Gender Identity Workshop, 20th March 2014
Coin Street Community centre, London

1. Introduction

This paper outlines the process and outcomes from a Gender Identity Workshop held in London on 20th March 2014. The workshop was arranged and facilitated by the Patient and Public Voice Team, NHS England with support and contributions from colleagues in Specialised Commissioning, Professor Steve Field, Maggie Morgan-Cooke, NHS Clinicians and members of the voluntary sector.

2. Context and Background

2.1 Two meetings were held in June 2013, one with members of Transgender communities, organisations and other stakeholders and the other with lead clinicians from the Gender Identity Clinics across England. At these meetings we committed to meet again to update people on progress made and continue to work together on this area. A further meeting was then held in November 2013 and we agreed to meet again in March 2014.

2.2 Participants on the day

- Transgender people and organisations who attended the previous workshops in June and November including people who had responded to the consultation on gender services and stakeholders of the clinical reference group.
- At the November meeting it was identified that it would be good to increase the number of Trans men in the group. Several new people attended including Trans men and they have agreed that they would like to be invited to future meetings (thank you)
- Clinicians from the majority of the Gender Identity Clinics in England
- The majority of lead Commissioners in this area
- Shortlisted applicants from the recent NHS England Excellence in Participation Awards - http://www.england.nhs.uk/ourwork/patients/exc-part-awrds/

  To view a film of their work click here: https://vimeo.com/user5146006/videos

  Their film is called - NHS Excellence Awards - Health Needs Assessment, just select this film and click to view

Other participants included Professor Steve Field and Maggie Morgan-Cooke who are leading the overall review into services, Dr John Dean who is the Chair of the Clinical Reference Group, a number of invited clinicians and other colleagues from NHS England, Specialised Commissioning.

2.3 Aims of the workshop

- NHS England to bring together different stakeholders to work in partnership and continue a conversation on a national level with trans 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
- To provide an update on the Gender Identity Services review being conducted by Professor Steve Field and Maggie Morgan-Cooke
- To continue to build the foundations for partnership working in the future

3. Outline of the day

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).

On arrival people registered and had a name badge showing their name and who they were representing.

To continue to reach a wider audience we again used our twitter hash tag for the workshop and displayed twitter conversations on a twitter wall. 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.

There were 745 posts of Twitter in total which lead to 1,047,848 impressions (number of impressions are described as the delivery of a post or tweet to an account's Twitter stream). The sentiment was more positive than negative.

The word clouds at appendix B show both the positive and negative sentiments.

Please click here to access the Twitter storify of the day:

http://storify.com/nagina_j/nhsgenderid-workshop

Olivia Butterworth, Head of public Voice, NHS England opened the day, welcomed everyone and explained who was in the room.

This was followed by two presentations on:

- An update on information collected and progress made on the Gender Identity Services review – led by Maggie Morgan-Cooke
- A summary of Specialised Gender Identity Specialised Clinical Reference Group Policy, strategy and initial draft recommendations to NHS England – Dr John Dean and Steve Hamer

After each presentation people had the opportunity to feed in their comments or raise questions.

(See appendix C for details of the questions and comments made following these presentations)

Following lunch we split into three of the workshop groups as they had proved the ones most people wished to attend:

- Group 1 – Children and Young People
- Group 2 – CRG – further discussions on how to prioritise services
- Group 3 – General Practice – Role of supporting Trans People

(See appendix D for the outcomes of these groups)

4 Next Steps

- Send out this report with the slides of the day
- Hold another workshop in Autumn 2014
- Please register for the network – see guidelines or e mail us at england.voice-scgd@nhs.uk
- The work regarding setting up patient reference groups covered at our November meeting continues - **Angela Medd and Rosie Ayub**
- If anyone would like to speak to Alison Austin regarding person centred planning please e mail england.voice-scgd@nhs.net and we will arrange this for you.
- If anyone has examples of good practice to share please send these to england.voice-scgd@nhs.net and we will share these. It's important to recognise where there is good practice so that we can learn from this and share it.
- **Maggie Morgan-Cooke** will keep the group updated re progress with the review.
- **Patrick Neville** to feed the outcomes from the meeting into specialised commissioning meetings and discussions.
- **Dr John Dean and Steve Hamer** will feed the information from their sessions into the work of the Clinical Reference Group
- The notes from the Children and Young People workshop will be fed into the relevant groups and the issues will be considered further in partnership with children and young people trans groups and organisations that represent them – **Patrick Neville**
- **Professor Steve Field** to liaise with relevant colleagues regarding the outcomes of the GP workshop at both the Care Quality Commission and NHS England

Patient and Public Voice Team
Patients and Information Directorate, NHS England
April 2014

Appendix A

AGENDA - Gender Identity Workshop

20th March 2014, Coin Street Neighbourhood Centre, London

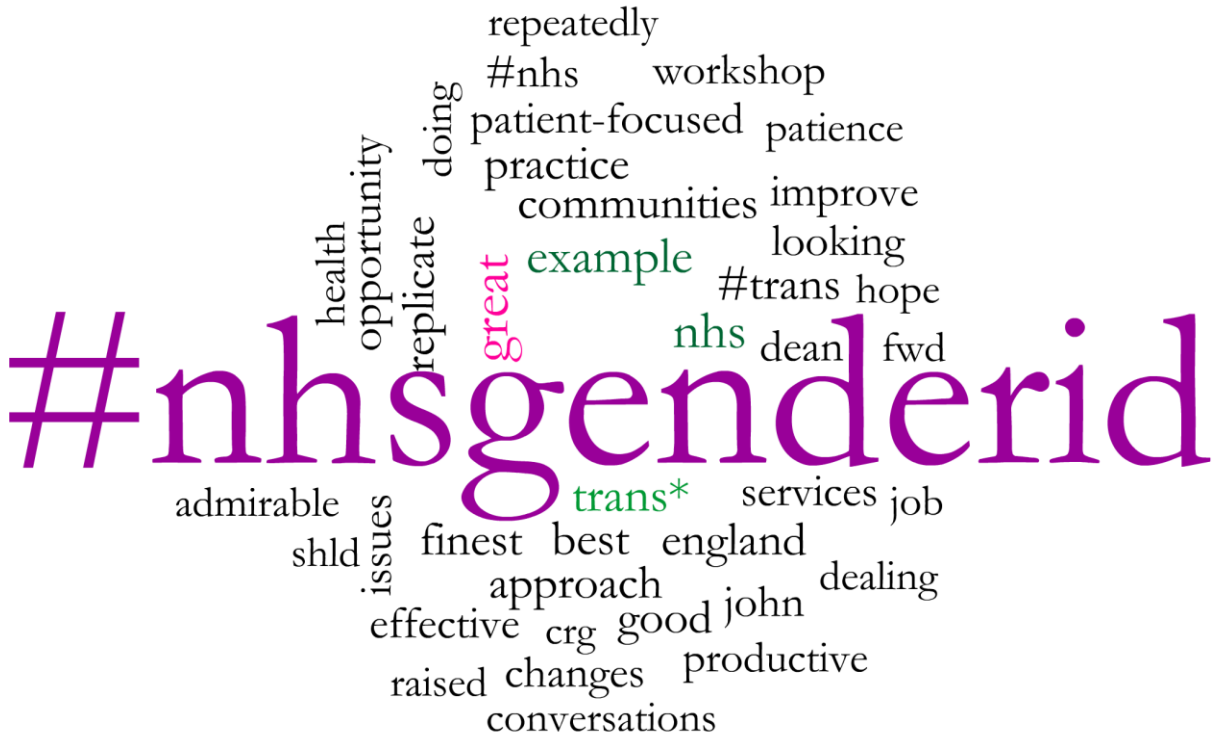
10.00	**Coffee on arrival**
10.30	Introductions, aims of the day
10.40	Update on Review – Maggie
10.50	Group work – questions from the review
11.30	Summary
11.35	**Coffee break**
11.50	Progress from the CRG – Dr John Dean and Steve Hamer (20 min presentation followed by questions)
12.30	Group work – Key questions to explore from CRG
13.00	**Lunch**
13.45	Reflections from the morning
14.30	Workshops – sharing good practice

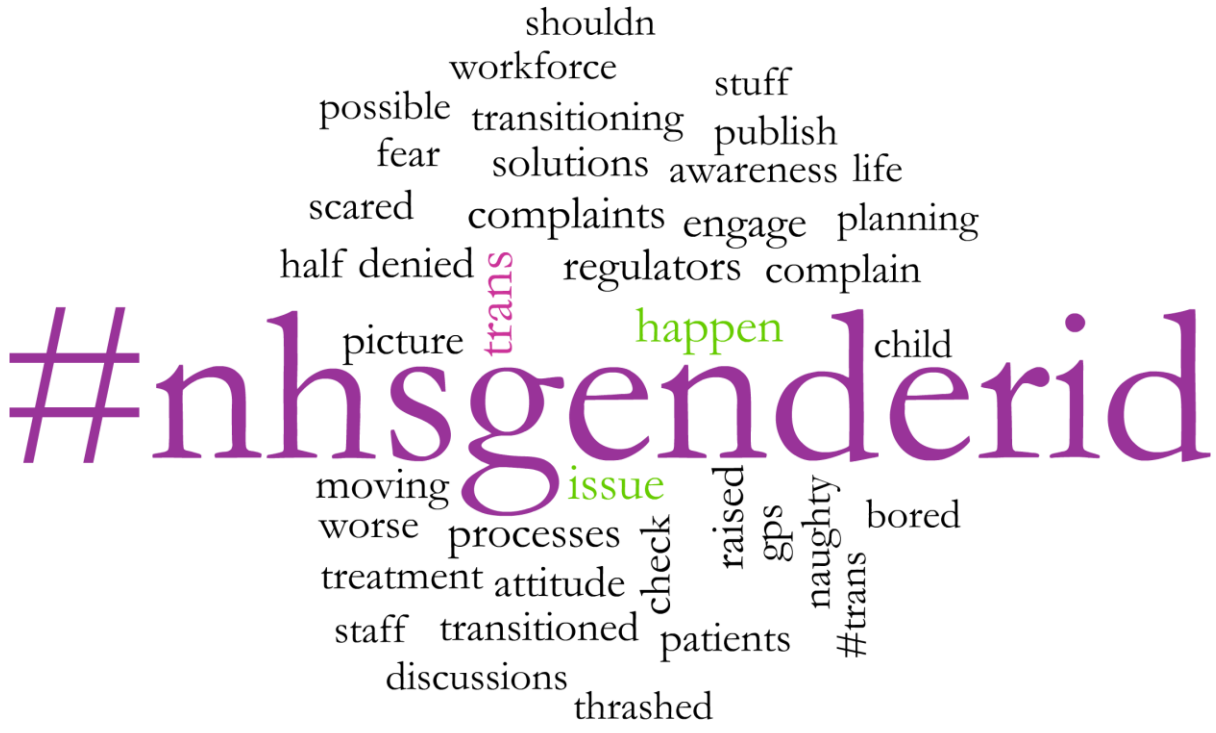
- CRG – further discussion on how to prioritise services
- Excellence in Public Participation in CCGs – Sonny Van Eden and colleagues
- Follow up on personalisation
- Children and Young People
- General Practice – Role of supporting Trans People

15.20	Feedback from the workshops
15.30	What are the key messages from today
15.50	Next steps
16.00	**Close**

Appendix B

Word Clouds to show the Twitter activity on the day





Appendix C

Large group discussion - following presentation on the Gender Identity Services review by Maggie Morgan-Cooke

- Need a breakdown of clinical figures
- Did the review cover the question of referral and route to services? – Why grouped with mental health?
- Is there a plan of action in the top line as referral rates increasing, waiting lists therefore increasing?
- What about outside of Gender Identity Clinics (GICs), what about other services e.g. Psychotherapy? Other professionals need more education
- Does waiting times mean wait from referral to be seen by a GIC?
- Will this include workforce planning?
- There is a lack of skills around Children and Young People – will you be looking at this?
- How do we educate/raise awareness of staff – what is the best way of doing this?
- What kind of education is planned for general provision? e.g. for people attending walk in clinics etc.
- What is there in place nationally to prevent invasive inappropriate questions in other general areas of the NHS?
- Some of training is a bit piece meal but some clinics do run days of training for their staff
- Is there an awareness raising model
- We need to work with Health Education England to make it better than it is
- If people have ideas on how we can strengthen this in the review, we would be keen for these to be put forward
- It is the whole pathway that the review looks at, not just the specialised experience. Needs to ensure it covers general experience outside specialised.
- Some of it isn't training but is about general values within the NHS. Needs to be appropriate – proposal put to CRG that everyone should do diversity training with people in gender id clinics doing it more often but issue that most equality training doesn't adequately address the underlying attitude towards trans gender issues therefore just doing current equality training won't solve it

Would the review be ok with making a firm recommendation that trans people can be part of supporting – not just expecting trans people to work for free?

- In other conditions there is a recognition for expert patients so there shouldn't be a barrier,

- Make it clear about how we could do this?

Yearlong exercise looking at trans care – is up and ready to roll – not being rolled out all over the country

- Maggie will follow up
- Is a lot of learning that has already taken place and the review must reference these things to ensure we don't lose what was good before

Local initiatives

- Need to have consistency nationally whilst acknowledging local need
- Need to ensure that change doesn't disadvantage other local areas – meet consistency nationally to a standard but with flexibility to meet local need
- It is a journey that we need to travel along
- Issues around boundaries e.g. Wales. NHS England responsible for defined parts of the pathway but not all of it. For example, before referral this is not part of specialised services.
- CRG needs to have consistency to deliver against the specification
- The review team have made a determined effort to collaborate and work with colleagues in Scotland, Wales and Northern Ireland to ensure we all learn from each other

Will the review be repeated?

- Would welcome this – need to ensure it's not just a report that gathers dust
- Is a root and branch look across whole of health and care provision
- It must be checked in future

Just simply a need for respect

- Huge variance in knowledge about the fact that gender variance exists, clinicians often delve into backgrounds and clinicians either send people away to come back when older or try to find something that is in their background
- Acknowledgement that children and young people need to be addressed but wouldn't do it justice to put into main review so need help to articulate strongly about how this should be addressed

Specialised Gender Identity Specialised Clinical Reference Group Policy, strategy and initial draft recommendations to NHS England – Questions raised following the presentation by Dr John Dean and Steve Hamer

1. Will we get copies of slides?
    a. Yes of course these will be sent out with the papers from the day

2. Why only two forms of facial feminising surgery?
    a. Facial feminisation can refer to all kinds of procedures. Feminising rhinoplasty and thyroid chondroplasty are the two procedures that, on the basis of feedback from patients, the CRG has identified as particularly valuable in reducing gender dysphoria and enhancing social functioning. The CRG has been considering a very wide range of interventions and has not yet completed its consideration of the complete range of facial feminising surgical procedures. Recommendations regarding other procedures of this type are likely to be included in future recommendations but not in the 2014/15 round.

3. Epilation – is amount of sessions at discretion of therapist?
    a. The Policy document covers issues of permanence; treatment effect for different skin types etc. are teasing out what to recommend in the policy but the top line is that people want it to be available everywhere in the country. The risk is that if it isn't specified on length of time / session's people will keep on coming back indefinitely. We need to be realistic.

4. Why is there no equality impact assessment?
    a. There will be one – this is for NHS England to do

5. Gamete storage – is this for people who've never had it or people who stop treatment in order to have it?
    a. It's for both

6. Can you explain 'appropriate' and 'timely' in this? (How long and who appropriate for – patient or clinician)
    a. Can't define these precisely, as each will vary according to context. This is a matter of judgement and should be agreed between service user and clinician on an individual basis.

7. Concern that the medical pathway is or seems to be very linear. It is very exclusive and directs down a set path. For example: what if you don't want hormone therapy but want a mastectomy (non-binary gender)?
    a. It's not possible to write a document to cover every eventuality. People with needs such as this will require a discussion with their clinician about an individualised care package for them. What interventions are needed for each individual, and the order of their delivery, is not fixed and should be decided on an individual basis. The guidelines do not describe a linear path but it must be a clinical judgment based on the individual circumstances of that patient. Where there is difference of opinion between clinician and patient, people have right to a second opinion.

8. Current guidelines are great but individual commissioners are not all following – there is a need to ensure people are not ignoring the guidelines.
    a. Need to ensure that practice set out in protocol is implemented and monitored.

9. Can you rephrase and clarify Real Life Experience (RLE)?
    a. No mention of monitored RLE – that is a concept from the past. However, guidelines do require a period of living in a (social) gender role congruent with gender identity. Do need some terms to describe having adequate confidence that the life changing things people are seeking are not going to cause them harm. There need to be a balance between requests from patient and clinical judgment.

10. Are you talking about independent psychological services that enable confidentiality to work? Dysphoria can often be tangled with other life issues but if people feel they will have to give the right answers to other professionals, this won't happen.
    a. These interventions are part of specialised gender identity services. If someone has depression, anxiety or similar that is unresolved, that is something that should be addressed within local psychotherapy services through GP services and we would support this. Psychotherapists working in GICs are a part of the GIC multi-disciplinary team; patients should be aware that if the multi-disciplinary team is to function effectively, in their interests, relevant information must be shared within the team. Patients are not restricted from seeking psychotherapy outside the GIC but that is not provided within the Gender Dysphoria care pathway.

11. 12 months in gender congruent identity is mentioned but we know that many GICs are asking for 2 years. We know there is a shortage in surgeons. How

will the reduction to 12 months be reasonably implemented? Is it 12 months before referral or 12 months to surgery?

a. UK good practice guidelines recommend at least 12 months and these are the overarching guide. Doctors have a duty to exercise clinical judgment to these guidelines so for most people there should be no reason for additional local restrictions or rules. Additional eligibility criteria should not therefore form part of routine practice but for some people a more extensive evaluation may be necessary. This shouldn't tie clinician's hands. But, if people disagree with clinician they should have opportunity to ask for a second opinion.
b. Persistent and well documented – can we change the wording? – There needs to be a balance between service users choice and taking reasonable steps to make a clinical judgement. The words "persistent and well-documented" are a direct quotation from the UK Good Practice Guidelines, which were published less than a year ago. These were developed by a group that included patient representation over a ten-year period; revision of the wording must wait for a review of these guidelines.

12. There are 7 clinics across country and people are entitled to choice. Within children's services there is only one so there is no option for a second opinion. This is against NHS policies and should be revised.
    a. We will feed this back to children and young people services along with feedback from this afternoon's workshop

General points raised

- What about equality of access regardless of where you live or your background and ability to speak up for yourself and your needs
- Can the Care Quality Commission incorporate some checks into their inspection process to ensure all services are equipped and trained?

Group 1 – Children and Young People

What do we have currently?

- Youth Services
- Tavistock and Portman clinic – referral

  CAMHS, G.P, Mermaids
- Network Model → All involved and young person
- Local CAMHS squeezed
- Bullying / stigmatisation
- Children + young people and families

  
- Puberty and self-harm – women
- Earlier intervention → pre-puberty → under 16 – 1 year before hormone treatment
- Little research evidence on hormone treatment
- Very complex – outreach South West
- Different views on what it should be!

Families – Mermaids

- Evidence base - need more parent and patient consultation,
  Chicken and egg situation - nobody is doing anything so no evidence.
- Lots of hard and fast rules - people end up butting against these
- There is nowhere else to go for services (can't get a second opinion, people are often afraid to speak out/complain because of this as nowhere else to go for services)
- Often parents 'don't want' to attend an appointment as it is difficult for them to accept they need to do this. If we make it hard for them (distance, time etc.) they won't go.

- People are frightened to publish information about things like ages of prescribing

- The evidence base will grow

- The issue around children and young people is the uncertainty about decisions to proceed – if things are not reversible, careful consideration is required

- Zuckers evidence – is dated

- Fear re America and Insurance Payments

- Tavistock and Portman do not base their research on Zuckers

- Lots of Dutch publications to refer to

- Lots of young people come through the CAMHS route

    - Staff start working with them
    - Make progress but when dysphoria is identified as the condition ……
    - Some families don't want to go to gender ID services as they want local services and find it hard to accept the condition
    - Nowhere else to go as not commissioning on an on-going basis
    - How can we share the expertise wider, more locally?

- Need Trans aware advocates to work with children and young people

- If young person faces resistance at home and in service, where do they go?

- Gendered Intelligence and Intercom trust - **Do not reach the North of England**

- Need a proper assessment / need local services and then some national

- Services rely on good relationships with families

- Parents get scared as they don't understand and want to be treated locally

- Training of CAMHS staff is an issue – need the opportunity to work with other organisations

- Alex from SafeT to send Polly Carmichael his address as the group were not invited to the Leeds Tavistock and Portman meeting

- Lucas Jay Honey – runs training sessions on Trans Awareness

- **<u>Really important to understand that different networks represent different parts of the country and it is important to include the right mix so people are represented</u>**

- Discussion around cross sex hormones – why always the same time (1 year) levels over the age of 16?

- Issues
    - Time on blocker
    - What age should cross sex hormones be given at
- We need to look at international learning

- Blockers put things on a pause and give people time to make up their mind

- It is important that a young person (in a position to make the decision) has the opportunity to fully understand what the results of this are: effects – ability to have a family in the future

- More CAMHS skills are needed

- More GP understanding (especially re blockers) - Access Issues GP Levels, biggest problem is here, this is the first place that young people go to for help and support clinically

- Awful when young people are not referred in a timely manner and the situation just gets worse for them

- Reality at up skilling staff is that it is unrealistic – not enough budget

- How do we get the direct voice of children – need access to groups run with children and young people. Great care needs to be taken with this.

- Need to be views representing all parts of the country

- Blockers funded through GPS – some less keen than others

- T&P will prescribe if they need to as GPS will not but families have to travel to pick up prescription.

- There is a working Group on Transition – GIC clinics / T+P

- Families feel that they can't speak out as there is only one provider

Conclusion of the group

- A review is required to look at how services are offered locally and nationally.
- Ask young people what they want **first,** don't decide for them
- Commissioners pay for a service and need to understand what is required so they can get and buy from their **providers**.
- Consider all areas – the whole child → Connect with social services
  → Take a holistic approach
- Look at access to services and barrier to services
- Provide support for research
- Don't forget rural areas
- Ensure patients are an integral part of decision making process
- T+P, Mermaid, Gendered Intelligence, Safe T included

Group 2 – CRG – further discussions on how to prioritise services

Issues and questions

- Epilation – should be criteria base on patient benefit and choice
- Where there are two options and one is cheaper, patients still need choice
- Shouldn't pursue treatments for some people that are never going to be effective – eg: laser treatment for some people
- Epilation rules (e.g.: number of interventions) should be comparable or not worse than CCG policies for the wider population
- Where does funding for individual surgery sit?
- CRG – requests for revision of surgery acceptable up to 12 months from surgery
- Treatment of complications funded as part of the pathway
- Later revisions may be done through an IFR
- Re post-operative – if have later complications should be asset and treated in transitioned gender role (i.e. trans women should be able to access services, such as gynaecology, in the same way as other women; this will require some changes in practice and attitude in other parts of the NHS, and will also have implications for training; this change will not occur overnight but we have to start somewhere; liaison with speciality Royal Colleges and the Health Education Authority will be needed)
- There is query about whether there should be one or two spec's
- Need clarity – what about where new treatments become available that weren't retrospectively available – distinction between availability and access!
- How can people hold services to account without punishment?
- Do breast implant augmentations need replacing?
- Discharge – and transitioning to mainstream services (e.g. hormones treatments) – needs to work through different scenarios
- Capacity – Gender Identity Clinics are already struggling. What is the systems response and what contingency planning is there?
- Need to think about GPs – would be good to establish a specialist network of expert GPs

Group 3 – General Practice – Role of supporting Trans People

Issues

- GP reluctance to prescribe hormones
- Possibly breaking the law by passing confidential data around
- The complaints system does not understand trans people – non responsive, nothing changes
- GP ignorance about issues and their responsibilities
- GPs providing excuses to avoid referral for treatment
- A problem when GPs give misleading information and don't hold their hands up and admit they don't know
- It is unlikely that GPs will have had exposure to a trans person during their training and therefore have limited experience or understanding
- One specific GPs attitude noted: There is no funding for this area, and no pathway for treatment
- Lack of knowledge, confidence, fear of getting it wrong
- Licensing of drugs is a blind alley
- Some rural GPs are ignorant about LGB&T
- Anonymity can sometimes be dangerous for trans people (example about a GP at a walk in clinic that asked inappropriate questions)
- Issue around ongoing care for trans people for other medical issues
- Within general practice this isn't an issue just facing trans people – many people with rare conditions or other issues also find GPs don't know enough about their situation – GPs are by nature, generalists not specialists and many GPs will never have encountered a trans person before
- Equality of access in rural areas
- Not all trans people want to access the voluntary sector

Solutions

- CQC advertising for expert patient inspectors for visits – a good opportunity for people to get involved and ensure trans issues raised
- CQC consultation – 9th April – make sure you have your voice heard in this
- Is there a need for a specialised GP – to support other GPs and give people choice to go to this GP (regardless of geographical boundaries)?
- Role for the CQC in raising trans awareness
- Definition of 'vulnerable people' within CQC work to include trans as a sub category
- No GP boundaries in future could enable specialised GPs to form enabling people to travel to a GP with more specialist knowledge

- Network of localised specialised clinicians to meet our needs at primary care level including nurses, GPs etc.
- Ensure there is an equivalent to ‘walk in centres’ / treatment centres for people who prefer anonymity
- Clear signposting to services / evidence
- Regulation of specialised GPs practices

Training

- Need trans awareness training across the board in the NHS, not just for GP’s (and including at undergrad level)
- Provide under graduate and work based training

Choice

- Give people a choice of access routes – VCS, primary care etc – what is right for them

Voluntary sector

- Investment in trans gender voluntary organisations / groups to ensure they can be part of the solution

Representation

- Opportunities for trans people to sit on boards of CCGs etc. to influence

Partnership working

- Resource for GPs and service users that they can use – that either can access
- A trans focus group in every CCG (or appropriate geographical area) - Just do it!