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RESEARCH ARTICLE

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Improving cervical screening rates among sexual minorities: Insights from Aotearoa New Zealand

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Abstract

Issue Addressed: Sexual minority women (SMW) experience inequities in health outcomes. The extant literature consistently suggests that SMW are much less likely than their heterosexual peers to engage in cervical screening. Using participant's voices, the focus of this study was to explore the ways in which cervical screening rates for SMW might be improved.

Methods: An online survey was completed by SMW ($N = 177$) aged 25–69 based in Aotearoa New Zealand and representing a range of sexual identities, ethnicities, and geographical regions. The analysis presented here was derived from open-ended qualitative responses to a single survey item: What do you think could be done to encourage more SMW (lesbians, wahine takatāpui, bisexual women, etc.) to engage in smear testing?

Results: Analysis of the data generated three main themes around how public health services could encourage more SMW to engage in cervical screening: Inclusive health services, clarity of information, and targeted health promotion.

Conclusion: The analysis showed that the inherent heteronormativity among health care professionals and the lack of clear and consistent information specific to SMW may be key factors contributing to lower rates of engagement in screening.

So What? Given that not engaging in screening is the main risk factor for cervical cancer, it is imperative that active consideration is given to these issues with a view to increasing participation rates among SMW.

KEYWORDS
early detection of cancer, health promotion, prejudice, public health, sexual and gender minorities

1 | INTRODUCTION

Sexual minority women (SMW) comprise a diverse group of people who primarily/exclusively have sex with women, are non-heterosexual, and may identify as lesbian, bisexual, takatāpui wahine, or queer. Most will be cisgender and self-identify as women, but others may gender identify as trans, non-binary or genderqueer. For simplicity, the term 'women' is used throughout this article to refer collectively to this group of people. The term SMW is used here to foreground the place of sexual activity in understanding sexual risk and the need to engage in cervical screening because of this. While this term is contested, it has been chosen for this article as the best fit for the group of 'sexual minority' women who are the subject of this article.

International research on cervical screening consistently shows that SMW are much less likely to engage in cervical screening than are heterosexual women.[1] While patterns of engagement vary considerably from one study to the next,[2] a sizeable percentage of SMW are overdue for screening or have never engaged in this process, placing them at risk of cervical cancer. Irregular or non- engagement in screening has consistently been shown to be highest among SMW who have never engaged in penetrative sex with men.[3–5] Trans men are also much less likely to engage in screening.[6–8]

A range of reasons are reported by SMW for not engaging in cervical screening, but commonly reported reasons specific to SMW are a belief that they are not at risk,[9–11] and having experienced heterosexism in health care.[11–13] In many instances SMW have at some point been told by a health professional that 'lesbians' do not need to engage in cervical screening.[3,10] This (mis-) information arose from both the (mis-)conception that semen is the main vector of cancerous cells on the cervix,[10] and a poor understanding of the sexual behaviour of SMW. While there are some SMW who do not engage in penetrative sex, the sexual histories of this group are diverse putting SMW at risk.[14]

Most cervical cancers are linked to a group of common, highly contagious, and high-risk human papillomaviruses (HPVs).[15] These viruses cause changes to skin cells on the cervix, which if not identified and treated early may develop into cancer. Cervical cancer is the most common gynaecological cancer, and the easiest to identify early.[16] Without intervention it results in premature death, so early detection is very important. Recently the World Health Organisation set targets aimed at the elimination of cervical cancer internationally.[17] The achievement of this goal is contingent on widespread HPV vaccination and high levels of engagement in cervical screening processes. The purpose of this study was to explore the ways in which the cervical screening process could be improved with a view to increasing engagement rates among SMW.

2 | METHODS

2.1 | Research design

The analysis presented here was based on data collected as part of a larger study of engagement in cervical screening among SMW in Aotearoa New Zealand (NZ). The study used a survey design to collect information about rates of engagement in cervical screening, reasons for engaging (or not), perceptions of why SMW might be less inclined to engage in screening than their heterosexual peers, and what could be done to encourage more SMW to engage in cervical screening. Part of the survey was based on questions asked in existing studies of cervical screening among SMW[13,18] with the remaining questions developed specifically for this study to access information about how engagement rates might be improved. Demographic information (e.g., age group, sexual identity, gender, ethnicity, geographic location) was also collected as part of the survey.

The analysis presented here is based on data from a single open-ended question: 'What do you think could be done to encourage more non-heterosexual women (lesbians, wahine takatāpui, bisexual women, etc.) to engage in smear testing?'. An analysis of other data from this study has been published in a separate article.[3]

Ethical approval for the study was obtained from the Human Research Ethics Committee (Health) at The University of Waikato, NZ (HREC2022#38). Participants were asked to indicate their consent to participate before entering the survey.

2.2 | Data collection

Data collection was undertaken between October 2022 and February 2023. The survey was hosted on Qualtrics, distributed wholly online, and targeted SMW who are aged 25–69 (the ages of eligibility for free screening in NZ).

Unlike many other western countries NZ largely lacks densely populated metropolitan areas where LGBTQ+ people might be more concentrated and (potentially) more visible. There are also few organisations/spaces specifically dedicated to lesbian, gay, bisexual, trans, queer, and so forth (LGBTQ+) people, and where these exist, they cater to youth (i.e., under 25 s). Therefore, online recruitment was deemed the best way to reach as many people as possible. To cast the net widely, the call for participants was disseminated through a range of means including professional networks, personal Facebook pages, and community groups with a focus on women's and/or sexual health. Specific attention was paid to ensure that relevant organisations outside of NZs two metropolitan areas (Auckland, Wellington) were also approached.

2.3 | Data analysis

The data analysed for this article comprised open-ended qualitative responses. Using an inductive approach informed by reflexive thematic analysis,[19] responses to the question 'What do you think could be done to encourage more non-heterosexual women (lesbians, wahine takatāpui, bisexual women, etc.) to engage in smear testing?' were subjected to a systematic and rigorous analysis.

All responses were first collated into a separate document and read multiple times by the author of this article to identify patterns in the data. Semantic coding was then applied to the data so that similar ideas were colour-coded into preliminary themes. For example, phrases such as 'rainbow friendly clinics', 'specialised clinics' and 'queer sexual health clinics' were all given the same colour code as they appeared to centre on a similar concept. Once all responses had been coded, the responses within each code were reviewed, and cognate codes grouped to form themes. The content of each theme was then reviewed to ensure internal consistency within, and distinctness between, each theme.

This resulted in the reduction of coded categories into three coherent themes.

3 | RESULTS

3.1 | Participant characteristics

A total of 117 respondents (of 206 who initiated the survey) met the eligibility criteria for inclusion. All participants were assigned female at birth, lived in NZ, and identified as non-heterosexual. Respondents self-identified with a range of sexual identities including lesbian or gay, bisexual, queer, pansexual, and takatāpui. Some participants (15%) identified as transgender, non-binary or genderqueer. A wide range of ages and ethnicities were represented within the sample, and although most were domiciled in Auckland, Wellington/Wairarapa, or the Waikato, just over a quarter (26.2%) lived in regional NZ. A detailed breakdown of the demographic characteristics of respondents is provided in Table 1.

TABLE 1 Demographic characteristics of participants ($N = 177$).

Variables	*N* (%)
Age	
Under 35	69 (39.0)
35–44 years	45 (25.4)
45–54 years	25 (14.1)
55 and over	35 (19.8)
Sexual identity	
Lesbian/Gay	90 (50.9)
Bisexual	33 (18.6)
Queer	25 (14.1)
Pansexual	11 (6.2)
Takatāpui	4 (2.3)
Other (e.g., sexually fluid, asexual)	11 (6.3)
Ethnicity[a]	
Māori	24 (13.6)
European (e.g., Pākehā/NZ European, British, Australian)	161 (91.0)
Pacific peoples	2 (1.1)
Asian	8 (4.5)
Middle Eastern/Latin American/African	3 (1.7)
Other	5 (2.8)
Geographical location	
Auckland	44 (24.9)
Waikato	39 (22.0)
Wellington/Wairarapa	45 (25.4)
Other North Island	23 (13.1)
South Island	23 (13.1)
Unknown	3 (1.6)

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[a]Categories are not mutually exclusive.

3.2 | Qualitative responses

Analysis of the data generated three main themes around how public health services could encourage more SMW to engage in cervical screening: Inclusive health services, clarity of information and targeted health promotion. Each of these themes is discussed below.

3.2.1 | Theme 1: Inclusive health services

A key theme in the data was the need for inclusive health services. This theme centred on the lack of adequately LGBTQ+ informed health professionals and the need for dedicated (i.e., LGBTQ+ specific) health services. One of the main issues here was the extent to which health services were, or felt, heterocentric; in particular, through the assumption of heterosexuality by health care professionals in interactions during appointments (e.g., asking about male partners; talking about penetrative sex as invariably penile). For example, several participants indicated that the questions asked by health care professionals often centred on assumptions of opposite-sex/gender partners: 'Just stop getting doctors and nurses to presume heterosexuality. Stop directly asking about male partners' (P152, lesbian, 45–54). This suggests the need for 'More open recognition of non-heterosexual identities by providers and open lines of questioning (e.g., not making an assumption of heterosexuality in how the questions are asked)' (P140, queer, 25–34).

Many respondents indicated that better education of health professionals was needed to deliver services that were affirmative and inclusive. Perhaps as a direct result of the apparent lack of inclusivity in mainstream healthcare services, many respondents indicated that it would be helpful to know which services are 'queer affirming' or 'rainbow friendly': 'advertising rainbow friendly clinics that people can go to' (P145, pansexual, 25–34), 'having a clinic or day for queer people' (P11, 45–54, lesbian), 'maybe having a registry of queer friendly practitioners' (P57, queer, 25–34). As one participant indicated, SMW often specifically seek 'queer-friendly' services suggesting that this is not a given: 'Clinics that are more obviously rainbow friendly—see lots of questions on queer Facebook groups asking for recommendations of queer friendly health services as it's hard to know' (P89, lesbian, 25–34).

3.2.2 | Theme 2: Clarity of information

Across the data set, there was a clear indication that information around 'risk' (of abnormal smear results and of cervical cancer) was unclear. As highlighted elsewhere in the survey data[3]—and indeed in the wider literature[18,20]—there is a persistent belief among some SMW that they are at little or no risk, particularly those who have never had sex with men. Some indicated that having clearer information about 'cervical cancer not being caused by penetrative heteronormative intercourse' (P106, gay, 25–34) and 'that cervical cancer doesn't just affect cishet women' (P127, queer, 25–34) would be helpful.

Here, the right to make an *informed* choice about engagement underpinned the responses of many participants. In particular, respondents highlighted the need for clear information about relative risk in relation to sexual practices and histories: 'Provide information about non-heterosexual women's risk factors and likelihood of having abnormal results' (P19, lesbian, 45–54), 'making clear what things are still risks even when you are not sleeping with men' (P65, gay, 35–44), 'better statistical evidence to show its importance' (P174, lesbian, 25–34). Greater clarity would help SMW to examine their assumptions and make informed health choices. As one respondent highlighted, 'Is my belief that heterosexual intercourse is the main risk factor for cervical cancer true? Maybe if I'm wrong, lots of lesbians are also wrong. Education around this could be useful' (P51, lesbian, 55–64). Similarly, others indicated that they needed to better understand the risk factors specific to SMW in order to assess their own risk of cervical abnormalities: 'Information, including evidence of which groups are most at risk of cervical cancer, or perhaps the major risk factors, so that non-heterosexual women can determine if they need to undergo this testing' (P25, lesbian, 55–64), 'Some wider awareness of the incidence of cervical abnormalities in non-heterosexual people with cervixes might raise awareness' (P86, pansexual, 35–44).

3.2.3 | Theme 3: Targeted health promotion

The most dominant theme in this study was the absence of cervical screening promotion specifically targeting SMW. Several respondents noted that engagement in screening could be enhanced by communicating directly with the community through promotion and outreach on LGBTQ+ networks, spaces, and groups. Many also highlighted the need for campaigns to specifically speak to this group: For example, 'targeted campaigns by and for non-het women, and non-cis AFABs [assigned female at birth]' (P16, queer, 35–44), and 'Perhaps goes without saying but targeted campaigns for these groups' (P90, bisexual/queer, 25–34). Many responses pointed to the importance of 'visible queer representation in advertising' (P125, bisexual, 25–34) in increasing engagement and the need for greater diversity in the messaging of campaigns promoting cervical screening:

> 'It would be helpful if their [sic] were posters that are 'coded' as women with non-straight sexual orientations/gender diverse to encourage screening – I'd love a poster with a picture of a woman who 'codes' as butch and a poster of a woman who 'codes' as gender diverse… We now have most ethnicities covered on posters etc., but no posters I know of that are recognizably encouraging LBTQ+++ people' (P14, bisexual, 45–54).

In NZ, health campaigns—including those for cervical screening—typically centre on fertility and motherhood to enhance engagement. While these speak to other marginalised groups (e.g., Māori, Pasifika), they often do not speak to the interests or lived realities of SMW:

> I am yet to see a public health campaign about it that includes anyone with dykey or butch or trans masculine vibes about them. And representation can help! A lot of ads in my lifetime have had more of a 'you are a mum, you are an aunty' kinda angle which doesn't feel super inclusive of my queer life (P61, lesbian, 35–44).

> A lot of public health campaigns directed at people identifying as women tend to use children/grandchildren/family as an emotional guilt trip, conveying messages of 'look after yourself so you can be a good mother' etc. But this simply doesn't apply to everyone & can play into gendered stereotypes. I think health campaigns would be better received if the focus is on the person & how we are worthy of receiving high quality healthcare because we're human (P110, bisexual, 25–34).

This, together with the absence of visibly 'queer' or 'lesbian' representation means that campaigns aimed at enhancing engagement in screening are not necessarily relatable for SMW.

4 | DISCUSSION

Existing studies predominantly focus on correlates of engagement in screening[8,18,21] or reasons for not engaging in screening[9,11,13] as a means for identifying how the purportedly low rates of engagement in cervical screening among SMW could be improved. In contrast, the analysis presented here is based on data derived from a survey item that directly asked SMW what could be done to encourage SMW to engage in screening.

The first theme centred on (the lack of) inclusivity in health services. Both the education of health professionals and being able to identify clinics/services that were 'queer affirming' or 'rainbow friendly' was seen as especially important for enhancing engagement. This is consistent with other studies highlighting the importance LGBTQ-affirming healthcare in increasing engagement in cervical screening in SMW.[8]

Secondly, clarity of information about risk of abnormal smears and risk of cervical cancer *specific to SMW* was also a strong theme. The analysis indicated that due to the prevalence of heterocentricity in gynaecological healthcare, many SMW read generic messaging (e.g., 'all women and people with a cervix') through a heteronormative lens, assuming it applied only to heterosexual women perpetuating the urban myth that cervical cancer is caused by sex with men, and that 'lesbians' are not at risk.[20]

The third theme pertained to the need for health promotion specifically targeted to SMW. Many participants indicated that they simply could not see themselves represented in information about, and campaigns promoting, cervical screening. While there is currently limited evidence that targeted interventions work for this population, there is ample evidence that this approach is more acceptable to sexually diverse (and gender diverse) people.[22] However, research with ethnically diverse populations indicates that targeted interventions result in statistically increased engagement in cancer screening.[23] While these studies indicate that no intervention was consistently successful it underscores the need for a range of approaches and representations.

Some of the findings differ from what might be expected given the findings of existing studies. For example, most studies suggest that one of the main reasons for suboptimal levels of engagement is the belief that 'lesbians do not need to engage in cervical screening as they are not at risk'.[9–11] While there is considerable ambiguity about the extent to which this is or is not true (as risk rests very heavily on an individual's sexual history and the sexual practices they engage in) very few participants in this study suggested educating SMW about the risk of cervical cancer and the importance of engaging in screening as a way of enhancing engagement.

Instead, the focus was on public health professionals providing clarity of information to enable SMW to make an informed choice about their own level of risk and the need to engage in screening. While some of the confusion arises from an historical legacy of (mis-) information about the extent to which SMW are or are not at risk, the likely reason for its persistence is the lack of clear—and targeted—information to the contrary. Simply stating that a person should engage in screening if 'they have a cervix' and even 'if you are a lesbian' is insufficient for enabling SMW to assess their own level of risk and the need for engagement in screening. Unclear information is an endemic issue for this population in relation to all areas of sexual health[24] and has a bearing on all forms of preventative sexual health care.

In line with recent research this study indicates the importance of affirming services in enhancing engagement in cervical screening among SMW.[8] Like other studies,[3,12] the analysis indicates that heterocentricity in healthcare, specifically interactions with healthcare professionals at cervical screening appointments, is one of the key reasons that many SMW avoid or disengage with cervical screening. While SMW should be able to attend any health clinic and experience interactions that do not reinforce heteronormativity, the reality is that this is not the case. For this reason, participants indicated a strong preference for dedicated 'rainbow-friendly' (or in some cases 'women-only') services. While it did not appear as salient in this data, other studies suggest that for some SMW (those who have not had penetrative sex, those who have not given birth, those who identify as gender diverse) the penetrative nature of cervical screening may be a significant deterrent to ongoing engagement in cervical screening.[3] The recent move to HPV testing which includes the option of self-swabbing may help to alleviate some of the anxieties around cervical screening experienced by these individuals.

One of the challenges highlighted by many participants was how difficult it is to ascertain whether specific services practiced inclusivity and the likelihood of getting to engage with a health professional who would engage with them in ways that were affirming and did not presume heterosexuality. Given that cervical screening is an intimate process, having to navigate the uncertainty of what the interpersonal encounter might be like would undoubtedly make SMW (especially those who are young) reticent to engage. While educating health professionals about inclusive practice is an integral part of improving the healthcare experiences of SMW, empowering SMW by providing a means of determining clinics or practitioners who exercise inclusive practices is an important measure for enhancing rates of screening.

The findings of this study indicate that while well-intentioned, attempts at being inclusive in cervical screening promotion have sometimes failed to connect with and engage SMW. Campaigns that centre on parenthood or fertility protection do not necessarily speak to this group. SMW are much less likely to be/become parents than are heterosexual women,[25] and many are not invested in the idea of pregnancy and parenthood. Additionally, information that is generically all-embracing (e.g., reference to 'all women' or 'anyone with a cervix') is not always effective in speaking universally to SMW.

For some groups of SMW, language that is intended to be inclusive may in fact be exclusionary. While the use of terms like 'people with a cervix' is helpful to some SMW (e.g., those who identify as trans, gender diverse, or genderqueer) for others—primarily those who are older and/or identify as lesbian—this may be alienating. The latter typically identify strongly as women, have lived through the stigma of being lesbian, and may experience the generic use of 'people with a cervix' as an erasure of their identity. While it is important to ensure that health messaging is inclusive of those who do not identify as women, it is equally important to ensure that it is inclusive of those who do—one size does not fit all.

4.1 | Limitations

While this study has added some insight into how public health organisations and health professionals might enhance engagement in cervical screening among SMW, it is important to note the study's limitations. The sample size was relatively small and comprised a self-selected sample of SMW. Although the sample included SMW of a range of ages, ethnicities, and geographical locations it is not necessarily representative of all SMW. Respondents were primarily white (either Pakehā or of European descent), mainly resided in or around urban areas, and are likely to represent a more affluent and highly educated demographic.

The findings therefore give us limited insight into the views of those who are rurally located, nor the nuanced perspectives that might gleaned from those whose other identities (e.g., ethnicity, socio-economic status, dis/ability) mean that their experiences of cervical screening might differ somewhat to those represented here.[8] Future research should focus on gaining an understanding of intersectional experiences of cervical screening to better understand the needs of who are multiply marginalised.

5 | CONCLUSION

As indicated in the extant literature, for a range of reasons SMW are much less likely to engage in cervical screening than are their heterosexual counterparts. This study focused on using participant voices to explore the way in which cervical screening rates among SMW might be improved. The analysis indicated that the provision of affirmative services, clarity of information, and specifically targeted promotion were key factors that might facilitate the engagement of SMW in cervical screening. Low levels of engagement mean that SMW are potentially an at-risk group for cervical cancer. It is therefore imperative that active consideration is given to these aspects with a view to engaging SMW who do not regularly participate in screening.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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 privacy or ethical restrictions.

ETHICS STATEMENT

Ethical approval for the study was obtained from the Human Research Ethics Committee (Health) at The University of Waikato, NZ (HREC2022#38).

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