








ORIGINAL ARTICLE

Acceptability of self-taken vaginal HPV sample for cervical screening among an under-screened Indigenous population

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Background: Human papillomavirus (HPV), the causative agent of cervical cancer, can be screened for using self-collected vaginal samples (self-testing). This may overcome barriers to screening for Māori women who suffer a greater burden of cervical disease than New Zealand European women.

Aims: This study aimed to explore the potential acceptability of HPV self-testing for never/under-screened (self-reported no cervical screen in 4+ years, aged 25+) Māori women by Kaupapa Māori (by, with and for Māori) mixed methods, involving hui (focus groups/interviews) and survey.

Materials and Methods: Community-based researchers ran hui with women in four regions ($N = 106$) and supported hui participants to collect survey data ($N = 397$). Healthcare providers (HCPs) were also interviewed ($N = 17$). Hui data were thematically analysed. Survey data were analysed by age group, rural/urban, primary health organisation (PHO) enrolment, and time since last cervical screen.

Results: Most survey participants were PHO-enrolled (87.15%) and attended regularly (71.79%), but did not attend regular cervical screening. A desire for bodily autonomy, including whakamā (embarrassment/shyness/reticence), was the most frequently cited barrier. Three in four women reported being likely/very likely to do an HPV self-test. Nine in ten women reported being likely/very likely to attend follow up if they receive a positive HPV test result. Women and HCPs in the hui emphasised the importance of health literacy, cultural competence and empathetic support.

Conclusion: The findings indicate that with a culturally competent introduction of HPV self-testing, many currently never/under-screened Māori women would be willing to be screened and followed up if necessary. HPV self-testing has the potential to save lives.

KEYWORDS

cervical screening, HPV self-sampling, HPV self-testing, Indigenous health, Kaupapa Māori

*The first part of the study was completed while authors were at the Women's Health Research Centre, University of Otago, Wellington, 23 Mein Street, Newtown, Wellington 6242, New Zealand.

†Our wonderful community-based researcher Tania Mataki passed away shortly before this paper was finalised. Her contributions to the research were invaluable. [Correction added on 17 January 2019, after first online publication: The author name "Bronwyn Rendell" has been corrected to "Bronwyn Rendle".]

INTRODUCTION

In Aotearoa New Zealand, Māori (Indigenous) women suffer a greater burden of cervical disease than New Zealand European (NZE) women.^{1,2} The current National Cervical Screening Programme (NCSP) recommends three-yearly cervical cytology for women aged 20–69 years.³ The majority of cervical cancers occur in women who have either not received screening or had infrequent screens.^{4,5} Thirty-four percent of Māori women do not attend regular screening, compared to 21% of NZE women.⁶

The cost of attending a clinic and perceived invasiveness of a pelvic examination are barriers to screening.⁷ These barriers can be compounded for Māori women by services that lack cultural competence.⁸ Correspondingly, Māori women are more than twice as likely as NZE women to be diagnosed with, and three times more likely to die from, cervical cancer.¹ This disease is the second leading cause of cancer death for Māori women aged 25–44 years.⁹

Upcoming changes to the NCSP include the transition to primary human papilloma virus (HPV) screening on clinician-taken cervical sample.¹⁰ This test is more effective in detecting pre-cancer changes on the cervix and preventing cervical cancer, than conventional cervical cytology.^{11–13} However, unless currently never/under-screened women take up this new test, cervical cancer incidence and mortality disparities may increase.

Self-collected vaginal specimens (self-testing or self-sampling) can be used for HPV screening. Recent evidence suggests that vaginal self-obtained samples provide sensitivity and specificity equal to clinician-collected specimens for detecting high-risk HPV types and cervical intraepithelial neoplasia 2+.¹⁴ HPV self-testing acceptability, feasibility and satisfaction studies among Indigenous and ethnic minority women found that HPV self-testing is preferable to cervical cytology, and potentially eliminates barriers to cervical screening.^{15–26}

To date, there are no studies published about HPV self-testing for Māori women. This paper describes a Kaupapa Māori (by, with, and for Māori)²⁷ study that explored the potential acceptability of HPV self-testing for never/under-screened Māori women. The objectives were to explore: never/under-screened Māori women's perspectives on HPV self-testing through face-to-face hui (focus groups and interviews; objective 1) and survey (objective 2), and healthcare provider (HCP) advice about HPV self-testing (objective 3).

MATERIALS AND METHODS

The study gained ethics approval from the Northern B Health and Disability Ethics Committee (ref: 16/NTB/77). This mixed methods research combined qualitative and quantitative data to examine the potential acceptability of an intervention to reduce disparities.²⁸

Face-to-face hui

Data collection involved hui with eligible women (self-identifying as Māori, self-reported no screen in 4+ years, aged 25+), recruited through community-based researchers (CBRs) in four regions – two rural and two urban. Hui discussion was recorded, transcribed and thematically analysed using NVivo qualitative data analysis software.²⁹ Thematic analysis entails reading and rereading the transcripts for an emergent conceptual framework, themes and subthemes.^{30,31}

Survey

Hui participants were invited to survey up to 10 of their eligible female peers (self-identifying as Māori, self-reported no screen in 4+ years, aged 25+). Surveys were administered by pen-and-paper or online through Qualtrics³¹ in the same four regions. Quantitative analysis of survey data compared participant responses by age, region (rural or urban), primary health organisation (PHO) enrolment, and time since last cervical screen.

Healthcare providers

The final data collection involved hui with (Māori and non-Māori) HCPs, including smear/sample takers, general practitioners, nurses, clinic staff and cytologists, in two urban centres. HCPs were asked their views on cervical screening and HPV self-testing. HCP hui data were also analysed thematically using NVivo.

RESULTS

One hundred and six eligible women participated in hui (South Auckland, 27; Christchurch, 25; Northland, 20; Tairāwhiti, 34). Three hundred and ninety-seven eligible women completed the survey (South Auckland, 116; Christchurch, 100; Northland, 79; Tairāwhiti, 96; other residence given, six). Seventeen HCPs participated in hui (Christchurch, eight; Wellington, nine).

Engagement with health services

Just over half the survey respondents (54.91%) were in the 25–39 years age group; most were enrolled with a PHO (87.15%) and attended regularly (71.79%). Half were four to five years past their last cervical screen (50.88%). One in seven (14.36%) had not screened in ten years or more (including those never screened), and one in six (16.37%) were unsure how long it had been since their last cervical screen (Table 1).

Barriers to screening

Women in the hui most frequently referred to a desire for bodily autonomy (retaining privacy, control over one's body) as a reason for not attending regular cervical screening. This encompasses concepts of whakamā (embarrassment/shyness/reticence), and

TABLE 1 Engagement with health services by age group ($N = 397$): primary health organisation enrolment, primary health organisation visits, time since last screen

	25–39 years old		40–54 years old		55+ years old		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Primary health organisation enrolment								
Enrolled	183	83.95	107	88.43	56	96.55	346	87.15
Not enrolled	20	9.17	8	6.61	0	0.00	28	7.05
Unsure	15	6.88	6	4.96	2	3.45	21	5.30
Total	218	100	121	100	58	100	397	100
Primary health organisation visits in past year								
No visits	53	24.31	27	22.31	8	13.79	88	22.17
1–3 visits	103	47.25	60	49.59	28	48.28	191	48.11
4+ visits	46	21.10	26	21.49	22	37.93	94	23.68
Unsure	16	7.34	8	6.61	0	0.00	24	6.05
Total	218	100	121	100	58	100	397	100
Time since last screen								
4–5 years	123	56.42	61	50.41	18	31.03	202	50.88
6–9 years	29	13.31	29	23.97	15	25.86	73	18.39
10+ years	29	13.30	14	11.57	14	24.14	57	14.36
Unsure	37	16.97	17	14.05	11	18.97	65	16.37
Total	218	100	121	100	58	100	397	100

TABLE 2 Barriers to screening, by age group ($N = 397$)

Reason	25–39 years old		40–54 years old		55+ years old		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Whakamā/shyness	103	47.25	56	46.28	24	41.38	183	46.10
Lack of time/other commitments	81	37.16	31	25.62	16	27.59	128	32.24
Fear of discomfort or pain	61	27.98	42	34.71	15	25.86	118	29.72
Cost/financial barriers	49	22.48	22	18.00	6	10.34	77	19.40
Remembering when to do it	38	17.43	17	14.05	10	17.24	65	16.37
Travel or distance issues	30	13.76	19	15.70	7	12.07	56	14.11
Previous bad experience	21	9.63	23	19.01	10	17.24	54	13.60
Smear takers not culturally responsive	16	7.34	12	9.92	8	13.79	36	9.07
Male smear taker	8	3.67	7	5.79	6	10.34	21	5.29

This question allowed respondents to choose as many options as they liked, so the column percentages do not add up to 100.

tapu (sacred/taboo/forbidden). The desire for bodily autonomy was often related to negative health experiences (eg, painful pelvic examinations, inappropriate actions/comments by HCPs).

'Whakamā' was the most common survey reason for not attending regular cervical screening. A lack of time and fear of discomfort or pain were also common reasons. Older women were more likely to mention a previous bad experience and were less likely than younger women to mention cost or other financial barriers (Table 2).

HCPs spoke of shyness/embarrassment being a major barrier, especially for younger women. Opinions varied about cost being

a barrier (as many clinics offer free cervical screening). Some highlighted hidden costs (transport, parking, childcare). A lack of health literacy about HPV and cervical cancer and a lack of appropriate/empathetic services were also raised as barriers.

Acceptability

Hui participant responses to the idea of HPV self-testing were generally very positive, with participants using terms such as 'easier', 'more comfortable', 'less intrusive' and 'brilliant'. Areas identified

TABLE 3 Implementation preferences by rural or urban ($N = 397$): receiving and returning the kit

	Rural		Urban		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Preferred way of receiving self-test kit						
Delivered by post	104	58.76	150	68.18	254	63.98
Community health worker delivers	65	36.72	50	22.73	115	28.97
Pickup from a health clinic	56	31.64	77	35.00	133	33.50
Pickup from a pharmacy/chemist	47	26.55	46	20.91	93	23.43
Preferred way of returning completed self-test kit to lab						
Prepaid post/courier	81	45.76	121	55.00	202	50.88
Drop it at a health clinic	103	58.19	94	42.73	197	49.62
Drop it at a pharmacy/chemist	41	23.16	62	27.73	103	25.94
Community health worker pickup	45	25.42	61	28.18	106	26.70

This question allowed respondents to choose as many options as they liked, so the column percentages do not add up to 100. A small number of women reported being unsure of how they would want to receive the human papilloma virus self-test kit ($n = 24$, 6%), or how they would want to return the completed kit to the lab ($n = 19$, 5%).

as important for HPV education included: relationship-building between communities and health promoters; including whānau/family in HPV education; and ensuring clear information about HPV vaccination.

Survey participants were asked about their preferences for HPV screening. Nearly two-thirds (61.21%) said they would prefer an HPV self-test to a clinician-collected vaginal swab or a cervical sample collected with a speculum, or to other options (see Figure 1).

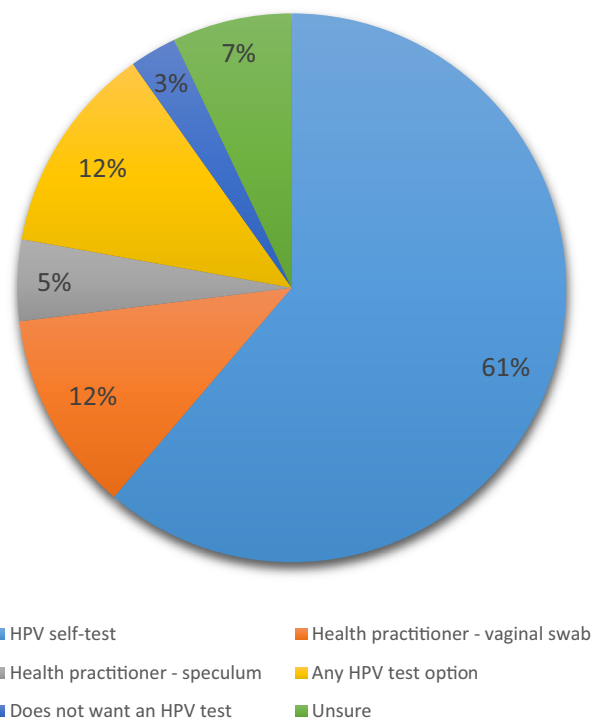
Overall, 73.3% of survey participants said they were likely/very likely to self-test if it was offered. Nearly half of those aged 25–54 years said 'extremely likely'. While the likelihood of doing a HPV self-test lessened slightly by age and by time since last cervical screen, very few women (19, 4.79%) said they would refuse an HPV self-test.

HCPs agreed that with appropriate support and education, HPV self-testing will benefit never/under-screened Māori.

Implementation

Hui participants suggested picking up the HPV self-test from a clinic, a pharmacy or other community venue, or receiving it by post/mail. The most frequently discussed means of getting a completed self-test kit (with sample inside) to a lab were dropping the kit off to a clinic or lab, or sending it by prepaid post or courier. However, concerns were raised about the reliability of post. Participants discussed the value of providing multiple options.

Nearly two-thirds of women surveyed said they would be happy to receive an HPV self-test kit by post. Having the kit delivered by a community health worker was popular for 40–54-year-olds, while picking up a kit from a clinic was popular with those aged 55+. Receiving a self-test kit by post or picking it up from a pharmacy/chemist were less popular options

**FIGURE 1** Preferences regarding HPV testing ($N = 397$).

with women who had not screened in ten or more years or ever. Compared with rural women, urban women were more in favour of receiving a self-test kit by post and less in favour of picking one up from a clinic (Table 3).

Half of the survey participants said they would like to return their sample to the lab by prepaid post/courier, and half said they could drop it at a clinic. Women aged 55+ years were less likely to choose the post or community health worker pickup. Women not PHO-enrolled/unsure were less likely to choose to drop it at

a health clinic or pharmacy/chemist. For women who had not screened in ten or more years or ever, post and dropping the sample at a clinic or pharmacy/chemist were less popular options. Rural women were less likely than urban women to say they would use the post to return their sample to the lab, and more likely to say they would drop it at a clinic (Table 3).

HCPs debated the efficacy of a post/mail-out system for HPV self-testing. Criticisms included referencing previous mail-out screening failures, mobile populations, an outdated post system, and a preference for women to be supported to do the test in an organised setting. Others argued that if women are already not visiting a clinic for a cervical screen, it might be difficult to get them there for a self-test. Flexibility to cater to diverse populations, such as through community outreach services, was suggested for optimum engagement.

Doing the HPV self-test

Hui participants most frequently said they would be happy to do the HPV self-test in a clinic or their own home, and emphasised having good support and education to increase their confidence about properly doing it. Participants highlighted the need for a flexible program, with different options.

More than three-quarters of women surveyed (77.83%) said they would be happy to do an HPV self-test in their own home, and almost one-third (29.22%) said they would be happy to do it in a clinic. Urban women were more likely (than rural) to say they would self-test at a community centre. More than half of survey participants (58.69%) said they did not want any support while self-testing. One in five said they would like whānau/family or friends to be around in case they needed help, while some (<15%) said they would like either a community health worker or health practitioner to be nearby, available to help.

HCPs talked about the importance of delivering empathetic cervical screening services, ie 'the process' – taking the time to put mind and body at ease. They emphasised that this process will be important for any new HPV-based cervical screening program.

HPV self-test results

In the hui, differences in preferences for finding out about results were often explained as being dependent on the results, with the common idea being that if negative a text is fine, but if positive it is better to find out in person or by phone. Some women emphasised the importance of results being delivered in an empathetic way.

Survey participants' most preferred ways of getting self-test results were by text (50.88%) or phone call (45.09%). Older women were less likely than younger women to want to receive a text asking them to call their health practitioner. Non-PHO-enrolled/unsure women were less likely to choose to receive results by email and more likely to choose a visit with a health practitioner. For women who had not screened in ten or more

years or ever, receiving communications by text or email were less popular. Compared with urban women, rural women were less likely to prefer to receive their test results by text or phone call.

HCPs emphasised the need for clear communication and appropriate/empathetic support for women, depending on the outcome of any tests. Concerns were raised about who would be responsible for HPV self-test results and making sure that women are added to the screening register when doing a self-test.

Views about follow up of positive tests

Hui participants had a mostly positive response to the idea of seeking further screening (cytology) or diagnosis (colposcopy) if a HPV test was positive – because knowing that something needs follow up would be a good motivator. Many women stated that they would prefer to go straight to a diagnosis rather than undergo two procedures (cytology and then potentially colposcopy).

The majority of survey respondents (nine out of ten) said they were either 'extremely likely' (61.46%) or 'likely' (26.45%) to seek follow up (cytology or colposcopy) if they received a positive HPV test result (Figure 2). Two-thirds of women who were 4–9 years since their last screen said they were 'extremely likely' to seek follow up (and 26.01% 'likely'), whereas, those who had not screened in ten or more years or ever were less likely (40.35% 'extremely likely'/40.35% 'likely'). Non-PHO-enrolled/unsure women were less likely than PHO-enrolled women to say they would seek follow up (41.18% 'extremely likely'/29.41% 'likely', vs 64.45% 'extremely likely'/26.01% 'likely'). Only seven

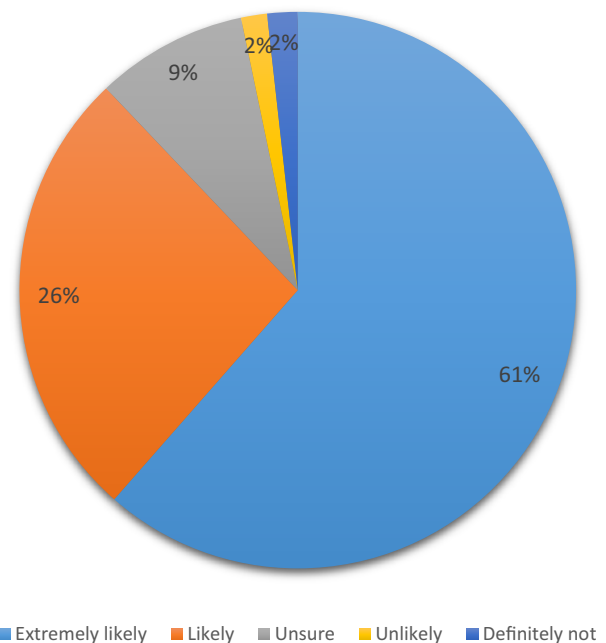


FIGURE 2 Likelihood to seek follow up (N = 397).

women said they would not seek follow-up if their HPV test result was positive.

HCPs wanted assurance that women would be supported appropriately and empathetically to have cytology or colposcopy if they had a positive HPV self-test result, and many supported going straight to colposcopy. Eliminating multiple clinic visits was stressed.

DISCUSSION

This study shows that HPV self-testing is potentially acceptable for currently never/under-screened Māori women. Three in four survey participants signalled that they would accept the self-test if offered it. The findings revealed five important themes.

First, issues relating to a desire for bodily autonomy are barriers to cervical screening for Māori women. Second, HPV self-testing appears very acceptable – while the likelihood of doing a self-test lessened slightly by age and by time since last cervical screen, very few women said they would refuse an HPV self-test.

Third, in terms of implementing HPV self-testing, never/under-screened Māori women and HCPs emphasised the importance of culturally competent services (ie, whānau-centred, empathetic and flexible to suit diverse needs). The post/mail was the lead preference for receiving and returning HPV self-test kits, although some women and HCPs expressed reservations about its reliability/efficacy. Internationally, mail-out self-test screening studies using different settings and designs have shown a wide range of return rates (8–93%).³² Fourth, there was a strong preference for HPV self-testing to happen at home with no support necessary. However, some women wanted to be able to do the HPV self-test at a clinic or community centre, and/or be supported by friends, whānau or a professional. The findings indicate that multiple options will work best to cater to different needs. HCPs emphasised the importance of supporting women to confidently screen.

Fifth, when receiving results, there was a preference for either a text or phone call from a health practitioner, although overall, women and HCPs want the delivery of results to be tailored to the situation, and done in a supportive/empathetic way. Women and HCPs placed importance on follow up for positive test results. However, care will need to be taken to ensure that those women who feel less confident to undergo cytology or colposcopy, such as those who are currently not PHO-enrolled/unsure or who have not screened in ten or more years or ever, are supported.

The majority of Māori women in this study were engaged in the health system, but did not screen. This is a system failure. The findings suggest that HPV self-testing could be very acceptable for Māori women who find current screening unacceptable. Recommendations for a culturally competent HPV self-testing cervical cancer prevention program include: a strengths-based whānau approach to HPV education, empathetic delivery of services, and flexibility – PHOs working closely with community health providers

to ensure standard recall, opportunistic in-clinic invitations to self-test, and targeted outreach.

Limitations

The study relied on self-reporting of last cervical screen, with potential for inaccuracies. However, other research indicates that it is more likely that participants incorrectly report that they have screened, rather than incorrectly report that they have not screened.³³ Although possibly not generalisable, the number of participants and the geographic coverage signal that the findings are a good representation of never/under-screened Māori women's views on the potential acceptability of HPV self-testing. However, limited information was gathered from women who said they would refuse the HPV self-test.

Strength

A large number of never/under-screened Māori women participated in this research, largely because community-based researchers used their networks to access typically considered 'hard-to-reach' women.

CONCLUSION

The findings indicate that with a culturally competent introduction of HPV self-testing, many currently never/under-screened Māori women would be willing to be screened, and followed up if necessary. HPV self-testing has the potential to save lives.

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