

Healthwatch Gloucestershire Report

Access to health and support services by the
Trans community and their families



March 2017

Disclaimer

Please note this report relates to findings in October 2016. This report is not a representative portrayal of the experiences of all service users, only an account of what was observed or contributed during the work by Healthwatch Gloucestershire.

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1 Introduction

1.1 Healthwatch Gloucestershire (HWG)

Healthwatch Gloucestershire (HWG) is the local independent consumer champion for health and social care giving patients, the public, service users, and their carers and families a stronger voice in how health and social care is planned and provided. It is one of 148 local Healthwatch organisations working with Healthwatch England (HWE).

Local Healthwatch functions are:

- To gather people's views and experiences of health and social care, and use them to influence those who commission and provide services, helping them to be more responsive to what matters to service users and the public and to enable the design of services around needs
- To provide the public with information and signposting to help them make informed choices about their health and social care needs
- To provide access to the Independent Health Complaints Advocacy Service seAp (Support, Empower, Advocate, Promote)

1.2 The Healthwatch network and people who are transgender or non-binary

In response to feedback from transgender people shared by the local Healthwatch organisations, HWE raised concerns with NHS England in May 2015 about the lack of communication and information for transgender people. It also raised concerns about people facing considerable delays in waiting times for assessment and surgery; and workforce issues including a lack of specialist consultants and a lack of planning¹.

NHS England took a number of steps in response to submissions from HWE and other organisations. It published an online blog, '*Improving communication about gender identity services*', the first in a series of regular updates about what NHS England is doing to improve gender identity services². NHS England also decided to invest an extra £4.4 million in providers of gender identity services to help reduce waiting times. It acknowledged that the need to recruit and train additional surgeons was the key limiting factor for reducing waiting times more quickly.

Local Healthwatch organisations continue to collect feedback from transgender or non-binary people. Earlier this year, Healthwatch Devon published its comprehensive *Gender Identity Report*³.

HWG actively seeks to gather the views and experiences of transgender or non-binary people and their families across the county, to fulfil its function in enabling all people living in Gloucestershire to have a voice in the way that health and social care services are planned and delivered.

1.3 Gathering the views and experiences of transgender or non-binary people and their families in Gloucestershire

Feedback collected by HWG suggested that the following issues were of particular concern to transgender or non-binary people in Gloucestershire:

GP surgeries and hospitals

- The impact of staff awareness of gender identity issues and attitudes towards transgender patients, particularly at GP surgeries
- The distress that can be caused by patients being misgendered, for instance in hospital
- Changing identity
- Changing an NHS number

Gender Identity Clinics (GICs)

- Long waits for the first appointment, following referral to a GIC by a GP
- A lack of support provided between referral and being seen at a GIC and the consequences of long waits without support, e.g. distress and sometimes attempted suicide
- The impact of having to travel long distances to GICs
- The need for local appointments
- The need for support for partners and families

Psychological therapies

- Delays in getting psychological support counselling for family members, causing distress to families coming to terms with a family member transitioning
- Barriers to accessing psychological therapies, namely being told it is too 'specialist'
- There are no specific NHS-commissioned counselling services. People are experiencing waits of up to a year for appointments with local private counselling services, for which they still have to pay

To learn more about these issues and find out about people's experiences, HWG invited a group of transgender and non-binary people (including young people under 25 as well as older adults), their partners and other family members through their local support organisation Gloscats, to an informal round table discussion in October 2016.

1.4 Gloscats

Gloscats was formed in 2005 by a small group of transgendered people, initially as an e-group; to address the lack of a social life for Gloucestershire's large, and largely closeted, trans community.

Gloscats is now a charitable trust, with various purposes including

- To provide a social networking and support group for trans people, their partners, family members and friends in Gloucestershire, Bristol and surrounding areas
- To campaign locally for equal opportunity and consideration for trans people in the community
- To work in partnership with other organisations that support its purposes, including GIRES, the Gender Trust, Press For Change, the South-West Transgender Equality Network and other local transgender support groups
- To engage with key stakeholders in the public, private and voluntary sectors to raise awareness and educate their organisations on trans issues. These stakeholders include the police, health services and local government
- To help facilitate access to appropriate services for local trans people

Gloscats meets regularly at the Station Hotel in Gloucester. More information about Gloscats can be found at www.gloscats.org.uk

2 What we learned

2.1 Personal stories

Several people shared their own personal experiences of seeking treatment and support.

C's story

“When I initially approached a GP about my gender dysphoria, she told me I hadn't gone in with enough information. She said I needed to come back with all the information she would need to refer me - the name of the clinic, contact details, the person who deals with referrals (which I never found, because to this day I have no idea where I'd find such information). It felt a bit like I was doing her job for her, but without the resources and knowledge she would have been able to access. Because of my age, I went from being used to going to the GP with my Mum, to going to the GP alone and asking “what should I do?” and the reply being “well, I don't know either!”

I waited 14 months between my GP referral and my first appointment at Charing Cross Hospital, which was just over a year ago.

Because the GICs are all so far away, there is so much to think about for the day; not just about the appointment, but having to plan the journey to London, finding the hospital and getting there on time, rearranging other commitments, that sort of thing. Before my first appointment, I had never been to London on my own before - it was really daunting to do all the preparation on my own.

At my first appointment, I was told I had to come out to my family, my university, everyone I had regular contact with, by the time of my second appointment - otherwise, they would not prescribe me hormones. So, I had six months in which to come out to all of these people - some of whom were really not supportive.

I then had 6-monthly appointments. The results from the tests my GP did didn't get forwarded to the hospital, so I had to chase this up. It was one year on from my first appointment, that I got my prescription. The worst bit was that I thought I was quite close after my second appointment; but then the letter came through saying that they were still waiting for information to come through from my GP, and this was really hard to accept.

I have some anxiety, and depression. They said I could have counselling at Charing Cross if I travelled up every two weeks, but this just wasn't feasible - either timewise, or financially. But I don't want to go somewhere for counselling where I don't know whether they will be transgender-friendly.”

K's story

"I've been out full-time, including at work, since August this year.

Last year, I had found myself getting worse and worse because of my dysphoria - I realised I was in a desperate state. I rang my work and said "I'm going to go and see my GP today and I'm going to ask him to sign me off". I rang the surgery and said I needed an appointment. They said I could have a telephone consultation with the GP, who rang me later that morning. I had a talk with the GP, and explained about gender dysphoria - he did sign me off, and booked me an appointment for a month's time.

In the meantime, I rang the 'Let's Talk' service as I was really anxious - I told them that I was so worried, about the stress I was putting on my partner, about my fears for my children and concerns that they might get bullied at school, and so on - but 'Let's Talk' said they wouldn't talk to me "because it's gender dysphoria".

I had such a lot of anxiety about going for that first meeting with my GP. And when you are feeling like that, and you go to the receptionist and you say who you are - I try using my 'little' voice - when the receptionist then asks you to speak up, that then means that everyone in the waiting room is looking at you.

When I went in to the GP's room, the first thing he said to me was: "Hello Sir, how can I help you?". So I said "well, would you mind not calling me Sir?". He said "of course, that's fine. What do you want me to do? Where do you want to go?" So I asked for help with someone to talk to.

I took some information about gender dysphoria, to help - and the GP said "this isn't enough information. Tell me the name of the person you want to see, at the clinic you want to go to". I felt I was being almost a bit too helpful for my GP - I sent him internet links, which he didn't look at, and he really just sat back and let me drive it. This meant I was not being given information, and also the information I was offering wasn't being checked to find out whether it was right, or out of date, or not.

I'm now having my gender treatment through a private health scheme through my employer. This is fine (although it means that vocal therapy is not happening, as apparently this is something which is only triggered through NHS treatment at a GIC).

There was just so much extra stress, on top of my gender dysphoria. My workplace was really supportive, and I would say that, if it wasn't for work, and for Gloscats, I honestly don't know what might have happened. When you reach that point, your mind is in desperation. At that time, I would say, if I could have taken a pill to 'cure' me, I would have done. No-one should feel that desperate and alone."

T's story - a parent's experience

“We went to see the GP (Dr S) in May. He was very compassionate and respectful when we saw him. Prior to our visit to the GP we had contacted an organisation called Mermaids who had originally advised us to contact him, and ask to be referred to the Tavistock and Portman Clinic rather than to CAMHS to avoid delay. They also advised us that there was a 4-month waiting list for an initial meeting.*

Dr S was very kind and referred us to the Tavistock & Portman NHS Foundation Trust in London. Our wait ended up being a 4-5 month wait for the appointment.

When we arrived at the clinic, we were struck by the human and compassionate approach - for instance, after we had arrived and spoken to the receptionist, we went up in the lift; and the two staff we were due to see were waiting to meet and welcome us out of the lift. They explained the process to us - how many times they would need to see us, and so on - and it was all handled with respect, understanding and experience. Experience was probably key to it, as it reassured us that Z was not alone and others had been there before.

It was realised after our third visit, that Z could go to University College Hospital for treatment. This is an expanding service, with more clinical staff including counselling staff, which is being put in place to try to reduce the waiting list. Z was in the last ‘batch’ of young people who got through relatively quickly; young people are currently waiting for about 18 months now. There are increasing numbers of young people coming forward.

Z is now receiving her hormone blocker through our GP service who have been very cooperative. Our GP (Dr S) retired shortly after our initial visit. Dr W took over and approved the blockers. Dr W and the nurse have been very sensitive and kind with us.

*However, we had terrible situations while we were waiting, when Z was really in a very bad way. Our GP didn't know about Mermaids or indeed any other groups. Z was his first experience of a transgendered patient. We weren't told about Gloscats, or POGTY**.*

.../continued overleaf

* Mermaids is a national organisation for children and young people who are trying to cope with gender identity issues, and their parents and families
www.mermaidsuk.org.uk.

** POGTY is Glos Parents of Gay and Trans Youth, a group for the parents of gay and transgender children <http://e-voice.org.uk/glospogty/>

T's story - a parent's experience - continued

Z felt really isolated and the waiting period was fraught for her. She self-harmed regularly, and twice tried to commit suicide. We did not feel the counselling she was receiving was often enough, or effective enough.

Eventually, after her second suicide attempt, Z was referred to a psychiatrist once a week as opposed to once a month with a counsellor. This did help. However, we realised that Z needed to meet other young transgender people. Once we had learned about POGTY through a transgender lady working in the police force, we started coming to the groups (there is one group for parents only, and one for parents and young people together), Z started to get support and it made a real difference to her. She needed to feel less different. It has been a lifesaver!

Incidentally, I've asked someone from the University College Hospital service to come to a POGTY meeting. They are going to come, to make this happen.

The Tavistock & Portman asked me "are you as a family getting any help?" I said "no - but we need some".

Parents don't realise at the time that they need support - they are so focused on their loved one. But I was in the dark on everything, and I put my trust in the NHS and in services. And, it is hard - as parents and siblings, we focus on the person going through it but we also feel a sense of loyalty to the 'old' person, who has been rejected by the 'new' identity. It is very painful for the family to lose the 'old' identity and could be comparable to a bereavement."

E's story - a partner's experience

“In October 2013, having lived with gender dysphoria for many years and growing increasingly distressed by it, I decided that I must end my life. I was lucky - rather than committing suicide I decided to get help. By searching the web I found a counsellor in Gloucestershire who appeared to have very strong understanding of gender and transgender issues. My partner was very supportive - she had seen my suffering get ever deeper and hoped that my counselling might relieve this.

After a year of counselling I decided I needed to ask my GP Practice in September 2014 for a referral to a Gender Identity Clinic. On the day I went in I specifically asked to see a female GP (rather than my usual male GP) - she was very empathetic, said she knew little about transgender patients or issues, but asked me to tell her all about what I was going through. After half an hour she said ‘I’m going to refer you, I’ll do the paperwork and send it off to the Health Trust as we will need funding’ (which as it turned out is incorrect).

I told my partner that I was going to be referred to a GIC as soon as she got home. What followed was five days of rage, abuse, tears, anger interspersed by periods of empathy and support while my partner struggled to cope - she forgot to eat, had very broken sleep and five days later had an epileptic attack, the first of her life, at around ten thirty on the Saturday night. I woke up and she had blood all over her pillow and was struggling to breathe through bubbles of blood and saliva. I thought she was going to die.

I put her in the recovery position and dialled 999 - the paramedic took eight minutes to come and almost immediately called in an ambulance.

When we got her to the hospital (in Hereford) it was full. She spent the first night in a noisy side-room in A&E, and then was moved just before midnight on the following night to a busy ward containing some dementia patients meaning she again got almost no sleep.

At that point she had still not been seen by a specialist ‘as it was a weekend’. She then had another seizure.

At that point the hospital started to get active - moved her to a quiet single room, got a specialist into her and started brain scans and diagnosis. She has had no seizures since. Because of this delay and the second seizure, this meant she could not drive for twelve months (rather than the six months after one isolated seizure). We run our own little business which requires her to travel both in the UK and internationally. It was not a good year.

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E's story - a partner's experience - continued

Just before I had my first GIC appointment (in July 2015, ten months after the GP referral) my partner became extremely verbally abusive - between half an hour and three hours every single day of the vilest gender- and sexual-based insults you can imagine. This culminated in a domestic violence incident where she came through a closed bedroom door, a closed bathroom door, physically grabbed me and screamed abuse in my face. At that point she shocked herself I think - she started to seek counselling.

At this point the only NHS support we had received around my gender dysphoria was my GP appointment and my first GIC appointment. All counselling support (two years for me and over a year for my partner) we had found and paid for ourselves. At the point my partner took her second overdose she finally went to the GP, who then provided short-term suicide support/counselling for her.

It is now two years since my GP first referred me. I have been diagnosed as transgender by my GIC and have legally changed my name and transitioned. I have hormone prescriptions and am patiently waiting to be referred for my operation hopefully sometime in late 2017.

While my partner and I share a home, we now lead mostly independent lives and are trying to work out how to be 'soul mates' or 'flat mates who share a house and have a twenty seven year history behind us' but we are sadly no longer a couple. We have very few mutual friends at all now. While my partner was in her abuse phase she also verbally attacked those friends who stood by me, and turned our mutual friendships into a battleground. That means our previous mutual support network of common friends no longer exists either.

Going forward I would strongly recommend NHS support for those dealing with a trans-partner or close family member. Lack of support left my partner:

- *having two seizures, being admitted to hospital and being now on permanent anti-epilepsy treatment for life.*
- *taking two overdoses, requiring suicide support/counselling.*
- *becoming an abuser, both verbally and then physically.*

One of the saddest things about being trans is that, while we can be diagnosed and transition our lives, for our partners there seems to be no help unless triggered by a medical emergency. I will always wonder what proper support for my partner before her seizures, overdoses and abuse phase might have achieved."

2.2 GP surgeries

People described both positive and less positive experiences of visiting their GP surgery. Some were very positive:

“One person at Gloscats went to Kingsholm practice, and saw a female GP there, who was excellent. This GP has done it all 'right first time', and sorted it”

It was felt that overall, there is not generally a lack of willingness among GPs to help; but (as illustrated by the personal stories) there is sometimes a lack of awareness about

- treatment for gender dysphoria
- where to signpost people for information and support
- how to relate to trans patients generally; which also extends to practice staff including practice managers and receptionists.

Members of the group reported that some GPs still believed that a person with gender dysphoria had to be referred to a mental health service in the first instance for assessment. Others told patients to “go away and think about it” for 6 months, and to come back and ask again if they still wanted to go ahead then. Others again were not clear about funding for GIC treatment.

People said that, when their GP didn't seem to know very much about gender dysphoria, they went to appointments armed with information themselves; but that they were aware of the risks and limitations of information they had found online. People also felt that GPs could be more proactive in their approach, for instance in relation to blood-testing.

“We know some GPs are more aware of gender issues; but because of practice boundaries we are restricted as to which GPs we can register with”

“It would be really helpful if GPs could say 'you are normal, this is where you need to go, you can meet other people'”

"There is a lot of waiting for referral and for treatment, and with transition there is an age pressure. Lots of people self-medicate - some people do this safely, but other people don't.

If, when you went to see your GP, they would say 'we'll refer you to a GIC. The GIC is going to need blood tests on your hormone levels, so let's get started with these now, and do this every couple of months so we can keep an eye on them'. This would mean that the GP would notice if a person's oestrogen levels were getting a bit high, for example, and they could then say 'please come in and talk to us, so we can sort this out, so you don't damage your kidneys'"

The General Medical Council (which registers doctors, sets the standards that they need to follow and which oversees UK medical education and training) publishes good practice and ethical guidance on its website; including guidance on gender dysphoria:

"If your patient requests treatment for gender dysphoria, experts agree the best way to meet their needs is to refer them to a Gender Identity Clinic (GIC) or gender specialist without delay" ⁴

As well as offering guidance on appropriate treatment, the GMC provides more general advice on working with transgender patients:

"The way you address patients who are transitioning or have transitioned is extremely important and taking care to use the right (i.e the patient's preferred) name and title shows that you are treating them with respect. If you are not sure how you should address someone, ask them, "how do you like to be addressed?" and also "what pronouns do you prefer people to use when talking about you?"

Employers have a responsibility to ensure that all staff are trained to understand trans issues. Trans women's voices can sound masculine on the phone. Sometimes misgendering a person is a genuine mistake for which the person making the mistake should apologise, and move on. Receptionists, practice nurses as well as doctors need to consider the long-term effects on mental health and wellbeing of trans people, if those they turn to for help don't treat them with respect. It may even prevent them from seeking healthcare at all" ⁵

2.3 Hospitals

Members of the group described positive and less positive experiences of hospital visits. For instance, two people from the north of the county who had visited Hereford County Hospital described their experiences:

“I visited Hereford for breast screening. I said “this is my first time doing this, and I’m trans... The nurse said “this is my first time screening a trans person too”, so we learned together, and it was OK”

“I’ve had some issues there. There have been situations where my records have still been showing the wrong gender despite my efforts to have them changed; situations where staff have shown a lack of understanding about how to relate to a trans person, or to the partner of a trans person”

Gloscats delivers awareness training to apprentices at GHNHSFT, and has received positive feedback from new staff who say they have found it helpful.

2.4 Changing identity, and changing NHS number

People reported mixed experiences around changing identity, and changing NHS number:

“My GP has been quite good. The practice changed all my records to show my new name, and the GIC helped me with arranging a new NHS number”

“I’ve changed my name by deed poll; but the GP has continued to use my old name. The GP has never asked me about how I would like to be addressed”

“My GP is really good - but, even now, I still sometimes get misgendered from my old records”

With regard to transition and getting a new NHS number, there did not appear to be a single recognised approach.

“I used to live in Herefordshire. My GP practice there changed my name on their records, but did not change my gender.

Now, I’m registered with a GP in Gloucester. They have got my correct name and correct gender on their records; but I’m still trying to get a new NHS number.

I’ve spoken to PALS. My GP thinks that it is the CCG which will assign new numbers. The Gender Identity Clinic thinks there shouldn’t be any problem getting a new NHS number.”

The group said that they recognised that the NHS had some quite legitimate concerns about the loss of information on medical records, because of the differences between male and female bodies. But confusion remained about what could or should happen.

“Sometimes we are told ‘you can change your NHS number, but you don’t have to, because the gender marker can be changed without changing the number’. It would be helpful to have some clarity”

2.5 Gender Identity Clinics (GICs) - long waits for first appointments

People reported long waits for their first appointment; C's story above describes a 14-month wait, and there were others:

"I waited 10 months from referral to first appointment - this was 6 months waiting for a letter to say I had an appointment, and then a further 4 months until the date of that appointment"

"I waited a year for my letter saying I had an appointment - the date of which was six weeks later"

"At the moment, only one GIC has a waiting time of under a year for a first appointment"

The group also observed that there was a difference between the funding for services for adults, and services for young people. The Tavistock & Portman NHS Foundation Trust had just received some additional funding; but the adult clinics had not. They said that Charing Cross GIC was closing, and were unclear what would happen for patients currently attending Charing Cross.

HWG contacted West London Mental Health NHS Trust, which explained *"the clinic is not closing, but rather changing from the management of West London Mental Health NHS Trust to that of the Tavistock and Portman. The treatment for current patients will be unaltered and the clinical staff are all confident that the change will lead to better treatment in the months and years that follow leaving West London Mental Health NHS Trust."*

Members of the group said that in their experience, the NHS tended to fund transgender 'projects' or 'events' rather than funding front-line staff.

2.6 A Lack of support provided between referral and being seen at a GIC

Members of the group said that one of the reasons they set up Gloscats was because there wasn't any other support arranged for people once they had their referral to the GIC.

“The crucial time for someone is that time when they are waiting for their first appointment at the GIC, which in most cases is a wait of at least a year. There is a real risk of suicide among people who are experiencing gender dysphoria. People contact Gloscats and often they are really disturbed”

All of the personal stories above illustrate people's real need for support.

“I think having counselling beforehand is critical. I spent a year in counselling (which I paid for myself) before I even approached my doctor to ask to be referred, as I was in a mess. This meant that, by the time I got to the GIC, I felt better. I chose to do this, because I could afford to do it - but lots of people can't afford it. And some people do need counselling all through the process”

2.7 The impact of having to travel long distances to GICs

The group observed that all of the GICs were at least a 2-hour journey from Gloucestershire.

“It is a 5-hour road trip for a 20-minute appointment”

This was not only difficult for people in terms of taking up time, but also financially:

"It is possible to claim travel costs back afterwards, but you still have to have the money to pay the fares in the first place. For instance, the return fare to Exeter is £80"

C's story illustrates that the costs of travelling, financially and in terms of time, means that some people are not taking up proffered treatment which could be of benefit.

The group agreed that, once a person has had their first appointment at a GIC, it would be better if there was some facility or pathway to enable them go to their local mental health trust for psychiatry appointments.

2.8 The approach taken by GICs

Members of the group reported that sometimes, they had issues with the approach taken by the GICs about treatment; in particular, in attaching conditions about name-changing, or informing personal contacts, to a treatment decision:

"The GIC says that a condition of receiving treatment is that you change your name"

"I felt really rushed to change my name - really pressured. I wasn't sure that I wanted to. I don't think this was fair. I ended up picking my new name on the spot"

"They threaten you - they say 'if you don't do this, we won't treat you'"

Members of the group raised other issues about the approach of GICs, for instance:

“When you visit the GIC, the psychiatrist asks questions about your sexuality, and your home life - but these are irrelevant. Gender identity is not about your sex life. It is about ‘being me’ and ‘living as me’”

2.9 Communication with GICs

People said that communication between the GICs and GPs felt disconnected. They also experienced problems contacting GICs themselves, for instance:

“If you try to contact The Laurels in Exeter by phone, it is never answered by a person - you always speak to an Ansaphone. And they don’t answer emails, unless they are about appointments”

Members of the group said that people had to act in a certain way in order to make progress. Some people struggled with this.

“I feel that transition works when the patient is ‘agent’, equipping themselves, navigating the ‘system’. I make time to study stuff, follow up tests results to make sure they don’t get lost, make the connections between professionals. But for people who aren’t active in this way, for whatever reason, then it won’t happen for them”

2.10 Support for families and carers

The group talked about the lack of support or information available to help partners and other family members, as described in T's story and E's story - and their experiences of the different impacts that transitioning had upon them. They agreed that a support group for partners, akin to the Glos Parents of Gay and Trans Youth (POGTY) group for parents, would be particularly welcome.

"My dad worries that he did the wrong things when I was growing up - but he was a great parent, who did the best he could with a trans kid"

"Some partners react with anger, at their partner going down a path which they feel is breaking up the family or the relationship"

"It is a bit like bereavement. The partner or family grieve for the loss of the 'old' person, who is no longer there"

Because of my situation, there is a distance anyway between me and my parents. I knew it wasn't going to be easy.

There is this feeling that we have to teach everyone else about trans. Also, some people are just not going to be supportive. My siblings are better than my parents - my parents are not supportive.

"When I started transitioning, I wasn't living with my family - I was already at university. My parents didn't know so much about what I was going through. But I could have done without having the extra pressure of educating my parents about my transition. As a consequence, resentment built up. There just wasn't anywhere for them to go for information and advice"

"When you transition as an individual, it impacts on your partner, your parents, your children. But there is no support structure for families. Gender dysphoria is a normal medical diagnosis - it is rare, but it is normal. If a person is diagnosed with cancer, there is a support structure for the family there - this is needed for gender dysphoria too. People are struggling with huge issues"

3 Recommendations

Following lengthy discussions with the group, HWG makes the following suggestions for improvement:

3.1 Giving GPs simple accessible information, which could bring about positive change

For instance:

- Include information about support groups (GAY-GLOS Youth, Gender Identity Research and Education Society (GIRES), Gloscats, Mermaids, Glos Parents of Gay and Trans Youth (POGTY), Transwiki) on G-Care (a locally-developed website designed for primary care clinicians, collating a range of useful local and national information including care pathways, clinical guidance, referral forms, clinical commissioning policies and patient information). This report includes a Directory of information at Section 0
- Gloscats to present at one of the Protected Learning sessions for GPs and practice staff

3.2 Clarification on the Gloucestershire policies regarding changes to genetic markers and NHS numbers

3.3 Recognition of the need for support between referral to a GIC and first appointment and the provision of this support

3.4 Introduction of a pathway to enable local access to mental health appointments once a person has had their first appointment at a GIC

3.5 Recognition of the need for information and psychological support for partners and families, and provision of appropriate support

4 Acknowledgements

HWG would like to thank Gloscats and in particular those people who contributed their personal experience to this report.

5 Formal responses to the report received from Commissioners and Providers

HWG submitted this report to the Commissioners and Providers listed below and invited them to submit formal responses to the recommendations:

- Together NHS Foundation Trust
- Devon Partnership NHS Trust re the Specialist Gender Identity Clinic
- Gloucestershire Care Services NHS Trust
- Gloucestershire Clinical Commissioning Group
- Gloucestershire Hospitals NHS Foundation Trust
- Herefordshire Clinical Commissioning Group
- Specialised Commissioning, NHS England South
- Tavistock and Portman NHS Foundation Trust re the Gender Identity Service
- West London Mental Health Trust re Charing Cross Gender Identity Clinic
- Wye Valley NHS Trust re Hereford County Hospital

The responses received are shown overleaf.

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8 March 2017

Dear Barbara

Re: Healthwatch Gloucestershire (HWG) report: Access to health and support services by the Trans community and their families

Thank you for sharing the final report regarding access to local services by the Trans community and their families with GCCG. We continue to develop a good relationship with Gloscats, GAY-GLOS and Glos Parents of Gay and Trans Youth (POGTY) and welcome the opportunity to respond to your suggestions for local services. Gloscats recently ran an awareness-raising session for our commissioning staff and we are keen to promote the valuable support they provide to the Trans community and their families.

We are pleased to confirm that work has already begun to provide a full range of information regarding gender dysphoria on G-Care, the CCG's online resource for GPs in Gloucestershire. In addition to providing details of clinical pathways, G-Care will also link to support services including those local groups listed in your report.

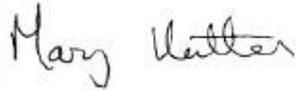
Information regarding changes to genetic markers and NHS numbers will also be detailed on G-Care. In the short term this will link to information provided by the BMA and other national bodies <https://www.bma.org.uk/advice/employment/gp-practices/service-provision/prescribing/gender-incongruence-in-primary-care>. However, NHS Digital is currently developing guidance on using the NHS number for patients who change their gender. We understand that consultation regarding this is planned for 2017; we intend to this consultation; and will continue to update our information in line with the outcome of this work.

As you may be aware, specialist services relating to gender dysphoria are commissioned by NHS England. We can confirm that local access to mental health services is available for all. Therefore, if someone who is undergoing treatment at a Gender Identity Clinic (GIC) develops a mental health problem, they have the same access rights as anyone else, as do their family. Your report suggests that this has been an issue for some patients and this is something that we will discuss further with colleagues at 2gether NHS Foundation Trust.

Whilst we do not commission counselling services generally, the Lets Talk service provides a range of support for those with less severe needs <https://www.talk2gether.nhs.uk/>. Links to this type of support, together with provision by the voluntary sector, will also be included on the gender dysphoria pages of G-Care.

We look forward to continuing to work with Healthwatch Gloucestershire and representatives of the trans community to ensure that we provide good quality services in Gloucestershire.

Yours sincerely



Mary Hutton, Accountable Office, GCCG

cc: *Becky Parish, Associate Director, Engagement and Experience, GCCG*

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7 March 2017

Dear Barbara

Re: Healthwatch Gloucestershire (HWG) report: Access to health and support services by the Trans community and their families

Please find by way of this letter GHNHSFT's formal response to the recommendations made that were relevant made to the organisation.

HWG Recommendation	Response to the recommendations
3.1 Giving GPs simple accessible information, which could bring about positive change	This recommendation is for GPs but there is information available to GHFT staff on the intranet which also directs staff to other information sources such as the ones listed. http://www.gloshospitals.nhs.uk/en/About-Us/About-the-Trust/EqualityandDiversity/Seldom-heard-communities/Our-transgender-patients/
3.2 Clarification on the Gloucestershire policies regarding changes to genetic markers and NHS numbers	Within the Records Management Policy there is an action card which advises staff how to process requests for change of name and or gender. http://glnt313/sites/glnhsft_policy_library/ActionCards/B0259%20RM6.pdf

Thank you once again for the report.

Yours sincerely



Suzie Cro
Head of Patient Experience

Chair: Peter Lachecki
Chief Executive: Deborah Lee



Barbara Piranty
Chief Executive
Healthwatch
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30th January 2017

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Dear Barbara

Many thanks for sending through a copy of your report about the Trans community and their families and giving us the opportunity to comment before you conclude it. I am aware that I am a few days late with my reply, so I do apologise for this. Dr Barrett has read through the report and he has made the following comments;

Counselling

It is agreed that it would be very useful indeed to offer counselling or other psychological support to the families and partners of transfolk, particularly in the earlier stages of treatment. Unfortunately, NHS England very specifically do not fund such counselling or support — funding is for patients only. Sometimes, if partners or family come to appointments with the patient they can be involved in the conversation (with the patient's consent, of course) because the patient is there as well and is the funded person. Under the current funding arrangements this is the closest we can get to providing help which we agree is needed.

Many other serious, life changing conditions like cancer, Parkinson's disease and Alzheimer's dementia have help for partners and families provided by the Macmillan nurses, the Parkinson's disease society, the Alzheimer's disease society and the like. These sometimes seem to be part of the NHS, located in hospitals and working seamlessly with the nurses, doctors and others in the clinical team. It's important to note, though, that these are all non-NHS organisations not funded by the CCG or Specialised Commissioning. It is very uncommon for the NHS to fund any help for family and partners of adult patients, perhaps because to do so for one group would necessitate funding many others, with catastrophic financial results.

Waiting Times

It is agreed that waiting lists are far, far longer than would be ideal and are about a year at the Charing Cross clinic — longer yet at others, it seems. There is an NHS England plan to be eighteen week referral to treatment compliant within five years for this and every English gender identity clinic. This clinic attempts to address the problems that follow from this by periodic workshops for several hundred patients on

the waiting list which are designed to inform them of all the things they can do in advance of their first appointment that will enable the appointment to go as well as possible and for treatment to be given as quickly as possible.

It is surprising to see a suggestion that patients should be seen at local psychiatric services given that the Parliamentary Women's and Equality Select Committee recently determined that psychiatric services are probably the very worst place people with gender dysphoria should be seen. Because people with gender dysphoria don't have a mental illness there has been a quite proper drive to prevent GPs making inappropriate referrals to psychiatric services when a referral to a gender identity clinic is indicated. This suggestion would seem likely to undercut that worthwhile message; further, local psychiatric services wholly lack expertise in gender dysphoria, this being the reason for a referral to a gender identity clinic in the first place.

The report doesn't make it clear how many people gave their views to the writers. It might be worthwhile noting that every single time every single patient at the clinic has an appointment of any sort they are afterwards given a questionnaire so that they can, entirely anonymously, immediately report how the appointment went. The response rate is about 50% and there is a high level summary of results sent with my letter. This includes the data for the last year. It should be noted that the degree of any discontent with the services is extremely low.

Future management of the clinic

Finally, it is important that you note that the clinic is not closing, but rather changing from the management of West London Mental Health NHS Trust to that of the Tavistock and Portman. The treatment for current patients will be unaltered and the clinical staff are all confident that the change will lead to better treatment in the months and years that follow leaving West London Mental Health NHS Trust.

Yours sincerely

Yours sincerely

A handwritten signature in blue ink that reads "Carolyn Regan". The signature is written in a cursive style with a long horizontal line underneath the name.

Carolyn Regan
Chief Executive

6 Directory

organisation	about	contact
GAY-GLOS Youth	A young people’s social group for lesbian, gay, bisexual, and transgender people and those exploring their sexual orientation	www.gay-glos.org/youth.htm youth@gay-glos.org
Gender Trust	A national charity providing support and an information centre for anyone with a question or problem concerning gender identity	www.gendertrust.org.uk Tel: 01527 894 838
General Medical Council (GMC)	The GMC's <i>Good Medical Practice - Advice for doctors treating transgender patients</i> aims to help doctors see how the principles of <i>Good medical practice</i> apply in relation to trans patients, and also to explain doctors’ duties under the <i>Equality Act 2010</i> and other legislation. It includes guidance on <ul style="list-style-type: none"> • Treatment pathways • Prescribing • Respect, confidentiality and the law • CPD and other useful information 	www.gmc-uk.org/guidance/28851.asp
Gender Identity Research and Education Society (GIRES)	A national charity which aims to give a voice to trans and gender non-conforming individuals and their families. It contributes to policy development regarding equality and human rights, especially in healthcare. It delivers training, e-learning and information to public and private sector organisations.	www.gires.org.uk Tel: 01372 801554

organisation	about	contact
Gloscats	<p>A charity with various purposes including</p> <ul style="list-style-type: none"> • To provide a social networking and support group for trans people in Gloucestershire, their partners, family members and friends • To campaign locally for equal opportunity and consideration for trans people in the community • To engage with key stakeholders in the public, private and voluntary sectors to raise awareness and educate their organisations on trans issues • To help facilitate access to appropriate services for local trans people 	www.gloscats.org.uk
Glos Parents of Gay and Trans Youth (POGTY)	A group for the parents of gay and transgender children in Gloucestershire	http://e-voice.org.uk/glospogty/
Mermaids	A national organisation for children and young people with gender identity issues, and their parents and families	www.mermaidsuk.org.uk
Press for Change	A legal support organisation for trans people in the UK. It seeks respect and equality for trans people in the UK, through case law, legislation, and social change	www.pfc.org.uk
Tranzwiki	A directory of groups campaigning for, supporting or assisting trans and gender non-conforming individuals and their families across the UK.	www.gires.org.uk/the-wiki

7 References

¹ Healthwatch England website, news 21 September 2015 - <http://www.healthwatch.co.uk/news/nhs-england-improve-communication-transgender-community>

² NHS England Blog <https://www.england.nhs.uk/tag/gender-identity/>

³ Gender Identity Report, Healthwatch Devon, March 2016 <http://www.healthwatchdevon.co.uk/wp-content/uploads/2016/03/Gender-Identity-Report-Final-Version-29.03.2016-1.pdf>

⁴ GMC *Good Medical Practice* ethical guidance http://www.gmc-uk.org/guidance/ethical_guidance/28852.asp

⁵ GMC *Good Medical Practice* ethical guidance http://www.gmc-uk.org/guidance/ethical_guidance/28861.asp