LGBTQ+ Health

Health Inequalities and Access to Treatment

April 2019
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Healthwatch Milton Keynes would like to acknowledge and thank the patients and service users who contributed, with such openness and honesty, their stories in order to improve the experiences of others.

We would also like to thank the hardworking team at Q:Alliance for their time and support, and their understanding and help to improve our knowledge of the diversity within the LGBTQ+ community.

A selection of the patient stories received during the collaborative project with Q:alliance have been included, verbatim, to provide insight into the issues being experienced by this vulnerable, and often marginalised, group of patients when seeking treatment.

We thank the Milton Keynes Clinical Commissioning Group (MK CCG) team for their willingness to work with us on a very complex area, and the continuing improvements they are making to ensure that local policies do not inadvertently discriminate on the basis of a patient’s gender or sexuality. MK CCG have also worked with Healthwatch and Q: Alliance on the issues raised in this report. They have provided insight into policy and have outlined the work they have done, and continue to undertake, in order to improve the patient experience. Their responses and comments are included in each section of the report.

HWMK have attached, in Appendix A, with permission from East Cheshire NHS Trust, the Transgender Support Policy for Staff and Service Users, that was developed, and is being used, to improve health outcomes as well as patient and staff relationships. We are appreciative of their willingness to share their ideas and good practice. Our recommendation is that the local Health and Social Care leaders use this document as a foundation to develop a similar approach to equality in Milton Keynes.
2 Introduction

In May 2018, staff from Healthwatch Milton Keynes and the Milton Keynes Clinical Commissioning Group were invited to, and attended, an ‘Introduction to LGBTQ+ awareness’ CPD/ information event provided by Q:alliance.

During this very informative session it was evident that there was confusion amongst professionals regarding best practice approaches toward people who identified as LGBTQ+, and anxiety about inadvertently offending a person by ‘getting it wrong’, whether this be related to a person’s pronouns, how to provide a good inclusive service, or even how to explain why those needs might not be able to be met. It was reassuring to be told that the best course of action was to simply ask the question.

It also became evident throughout the afternoon that people identifying as LGBTQ+ faced difficulty when trying to access health care. With a focus on listening to and working with under-represented groups Healthwatch Milton Keynes (HWMK) agreed a project with Q:alliance to gather experiences of care and treatment from their members and others who identify as LGBTQ+.

This report highlights the health inequalities experienced by people when health professionals are unsure how to provide treatment or clinical advice to people with specific needs, which may be outside the experience of that professional. The report focuses largely on the inequalities experienced by people with Gender Dysphoria as they are, in the main, the most affected.

Milton Keynes Clinical Commissioning Group

Healthwatch have supported MK CCG to review its equality objectives using NHS England’s Equality Delivery System (2) toolkit which supports NHS Organisations to identify and improve NHS performance for people from protected characteristic groups. MK CCG gathered a range of evidence and in October 2018 invited external stakeholders including Q:Alliance and Healthwatch to review how well people from protected characteristic groups fared compared to the rest of the population. As a result of the feedback, MK CCG reviewed and revised its equality objectives to include an objective specifically targeted at Primary Care and the experience of people from the Transgender/Trans* communities. The objectives and evidence template is displayed on MK CCG’s equality website: https://www.miltonkeynesccg.nhs.uk/equality-inclusion-and-human-rights/
3 How we collected patient voice

Together with Q:alliance, HWMK collected information regarding issues that people identifying as LGBTQ+ encountered when dealing with health and social care providers. We ran the consultation for 6 weeks and received 17 responses, 2 of which were sent by lesbian or gay respondents with the remaining 15 being sent to us by Transgender respondents.

Q:alliance and HWMK shared the following on their social media and websites:

Let’s Talk GP’s and Health Professionals.

Q:alliance are working with Healthwatch Milton Keynes to gain an understanding of the LGBTQ+ community's experience of working with GPs in Milton Keynes. We are specifically interested to know what experiences Transgender or Intersex people have had, following multiple concerns being raised to us by the community. This information will be used by Q:alliance and Healthwatch Milton Keynes to directly challenge GPs and change working practice within our community, where possible.

You can submit your feedback directly on the Healthwatch Milton Keynes website at the following link:
https://www.healthwatchmiltonkeynes.co.uk/content/speak-out

Alternatively, you can email trans@qalliance.org.uk in confidence. All emails received will be monitored by our Trans representatives.

Healthwatch are also keen to understand the experience of general healthcare within MK from the LGBTQ+ community and are happy to receive this feedback via their link.

Please note that any emails sent to us as part of this campaign will be deleted upon its conclusion and your details will not be kept. Q:alliance understands that any emails sent to us with your experience will be shared with Healthwatch for the purpose of this campaign and that you consent to this by emailing in.

Many responses from people suggested ways in which the author felt that the situation could be improved and means our recommendations reflect what this cohort of patients believe good care would look like for them.
4 Fertility and LGBTQ+

“6 months ago, I went to my GP as a same sex couple looking to start a family. I went not knowing the process and booked my appointment stating what we wanted to talk about.

My GP told me they did not know either after I had to explain why we were there. They had clearly not read the notes and therefore it was a wasted trip as they advised they would have to find out what to do.

We have had several tests done now and still have not been told what we are entitled to, what the process is or even how it all works.

We feel quite let down having now been referred to infertility clinic for myself (Some issues with ovulation) and still none the wiser what the process is.

It is a difficult and confusing time and there doesn’t seem to be any support or knowledge from our doctor” - response received via Healthwatch Website

Although it would have been useful for the research to be done before the patient attended the appointment, our research found that it may be challenging for a GP to gain awareness of local processes.

The NHS states that same sex couples should be offered NHS fertility treatment. NHS Fertility treatment is offered to heterosexual couples who have been unable to conceive after a pre-determined period of unprotected intercourse and to same sex couples who have been unable to conceive after up to six privately funded cycles of intrauterine insemination (IUI), using donor sperm from a licensed fertility unit¹. After this time, couples can apply to their local Clinical Commissioning Group (CCG) to have further NHS funded IUI.²

MK CCG adopted the East Midlands CCGs IVF policy on 01/04/2014. Section 5 of this policy states that: “CCGs will fund IVF treatment for same sex couples provided there is evidence of subfertility defined by no live birth as per local CCG policy following Artificial Insemination”. MK CCG’s Assisted Conception- IUI and DI Policy says that “Donor Insemination is available for same sex couples if they have undertaken 6 self-funded cycles of Artificial Insemination”.

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² https://www.nhs.uk/conditions/artificial-insemination/
The cost of privately funded IUI ranges from around £800 to £1,300 for each cycle of treatment. These are not costs incurred by heterosexual couples in the period before they are deemed eligible for NHS fertility treatment.

Although we did not have any response specifically regarding fertility from transsexual patients, it is likely that this group of people will face the same difficulties accessing these services as they have in other areas of treatment.

Transitioning treatment results in loss of fertility. The way to prevent this is extraction and storage of eggs and sperm, a process known as gamete extraction and storage, which allows transgender people to have their own biological children post-transition.

NHS England believe that their policies do not discriminate against trans people. However, while patients undergoing other forms of medical treatment which may impact on fertility, such as chemotherapy, are routinely offered access to fertility services, Lui Asquith of the charity Mermaids which supports transgender children and their families, said:

“Currently, the NHS offers little signposting and assistance to [those] wishing to preserve their fertility prior to necessary gender-affirming treatment, despite it being a well-documented, funded option offered to patients about to undertake other life-enhancing treatments that may impact fertility”

In August 2018, the Equality and Human Rights Commission (EHCR) sent NHS England a pre-action letter, the first step towards judicial review proceedings, if policies which discriminated against transsexual patients were not updated. The EHCR stated that

“Our laws and our values protect those who seek treatment for gender dysphoria. This means that, where appropriate, treatment should be made available in order to ensure that access to health services is free of discrimination. A choice between treatment for gender dysphoria and the chance to start a family is not a real choice. We have asked NHS England to reflect on the true breadth of their statutory mandate and the impact on the transgender community of these outdated policies” - Rebecca Hilsenrath, Chief Executive, EHCR

In March 2019, the EHRC dropped its legal challenge after NHS said that they would issue new guidance to all CCGs advising that refusal to offer fertility treatments to people who are transitioning will need strong justification and that a failure to provide this could be challenged in court. However, after the legal proceedings

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3 Ibid.
4 https://www.theguardian.com/uk-news/2018/aug/04/nhs-trans-patients-equal-access-fertility-services
5 Ibid.
were stopped, NHS England softened its stance and said it would leave decisions to individual over provision of fertility services to individual CCGs.⁶

Milton Keynes Clinical Commissioning Group:

*MK CCG recognises that difficulties starting a family can be distressing for any couple and clear information about the NHS support available is key. All MK CCG policies and criteria including for Fertility are openly available on MK CCG’s website at the following link [https://www.miltonkeynesccg.nhs.uk/referrals-and-priorities-policies/](https://www.miltonkeynesccg.nhs.uk/referrals-and-priorities-policies/)*

All GPs are required to use policy criteria and pro formas to apply for funding. MK CCG has committed to providing clarification to GPs on access criteria for same sex couples or individuals transitioning. Individuals themselves are also welcome to contact MK CCG directly for any policy criteria clarification.

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5 LGBTQ+ Stories

These are a selection of patient stories as provided to Q:alliance and Healthwatch Milton Keynes to provide a fuller picture of the issues being experienced by people at all stages of their transition journey.

Patient A

“I was diagnosed privately with transsexualism in December 2017. Prior to that, I had to change GP and practice in early 2017 due to my original GP’s refusal to co-operate fully in my treatment. I am male to female.

To go back to the start: In November 2016, I booked an appointment and explained about my feelings of Gender Dysphoria to my GP and said that I would like to see a specialist. I was aware that I had had Gender Dysphoria for as long as I can remember. I had been living some of the time as a woman for two and a half years at that point, though at that time I was presenting as male at work.

After two letters from me to chase up whether I would be referred or not, my GP sent a terse letter dated 28th. November 2016, stating that "You have been referred to the Gender Dysphoria Clinic, but we are not prepared to prescribe unlicensed medication in Primary Care". He did not explain what he meant, but I suspected that he meant HRT.

In January, I was copied in on a letter from Dr [X] at Daventry GIC (Gender Identity Clinic) to my GP, stating that my GP should either complete a "memorandum of understanding" or give a detailed explanation of why I should be seen "for assessment only", otherwise he would not accept the referral. I became concerned and booked a short-notice appointment on the 12th January to see my GP. I presented as female at the appointment. He confirmed that the problem was indeed because HRT for transsexuals was not licensed by NICE.

I politely pointed out to him that doctors are allowed to prescribe hormones to us "off license", and that the NHS Interim Protocol on Gender Dysphoria states that GP’s should co-operate with the GIC. I also stated that I am a person who is able to understand the risks if he explains them and give informed consent. Additionally, I pointed out that I have transgender friends in Milton Keynes who are being prescribed HRT by their GP’s, and that the same hormones are prescribed to menopausal women.
He said that nothing would change his “beliefs” and suggested that if I knew of a GP who was prescribing HRT to a transsexual patient in Milton Keynes, I should transfer to that GP. The impression I got at this point was that he was keen to get rid of the responsibility for me. I transferred to a GP surgery where I know that there is at least one other trans person. However, I was only able to do that because of the support I had from the trans community - if I had been more socially isolated I might not have been able to do that. I was also fortunate in that the new surgery was nearer than the previous one (because the previous one had relocated) so there was no problem of catchment areas.

Incidentally, my original GP showed a disturbing lack of knowledge of the treatment of transgender patients, despite admitting that I was not his first such patient, e.g. he thought that I was asking for a referral to the Tavistock clinic, though even I knew that that clinic is only for people under the age of 18. I felt that he had not taken the time to acquaint himself with guidance from the GMC (General Medical Council), the CCG (Clinical Commissioning Group) or the Gender Identity Clinics. Another thing that concerns me is that he mentioned that I was the third person to come to him with gender dysphoria, and that he told the others the same things.”

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**Patient B**

The patient lives in Milton Keynes and attends a GP practice in MK.

She has had three issues: When she initially told her GP that she was transgender, about four years ago, her GP’s immediate reaction was to say that they couldn’t help, no help was available on the NHS. A year or so later, she transferred or was transferred to another GP at the same practice who said that help was available and referred her to Daventry GIC.

The second issue is that the patient was then diagnosed as transsexual around about August 2015 at Daventry GIC and her GP agreed to the shared care plan but said that they could not change her name on her patient record to her preferred female name until she changed her name by deed poll.

The reason why this is a particular issue for the patient is that the GP surgery has a display board in the waiting room to call patients forward for their appointments, and she said that if she goes to the appointment presenting as female, she will feel very uncomfortable and exposed to public scrutiny if her male name flashes up. Apparently, the name on the display system had to match her name on the medical record, it can’t use her “preferred name”.

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A third issue is that when her medical records were shared between her GP and Daventry GIC, all her correspondence from Daventry, which had been addressed to her in her female name, started coming addressed to her male name.

**Patient C**

The patient expressed feelings of Gender Dysphoria to her GP about three to four years ago. However, her GP initially referred her to ASTI, the Mental Health team, for a Mental Health assessment. This is not in accordance with the NHS protocol for treating transgender patients; it was required in the past, but the protocol was updated some years ago.

She felt that ASTI were completely lacking in knowledge about transgender patients (she left because she found the appointment to be insulting) and feels that this referral wasted her time when she could have been on the waiting list for the Gender Identity Clinic. She has now been diagnosed as Transsexual and is receiving HRT.

She said “I found personally the ASTI team member who interviewed me was inadequately trained during interviewing process which was totally irrelevant to me suffering from gender dysphoria. It’s also worth pointing the interviewer constantly used wrong gender pronouns which I found disturbing considering other Trans suffering from mental health issues might have to deal with such ignorant staff behaviour during interviews which could put them through considerably more stress.”

**Patient D**

“I am, post op trans female. I have been diagnosed with BPD.

My main issue is that I have been waiting over a year for therapy, with no sign of it any time soon. Also, I am waiting for my Doctor to get me a referral for appropriate medication to be assessed. I have no idea why it is taking so long and I can't get an appointment long enough for me to discuss my issues. In addition, the only way to get an appointment is to queue outside the surgery at 8.00am, take a ticket, and wait until 8.30 for the vague possibility of an appointment that day. I have twice done so, only to find that all appointments are gone by the time I am called back to the reception. This is most diabolical.

I have medication injections that can only be administered by certain doctors.
In general, I feel that the staff are ill advised/trained in dealing with diversity, i.e. the trans and agender community. My medical practice is over crowded with more patients than it is possible to deal with effectively.

Also, mental health services are APPALLING in Milton Keynes. I often feel suicidal, and I can’t get any support, or even get anybody to take me seriously I have also experienced prejudice from medical staff, obviously to me, due to my gender status. This is simply not acceptable.”

Patient E

“This relates to my experience of healthcare as a transgender person.

I am currently in the early stages of medical transition and have been referred to the Gender Identity Clinic by my GP.

Whilst the GP I saw was empathetic and referred me without me having to fight too much, I do feel that there is a lack of knowledge/training on trans healthcare and the current process. For example, the GP I saw at the appointment where I requested a referral said they’d have to apply for funding which made me feel anxious and that I’d have to try and find money for treatment myself (which I’d struggle to afford). Following a conversation on an online support group, I then discovered that this was part of the old process and was no longer required.

On the whole, the administrative staff and practice nurse at my surgery have been fantastic.

The main issue I had was around getting a GP’s letter for sending off to the passport office. I provided a template for them to use which contained the specific wording that the passport office required to change my gender marker on my passport. They initially told me they couldn’t do me a letter, then after me pointing them in the right direction did write a letter but the content was incorrect, and the GP didn’t sign it. I paid for this service.

Needless to say, the passport office rejected the letter. It took a conversation with the Practice Manager via telephone, where I had to educate them on the correct process and wording to use, to get the correct letter.

This particular experience left me feeling quite angry and upset and happened to catch me at a point when I was feeling quite low.

To date, I am still unsure as to whether my medical records have been updated correctly. I feel that training would benefit both patients and staff and make the process easier for everyone.”
Patient F

“In the case of Urinary problems clinicians need to be able to order a PSA (prostate-specific antigen) test on Trans women to exclude the possibility of prostate problems. Whilst it is possible to do this, it seemingly needs the clinician to send a multitude of emails. This is a less than satisfactory system which can be fixed.

After outing myself to a Nurse, I complained of feeling faint and extremely thirsty to the point where I asked my visitors to bring me some salt and water. However, when I complained about the fact that I had been left just sitting in the Ambulatory emergency unit for 6 hours, I was told that my Blood count at 8:40 was well within in the “MALE” range. Was this called for? The answer is no! This actually made me feel like I wanted to just get up and walk away. My friends who are aware of the situation cannot understand how someone can even address me in this manner.

This senior Nurses comment was also made in front of another Nurse, who I had not shared any information with. This was an unacceptable comment but now my Trans status was being shared with an Auxiliary Nurse. This was a clear breach of Section 22 of the Gender Recognition Act.”

Patient G

“My first referral to the GIC didn’t go through to the GIC (so wasted 7 months of waiting), second one went through and had 14 months wait until the first appointment.

Letters from GIC are often late and my report from my first assessment in March 2018 still hasn’t arrived. Staff are fab at the GIC.
Milton Keynes Clinical Commissioning Group:

MK CCG acknowledges the wide range of experiences shared within the report.

In January 2019, MK CCG invited Q:Alliance and Clinicians from NHS England’s regional Gender Identity Clinic (provided by Northamptonshire Healthcare NHS Foundation Trust) to provide a full Practice Learning Time session to Milton Keynes GPs to raise awareness about attitudes and access to healthcare difficulties from an individual’s point of view. Clarification was provided about NHS England’s commissioning pathway for Gender Dysphoria.

MK CCG has previously circulated information to GPs on the Gender Recognition Act, NHS England’s process for re-issuing NHS Numbers to individuals and General Medical Council training on appropriate sharing of information. We will ensure that GP updates and awareness raising occurs on a regular basis.
6 Data Protection and LGBTQ+

During our experience gathering exercise, representatives of Healthwatch Milton Keynes were invited to take part in a meeting between Milton Keynes Clinical Commissioning Group’s (MK CCG) Director of Quality and Nursing, Complaints and Patient Experience Lead, Senior Engagement, Communications and Marketing Lead, and two women who had raised concerns about the way in which the health system identified them as transgender following transition, particularly through clinical correspondence.

The women had raised their concerns with MK CCG previously in 2016 at a meeting attended by MK Hospital, Central North West London Trust and Milton Keynes Council but raised the same issues again at the MK CCG Annual General Meeting in 2018, as they felt they were not being heard. MK CCG had undertaken some work around the areas of concern but had not provided the women with an update on what this work was and what the expected outcomes would be.

During the meeting, MK CCG representatives told us that they had been working with Q:alliance on reducing health inequalities amongst people identifying as LGBTQ+. One of the challenges with this approach is that this group of women have all transitioned and identify as women. Q:alliance is an organisation which celebrates diversity and work toward gaining equality for the LGBTQ+ community. However, this group of women - because they identify as women - did not feel that they were necessarily represented by the organisation.

The group spoke of their objections to health professionals listing their Trans status on clinical referral documents with no explicit consent from them, irrespective of what the referral was for. There was some discussion about the balance of clinical need for the information and the women’s’ right to be treated as women rather than as Transgender but there has not been a local approach agreed to date that could be disseminated to the local health system.

Milton Keynes Clinical Commissioning Group

While, at the time of the meeting described above, MK CCG had not yet completed the EDS2, we had undertaken a wide range of awareness raising and provided an action plan to the women. MK CCG had shared details of the Gender recognition Act with Primary Care as a result of an additional issue experienced by one of the women. MK CCG have also ensured that their contact with Q:Alliance will mean that there are Trans people around the table at the EDS2 reviews.

MK CCG acknowledge this difficult position for those who have transitioned and expect, through its continuous awareness raising, training links and opportunities, that improvements and reasonable adjustments will be seen going forward.
7 What can be done?

The variety of patient and service user experience shared with us during this project demonstrates that poor or under-developed knowledge of LGBTQ+ citizens’ needs, care pathways and information governance impacts on the patient journey and can result in them feeling that they are experiencing health inequalities from the health and care system.

We highly commend the recent provision of a recent GP ‘Protected Learning Time’ education session put on by MK CCG and delivered by staff and patients from the Daventry Gender Identity Clinic. Healthwatch were invited to attend and we were pleased to see so many Doctors attending the session and engaging positively.

We recommend that further sessions along the LGBTQ+ theme are regularly scheduled as there was a lot of information to take in, in a single session and many professionals were immediately asking how they could further their knowledge in this area.

We recommend that further exploration is made of the engagement session with MK CCG regarding the transfer of information about Trans status in clinical correspondence, so an agreed local system can be adopted, which strikes and appropriate balance between patient rights to privacy and consent, and clinical requirements for information sharing.

Milton Keynes Commissioning Group

The PLT education session was part of MK CCG’s revised equality objective action plan which was developed with the support of Healthwatch representatives.

As part of MK CCG’s revised equality objectives and action plan, a regular bulletin will be circulated to Primary Care to raise awareness of NHS England and General Medical Council guidance.
During our project, we researched whether there were any best practice areas, or guidance available to our local system. We found a section from a very helpful guide called ‘Living my Life’ on the NHS UK LiveWell webpage which contains information for both service users and professionals about providing the best possible services for trans people.

We have taken the liberty of rearranging the text so that the question of how to strike the balance between patient confidentiality and clinical need is suggested at the top of the list.

Trans people’s general health needs are the same as anyone else’s. They can be diabetic, have dental problems, get stomach bugs, have high blood pressure, may need to see a podiatrist etc. However, there are additional health needs that may be linked directly to their trans identity such as mental health issues that have their roots in experiences of discrimination and transphobia. It is also important to remember that some trans people experience mental ill health that is completely separate from their gender identity and should be treated as such.

Here are some tips for services that will help them provide an excellent service for trans people

- Under the Gender Recognition Act it is illegal to disclose someone’s trans status without prior consent or to anyone who does not explicitly need this information.
- Always use the name and title (e.g. Mr, Mrs, Ms, Mx etc.) that the trans person wants to be called. If you are unsure about a person’s gender identity, or how they wish to be addressed, ask for clarification. Doing this shows a level of understanding of trans issues.
- Make sure that you are aware of local trans support services / support groups and referral pathways.
- Do not comment on a trans person’s appearance or ‘passability’ unless they specifically ask for your opinion.
- Do not confuse being trans with sexual orientation. It is a gender issue. Trans people can be heterosexual, lesbian, gay, bisexual or asexual.
- Become knowledgeable about transgender issues. Get training on trans issues and know where to access resources.
- Remember that not all trans people are the same. Like everyone else, different trans people have different identities, experiences, needs, and interests.
• Welcome trans people by getting the word out about your services and displaying trans-positive information in your workplaces.

• Establish an effective workplace policy for addressing discriminatory comments about and behaviour towards trans people

This text is contained on page 25 of the booklet ‘Living my Life’

Appendix A: Transgender Support Policy for Staff and Service Users

The author of this report, Lyn Bailey, Equality & Patient Experience Manager, has given permission for the report to be used by the Milton Keynes system leads to use as best practice guidance in developing local policies. She has also suggested that she would be happy to talk through any queries and go through the challenges that the trust faced when implementing this.

10 Appendix B: Additional Information

- For complaints about GPs or GP Practices individuals should approach the Practice Manager if possible to raise concerns so these can be handled in line with the practices complaints policy and procedures.

- NHS England has retained oversight of Primary Care Complaints and so complainants also have the option to discuss concerns with NHS England:

  NHS England Customer Contact Centre
  Telephone: 0300 311 22 33
  Email: england.contactus@nhs.net
  NHS England
  PO Box 16738
  Redditch
  B97 9PT

- If you need help or support to make a complaint, you may wish to speak with the NHS Complaints Advocacy Service- please see link to their website which has contact details and information https://www.seap.org.uk/ or telephone 0330 440 9000

- For any questions, queries about MK CCG’s local policies and criteria or who to approach to raise concerns, contact MK CCG’s Patient Experience Lead on 01908 278684 or email MKCCG.complaints@nhs... for advice

- For more information about NHS England’s specialist commissioning policies and guidelines please see the following links:
  https://www.nhs.uk/conditions/gender-dysphoria/guidelines/

- For information about how your GP Practice should advise NHS England’s Primary Care Support England service of gender reassignment please see the following link: