

Research shows one size doesn't fit all for cervical screening in the trans and non-binary community

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The soft thud as once every few years a cervical screening invite lands on the doormat.

A gentle reminder to book a cervical [screening](#) appointment, should it be wanted. But for [transgender men](#) or non-binary people assigned female at birth, this invite may not be automatic and getting access to this service can be much more difficult at every step of the way.

"LGBTQ+ people in general, and particularly trans people face a lot of inequalities with regards to their health," says Dr. Alison May Berner, a cancer specialist at the Cancer Research UK Barts Centre and part time registrar in adult gender identity.

According to a report put together by Stonewall, a quarter of LGBT people have faced a lack of understanding for their specific health needs by healthcare staff, which rises dramatically to more than 3 in 5 for trans people. And 1 in 6 (16 %) trans people said they have been refused healthcare because of being LGBT.

Berner has spent the past three years working with LGBTQ+ communities to understand why such startling inequalities exist.

"There's more we can do to try to work with the LGBTQ+ population to identify why some of these inequalities are occurring and level the

playing field, doing that in a way that's acceptable to trans and non-binary people, not putting something upon them."

The importance of the cervical screening programme

An area of concern for Berner and the team is cervical screening, which can help prevent cervical cancer from developing and saves thousands of lives each year in the UK. But not everyone has equal access to this service.

Cervical screening is for everyone with a cervix

Not all trans men or non-binary people assigned female at birth have surgery to remove the cervix. For those that don't, the NHS recommends they undertake cervical cancer screening with the same frequency as cisgender women. But we know there are many barriers to this, and they face many inequalities in accessing care.

Every year just under 5.4 million people are invited to cervical screening in the UK, with invites based on GP records (data from England, Scotland, Wales and Northern Ireland). Of these, around 72% take up the invite. However, there is no overall data of how many trans men and non-binary people are eligible for and attend screening.

Stewart O'Callaghan is the founder and executive director of Live Through This, a charity that supports and advocates for LGBTIQ+ people affected by cancer. "Trans and non-binary patients seeking cervical screening face numerous barriers ranging from not receiving an invite due to the NHS not recording a person's transgender status on their patient record, to samples being refused from the lab if samples are marked as male. It is important trans patients' experience of screening is as straight forward as their cisgender peers," they say.

What do the terms cisgender and transgender mean?

Those who identify with the gender they were assigned at birth, usually a decision made by a doctor based on physical characteristics, are referred to as cisgender. For transgender people, their identity and innate knowledge of who they are is different to their gender assigned at birth.

Trans, or transgender are broad terms that can mean different things for different people. A trans woman is a woman but was thought to be male when she was born. Likewise, a trans man is a man, but was thought to be female when he was born. Lots of people don't identify as either a man or a woman and might describe themselves with another identity, such as non-binary.

There's no one 'right' way to be trans. Trans people do not have to dress or act a certain way to conform to societal norms and, though it is really important for some trans people, they don't need to have medical treatment to change their physical appearance unless they want to. The experience of trans and non-binary people is varied, and the best way to understand what being trans is like is to seek out authentic stories told by transgender people.

Berner wanted to know more, so decided to undertake research asking trans men and non-binary people directly about their experiences of cervical screening. Believing passionately that "there needs to be more investment into research for trans health. Not focusing just on how we deliver gender affirming care, such as hormones and surgeries, but how can we best safeguard the rest of a trans person's health."

Trans men and non-binary people's attitudes to cervical screening

"I thought about the need for this research towards the end of 2017, realising this was an area of unmet need. And at the same time Jo's Cervical Cancer Trust were also coming to the same conclusion," recalls Berner.

"We all agreed if we were going to produce the best information for trans and non-binary people and improve the field, we needed more than a casual survey, we needed a robust research study."

Results from the study were published today in the *British Journal of General Practice*.

Berner and the team asked 140 trans men and non-binary people to share their past experiences and attitudes towards cervical screening.

"The study showed having a male gender marker on healthcare records, meaning patients aren't automatically called and reminded for screening makes it less likely that someone will make their cervical screening appointment," explains Berner.

"The experienced or anticipated stigma, as well as discrimination from health care professionals which, unfortunately, still continues, even though it's reducing, is also distressing enough to act as a barrier to seeking care."

Berner adds that a poor understanding of trans health by the healthcare provider, or the fact GPs or nurses may not have had good training in how to approach cervical screening in this population, can also present problems.

"There is a lack of understanding around the broader context of what trans men and non-binary people might have been through as part of their transition, or how to use the correct pronouns or terminology,

which is incredibly off putting for patients."

"If an invitation lands on your doormat, saying, dear Miss Jones and you're in fact, Mr Jones, you're not really going to want to visit that service."

On top of this, people reported seeing mainly female-centred information materials, leaving recipients not wanting to engage with materials they didn't feel were inclusive of them.

"These barriers can be incredibly damaging. As well as making trans and non-binary people less likely to attend screening, they can also trigger gender dysphoria," says Berner. This is a sense of unease or distress a person may have because of a mismatch between their biological sex and their gender identity.

What could improve access to cervical screening?

Berner's work highlights barriers faced by the trans and non-binary community that many people perhaps hadn't ever considered. And yet most can be overcome through education of healthcare providers, greater awareness of gender terminology and the provision of tailored services.

One such service is the No Barriers Cervical Screening Project, which operates at 56 Dean Street in London.

Another, Clinic-T, is run by Dr. Kate Nambiar in Brighton, "As a clinician who does cervical screening for trans patients, I see the worry people have about how they will be treated. For many [trans people](#), because the test is invasive and can trigger dysphoria, they simply avoid getting it done. Yet there are many things as clinicians we can do to reduce the discomfort, putting in place simple interventions. That's not to say these things can't also be done at non-specialist services—in most

cases, a little education in the needs of the trans and non-binary population can go a very long way."

Berner's research backs this up, finding that trans men and non-binary people were more likely to go for cervical screening when their non-specialist healthcare providers educated themselves to be more accommodating.

Berner says, "the best way to facilitate screening and overcome these barriers are specialist services that offer a tailored approach. Whether it be scheduling additional appointment time, using muscle relaxants to help with the process or knowing how to correctly gender someone—using the right pronouns and making people feel welcome and at ease.

"Improving information materials to make them more inclusive or targeted for trans and non-binary people could also help increase screening uptake. And the option to self-sample for HPV. Self-sampling is being piloted in the UK and has been successful in other countries including the US."

For Berner, the major finding is we shouldn't do screening as a one size fits all. "We need to think carefully about what different types of information people might need, it may be gender neutral information or bespoke information."

Berner also believes the service needs to rethink how it invites people so that everyone is free to make an informed choice about screening. "Not everybody will feel comfortable with a call and recall, but some people want it, and there needs to be the option to receive a cervical screening invite even if they have a male gender marker. There needs to be the ability to opt in or opt out. Inviting people in a way that is acceptable to them. And providing them with a service that makes them feel

comfortable."

Above all, Berner believes that a bespoke attitude to screening could benefit everyone, a conclusion echoed in Sir Mike Richards' screening review. "If a cis woman has had a traumatic hysterectomy, she may want to opt out of receiving cervical screening reminders. So, let's do away with a one size fits all approach and provide the best care we can for everyone's individual needs."

More information: Alison M Berner et al. Attitudes of transgender men and non-binary people to cervical screening: a cross-sectional mixed-methods study in the UK, *British Journal of General Practice* (2021). [DOI: 10.3399/BJGP.2020.0905](https://doi.org/10.3399/BJGP.2020.0905)

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