sharing best practice	NHS England
Ensure that provision of peer support is part of the pathway that people are offered	NHS England
Create an offer to the General Medical Council to support training	Voluntary sector organisations
'Sell' services in a way that people recognise what your organisation does, so that people can see the quality of your work	Voluntary sector organisations
Support voluntary sector organisations to develop them to be commission/funding ready	Voluntary Sector Strategic Partners Programme (www.voluntarysectorhealthcare.org.uk/)
Develop a collective training offer from the voluntary sector in each locality to support CCGs/local authorities etc	National Association for Voluntary and Community Action (NAVCA) and voluntary and community sector infrastructure organisations
Map the voluntary sector organisations that work in this area	Voluntary sector Strategic Partners

49. There was clear recognition during the feedback session, following the workshop, that there are many local voluntary organisations which are very

busy, "filling in the gaps", and bringing real added value to the table – but are not getting paid to do this work.

50. Voluntary organisations need the expertise of others to support them in making bids for funding and/or developing business cases, and there needs to be a collaborative drive to establish a set of standards, by which the many voluntary organisations can be measured and the quality of their work assured.

5.3 Workshop 3 – Informed consent

51. Some clear themes emerged during this workshop, which was led by Zoe Playdon and Jude Orlando Enjolras:

- Equality of access to services. This includes the requirement that NHS specialised commissioning must address the violation of the 18 week waiting time rule as a matter of urgency.

- Access to services should be the same as for any other treatment, with no additional or excessive barriers/rules/tests to receiving that treatment;
- The starting point for any discussion with a GP or other medical professional should be: what does this mean for you? What would you like from me? What information do you need? Discussion around the options available;
- This approach fits in with a personalised care model and individual plans but the view is that this can never be wholly achieved while the services sit within mental health and the standards are set by psychiatry.

- Budget and role of gatekeepers

- This was discussed in terms of people not always having everything they want, as NHS funding is limited;
- GPs have always been gatekeepers, for any treatment, and this is the case for trans people;
- GPs need to act in a way that firstly 'does no harm' and have to assure themselves that this is the 'right' thing to do;
- It is the person who signs the prescription who is liable to litigation;
- GPs need to ensure that people have the right information to make a decision, and also have the capacity to make that decision. People felt that this should be same test as is applied to every other somatic condition;
- If people were listened to, they would not be pushed into receiving treatments that they did not want which, in turn, would save money.

- Trans and non-binary people are forced into a set narrative by a standards of care model.

- People felt that they were not allowed to have a personalised model because they are pushed along a set pathway, that is based on a standards of care model instead of one based on informed consent.

- Informed consent model

- The same tests could be applied for any somatic treatment, so not two years of psychotherapy required; is the person capable of giving informed consent? Does the person have the right information to enable them to make an informed decision? Is the treatment required available?
- People felt that they should be able to sign a consent form and that there should be protection for the clinician against litigation if someone changes their mind at a later date (people change their mind about treatments/operations in other treatment areas).

- People in the room

- There was a feeling amongst some of the professional organisations in the workshop that the specific people representing the organisations were, to some extent, already advocates for this area of work. Representatives were not necessarily the people who could make decisions, and therefore we were not talking to the right people. It was also noted that some key organisations were missing.

52. Potential actions from this workshop were as follows:

What needs doing?	How should it be done?	Who should own/lead this?
Treat this as a somatic condition and treat in the same way as other somatic conditions		
Psychiatry should be withdrawn from this programme of treatment (Both the interim and proposed policy and service specification state that clinicians no longer need to be psychiatrists)	Negotiation with Royal College	NHS England/Royal College
Workforce planning to focus on physician and surgery-led services		
Training and education for GPs and Royal Colleges starting with the most senior staff	Training and awareness-raising for all around treatment for trans and non-binary people in relation to somatic condition and informed choice	Health Education England
Managerially relocated from mental health	Internal debate which leads the way	NHS England

services		
Complaints from all trans and non-binary people to be taken seriously		GMC

53. There was some debate in the plenary session following the workshop about whether the current service specification for gender identity services could be re-worded to incorporate some of the thinking discussed about somatic condition and the withdrawal of psychiatry. It was pointed out that the development of the service specification is subject to strict governance processes within NHS England and therefore it was not within the gift of those in the room to simply change the wording without taking any proposed changes through due process, including consultation.

5.4 Workshop 4 – Person-centred care and support

54. This workshop, led by Susan Gilchrist, focused on the experience of trans and non-binary people in terms of personalised care and the support offered to them throughout the course of their lives.

55. In general it was felt that there were a number of approaches that could be taken from other areas of healthcare and used within gender identity services very quickly e.g. the personalised health passport, which includes details relating to a person, such as how they prefer to be referred to; their stated aims and aspirations for treatment; their preferred support networks etc. Other options discussed were an online, individually owned care plan, or a care planning approach, that includes the role of the care co-ordinator who could take on some of the bureaucracy of dealing with hospitals, gender identity clinics and other community-based interventions.

56. There was a suggestion from the Royal College of Nursing that we should push forward with a less consultant-led model, increasing the training/availability/input of nurse practitioners, thereby allowing trained nurses to deliver key parts of the care pathway, and freeing up other clinicians elsewhere. This would increase capacity and reduce costs.

If you have cancer and refuse chemotherapy or radiotherapy, because you don't feel it is right for you, you aren't thrown off the cancer pathway, or exiled from other interventions (Guy Thomas, Royal College of Nursing).

57. Potential actions arising from this workshop:

What needs doing?	How will it be done?	Who should own/do this?
Less consultant-led care/less paternalistic approach Some aspects of the care pathway to be delivered by other health professionals (and speed up care)	Stronger use of multi-disciplinary team (MDT) Better use of engagement approaches/therapies/support approaches Nurse-led interventions A care coordinator to support individuals	Gender identity clinics Service specification to outline stronger requirements Providers NHS England to set expectations Royal College of Nursing
Design a new person-centred care model Encouragement of different approaches, including different provider combinations. Avoiding unwanted interventions/having to 'play a role' to get treatment	Co-production of events including trans and non-binary people to focus on effective, individualised and non-linear pathways	NHS England to lead new model of care approach Commissioners to build into tendering and commissioning process
Develop a shared decision-making approach	Build into the service specification Set the tone for culture change	NHS England Royal Colleges Health Education England Take from other health areas' best practice
Personalised care plan for all trans service users Personalised outcomes are agreed and form the basis of the proposed interventions/support/pathway Online option – individuals own their own data plans and invite others to contribute	Build into the service specification	NHS England Royal Colleges NHS Choices Health Education England Take from other health areas' best

		practice Care Quality Commission
Develop a gender portfolio, similar to health passports, birth plans. Information would include how I want to be treated; stated aims re: interventions; preferred pronoun; preferred support networks	Build into the service specification Build in to training	These exist elsewhere so use best practice Providers and trans community to develop Care Quality Commission
Importance of the voluntary sector and advocacy GP is not always the first port of call Voluntary services are vital for on-going diversity of support throughout	Alternative funding approaches Better connectivity and networking	
Better networking and connectivity to support (better use of IT)	e.g. where can I get support? Type into NHS Choices 'I am non-binary' and information pops up on treatment options, support groups, nearest clinics for xyz	NHS Choices and trans community
Develop a 'Buurtzorg Nederland model'[4] A more community asset-based approach to primary and community/local care (Dutch model)	Focused on the inclusion agenda (not necessarily trans) Focused on community needs and assets Needs some developed budgets Needs strong inclusion planning	Local authorities VCS CCGs NHS England for integrated pathways

5.5 Workshop 5 – Building the evidence

58. This workshop, led by Dr Nick Douglas, focused on the clinical and social research needed to support quality outcomes.

[4] http://buurtzorgusa.org/about.html

59. Key issues were:

- Trans and non-binary people need to be empowered and resourced to produce the evidence, from an independent perspective. This includes making use of the contributions of community and voluntary organisations;
- The NHS needs to acknowledge the systemic inequalities experienced by trans and non-binary people, and to commission and publish research on how to tackle this;
- NHS England needs to develop a five-year research strategy for trans and non-binary people, involving academia, to include the production of high quality, independent research articles published in peer reviewed journals. The gender identity clinics should be obliged to carry out, and publish, research in peer reviewed journals;
- The NHS needs to gather data on trans and non-binary people in the workforce; the needs of trans and non-binary people; the use of all NHS services by trans and non-binary people (including via national patient surveys); the outcomes from different specialist services (gender identity clinics, surgery etc) for trans and non-binary people – evidence of their effectiveness.
- Helping to build the evidence from a Public Health England perspective;

60. A commitment was made, in this session, by Will Huxter, Regional Director for Specialised Commissioning (London) and senior responsible officer for the Gender Identity Services Task & Finish Group, to review the findings from NHS England's visits to gender identity clinics and to use these as the basis for recommendations for change and improvement.

61. Other commitments came from Health Watch Devon, to develop some local research into the needs of the trans and non-binary community; ClinicQ offered support from their learning on how to improve demographic data collection for the trans and non-binary community; NHS England to look into research and evidence gaps, and to raise the issue of demographic data collection with NHS England's Insight team, and colleagues working on the Information Standard.

> ***Trans people should be at the heart of evidence gathering – we are not human specimens. (Dr Nick Douglas)***

5.6 Sticky wall actions

62. In addition to the actions outlined in the individual workshops, a number of attendees posted actions up on the sticky wall in the main Symposium room.

63. Actions included reporting back on systemic issues relating to equality and diversity in the NHS – something that the Equality and Human Rights Commission might be able to assist with; plus potential to pick up on some work that the Commission is doing on LGB&T hate crime. Could we look at

bullying experienced by trans and non-binary people in the health service as part of this work?

6 Next steps

64. Olivia Butterworth, NHS England's Head of Public Participation, closed the Symposium by talking about the need to harvest the expertise in the room in order to take all of this work forward.

65. A number of actions will be implemented during the coming months, including:

- sharing this report will all Symposium attendees, and encouraging them to circulate it more widely;
- convening a meeting between NHS England, Health Education England, arms-length bodies (i.e. those organisations which regulate the health and care sector; establish national standards, protect patients and the public, and provide central services to the NHS), and the Royal Colleges, to discuss the development of a shared improvement plan;
- writing to Health Education England to impress on them the significant role they can play in improving the training and education issues raised at the Symposium;
- The British Association of Gender Identity Specialists facilitating an emerging discussion between different professions (medical practitioners, psychologists, psychotherapists, nurses, speech and language therapists, and others) on their workforce and training needs;
- NHS England facilitating the process of workforce planning and development with Health Education England, relevant Royal Colleges, the British Association of Gender Identity Specialists, and other relevant professional organisations, and with regulators, in order to meet the current and future needs of the NHS;
- connecting to the work being undertaken by the Royal College of Nursing Congress on LGB&T issues;
- talking to BIG Local, National Council of Voluntary Organisations and Regional Voices about the development of infrastructure support and capacity building programmes which are relevant and accessible to voluntary trans and non-binary organisations;

66. Planning will also start in readiness for the next meeting of the Transgender and Non-Binary Network in November, where delegates can expect an update on progress made against some of the actions outlined in this report.

Appendix A: Who was in the room?

Samir Jeraj Race Equality Foundation	Dr John Dean The Laurels Gender Identity Clinic, Exeter; Chair of NHS England's Gender Identity Services Clinical Reference Group (CRG)	Onur Yelekci Department of Health
Susan Gilchrist SIBYLS	Dr Nick Douglas Personal capacity	Dr Leighton Seal Royal College of Physicians
Yael Bradbury General Medical Council	Frances Newell Patient & Public Partnerships Specialist NHS England	William Cox Mermaids & Generate
Jason Stamp Chair, Specialised Services Patient and Public Voice Assurance Group	Leanne Wilkinson Healthwatch	Carole Reece NHS England
Guy Thomas Royal College of Nursing	Luis Guerra Public Health England	Suzanna Lee Race Equality Foundation
Anna Braczek Healthwatch Dorset	Tara Stone Tyne Trans	Will Huxter Regional Director of Specialised Commissioning (London), and Chair of the Gender Identity Services Task & Finish Group NHS England
Jenny-Anne Bishop Unique TG Network Transforum	Paul Howarth Government Equalities Office	Dr Vicky Osgood General Medical Council
Dr Vicky Osgood Director for Education and Standards General Medical Council		
	Rafik Taibjee Royal College of GPs	Nic Bray Transgender Information
Jude Orlando Enjolras Personal capacity	Kay Leacock UK Trans Info	Professor Zoe Playdon University of London
Rachael Ridley Royal College of Nursing	Dame Barbara Hakin National Director of Commissioning Operations NHS England	Christina Richards British Psychological Society
Helen Fenlon Trans Youth TPSS Support Group	Dr James Barrett British Association of Gender Identity Specialists	Bernard Reed Gender Identity Research and Education Society

		(GIRES)
Terry Reed GIRES	Professor Steve Field Chief Inspector of General Practice Care Quality Commission	Felix Fenlon TPSG Hull (service user group) Trans Youth Hull
Matthew Mills Royal College of Speech and Language Therapists	Ayaz Manji Stonewall	Steve Hamer Accountable Commissioner – Gender Identity Services CRG NHS England
Dr Helen Greener Royal College of Psychiatrists	Tim Dalby Information Governance Alliance	Tanner Gibbins-Klein Trans Healthcare Training
Jeremy Glyde Head of Clinical Effectiveness Team (Specialised Services) NHS England	Liz Prendergast Equality & Human Rights Commission	Olivia Butterworth Head of Public Participation NHS England
Jo Stringer Senior Communications Manager (Specialised Commissioning) NHS England	Angela Medd Patients & Partnerships Project Support Manager NHS England	Emma Easton Patient & Public Partnerships Lead NHS England
Rosie Ayub Patient & Public Partnership Account Manager NHS England	Alice Williams Public Engagement Lead NHS England	Ceris Challenger Project Coordinator, Strategic Change Management Team NHS England