

## ORIGINAL ARTICLE

# Uptake, experiences and barriers to cervical screening for trans and non-binary people in Aotearoa New Zealand

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**Background:** Little is known about experiences and barriers for trans and non-binary (TGNB) people eligible for cervical screening in Aotearoa New Zealand.

**Aims:** To identify uptake, barriers and reasons for delaying cervical cancer screening among TGNB people in Aotearoa.

**Materials and Methods:** The 2018 Counting Ourselves data on TGNB people assigned female at birth aged 20–69 years who had ever had sex, were analysed to report on experiences of those who were eligible for cervical screening ( $n = 318$ ). Participants answered questions about whether they had taken part in cervical screening and reasons behind any delays in receiving the test.

**Results:** Trans men were more likely than non-binary participants to report that they did not require cervical screening or were unsure if they needed it. For those who had delayed cervical screening, 30% did so due to feeling worried about how they would be treated as a trans or non-binary person and 35% due to another reason. Other reasons for delay related to general and gender-related discomfort, previous traumatic experiences, anxiety or fear of the test and pain. Material barriers to access included cost and lack of information.

**Conclusions:** The current cervical screening program in Aotearoa does not consider the needs of TGNB people, leading to delayed and reduced uptake of cervical screening. Health providers require education on the reasons TGNB people delay or avoid cervical screening in order to provide appropriate information and affirmative healthcare environments. The human papillomavirus self-swab may address some of the existing barriers.

## KEYWORDS

cervix uteri, gender dysphoria, gender identity, transgender persons, uterine cervical neoplasms

**INTRODUCTION**

Although cervical screening programs are applicable for trans and non-binary (TGNB) people who have a cervix, health promotion in this area is almost entirely targeted at cisgender (non-transgender) women. In Aotearoa New Zealand (hereafter Aotearoa) about 160 people develop cervical cancer each year and about 50 die from it.<sup>1</sup> The National Cervical Screening Program, established in 1990, dramatically reduced the incidence of cervical cancer, and reduced the mortality rate by 72%.<sup>2</sup> Cervical screening is recommended for anyone in the eligible age bracket (currently 25–69 years) who has a cervix and has ever been sexually active. However over 85% of people who develop cervical cancer in Aotearoa have either never been screened or have been infrequently screened.<sup>3</sup> Cervical cancer is preventable and treatable when found early, so it is essential that any barriers to this potentially lifesaving test are removed. There are documented inequities in cervical screening rates for some demographics in Aotearoa, such as Māori and Pacific women,<sup>4</sup> but rates of cervical screening uptake and any barriers for TGNB people assigned female at birth (AFAB) are unknown.

Overseas studies show TGNB people AFAB have lower participation rates in cervical screening relative to cisgender women.<sup>5–7</sup> Such inequities are the results of multi-layer access barriers, which include TGNB people not finding a health provider they feel comfortable with or who is competent in transgender care, and experiencing the procedure as emotionally traumatic.<sup>5,8</sup> Resources have been developed overseas to provide appropriate cancer screening information for TGNB people,<sup>9</sup> but none exist in Aotearoa. The New Zealand Government's 'time to screen' website does not refer to TGNB people, stating that 'all women between 25 and 69 ... should have regular three-yearly smear tests.'<sup>10</sup> This use of gendered language could further contribute to reluctance to seek cervical screening or an uncertainty about whether it is required.

This paper reports on findings from questions relating to cervical screening from the nationwide *Counting Ourselves: Aotearoa New Zealand Trans and Non-Binary Health Survey*. This is the first paper to explore uptake, experiences, and barriers to cervical screening for TGNB people in Aotearoa. Much of the overseas research on cervical screening in trans populations reports on findings relating solely to trans men, whereas we also analyse the experiences of non-binary AFAB.

**MATERIALS AND METHODS**

**Procedure**

The *Counting Ourselves* survey received ethics approval from the New Zealand Health and Disability Ethics Committees (approval number 18/NTB/66/AM01). This community-based survey was open to any TGNB people, aged 14 years and over, living in

Aotearoa. Targeted recruitment strategies used social media and networks linked to TGNB communities and health professionals working in transgender health. The survey received a total of 1178 valid responses between June and September 2018.<sup>11</sup> For this study, the sample was limited to people AFAB who had ever had sex and were aged 20–69 years (the age eligibility for cervical screening at that time; in 2019 this changed to 25–69 years).

**Participants**

Table 1 presents demographic details of participants who completed the questions on cervical cancer screening (*n* = 318; mean age = 29.78 years). A high proportion were New Zealand European/Pākehā and young adults.

**Measures**

**Demographics**

We determined participants' gender based on two items asking about gender assigned at birth and current gender identities. Trans men were AFAB participants who selected man, trans man, or transsexual as their gender. Non-binary AFAB participants comprised those who did not solely identify as one or more of the options above. This ensured the capture of 100% of survey respondents who had, or had previously had, a cervix.

**TABLE 1** Demographic details of *Counting Ourselves* participants who were trans men or non-binary assigned female at birth (AFAB) aged 20–69 (*N* = 318)

| Variables                                     | Mean (SD)/ <i>n</i> (%) |
|---|-------------------------|
| Age   | 29.78 (9.01)            |
| Ethnicity†                                    |                         |
| New Zealand European/Pākehā                   | 232 (73.0)              |
| Māori   | 48 (15.1)               |
| Pacific Islander                              | 6 (1.9)                 |
| Asian   | 21 (6.6)                |
| Others including Middle Eastern/Latin/African | 11 (3.4)                |
| Gender groups                                 |                         |
| Trans men                                     | 129 (40.6)              |
| Non-binary AFAB                               | 189 (59.4)              |
| Regions‡                                      |                         |
| Wellington                                    | 104 (33.4)              |
| Auckland                                      | 97 (31.2)               |
| Canterbury                                    | 31 (10.0)               |
| Other North Island                            | 45 (14.4)               |
| Other South Island                            | 34 (11.0)               |

†Participants were allocated a single ethnicity group through prioritised ethnicity protocol in the priority order of Māori, Pacific Islander, Asian, Others and New Zealand European.<sup>12</sup>

‡Seven participants did not provide a postcode.

We used the same question as the New Zealand Census to ask participants about the ethnic group or groups they belong to, allowing participants to select multiple options. To examine differences across ethnic groups, we assigned a single ethnicity for each participant using the Ministry of Health's ethnicity prioritisation order of Māori, Pasifika, Asian, Other Ethnicity, and then European.<sup>12</sup>

### Cervical screening

Participants were asked 'Which of the following cancer screenings or tests do you think you should have, either now or at some point in the future?' For cervical screening the response options were: *Yes, I would need this*; *No, I would not need this*; and *I'm not sure if I would need this*.

Participants who responded that they would require cervical cancer screening, were asked 'In the last 12 months, did any of the following happen to you regarding cervical cancer screening (also called a Pap smear)? Mark all that apply.' Participants were classified as having experienced delayed access when they reported either being worried about how they would be treated as a trans or non-binary person, or because of another reason (with space for an open text response). The other two response options were 'I have received a Pap smear' and 'I do not need Pap smears'.

At a separate point in the survey, participants were asked the following open question: 'Is there anything else about your experiences accessing healthcare that you would like to share with us here?'" This resulted in 80 responses of which 31 related to cervical screening and were included in our analysis.

### Data analysis

In IBM SPSS v27, we employed  $\chi^2$  goodness-of-fit tests to identify demographic group differences for various cervical cancer screening outcomes. A *P*-value of <0.05 was taken to indicate statistical significance. Free text comments were analysed based on a conventional content analysis to identify themes about reasons for delaying or not obtaining cervical screening, as well as other general comments related to cervical screening.<sup>13</sup> Two authors generated a coding schema and together with the other authors developed the theme map and selected exemplar quotes for each theme.

## RESULTS

Close to nine-tenths (88.4%) reported that they would require cervical screening while slightly over one-twentieth (6.3%) were unsure. Table 2 presents the gender and age group differences for participants considering cervical screening. A higher proportion of non-binary AFAB participants reported requiring a cervical screening. Trans men were more likely to report being unsure or not requiring a cervical screening.

Table 3 shows participants' experiences of accessing cervical screening in the last 12 months. Three-tenths had delayed or not had a cervical screening due to feeling worried about how they would be treated as a trans or non-binary person (30.0%) and slightly more delayed or did not get a smear for another reason (34.5%). We found statistically significant gender differences for participants who were worried about mistreatment due to their trans or non-binary identity, with trans men being more likely to report so.

Most of those who had delayed or decided not to have a smear test for other reasons answered the free text part of the question explaining their reasons (*n* = 108; 96.4%). Figure 1 shows a map of the themes found in our content analysis of these responses. The subthemes came under the broader themes of discomfort and barriers to access, which are described in more detail below.

### General discomfort

#### Gender-related discomfort

Several participants commented that they avoided cervical screening due to experiencing or anticipating gender dysphoria with the test, with some noting they had delayed screening for years because of this. One participant commented that 'dysphoria about the whole [screening] thing puts me off going'. Some described anticipating that dysphoria would be heightened by the physical contact involved in the screening process; as one participant put it, 'I don't like having my genitals touched, especially if I am in a dysphoric state'.

Gender-related discomfort for some participants was related to being misgendered, both in interactions with healthcare

**TABLE 2** Percentage of participants who thought they should have cervical screening (*N* = 318)

|                                     | Yes, <i>n</i> (%) | Not sure, <i>n</i> (%) | No, <i>n</i> (%) | $\chi^2$ statistics                                |
|-------------------------------------|-------------------|------------------------|------------------|--|
| Gender groups                       |                   |                        |                  |  |
| Trans men                           | <b>99 (76.7)</b>  | <b>12 (9.3)</b>        | <b>18 (14.0)</b> | $\chi^2(2) = 29.94,$<br><b><i>P</i> &lt; 0.001</b> |
| Non-binary assigned female at birth | <b>182 (96.3)</b> | <b>5 (2.6)</b>         | <b>2 (1.1)</b>   |  |
| Ethnic groups                       |                   |                        |                  |  |
| European and Others                 | 218 (89.7)        | 11 (4.5)               | 14 (5.8)         | $\chi^2(4) = 4.07,$<br><i>P</i> = 0.396            |
| Māori                               | 40 (83.3)         | 5 (10.4)               | 3 (6.3)          |  |
| Pacific Islander and Asians†        | 23 (85.2)         | 1 (3.7)                | 3 (11.1)         |  |

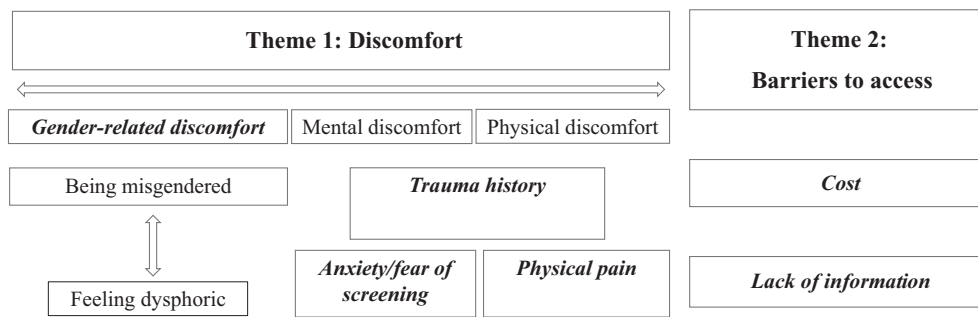
Cells were bolded when adjusted standardised residual is outside the range of standard normal distribution ( $\pm 1.96$  at 5% level).

†Due to small number of participants, those who identified as Pacific Islander and Asians were collated as a group.

**TABLE 3** Demographic differences for accessing cervical cancer screening among participants who thought they required cervical screening in the last 12 months

|                                     | Delayed because worried about treatment as a trans or non-binary person | Delayed because of another reason | Have received it              |
|-------------------------------------|---|-----------------------------------|-------------------------------|
| <b>Gender groups†</b>               |   |                                   |                               |
| Trans men                           | <b>46 (46.5)</b>  | 37 (37.4)                         | 38 (38.4)                     |
| Non-binary assigned female at birth | <b>38 (20.9)</b>  | 60 (33.0)                         | 83 (45.6)                     |
|                                     | $\chi^2(1) = 18.83, P < 0.001$  | $\chi^2(1) = 0.37, P = 0.541$     | $\chi^2(1) = 1.09, P = 0.298$ |
| <b>Ethnic groups</b>                |   |                                   |                               |
| European and Others                 | 62 (28.4)   | 78 (35.8)                         | 95 (43.6)                     |
| Māori                               | 11 (27.5)   | 15 (37.5)                         | 18 (45.0)                     |
| Pacific Islander and Asians†        | 11 (47.8)   | 4 (17.4)                          | 8 (34.8)                      |
|                                     | $\chi^2(2) = 3.86, P = 0.145$   | $\chi^2(2) = 3.30, P = 0.192$     | $\chi^2(2) = 0.73, P = 0.695$ |

†Due to small number of participants, those who identified as Pacific Islander and Asians were collated as a group. Cells are bolded when adjusted standardised residual is outside the range of standard normal distribution ( $\pm 1.96$  at 5% level).

**FIGURE 1** Map of themes found in content analysis of responses. *Note:* The headings in italics denote subthemes.

professionals and written communication. One participant shared that ' [I]t was unpleasant getting a [recall] letter calling me a woman', when discussing a communication from the Ministry of Health.

Some participants' comments suggested that being misgendered, or having to enter health environments designed for women, could trigger gender dysphoria. Several said that getting a smear test reminded them of having body parts they did not associate with. Some described this as awkward or distressing.

### Anxiety and fear

Many participants attributed their avoidance of screening to being nervous about the screening procedure. Some expressed uncertainty about what the procedure entailed. A few expressed anxiety about discussing screening with their healthcare provider, due to awkwardness or feeling distressed about the prospect of being screened.

*Even when I have concerns related to genitals or 'private' areas I have a huge amount of anxiety about asking a ... health professional about it. A few times I have eventually forced myself to get care and treatment but found the experiences quite traumatic and am back to avoiding getting care.*

As this comment illustrates, for some participants, anxiety contributed to them avoiding care or putting off making appointments.

### Trauma history

Another subtheme identified was the impact of previous trauma after non-consensual medical procedures, or disrespectful or inappropriate treatment in healthcare settings.

*I feel uncomfortable about someone being near my places because I have not had consensual doctor treatment with different treatments in the past and I struggle to feel safe and like they would stop if I asked.*

Some participants also disclosed that past sexual trauma prevented them from being screened, and these experiences increased distress or fear around the invasiveness of cervical screening.

### Physical pain

Many cited the physical pain involved in cervical screening as a barrier, some of whom mentioned previous experiences of the process being uncomfortable or invasive. A few participants noted that the pain was worse since they had been on testosterone.

*I have a bad reaction to the physical process. It is very painful, and sometimes traumatising.*

*Pap smears are a lot more painful now that I'm on hormones*

## Material barriers to access

Although not as predominant as discomfort, some participants also noted material barriers to accessing care. Cost was considered a barrier by some who were unable to afford healthcare appointments. A few participants were unsure if they needed to be screened (eg because of their sexual history) or had not been given information about screening. A few commented on 'administrative hurdles', as one person put it, including that they were unsure if they would receive recall letters about cervical screening due to how their gender was recorded: 'I have not received any reminders about a Pap smear, and I'm unsure if this is usual for my age or if it is because my sex marker is not F'.

## DISCUSSION

Our findings reveal high rates of TGNB people delaying or not having a cervical smear test, often relating to various forms of discomfort, anxiety and trauma, as well as material barriers to access such as cost and a lack of information. While anxiety, fear and physical discomfort relating to smear tests is not uncommon among cisgender women,<sup>14,15</sup> and although some of the reported barriers such as past trauma cannot be removed entirely, our findings show that much of the reported discomfort was specific to participants' gender diversity, or how their gender was perceived within the healthcare context.

As gender dysphoria can be often heightened by external factors, such as gendered language or lack of knowledge about TGNB people and their needs,<sup>16</sup> many of the external factors that exacerbate this discomfort can be mitigated by health systems being alert to the reasons behind TGNB peoples' delay or non-attendance for smear tests, and by making changes to ensure the experience is more comfortable for this population. Providing cervical screening in an environment where a person's gender is affirmed would likely alleviate some of the discomfort. Health systems can also update electronic systems so that recall letters use correct names, titles, pronouns and gender details, and ensure that staff are trained to avoid the negative impacts of misgendering.

We found past sexual violence experiences had an impact on the ability of TGNB participants to access cervical screening. An earlier *Counting Ourselves* analysis revealed almost half (47%) of all participants reported someone had tried to have sex with them against their will.<sup>11</sup> Health providers need awareness of this to enable them to take into account the effect of past trauma when discussing cervical screening with their TGNB patients, and to work from a trauma-informed approach.

Our results identified lack of information as a barrier to cervical screening, and that it was common for trans men to feel unsure about whether they needed cervical screening. TGNB-specific cervical screening resources need to be available and promoted in Aotearoa, combined with education for health professionals about the reasons why TGNB people may feel anxious, how they can help people to feel more at ease, and practical information to improve physical comfort with the procedure. TGNB people who have a cervix may be on testosterone hormone therapy; this can result in vaginal atrophy which affects the comfort of a smear test, as well as sample quality.<sup>5,17</sup> Health providers generally lack knowledge about how this may impact on both the comfort of a cervical smear test and the test result, as it is not routinely taught.<sup>18</sup> Our results show that past or feared physical pain was a common reason for cervical screening delay. The effects of testosterone on the vagina, and ways to increase physical comfort (such as topical oestrogen) should be included in the smear taker education. These measures could contribute to improved experiences and uptake of cervical screening for TGNB people.

In 2023 cervical screening in Aotearoa will change to a human papillomavirus (HPV) swab test which can be self-taken by the patient in private, a change which has already occurred in Australia. This test is likely to be more acceptable and is expected to help reduce inequities for cisgender Māori and Pacific women.<sup>19,20</sup> It is not known whether this will improve cervical screening for the TGNB population, but it seems likely that it will address some of the concerns found in this study. Studies in the United States and El Salvador found that the HPV self-test was acceptable to the majority of trans men who took part.<sup>21,22</sup> Future research should explore the accessibility and acceptability of the self-test for the TGNB population in Aotearoa.

A limitation of our paper is that despite the cervical screening program being three-yearly, participants were only asked about their cervical screening uptake in the last 12 months. This led to us being unable to conclusively comment on rates of cervical screening uptake for TNB people in NZ. We have only reported on findings related to TGNB AFAB participants, but we note that some trans women participants indicated they felt cervical screening was relevant to them. Those who have undergone vaginoplasty to create a neo-vagina do not require cervical screening as they do not have a cervix.<sup>23</sup> Trans women who have a neo-cervix created from penile tissue may be susceptible to HPV genital infection,<sup>24</sup> and examinations to look for HPV related lesions are recommended. Future research is required to explore whether HPV swab screening is of benefit.

Our reporting of non-binary people's experiences adds data relating to cervical screening for this under-researched group. The *Counting Ourselves* survey was most successful in reaching participants via online platforms and may therefore be less representative of TGNB people from harder-to-reach groups such as Pasifika and Asian people, and older adults.

The current cervical screening program in Aotearoa does not consider the needs of TGNB people, leading to delayed and reduced uptake of cervical screening. Health promotion information

specifically aimed at TGNB people is needed, as well as education for health professionals who perform smear tests. The introduction of the HPV self-test has the potential to improve uptake and comfort for TGNB people, but this needs to be further explored to ensure equitable outcomes.

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## Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to ethical restrictions.

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