
Healthwatch Kent Spotlight Series

**Giving the Trans & Non-Binary
community a voice**

November 2021

Around 17,600 people are estimated to be part of the Trans & Non-Binary community in Kent and Medway. At the moment, if people from Kent & Medway need to use Gender Incongruence services they must travel to the Tavistock & Portman Trust in London, which is the nearest out of eight clinics across England. Tavistock is the only clinic which has services for people under the age of 17.

At the time of writing, 9,667 people are on the waiting list for the Gender Identity Clinic (GIC) in London. People who were referred back in October 2017, are only now getting their first appointment, making it up to four year wait for an initial discussion.

In 2019, the Sexual Health service at Kent Community Health Foundation Trust sent a survey to the Trans & Non-Binary community, asking for their feedback about using healthcare services in Kent & Medway. 78 people responded to the survey.

We offered to analyse the feedback. We also wanted to hear from more people and understand more detail about their experiences, to see if these tied in with the themes from the survey.

We spoke to a further 14 people from the Trans & Non-Binary Advisory Group at KCHFT, to hear how their stories and experiences tied into the themes from the survey results. Over the past six months we have met regularly with representatives from this group to develop our understanding of the issues, where the barriers to access lie and where we could work together with other healthcare providers to drive some positive change. The group's input has been key to the development of this report and to bring awareness to the healthcare needs of the Trans and Non-Binary community in Kent and Medway.

What were the headlines?

We heard a range of stories but some key themes emerged:

- People reported that they felt their GP had not listened to them or understood them
- We heard about the need for more emotional & mental health support
- Improved awareness and understanding amongst professionals is needed
- The impact that long waiting times has on people's mental health, particularly for younger people
- Availability and accessibility of services, with some gaps in specialist support for example, counselling and post-operative care

What are we recommending?

Whilst there are many potential areas for improvement highlighted in this report, we have focused on aspects where we feel we could make a difference.

For many trans & non-binary people, accessing healthcare services starts with a visit to their GP

- 1** We would like to see one Primary Care Network (PCN) within each of the four Health and Care Partnerships in Kent adopt a commitment to supporting trans & non-binary people and their healthcare needs.

The use of pronouns in email signatures or wearing of pronoun badges should be considered standard practice. Through this report, there is a strong theme of trans & non-binary people feeling that GPs have a lack of awareness and understanding of their basic healthcare needs. We would like each of these four PCNs to be clear on how they plan to improve support for trans & non-binary people.

- 2** Establish a Pride in Practice scheme between the GPs within these 4 PCNs.

This group of GPs would have a strong understanding of the barriers identified in this report and would work to improve access to services for the trans & non-binary community, through raising awareness with other GPs.

- 3** Improved support for people waiting for an appointment with the GIC (Gender Identity Clinic)

Having the right healthcare whilst waiting for an appointment with the Gender Identity Service is important, as this can take up to four years. This could be inspired by the successful CliniQ models, which we talk about in more detail later in the report. Through our research, we have found that Sexual Health teams might be well placed to provide these services in Kent and Medway, due to the relationship they have with the community.

- 4** We would like to see senior commissioners from the CCG (Clinical Commissioning Group) attending or engaging in the Forum run by the KCHFT Trans & Non-Binary advisory group, to widen their knowledge and understanding of the issues highlighted by this report.

- 5** We ask that the CCG (Clinical Commissioning Group) commit to discussing the establishment of local Gender Identity services, where trans & non-binary individuals can begin accessing care. This aim is to reduce the current waiting time that people experience for their first appointment at a Gender Identity Clinic.

The NHS standard wait time for a patient to receive treatment is 18 weeks. We have heard from people that have waited up to four years for their first appointment after GP referral. With the number of individuals looking for help with Gender Incongruence increasing the service should be delivered as a primary care service with local clinics involving multi-disciplinary teams to provide care.

The feedback in detail

GP issues

The most frequently raised issue was accessing or talking to their GP. We heard that people felt that the GP had not listened to them fully and had a lack of understanding of their needs. Comments included:

- “I had a good experience with changing my name and pronouns. There had been one doctor who tried to understand what I needed and had been helpful with getting referrals”
- “Updating my gender and NHS record with my GP was extremely difficult and I had to put in a formal complaint to have it resolved”
- “I have felt largely abandoned by the NHS & my GP so I am fortunate to be able to fund a private transition. I feel genuine sympathy for anybody relying on the NHS who is just starting their journey”
- “My GP doesn’t even know how to monitor my hormone levels so I organise that too”
- “While based in Canterbury for Uni, I always found it very 50/50 if the GP I saw was transphobic or not”
- “I have had NHS GPs out me at work, and refuse to treat an unrelated illness (underactive thyroid) for months because they didn’t know how to treat a trans person. This was before I had started to medically transition. I’ve had Drs refuse to look at my genitals even though it was medically necessary. I’ve also had Drs agree too, and then make inappropriate comments about my body. Luckily I’m body confident but transgender guys have it hard enough handling having a body they wish was different without a Dr pointing out it’s different to mainstream bodies”
- “I have found that my current GP practice is very supportive but this has not always been the case. When I first asked my previous GP for help with my gender identity, they were not supportive. After I provided details of the NHS Gender Identity Clinic, they advised they would refer but I discovered after a year they had not. This affected my mental health badly and I did not think the NHS were treating my incongruence seriously. I found an alternative route for treatment via a private clinic and when my Gender Specialist asked for my GPs support, they advised they would only do so privately not as my NHS GP, they then refused to treat me and removed me from their patient list. I was given a list of GPs to contact to take me on as a patient. After being interviewed by six other local GP’s I eventually found one who would support my needs for Hormone Replacement Therapy (HRT).”
- “I am not sure how to go about accessing services through the NHS as my GP is not very helpful and does not want to speak about medication, as I access medication elsewhere.
- I am receiving an off-license prescription with a provider who was looking to set up a shared care agreement, however my GP would not engage with me, was not approachable and would not support my use of medication. I therefore felt that my GP would reject any request for help.”
- “GPs are refusing to prescribe my medication (contrary to my shared care agreement) so I have to travel up to London every 3 months to get injections. My mother would have been happy to administer the injections if shown how to and if the GP would prescribe.”
- “GPs do not appear to have much information on support networks available.”

The Medway Gender Sexual Diversity Centre (MGSD) told us that GPs are a crucial element in accessing NHS Gender Services. You need to be registered with a GP to be allowed on the waiting list. They told us about a reluctance of some GP services to take on Shared Care Agreements with Gender Specialists and that this forces patients to access services elsewhere including private or self-medicating. They told us that there is a “Pride In Practice” initiative (run by the LGBT Foundation) which is a program for training GPs about the issues and needs that trans & non-binary people face when accessing health services. They feel something similar being run throughout Kent could improve many people’s experiences.

Waiting times, delays & referrals

The issues around waiting times were mostly related to Gender Identity Clinic (GIC) appointments but also included lengthy waits for hormones, waits for hair removal and delays with paperwork. Comments included:

- “The NHS is amazing but the waiting times are very, very, very long”
- “The pathway to gender services through the NHS is drawn out and causes unnecessary distress. The range of treatments offered after the unacceptably long waiting time are limited token gestures”
- “I’ve been on the waiting list for the gender identity clinic for two years, we really need more of those available”
- “I’m still yet to get my first appointment with the GIC after nearly two years of waiting”
- “My son came out when he was 10 though I knew before and has now (aged 12) transitioned socially and at school. However, he has a 20+ month wait to be seen, this is too long to expect anyone to wait for a medical need”
- “There are extreme waiting times to see a gender specialist and rising numbers of referrals - delays in getting hormones and/or blockers”
- “Waiting times for surgery are approx one year plus”
- “You need to get a referral for gender reassignment surgery before electrolysis/laser treatment even starts”
- “There are delays in being referred to a GIC or no referral being done at all.
- “I’ve had to constantly chase everything - delays in paperwork being completed - or wrong paperwork being sent out”
- “My son had been signed up to NELFT but there did not seem to be any interim care between them and Gender Identity Clinic. It seemed wrong that there is nothing between them and this felt like neglect.”

The Medway Gender Sexual Diversity Centre (MGSD) told us that extremely long waiting times can lead to poor mental health and wellbeing, with issues of isolation, depression, self-harm and suicidal ideation.

Gender Identity Clinic (GIC)

We heard a range of comments associated with Gender Identity Clinics. Comments included:

- “With the GIC clinic I felt that I was constantly being given the wrong information and again had to put in a formal complaint to get the answers to my questions”
- “I went to London first to start my journey, with hormone treatment & counselling. I began hormones before transition and coming out at work. I came out at work in December 2015. I was referred to GIC-waited for surgery for wife to adjust -operation now in 2 weeks”
- “I was referred to the NHS Gender Identity Clinic June 2015, my first appointment was July 2016, I started taking hormone therapy June 2017, then had a bilateral mastectomy as part of gender transition January 2019”
- “Something I didn’t expect, and something the GIC didn’t discuss with me, was feeling extremely low/ down following my gender confirmation surgery. As getting the surgery had been my goal in life for such a long time, once I had achieved this and had some time to heal, I had not felt sure what to do next.”
- “I had been signed off from the GIC support before I’d had my operation. Usually by the time someone has gender confirmation surgery they are no longer with the GIC.”
- “The GIC needs to be mindful that support needs to be ongoing as the challenges faced by transgender and non-binary people do not suddenly stop following surgery”

Lack of local service & support

Participants told us about travelling out of Kent and Medway to access services that are not available locally, and also spoke about the absence of support services.

- “I have to travel to London for gender related care which is expensive and stressful”
- “I have asked for hormone blockers and testosterone but no services have been offered. I feel like no one is listening and I’m stuck in this body with no one to help me move forward in my life”
- “I find there’s a lack of help for trans people. I found the GIC and they are helpful but there is lack of information out there or any support for myself. I’ve had to find a lot of things I needed to know online and it’s not always trustworthy information that you read on google so I’m not sure if it’s correct or not”
- “There is a lack of Trans healthcare/help and the services are unclear and hard to find. HRT has a long waiting list and I feel it’s impossible to get anywhere to help me”

The Medway Gender Sexual Diversity Centre (MGSD) told us that there are organisations in Kent & Medway providing voluntary support for adults as well as young trans & non-binary people such as MGSD, Metro charity running “Stand Out” groups and Porchlight’s “Be You” groups.

They also told us that there is a lack of locally commissioned support services for trans & non-binary people, their parents and carers, and the partners of trans and non-binary people. They told us CAMHS will usually only become involved if there are other mental health issues (such as self-harm of suicidal ideation). It is felt, by those working in this space that there is not enough provision for specialist counselling services for trans & non-binary people in Kent & Medway.

Surgery

We heard a couple of issues that people had when accessing surgery;

- “I identify as nonbinary and would like to get the chest surgery to make my body more in line with my appearance but I’m not sure where to go. I’m not sure on how GICs (Gender Identify Clinic) deal with nonbinary as opposed to transgender”
- “I’m a non-binary transgender individual awaiting to start hormones in about a year then progress onto top surgery. I still struggle immensely with my internal gender and my mental health”

Education & Understanding

We heard about some of the issues around general education, and the lack of understanding around trans issues;

- “I found the staff always great but just general education is needed”
- “There are some ignorant NHS staff, of even basic care for trans people”
- “I was told that I am too complex for the service and have had to pay for therapy on several occasions to be able to get the support that I needed, that was separate from my gender issues.”
- “Service providers appeared to be happy in the area they are confident to help but feel out of their depth if there are multiple considerations and then do not seem to want to help.”
- “Whether treating mental or physical health, there does appear to be an issue that some staff do not wish to deal with people they consider ‘complex’”
- “An A&E doctor had pulled up my old medical record after I had been told that the records would be combined, and the Doctor had called me by my deadname (forget or use another name repeatedly). At the time, I needed support due to my mental health and being referred to by my dead name, which I had advised them not to do, exacerbated the situation.”
- “My school won’t let me use my preferred name only my birth given name. They said it’s because there is a danger of bullying from being singled out, but these bullies don’t exist”
- “At school the other students and teachers dead name me even though they have known me for a long time. I’ve also often been misgendered on many occasions and that really hurts”

The Medway Gender Sexual Diversity Centre (MGSD) felt these comments reflect the wider societal issues around lack of awareness and support needed for people with the condition Gender Incongruence. They also told us that many organisations have a lack of awareness of the barriers to accessing services. These barriers can include staff being unaware of gender identities, lack of knowledge around gendered language (such as pronoun use), understanding the way that data is collected and refusing to amend documentation to reflect an identity. Another example includes forcing trans men or women to attend clinics that are associated with a person’s birth sex for healthcare provision.

Psychological/Therapies

Participants spoke about the mental health and emotional support available:

- “There needs to be better/more mental health services for Trans and non-binary people”
- “NHS waiting times have massively affected my mental health and any steps that can be taken to reduce them should be”
- “The Psychosexual Therapy team have been wonderful and very helpful”
- “The free counselling available through NHS or MIND is not usually holistic. A lot of counselling techniques might be tailored for substance abuse and focused on coping methods for various issues but do not really work if the issue is your gender identity as you cannot do anything to avoid it.”
- “The difference between an NHS Counsellor and private Counsellor for me, has been that the NHS was cut and dry and the private service more holistic.”
- “Professionals need to be aware that trans and non-binary people have had to mask / hide who they are, and this has an impact on their mental health and is very tiring”
- One person said that even their family members struggle to understand their identity, and refuse to accept their gender and chosen name. This has caused much tension and family disputes.

Socialising

We heard some comments about going out and about, to socialise:

- “My girlfriend is transgender and there doesn’t seem to be a lot of places in Medway you can go and feel safe”
- “I want somewhere for more social activities for Trans and non-binary people”
- “The XXXXX project have really helped me. I don’t have friends in real life but I have friends here who help and support me and I wouldn’t have them if not for the groups”

Suggested service improvements

People talked about what they would like to see for the trans & non binary community in the future:

Flexible and timely access to services

- “Late openings - some trans people feel comfortable in the dark. Arrange buddy systems for support; travel to clinics and going out”
- “We need a range of accessible services throughout the day”
- “Signposting for bloods, swabs for pre-operative test for quick turnaround”
- “Better sharing of support groups”

Education Settings

- “Arrange open evenings for people to meet and get information for Secondary Schools and Children and Families; SENCO, Child Welfare Officer and Social Workers”

Sexual Health & screening tests

- “Rebranding the Sexual Health Clinic. We need additional services like those provided through the cliniQ style services.”
- “Awareness of doing what is needed e.g. a PSA test for a trans woman”
- A representative from Sexual Health expressed that with the right funding, they would love to provide these services through a local clinic model.

Are these stories unique to Kent & Medway?

The national LGBT survey in 2017 by the Government found that 21% of trans respondents felt that their specific needs were ignored or not taken into account when they accessed, or tried to access, healthcare services in the 12 months preceding the survey.

18% said that they were subject to inappropriate curiosity and 18% also said that they avoided treatment for fear of discrimination or intolerant reactions [1].

It is widely understood that GPs have a broad area of knowledge but cannot be expected to be experts in any given area. Detailed advice about gender identity issues and associated treatments does not fall within the remit of a GPs education and training. The General Medical Council (GMC) suggest that if GPs feel that they have a lack of knowledge or experience about the healthcare needs of trans people, they should ask for advice from an experienced gender specialist and address their training needs as part of continued professional development (CPD). This CPD would, of course, not reduce the need to access specialist advice and support [2].

We cross checked our findings with a London based support group called Spectra.

They told us their clients are facing similar issues to those we have heard in Kent & Medway.

Spectra told us that the issues that their clients currently face are predominately isolation and transphobia across healthcare, education, employment and mental health. Other commonly raised issues include:

- Imposter syndrome (as a non-binary person)
- Not feeling safe, especially with a lot of negative trans representation in the media
- Lack of inclusive sex education
- Waiting lists for HRT, surgeries and counselling
- Navigating dating, especially as a non-binary person
- Immigration status (particularly being concerned about coming out and being fired due to being in the country on a work visa)
- Lack of trans & non-binary (TNB) safe spaces
- Finances from being estranged from the family at a young age (or at any age)
- Mental health issues, such as PTSD, complex PTSD and complex emotional difficulties.

[1] National LGBT Survey: Summary report - GOV.UK (www.gov.uk)

[2] <https://www.rcgp.org.uk/-/media/Files/Policy/A-Z-policy/2019/RCGP-position-statement-providing-care-for-gender-transgender-patients-june-2019.ashx?la=en>

Recognising the progress to date

Whilst this report highlights many of the barriers people from the Trans and Non-Binary community are facing when accessing the health and social care services they need, we are aware of some amazing work being done across the UK, including Kent and Medway, which stands as an example of best practice to influence and shape development to the services we have in Kent and Medway.

These include:

- The Be You Project is working with KCHFT School Health providers to develop training for school nurses. School Health will meet with the Be You Project to help identify any further issues, specifically for young people.
- KCHFT School Health providers are implementing the use of pronoun badges for their staff.
- Some Kent based NHS Trusts have worked with MGSD Centre to deliver a package of training on Gender Identities & barriers to accessing their services to staff.
- There are a number of examples of best practice in healthcare, tailored to meet the needs of gender diverse people, across the UK. These include the CliniQ model (London), Clinic T (Brighton), and the pilot project currently running in Manchester. This project is looking to replicate the services of the Gender Identity Clinics and the Welsh Gender Service which integrates primary, secondary and tertiary care.
- The GIC pilot project in Manchester started in December 2020, and is the result of years of joint working between healthcare professionals to champion the needs and voice of the LGBTQIA+ community. The GIC pilot project will run for 3 years and seek to obtain and review feedback from patients along the way. Organisers of the pilot had been looking at issues in the care pathway, which were largely the same as those identified in Kent and Medway through this report.

- **The successful Pride in Practice scheme, where GPs register with the LGBT Foundation in Manchester to receive specialist training. Practices were given an award (bronze, silver or gold) dependent on the training they completed, to display in their surgery and promote their support for the LGBT community. Some GPs ran specific support projects, such as HIV support, as part of this scheme.**

How did we go about it?

Kent Community Health Foundation Trust (KCHFT) shared the findings from their survey with us. This gave us feedback from 78 people, 19.48% of them identified as non-binary, 27.27% transgender, and 1.3% intersex.

5% of respondents were aged between 13-17, 25% were between 18-24 and the remaining 70% were over 25.

We also heard from members of the Trans & Non-Binary Advisory Group at KCHFT, Porchlight's Be You Project, and the Medway Gender Sexual Diversity Centre (MGSD) who shared their personal insights. We worked hard to ensure the group felt this report reflected the wider picture of the issues faced, as well as their individual experiences. We also heard feedback via the Kent User Forums who had first hand experiences from the trans community.

We then cross checked the experiences of people within Kent & Medway with the London based support group Spectra to understand if the issues we've heard are unique to Kent & Medway, which helped to build more of a national picture

With thanks....

To everyone who took the time to share their stories with us either directly or through the KCHFT survey. Your feedback has enabled us to put a spotlight on the issues faced by your community.

Thanks also to participants from the KCHFT Trans and Non-Binary Advisory group, who have worked with us to develop and build this report. Thanks to the following organisations who are working hard to make a change for the trans and non-binary community:

- Kent Community Health Foundation Trust who deliver community NHS services across Kent
- Members of the Trans & Non-Binary Advisory Group run by KCHFT
- Porchlight who run the Be You project in Kent
- Medway Gender Sexual Diversity Centre
- Spectra

If you would like to share your story with us, we would love to hear from you.

You can reach us anytime through the following routes:



Online:

www.healthwatchkent.co.uk



By Telephone:

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By Email:

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