


# Are women-who-have-sex-with-women an ‘at-risk’ group for cervical cancer? An exploratory study of women in Aotearoa New Zealand

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## ABSTRACT

**Background.** International research consistently indicates that women-who-have-sex-with-women (WSW) are less likely to engage in cervical screening than heterosexual women. In the main, studies have explored rates of engagement and highlighted some reasons for non-engagement. This study extends on this work by exploring perceptions among sexual minority women (WSW) for lower rates of engagement among WSW more generally and is the first study on this topic undertaken in Aotearoa New Zealand. **Methods.** A sample of 177 self-identified WSW domiciled in New Zealand completed an online survey about their engagement in cervical screening, reasons for engaging (or not) in cervical screening, and perceptions of why SMW might be less likely to engage in cervical screening. **Results.** Fewer than half of participants had engaged in cervical screening every 3 years as recommended, with women who had only ever had sex with other women being significantly less likely to have engaged in screening. A lack of clear information about risk relative to sexual history, heteronormativity, and the invasive nature of screening were the dominant reasons for lower engagement among WSW. **Conclusions.** A legacy of misinformation, and endemic heteronormativity in public health messaging around cervical screening is a significant barrier to engagement in screening for WSW. To increase engagement in screening among WSW, public health information needs to specifically address the needs of WSW.

**Keywords:** cervical cancer prevention, cervical cancer risk, cervical screening, health education, lesbians, New Zealand, sexual health, sexual minority women.

## Introduction

Cancer of the cervix (the entrance to the uterus from the vagina) is one of the most common forms of cancer and without prevention and intervention it has a high death rate. Internationally, it is the fourth most common cancer in women.<sup>1</sup> Almost all cervical cancers are linked to high-risk human papillomaviruses (HPV), a group of common, highly contagious, viruses that spread through intimate skin-to-skin contact.<sup>2</sup> Without intervention, about 80% of adults (all genders) will have HPV at some point but it most commonly occurs in young women.<sup>3,4</sup> In most instances, people are not aware that they have been infected as HPV is often asymptomatic. These viruses can cause changes to skin cells on the cervix that if not found and treated may develop into cancer, typically in middle adulthood. However, if the cell changes are detected early and treated, deaths from the disease are largely preventable. The World Health Organization has developed a global strategy aimed at acceleration of the elimination of cervical cancer through key goals and targets.<sup>5</sup> Increasing cervical screening rates is the main way of achieving this.

Consistent with current public health guidance in Aotearoa New Zealand (hereafter, NZ), it is recommended that everyone who has a cervix, is aged 25–69 years, and is sexually active undergoes cervical screening every 3 years. Cervical screening has traditionally been undertaken through a process known as a Papanicolaou smear (or Pap smear) in which cells are collected from the cervix and subjected to testing to

identify any cell changes that may be precancerous. With the now established evidence that almost all cervical cancers are caused by HPV, many countries have moved to routine HPV testing as the primary means of screening.<sup>3</sup> In NZ, this change only started in September 2023. Uptake of cervical screening in NZ is currently around 67%, well below the 80% target set by the National Screening Unit.<sup>6</sup> There are sizeable disparities in engagement by socioeconomic status and ethnicity,<sup>7</sup> with rates of engagement particularly low among Māori (55.7%), Pacific (56.7%), and Asian (55.6%) women, while rates for Pākehā/European and other ethnicities combined are around 75%.<sup>6</sup> With screening, both the prevalence of cervical cancer and the death rate decrease substantially. Although there are a range of risk factors for cervical cancer (e.g. genetics, smoking, diet, number of sexual partners) the most common risk factor is not having regularly undergone screening. Although women-who-have-sex-with-women (WSW) are known to experience health inequities,<sup>8,9</sup> publicly available data on cervical screening in NZ does not give any indication of the rates of engagement in this group.

In NZ (as elsewhere), WSW are a diverse group that includes people who may self-define in a range of ways including as lesbian, bisexual, takatāpui wahine, or pansexual. To maintain simplicity the terms 'women' and 'WSW' are used throughout this paper, but it is important to note that some people whose experiences are represented in this paper may gender identify as 'trans' or 'non-binary' rather than as women. While current public health guidance clearly indicates that all women should engage in cervical screening, existing research consistently reports that rates of engagement among WSW are substantially lower than for heterosexual women. For example, a systematic review and meta-analysis of primarily US studies<sup>10</sup> indicates that WSW were 10% less likely to engage in screening than heterosexual women, placing them at greater risk of late diagnosis of cervical cancer. Noticeably lower participation rates are also corroborated by data from some US clinics,<sup>11,12</sup> and studies undertaken in Australia<sup>4,13</sup> and the UK.<sup>14,15</sup> In addition to those who have never participated in screening, many WSW do not regularly engage in screening or are well overdue for testing. Among WSW, those who are overdue or who have never been screened could be as high as 37%.<sup>13</sup> However, there is considerable variation between studies regarding whether WSW have lower participation rates than heterosexual women.<sup>16</sup> Rates of engagement are lowest among those who have never had sex with men.<sup>4,13,17</sup> A range of reasons are cited for non-engagement in screening, but the barriers and facilitators to uptake in screening in this population are not well understood.<sup>16</sup>

More than 25 years have passed since the National Lesbian Health Survey<sup>18</sup> was undertaken in NZ. More recently, the Counting Ourselves survey has provided some insight into the uptake, experiences, and barriers to cervical screening among trans and non-binary people in NZ.<sup>19</sup> While some WSW may identify as trans or non-binary, many will be cisgender.

Consequently, there may be quite different reasons for engagement (or not) in cervical screening among WSW more generally. To date, no study has specifically focused on cervical screening among WSW in NZ. Drawing on insights from feminist perspectives on lesbian health psychology,<sup>20</sup> the purpose of this study was to explore engagement in cervical screening among WSW in NZ with a view to understanding the extent to which WSW might be considered an 'at-risk' group for cervical cancer. To accomplish this, the study focuses on patterns of engagement in cervical screening, reasons for engaging (or not) in cervical screening, and perceptions of why WSW might be less likely to engage in cervical screening.

## Materials and methods

### Data collection

This study used a survey design. In the first instance the survey was developed by drawing on questions asked in other studies of cervical screening in WSW. Like existing studies, the survey developed for this study explored the extent to which WSW engage in cervical screening. Participants were asked whether they had ever been for a cervical smear test, what the reasons were for their engagement or not in cervical screening, and a range of other questions about their experiences of cervical screening. In addition, bespoke questions were developed to explore other risk factors for cervical cancer (e.g. smoking, number of sexual partners, and HPV vaccination), and perceptions of why WSW might be less inclined to engage in cervical screening. The survey comprised a mix of fixed and open choice response formats. Prior to promotion of the survey, questions were independently reviewed. Reviewers included two lesbians (one who was a recently retired nurse experienced in carrying out cervical screening), a wahine Māori, and an Asian woman. Some changes were made to this survey as a result of feedback from this stakeholder group. A copy of the survey instrument is available on request.

The survey was produced as an online survey hosted on Qualtrics. To reach as many WSW as possible, multiple approaches were used to disseminate the call for participants including advertising through professional networks, and through Facebook friends. In addition, many community organisations that focus on women's health, Māori women's welfare, LGBTQ+ support, and sexual health were disseminated the call via their online mailing lists, social media pages, and physically displaying posters in their premises. Attention was paid to ensuring dissemination beyond metropolitan areas (Auckland and Wellington) to ensure those living in regional areas were also included.

Ethical approval for the study was obtained from the Human Research Ethics Committee (Health) at The University of Waikato, NZ (HREC 2022#38). The survey targeted WSW (lesbians, takatāpui wahine, bisexual women, etc.) domiciled in NZ, and aged 25–70 years, the eligibility age for cervical

screening in NZ. Detailed information for participants was provided at the beginning of the survey. Immediately following this, participants were asked to indicate their consent to participate by responding to the questions ‘having read the information provided, do you wish to take part in this survey?’. Data collection was undertaken between October 2022 and February 2023.

## Data analysis

Statistical analysis was undertaken in IBM SPSS ver. 27. As this was an exploratory study, all questions with fixed choice responses were initially analysed using descriptive statistics, primarily percentage responses. Key questions (e.g. ‘have you ever had a cervical smear test?’) were then analysed to compare group differences based on age, sexual identity, and type of sexual relationships (e.g. exclusively with women, with both men and women, etc.). Pearson’s chi-squared testing was used to analyse potential group differences.

Qualitative data from the open-response question that asked about potential reasons that non-heterosexual women might engage less in cervical screening, was analysed thematically using a conventional content analysis. The responses were collated into a word-processing document and manually reviewed using the inductive process of semantic coding. This involved assigning a code (or label) to each response to reflect the single dominant idea in the response. The codes were then deductively reviewed to collate responses into distinct thematic groupings that reflected categories of reasons why WSW might, or might not, engage in cervical screening.

## Results

### Sample

A total of 206 self-identified WSW participated in the survey. Prior to undertaking the data analysis, the responses of ineligible participants (e.g. those who were not based in NZ) and those who withdrew from the survey partway through (i.e. did not complete most of the survey) were removed from the data set. The final sample comprised 177 women (assigned female at birth) living in NZ who identified as non-heterosexual (e.g. lesbian, bisexual, wahine takatāpui, pansexual, queer). Around 85 per cent of participants identified as female, with the remainder identifying with another gender (e.g. transgender; non-binary; genderqueer). Participants represented a range of ages, ethnicities, and geographical locations (see Table 1 for a full demographic breakdown of the sample). Most participants (84.7%) were aware of the link between HPV infection and cervical cancer.

### Engagement in cervical screening

Of those who completed the survey, 91.5% indicated that they had at some point engaged in cervical screening. However, in

**Table 1.** Demographic breakdown of sample.

| Variables   | Percent (n) |
|---|-------------|
| Age (years)   |             |
| 18–24   | 1.7 (3)     |
| 25–34   | 37.3 (66)   |
| 35–44   | 25.4 (45)   |
| 45–54   | 14.1 (25)   |
| 55–64   | 8.5 (15)    |
| 65+   | 11.3 (20)   |
| Sexual identity   |             |
| Lesbian/gay   | 50.9 (90)   |
| Bisexual  | 18.6 (33)   |
| Queer   | 14.1 (25)   |
| Pansexual   | 6.2 (11)    |
| Takatāpui   | 2.3 (4)     |
| Other (e.g. sexually fluid, asexual)                            | 6.3 (11)    |
| Ethnicity <sup>A</sup>  |             |
| Māori   | 13.6 (24)   |
| European (e.g. Pākehā/NZ European; British; Australian; German) | 91.0 (161)  |
| Pacific Peoples   | 1.1 (2)     |
| Asian   | 4.5 (8)     |
| Middle Eastern/Latin American/African                           | 1.7 (3)     |
| Other   | 2.8 (5)     |
| Geographical location   |             |
| Auckland  | 24.9 (44)   |
| Waikato   | 22.0 (39)   |
| Wellington/Wairarapa  | 25.4 (45)   |
| Other North Island  | 13.1 (23)   |
| South Island  | 13.1 (23)   |
| Unknown   | 1.6 (3)     |

<sup>A</sup>Participants could select more than one ethnicity, so does not add to 100%.

this sample, fewer than half of participants indicated that they were engaging in cervical screening every 3 years as recommended. Just over a fifth of participants (21.6%) have only occasionally participated in screening while 8.5% have never participated (Table 2).

A chi-squared test of independence was performed to examine the relationship between type of sexual relationship (e.g. exclusively with women; with both men and women; etc.) and engagement in cervical screening. Women who had only ever had sexual relationships with women over their lifetime were much less likely to have engaged in cervical screening than were any other group:  $\chi^2(4, N = 173) = 20.76, P < 0.001$ . Chi-squared tests of independence were also undertaken for age, sexual identity, and gender. A significant relationship was also found between age and ever having engaged in cervical screening. Those under the

**Table 2.** Levels of engagement in screening.

|   | N   | %    |
|---|-----|------|
| Which of the following is most true of you?                   |     |      |
| I have been for a smear test every time I have been called up | 77  | 47.5 |
| I have been for a smear test most times I have been called up | 50  | 30.9 |
| I have only been for a smear test occasionally                | 35  | 21.6 |
| When was the last time that you had a smear test?             |     |      |
| Within the past 3 years                                       | 117 | 72.2 |
| About 3–5 years ago   | 23  | 14.2 |
| More than 5 years ago   | 22  | 13.6 |

age of 35 years were significantly less likely to have engaged in cervical screening than participants in older age groups:  $\chi^2(2, N = 174) = 6.52, P = 0.038$ . No significant differences were found by sexual identity ( $\chi^2(3, N = 174) = 2.09, P = 0.553$ ) or for gender identity ( $\chi^2(2, N = 174) = 5.85, P = 0.054$ ).

### Reasons for engagement or non-engagement

Of participants who had engaged in cervical screening, the main reasons for engagement were that current health advice recommends it (53.1%), being tested regularly meant not having to worry too much about getting cervical cancer (37.9%) and wanting to know that any changes in the cervix were detected early (43.5%). Having previously had an abnormal smear and having had, or knowing someone who had, cervical or uterine cancer was also a strong motivator for regular engagement in screening: 'I have had close calls in the past. I know I need to be vigilant' (P64, bisexual, 35–44 years old), 'I have cervical cancer in the family and my mum is a nurse and has always stressed the importance of tests like this' (P136, queer, 25–34 years old).

Reasons for not engaging regularly (or at all) in cervical screening were much more varied, and generally attracted a low percentage of participants in each case. One of the most common reasons was never having had sex with a man (10.2%). Other relatively common reasons included experiencing homophobia in health care settings (5.6%), having been told by a health professional that as a lesbian a smear is not necessary (5.1%), believing themselves to not be at risk of HPV infection (4.8%), and having a pelvic pain disorder that makes penetration difficult or painful (4.0%). Several participants also indicated that pain, shame, fear, and past sexual trauma/abuse were also factors in their non-engagement.

### Perceptions about why WSW might be less likely to engage in cervical screening

An analysis of qualitative responses about why WSW might be less likely to engage in cervical screening than heterosexual women indicated four main reasons: (1) beliefs/perceptions that WSW are not at risk; (2) heteronormativity in health

care; (3) that publicity around cervical screening does not speak to WSW; and (4) the penetrative nature of cervical screening feeling particularly invasive. Illustrative data extracts for each of these themes are in Table 3. Responses that fall within theme 1 highlight an historical legacy of misinformation in which WSW have acquired the impression, or have been directly told by a health professional, that they do not need to engage in cervical screening because not having sex with a man (or person with a penis) means that they are not at risk of cervical cancer. Theme 2 primarily relates to specific instances of heteronormativity. The process of cervical screening itself is not inherently heteronormative. Typically, heteronormativity is manifested through uncomfortable encounters with health professionals in which the patient is assumed to be heterosexual (e.g. assumptions that one's partner is of another sex/gender; discussions of contraceptive use). Theme 3 centred on cervical screening publicity not focusing on WSW. A key issue here was the way in which there is a lack of clarity around what constitutes 'sexually active'. Given that the term 'sex' is so commonly assumed to be synonymous with 'sexual intercourse' participants were not always sure that engaging only in woman-to-woman sex counts. A number of participants also felt that the screening process was particularly invasive, especially those who had never engaged in penetrative sex, do not find penetrative sex pleasurable, or who have experienced rape or sexual assault. As one participant highlighted 'if there is blood screening for prostate, surely there is something for wahine [women] that isn't as invasive' (P114, lesbian, 35–44 years old).

### Discussion

The purpose of this study was to explore engagement in cervical screening among WSW in NZ with a view to understanding the extent to which WSW might be considered an 'at-risk' group for cervical cancer. Many of the participants in this study regularly engaged in cervical screening, but at just 43.5% this is well below the national screening rate of 67%, and on a par with rates of engagement for Māori, Pacific, and Asian woman in NZ. This is also well below the rates reported in overseas studies.<sup>13,21,22</sup> However, like other studies it indicates that WSW are less likely to engage in cervical screening than are heterosexual women.<sup>10</sup>

The reasons for irregular or non-engagement in screening among participants were varied. However, being told that lesbians do not need to engage in screening and believing that one is not at risk were commonly reported. This is congruent with findings of other studies of cervical screening among WSW where a belief about WSW not needing to engage in screening and/or not being at risk was also prevalent.<sup>14,22</sup> It is, however, noticeably different from the reasons reported by trans and non-binary people where gender related discomfort



**Table 3.** Perceptions of why WSW are less likely to have a smear test.

| <b>Non-heterosexual women (lesbians; wahine takatāpui; bisexual women; etc.) are less likely to have a smear test than heterosexual women. Why do you think this is?</b> |   |
|--|---|
| Not at risk and/or do not need a smear   | <p>'There is a belief that if you are not having sex with a man it is not necessary' (P6, queer, 25–34 years old)</p> <p>'I believe that heterosexual intercourse (i.e. penetration of the vagina with a penis) is the main risk for cervical cancer' (P51, lesbian, 55–64)</p> <p>'Semen is the leading cause of cervical cancer' (P33, lesbian, 55–64 years old)</p> <p>'Because doctors tell us that if we're not sleeping with men we don't need to (I've gotten that 'advice' myself). I've had to advocate for myself and convince my primary care providers that women who don't have sex with men still need to get tested. (P16, queer, 35–44 years old)</p> <p>'I have [had] many GPs over this time and none of them have recommended smears to me' (P20, bisexual, 35–44 years old)</p> <p>'I asked for one but the doctor told me I didn't need one' (P82, asexual, 45–54 years old)</p> |
| Heteronormativity in health care   | <p>'Distrust of [the] health system' (P111, bisexual, 35–44 years old)</p> <p>'Assumption of being straight in all the banter to help you get relaxed' (P32, lesbian 65+ years old)</p> <p>'Non-heterosexual women feel alienated or uncomfortable as a lot of questions from healthcare providers are targeted towards sex with cisgender men (risk of pregnancy, contraceptives, etc) so non-heterosexual women may not feel their circumstances are recognised.' (P140, queer, 25–34 years old)</p> <p>'Wanting to avoid the awkward questions around whether they could be pregnant and having to explain that they don't need to be on contraception when sexually active.' (P145, pansexual, 25–34 years old)</p>   |
| Publicity does not speak to WSW  | <p>'The information provided about smears isn't targeted at queer women' (P88, 35–44 years old)</p> <p>'Advertising tends to target heterosexual women' (P103, lesbian, 25–34 years old)</p> <p>'I'm a little unclear on who needs a smear and when – because I'm pretty sure most guidance associates needing a smear with being sexually active, and I'm unclear if the sex I'm having 'counts'. I imagine it's the same for many other women. (P46, queer, 25–34 years old)</p> <p>'... 'sexually active' might be assumed to be vagina-penile penetrative intercourse' (P123, queer, 25–34 years old).</p> <p>'Lack of information on whether we are at risk. Never hearing any statistics to show the level of risk. Not enough education to show why women who have sex with women are still at risk' (P174, lesbian, 25–34 years old)</p>  |
| The penetrative nature of screening feels invasive   | <p>'We are less likely to engage with sexual and maternal healthcare' (P167, queer, 35–44 years old)</p> <p>'I can only speak for butch women but a lot of us don't want to be in a vulnerable position that involves any form of genital penetration, particularly when you don't know the person doing it and how they will treat you.' (P166, lesbian, 25–34 years old)</p> <p>'For me, afab [assigned female at birth], non-binary and androgynous presenting its hugely body dysmorphic and painful to have anything inside my vagina.' (P164, non-binary and date women, 35–44 years old)</p>   |

and similar issues dominated.<sup>19</sup> The assumption that lesbians are at low risk or no risk of STI transmission<sup>15</sup> has historically resulted in a perception that women who have only ever had sex with women are not at risk. This is a perception that has persisted.<sup>21,23</sup> This is partly premised on the false assumption that HPV is only transmitted through penetrative sex.<sup>4</sup> A major contributing factor to this widespread assumption has been the lack of availability of clear and consistent sexual health information aimed at WSW (S. J. Ellis, unpubl. data). In addition, advice given to WSW – particularly those who identify as lesbian – about the need to engage in cervical screening has frequently been premised on an ill-informed understanding of sexual behaviour between women. While there are some WSW who have/do not engage in penetrative sex, the sexual histories of this group of women are diverse. SMW may engage in a varied sexual repertoire including (but by no means restricted to) oral–vaginal sex, digital penetration, and/or use sex toys; all practices that could potentially transmit HPV (and other STIs). In addition, the fact that many WSW may have had sexual relationships with men as well as women, and/or have had multiple sexual partners, are often discounted despite these being factors that (potentially)

increase the risk of HPV infection.<sup>24</sup> Based on these assumptions, many WSW have at some point been told by a health care professional that they do not need to engage in cervical screening.<sup>14</sup>

Consistent with the findings of other studies,<sup>4,13,17</sup> in this study women who have only ever had sexual relationships with women were significantly less likely to have engaged in cervical screening. While unsurprising, being told that you do not need to engage in screening or that you are not at risk are invariably premised on the idea that risk is associated with penetrative sex with men. This implies that those who have never had sex with men do not need to engage in screening. For this group, and also for some other WSW, the penetrative nature of cervical screening itself may be problematic. Given that WSW are less likely to have engaged in gynaecological processes in relation to fertility, pregnancy, and childbirth, the screening process may seem particularly invasive. HPV self-testing is a less invasive process than cytological screening, therefore the change to HPV testing as the initial screening process may be more positively received by WSW. In addition, there is a heteronormative assumption that all women enjoy sexual penetration

and will therefore not find cervical screening particularly problematic. While many WSW engage in penetrative sexual practices, some (for a range of reasons) do not find penetration pleasurable and so do not engage in those types of sexual practices. For these women, cervical screening may seem especially invasive.

As well as these personal reasons for low engagement, in analysing the data it was apparent that issues relating to systemic prejudice create significant barriers to engagement. A key factor is that WSW may have disengaged with health care processes generally, due to repeated experiences of being assumed to be heterosexual and/or having their specific health needs overlooked by health care professionals.<sup>9,10</sup> The analyses presented here indicate that conversation/discussion during cervical screening appointments were often heteronormatively framed through, for example, talk about opposite sex/gender partners and/or contraceptive use. Systemic prejudice in health care, including heterosexism in interpersonal encounters with health care professionals, is also implicated in low rates of engagement in screening.<sup>25,26</sup> Added to this, there are few instances where information about sexual identity (or similar constructs) are routinely – or ever – collected in NZ health care settings. This is a system-level failure that, unlike other groups with low participation rates in NZ (e.g. Māori, Pacific, and Asian women), makes it near impossible to know whether WSW in NZ are an ‘at-risk’ group in the context of cervical screening/cancer. Without this information there is no indication of how many WSW are diagnosed with cervical cancer, and of those how many have never had sex with men. There is, therefore, no evidence base to understand the prevalence of cervical cancer diagnoses among WSW relative to sexual history. This makes it difficult for WSW to make an informed choice about engagement in screening processes producing a health inequity in relation to cervical cancer risk.

### Implications for public health

Given that not engaging in screening is the dominant risk factor for cervical cancer, WSW may therefore be an ‘at-risk’ group. While current public health advice recommends that all women engage in cervical screening, WSW have the right to make an informed choice. As indicated earlier, many WSW find this process particularly invasive and therefore want to better understand their level of risk. Too often sexual health advice is simply generalised to all women without consideration of the cultural complexities that underpin engagement and/or providing adequate justification that a process or practice is relevant to WSW, particularly those who have never had sex with men. Predominantly, the promotion of cervical screening orients to a heteronormative perspective that means many WSW simply do not see themselves represented. The provision of clear, consistent, and relatable information about sexual health for WSW is therefore important for improving uptake of cervical screening

among WSW. Like other marginalised groups (e.g. wahine Māori; Pasifika women), for WSW, being able to see themselves represented is an important determinant in engagement in preventative healthcare, including cervical screening.

This study highlights the impact of endemic heterocentricity in both public health promotion of cervical screening and smear-taking practice. Participants specifically talked both about the themes and language used by practitioners while screening (e.g. talk about pregnancy/contraception; assumptions of an opposite sex/gender partner) as well as broader issues of heteronormativity in the health care system more generally and the way in which the needs of WSW are seldom actively considered. The first of these could be mitigated by using inclusive language and avoiding heteronormative talk. Treating sexual diversity as the norm rather than heterosexuality would be an effective way to ensure inclusivity at a system level. Recognising gender diversity is also important.<sup>19</sup> but it should not be assumed that WSW are necessarily gender diverse. While some may be trans or non-binary, many will be cisgender. Care should therefore be taken to ensure that gender and sexuality are not conflated, and that WSW are validated.

Understanding the sexual histories of all those attending for screening would be useful in ensuring that WSW are identified and addressed appropriately in the screening process. One way of doing this would be to add sexual identity/orientation (and gender) to intake forms. However, this may not be helpful. The labels that people use for defining their sexual identity/orientation may not be that informative in that identities do not necessarily map neatly onto sexual histories. Asking if individuals to indicate whether they have had sexual relationships exclusively with women, with both men and women, with people of a range of genders, etc. are likely to be more helpful in identifying WSW. Having access to this information alongside information about gender would facilitate health care professionals’ ability to respond appropriately. Routinely offering a smaller speculum may help to address the anxieties of those who have never engaged in penetrative sex, or who for other reasons find penetration especially invasive.

### Strengths and limitations of this study

The main strength of this study is that it is the first – and only – study to explore engagement in cervical screening among WSW in NZ. While some participants in this study identified as trans or gender diverse, most participants (85%) were cisgender. The findings of this study showed some similarities but also marked differences from the findings of a recent study of trans and non-binary people and cervical screening in NZ.<sup>19</sup> This highlights that focusing on subgroups of the LGBTQ+ community separately is important for getting a more nuanced understanding of the reasons underpinning non-engagement.

It also extends on existing (overseas) studies by providing an insight into some of the individual and systemic reasons

that engagement in screening among WSW may be much lower than for heterosexual women. However, this study relied on reported information from a relatively small, and self-selected, community sample of WSW. As such, it cannot be guaranteed that the findings reported here are representative of WSW in NZ more generally. That the findings relating to levels of engagement in screening, and reasons for engaging (or not), are similar to those in other studies indicates that low rates of engagement in screening among this group are an issue that needs addressing.

Another limitation of this study's sample is its use of an online survey to collect data. Unlike most other Western countries, NZ largely lacks the densely populated urban areas where WSW might be more concentrated. Therefore, there are few dedicated organisations and spaces from which to directly recruit research participants, and in many parts of the country there are none. So, while an online survey was deemed the best way to reach the target population, some participants (e.g. those who are less digitally literate; those with no/limited access to the internet) will have unintentionally been excluded. Despite this, effort was invested to specifically target a wide range of participants including Māori, Asian, and regionally located WSW. However, due to the limited capacity of community organisations to actively promote the research the voices of these groups are undoubtedly underrepresented. Furthermore, as a small-scale study with a relatively small sample, it was not possible to explore the impact that intersectionality (e.g. being a WSW and Māori) might have on the engagement of WSW in cervical screening.

## Conclusion

Together the findings of this and previous studies suggest that WSW – especially those who have never had sex with men – may be at risk of cervical cancer due to not regularly engaging in cervical screening. The situation is complex in that there is a legacy of historical misinformation coupled with a lack of a clear evidence base that indicates why WSW may be at risk. In particular, there is a lack of information that directly addresses women who have only ever had sex with other women. As indicated in relation to Māori and Pacific engagement in screening 'adaptation of health-care systems to meet patients' cultural needs is just as important as simply encouraging patients to access what is available' (p. 571).<sup>7</sup> This is equally true of WSW. Implicitly including WSW through generic statements (e.g. 'all women who are sexually active') is not enough. Such statements are value-laden and therefore easily read in a heteronormative way (e.g. 'all women' = heterosexual women; 'sexually active' = heterosexual intercourse) and simply reinforce heteronormativity and indicate to (some) WSW that cervical screening is 'not for me'.

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**Data availability.** The data from this study is not publicly available.

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