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Why do transgender people struggle to get cervical screening?

Cervical cancer is largely preventable. In the UK, our effective cervical screening programme means that abnormal cell changes and HPV can be detected early. But trans, non-binary and intersex people face challenges and discrimination which prevent them getting the cervical screening they need.

Cervical screening is a prime example of the struggles transgender, non-binary and intersex people experience in healthcare. People who have cervixes but don't identify as women face barriers when accessing potentially life-saving screenings because of issues with computer systems, discrimination from staff and fears about how they will be treated.

Can trans people get cervical cancer?

Anyone who has a cervix, including trans, non-binary and intersex people, can get cervical cancer.

There isn't much data on the number of trans, non-binary and intersex people attending cervical screenings because trans-status monitoring isn't yet mandatory within the NHS. However, anecdotal evidence shows that many avoid, aren't invited to or are turned away from cervical screening based on their gender identity.

Some people find the process stressful, traumatic or triggering for their gender dysphoria. Where research into the experiences or needs of trans, non-binary and intersex people is available, it tends to be in small sample sizes which aren't representative of the whole population.

Varied experiences

"I've generally had quite positive experiences around gynaecological services but I'm putting it in perspective against some of the horror stories I've heard from friends, rather than comparing it to best practice," explains one person I spoke with.

Much of their care has been provided by specialist trans services like CliniQ in London and Clinic T in Brighton. Many people in the LGBTQ+ (lesbian, gay, bisexual, transgender and queer) community choose sexual health clinics over gynaecology services for screening as they tend to be more openly inclusive and prepared to cater to different needs.

"Probably the most frustrating thing that's happened is the repeated insistence, either on the phone or in person, that I'm in the wrong place or calling about the wrong thing when I've been trying to access diagnosis and treatment for unusual gynaecological symptoms," they continue.

"I work in the health system, and trans people are generally very well experienced in self-advocating and researching their health concerns anyway. But if the receptionist had taken the time to look at the letter I handed her before trying to turn me away she would see I was definitely in the right place!"

There is a lack of knowledge - and large-scale research - about the effects of hormone therapies and surgeries for trans, non-binary and intersex people. This means that healthcare professionals aren't always aware or sure of how these can affect treatment or conditions. And a lack of understanding about the reasons someone may choose not to have hormone therapy or physical surgical changes can lead to invasive questioning for patients.

"A few years ago, I went through months of referrals and invasive tests with no conclusions. Clinicians and practitioners didn't know enough about the effects hormone treatments might have on our reproductive health to be able to explain what was going on," they explain.

Another person, who hasn't yet attended a cervical screening, explains their concerns about how they would be perceived by others. "I'm scared about going to a future cervical screening and either being addressed as a woman or looking more masculine – depending on where my medical transition takes me – and being questioned as to why I'm there," they explain.

"I'm also worried about making women who might not want a person who looks more male in the waiting room with them uncomfortable. I'm still not sure how to find a way to get around this. The safety of others trying to access these important services is something I really care about."

System error

At an admin level, the IT and systems used by the NHS don't always work for people who aren't cisgender (people who identify with the gender they were assigned at birth). If someone who is trans changes their gender on NHS records – for example, from female to male – they risk not being sent a letter calling them for cervical screening.

Yet, if they don't make this change, they risk being misgendered across services and communication within healthcare. And the way the system works means that transgender women who do not have a cervix and cisgender women who have had their cervixes removed may be sent unnecessary calls for screening.

"Only people who have an 'F' marker on their medical records will be called for a cervical screening test. If someone requests a smear anyway and their sample is marked with an 'M' when it arrives at the lab, it is likely to be rejected," says Harri Weeks of The National LGB&T Partnership. The charity is currently working on projects with the NHS and Public Health England to improve gender monitoring and the inclusivity of screening programmes.

Educating the professionals

There's little doubt that healthcare professionals need to be given more training to better support trans, non-binary and intersex patients and feel comfortable asking the right questions.

"Clinicians may not know how to speak respectfully with patients who vary from the norm they're expecting, be this in their gender, anatomy or sexual activity. This, or even just the fear and expectation of this, can make people hesitant to seek out care," explains Weeks. "Clinicians may not know, for example, that testosterone use can have an effect on the tissues of the vagina and cervix. That makes it harder to collect a cervical screening sample and sometimes makes the use of a speculum more uncomfortable."

A large part of this comes down to communication and asking the right questions to make patients feel comfortable. "Quite simply, patient care should always be person-centred. Most recommendations about good care for trans, non-binary and intersex people are simply an extension of this," they explain.

"Ask people if they have any concerns, make them feel welcome, comfortable and safe. Explain what needs to happen and why and discuss any adjustments that might be necessary. It's important to keep learning, but equally important to not treat trans, non-binary or intersex patients as an education opportunity - they're there to receive care."

Inclusive language

In the past, charities and health organisations have marketed cervical screening campaigns at women. There is a gradual move towards a gender-neutral approach to encourage all at-risk groups to go for their screenings. The language used in campaigns, in health information and by healthcare professionals can make all the difference for people looking to access cervical screening. This was highlighted by one man I spoke with.

"As someone who gets periods but doesn't identify as a woman it can be really lonely seeing campaigns about 'women's health' when what's discussed affects me too but I'm not a woman," says Alex. Progress is being made to make organisations more inclusive, he reflects. But backlash from the media and online can dissuade others from doing the same, as well as putting trans people on the receiving end of hate.

Gynaecological cancer charity The Eve Appeal recently released advice for trans, non-binary and intersex people and the healthcare professionals treating them. Their aim was to help make cervical screening easier and combat the lack of inclusive information out there. Their tips include:

- Asking for the smallest speculum available.
- Using a vaginal moisturiser before the appointment.
- Not feeling pressured to complete the screening on your first visit.

Changing the language used in advice can be as easy as saying 'people with cervixes' rather than women: not all women have cervixes and not all people with cervixes are women. This simple change can make a big difference in getting the right people to the right service.

"At the end of the day we all want the same thing which is accessible healthcare for all that doesn't exclude, or cause harm to, another person," explains Alex.

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