Pasifika women's knowledge and perceptions of cervical-cancer screening and the implementation of self-testing in Aotearoa New Zealand: A qualitative study

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Summary

Background In Aotearoa New Zealand, Pasifika women have a higher rate of cervical cancer incidence and mortality than European/Other women and a lower screening rate. Despite actions to reduce the barriers, there has been little change in screening coverage for Pasifika women since 2007. Novel strategies are therefore required. Persistent cervical infection with oncogenic human papillomavirus (HPV) causes virtually all cervical cancers and HPV testing will be implemented in Aotearoa in 2023, with women being able to choose to self-test. We undertook a qualitative focus group (FG) study with Pasifika women to explore their perspectives on the barriers to, and facilitators of, HPV self-testing and how best to implement this in Aotearoa.

Methods A trained female Pasifika Research Assistant facilitated participant recruitment and the FGs. Eligible participants self-identified as Pasifika, were aged 30-69 years, in the Wellington area, who had never been screened or who were overdue (>5 years) for cervical-cancer screening. Recruitment was predominantly through Pasifika keyinformant networks and in collaboration with Pasifika primary care providers. Participants were offered face-to-face FGs but, due to occasional Covid-19 restrictions and personal preferences, FGs via Zoom were also used. The FGs were audio-recorded and transcribed verbatim. The FG transcripts were thematically analysed.

Findings Seven FGs were conducted with 24 participants. We identified five main themes around barriers and potential facilitators of HPV self-testing in Pasifika women: 1) perceptions and knowledge of cervical-cancer screening; 2) challenges to engaging in organised cervical screening; 3) perceptions of self-testing for HPV and challenges women face when deciding to self-test; 4) enthusiasm for an HPV self-test; and 5) information and communication. Knowledge about cervical cancer and screening varied considerably among participants, with some never having heard about cervical-cancer screening. The main challenges that were raised were personal privacy and confidentiality and time management. There was consensus around the need for adequate, consistent, and accurate accessible information to boost the confidence of women undertaking self-testing. In general, the participants were eager for self-testing to be made available soon. This was accompanied by the need for the promotion and implementation of self-testing to include a collective/community approach consistent with Pasifika worldviews.

Interpretation Although participants were enthusiastic about HPV self-testing, multi-level and interacting barriers exist to participation by Pasifika women in HPV self-testing. Implementation of self-testing in Aotearoa New Zealand should be accompanied by clear information about the entire process, using culturally appropriate tailored educational campaigns in different Pasifika languages.

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Introduction

The Aotearoa New Zealand National Cervical Screening Programme (NCSP) was established in 1990. The current recommendation for cervical screening is a regular,



Research in context

Evidence before this study

Pasifika women in Aotearoa New Zealand have a higher rate of cervical cancer incidence and mortality than European/Other (the dominant population group) women and a lower screening rate.

Primary human papillomavirus (HPV) testing will be implemented in Aotearoa in 2023, with the option to self-test. Although self-testing has been shown to be acceptable to Pasifika women in Aotearoa, there is a paucity of information about how best to encourage Pasifika women to engage with cervical screening.

Added value of this study

We sought to explore Pasifika women's perspectives on the barriers to, and facilitators of, HPV self-testing and how best to implement this in Aotearoa. We included never and under-screened women since they are the least well served by the current screening programme.

We ran seven focus groups with 24 participants who identified as Samoan, Tongan, Fijian, Cook Islands, Papua New Guinean, and Mixed Pasifika ethnicity. The main challenges that were raised were personal privacy and confidentiality and time management. There was consensus around the need for adequate, consistent, and accurate accessible information to boost the confidence of women undertaking self-testing. In general, the participants were eager for self-testing to be made available soon. This was accompanied by the need for the promotion and implementation of self-testing to include a collective/community approach consistent with Pasifika worldviews.

Implications of all the available evidence

Inequities in cervical-cancer screening, incidence and mortality remain high among minority women, including Pasifika women, in Aotearoa New Zealand. The introduction of HPV self-testing has the potential to reduce those inequities, particularly if it is implemented with clear information and culturally appropriate tailored educational campaigns in different Pasifika languages.

three-yearly, cervical smear for all people aged 25-69 years with a cervix or vagina who have ever been sexually active; however, around 170 women are still diagnosed with cervical cancer and approximately 50 women die from the disease every year.^{1,2} Pasifika women have a higher rate of cervical cancer incidence and mortality than European/Other women: 6.I vs 5.7 and 3.5 vs I.3 per 100,000 respectively³ and a lower screening rate.⁴ The reasons for low participation in the NCSP can be summarised as health-system failure, differential access, attitudinal bias (racism), and quality of care.^{5–9} In 2018 (the year in which the last census was taken), 8.I% of the population in Aotearoa New Zealand

were self-identified as Pasifika. Porirua (26.3%) and Wellington (5.1%), the areas from which our participants came, have relatively large communities of Pasifika people.¹⁰ There has been little research published that specifically investigates why Pasifika women in Aotearoa New Zealand do not access cervical screening but we have previously carried out semi-structured interviews with health-care providers, Pap smear takers, and community workers in the Wellington region to investigate this issue.⁶ Six interrelated themes were identified: the funding and practice of service delivery; family always coming first; the cost of screening services; type of employment; the appropriateness of information; and attitudes to self and screening.⁶ Actions to reduce these barriers, including offering free smears and practice-level data matching to identify underscreened women in order to offer support, have been undertaken across the country. Despite these measures, there has been little change in coverage for Pasifika women since 2007. Novel strategies are therefore required to improve cervical-screening participation in Aotearoa New Zealand.

Persistent cervical infection with oncogenic human papillomavirus (HPV) causes virtually all cervical cancers^{11,12} and the World Health Organization recommends primary HPV-based screening for early detection of cervical cancer.13 In high-resource settings, using HPV testing for primary cervical-cancer screening could increase the efficiency of the existing screening programme, more effectively identify women at risk of precancerous changes, and therefore reduce the incidence and mortality from cervical cancer. The New Zealand Government announced in Budget 2021 that they will move from primary liquid-based cytology testing to HPV testing in 2023, with women being able to choose to self-test.¹⁴ The use of self-collected cervicovaginal specimens for HPV testing addresses a number of barriers to participation in clinic-based screening,^{II} and recent research in Aotearoa New Zealand found that Pasifika women generally find self-testing acceptable in cervical-cancer screening.^{15–17}

Following our earlier work,^{15–17} we undertook a qualitative focus group (FG) study with Pasifika women to explore their perspectives on the barriers to and facilitators of HPV self-testing and how best to implement an HPV self-testing-based screening programme in Aotearoa New Zealand.

Methods

For this qualitative FG study, we developed a FG guide (see Appendix 1) through discussion with Pasifika key informants to facilitate discussion with Pasifika women about questions that are sensitive and culturally complex (talking about sexually transmitted infections and topics such as cervical-cancer screening is seen as taboo and embarrassing by some Pasifika women). The guide included open-ended questions aimed at facilitating discussion amongst participants. The FG facilitator used the guide to prompt areas of discussion for the participants but allowed the conversation to go where the participants wished.

To further ensure cultural safety, a trained female Pasifika Research Assistant facilitated participant recruitment and the FGs. Food and drink, as well as opening and closing prayers, were offered. The participants were asked if they were comfortable with the male Pasifika researcher (SF) staying in the room/ Zoom call and he left if they were not (we also assessed body language to judge if the participants were uncomfortable with his presence).

The study received ethical approval from the Massey University Human Ethics Committee: Southern A (application SOA 20/16) in June 2020.

Participants

Eligible participants self-identified as Pasifika and lived in the Wellington area (the capital city of Aotearoa New Zealand). Cost constraints meant that we were unable to carryout FGs in other areas, but Wellington city and nearby Porirua have a significant Pasifika population. We included only women who had never been screened or were overdue $(\geq 5 \text{ years})$ for cervical-cancer screening because they are the least well served by the current screening programme. Although cervical screening is recommended for all women in Aotearoa New Zealand from age 25–69,¹⁸ the prevalence of HPV infections in women <30 years is high and most infections clear without causing cervical abnormalities; this reduces the specificity of HPV testing.¹⁹ We therefore thought it likely that the Ministry of Health would introduce primary HPV screening in women aged \geq 30 years. The age range for our study was therefore 30 -69 years. Recruitment was predominantly through Pasifika key-informant networks and in collaboration with Pasifika primary care providers in the Wellington region.

Participants were recruited via telephone with the study described verbally and were provided with a participant-information sheet by email or in person. All participants signed a consent form at the beginning of the FG that they attended. The participants were given a koha (Māori word for gift): a NZ\$40 supermarket voucher) for their time and effort. Participants were also recruited through face-to-face and Pasifika community outreach.

Data collection

A total of seven FGs were conducted with 24 participants between November 2020 and March 2021. We decided that we had undertaken a sufficient number of focus groups when data saturation was achieved (no new information was emerging from the focus groups). Four FGs were conducted via Zoom and one FG each was conducted at a private home, a community venue, and at the Massey University Wellington campus. Each FG lasted approximately 40 to 70 minutes. None of the participants left the study before the FGs were concluded.

Participants were offered face-to-face FGs but, due to occasional limitations in public gatherings because of Covid-19 restrictions and personal preference, FGs via Zoom were also used. The FGs were audio-recorded (with participant consent) and transcribed verbatim by a professional service under a confidentiality agreement. We also took notes during the sessions. The participants were asked about and were comfortable and agreeable for the FGs to be conducted in English.

Participants were shown a FLOQSwabTM (Copan Italia, Brescia, Italy) as an example of an HPV self-testing device. We chose the FLOQSwabTM because we had recently successfully used this device in a RCT.¹⁵

Data analysis

The FG transcripts were thematically analysed.²⁰ The following steps were taken in the analysis: i) thoroughly reading and re-reading the transcripts and notes taken during the FGs; and (ii) noting down initial ideas independently by one of the co-Principal Investigators and a research assistant. These were further discussed to begin generating initial codes across the data and the (iii) potential themes that emerged. Transcripts were uploaded into the qualitative software NVivo12 and each was coded according to the identified themes. The themes were then reviewed and discussed further by both co-Principal Investigators and the research assistant to determine the relevance of the data grouped by theme and how the identified themes work within some of the FGs or across all the FGs. We further explored (iv) whether themes are distinct from each other and degrees of any overlap and supported by the data. Table I demonstrates the process of reviewing of the themes and splitting the themes into (v) sub-categories that further define the essence of each theme as part of the (vi) final write up.

Quotations, used almost verbatim, but with minor changes to improve readability, have been extracted from the data where they gave a good example of a finding or captured what several participants said.

Role of the funding source

The funder had no role in any aspect of the study, other than funding the research collaboration that provided the financial resources to conduct the study.

Results

The characteristics of the participants are described in Table I.

Characteristic of participants	Number	Per cent ^a
Pasifika ethnicity		
Samoan	10	41.7
Tongan	7	29.2
Mixed Pasifika ethnicity	3	12.5
Fijian	2	8.3
Cook Islands	1	4.2
Papua New Guinea	1	4.2
Screening status		
Under-screened	18	75.0
Unscreened	6	25.0
Age group		
30-49	15	62.5
50-69	8	33.3
70-89	1	4.2
a May not equal 100.0% due to rounding.		

As shown in Table I, one participant was older than our study age range. This was due to a misunderstanding by the participant. We decided to include her in order to honour her effort in travelling to the FG location and contributing to the FG (we did not learn her age until the end of the FG). The proportions of Pasifika ethnic group in our study are not dissimilar to the national distribution in Aotearoa New Zealand.

The main data analysis was undertaken by the Pasifika researcher (SF) with assistance from the Māori researcher (MG), and therefore had a Pasifika lens. Five main themes emerged:

- Perceptions and knowledge of cervical-cancer screening;
- Challenges to engaging in organised cervical screening;
- Perceptions of self-testing for HPV and challenges women face when deciding to self-test;
- Enthusiasm for an HPV self-test;
- Information and communication (these were highlighted throughout the conversations and are therefore discussed throughout the results rather than as a separate theme).

Key themes and related categories and quotations are outlined in Appendix 2 and briefly described below.

Perceptions and knowledge of cervical-cancer screening

The majority of the participants had some knowledge of cervical cancer and cervical-cancer screening. It was evident from the FGs, however, that the participants' perceptions and knowledge of cervical cancer and cervical-

cancer screening varied considerably. In relation to need for cervical screening, participants' responses ranged across: knowing that it can save one's life; doing it for one's children; and believing that it is needed only if one is sexually active, which included believing in disengaging from screening if one was previously sexually active but is no longer so. At least one participant had not heard of, or was unaware of, cervical-cancer screening: "I didn't know anything about cervical screening until I got the flyers for this study for a month ago" (FG 3). Many participants mentioned the need for more information and others said that some of the health information and education available was highly targeted and lacked the benefits that would have been achieved through a holistic approach. This remained true even if the health promotion was undertaken at the early stages of life: "In school...we had sex ed[ucation] but it was all about preventing pregnancy; there was no discussion on other things" (FG 1). Furthermore, consent from parents for vaccination during high-school years meant girls received an injection that was explained as helping to: "...prevent some things and that they told us what HPV was but, at that age, you don't really understand" (FG I).

In addition, the information about the process and results of cervical-cancer screening was seen as either limited or not client-friendly, such that they were inadequately understood or conveyed: "My impression of it or what I know about it is just that you go in, you get something put up there, it's uncomfortable, it doesn't take long and then they maybe give you a bit of info" (FG 4). According to one participant, there may be a: "...lot of follow up...and it's always on the [my General Practitioner's health app], but in terms of beyond the experience...I don't know what they're looking for" (FG 4). A number of the participants who had undertaken cervical screening agreed that it is easier to participate when you have had children as it is then less embarrassing.

Challenges to engaging in organised cervical screening

Several key issues dominated the discussions on challenges for Pasifika women to engage in organised cervical screening. Among these was the need to maintain privacy, which often led to the consideration of going out of the women's residential areas to get tested. As described by one participant: "If you happen to go in on a Wednesday, then everybody knows you're going to see the lady doctor and then they start putting their own spin on it" (FG I). This use of services outside one's usual provider incurs extra cost as well as time.

In some relatively closed Pasifika community environments, some participants preferred non-Pasifika cervical-screening staff as it lessened the likelihood of someone knowing them. On the other hand, another participant preferred someone she can talk to in her first language because: "...*if you speak in English...everyone can hear this conversation"* (FG I).

The concern with personal privacy and confidentiality issues was sometimes no longer seen as a substantial challenge after continued exposure to, and familiarity with, services and was overtaken by the need for time to attend to screening: "I've had four kids and you soon lose all dignity with what the sort of examinations you have as a mother - so I have no problems with that. But for me, it was always time, I was time poor" (FG 5). According to one participant, being 'time poor' often translates to their own health being placed behind others "... important stuff of just functioning and keeping families operating" (FG 4). This was confirmed by others who stated that regardless of whether you are Pasifika, Māori, or otherwise, it is: "... inherently a cultural norm that women will put themselves last. So, if you don't address that kind of stuff, it will only be as successful as women actually turn over and go...we've always talked about listening to your body but women always put themselves last" (FG 3).

Perceptions of self-testing for HPV and challenges women face when deciding to self-test

The perspectives of participants on self-testing for HPV were generally positive as it addresses issues with privacy and convenience and was considered culturally acceptable. A general consensus among participants was the need for accessible information that is adequate, consistent, and accurate because a substantial degree of confidence is required for women to carry-out the selftesting.

At the same time, the sensitive nature of the topic and of the sampling technique at the individual level requires appropriate information-delivery modes, preferably at the personal level rather than an all-out public approach: "...having to feel embarrassed because I'm watching it on TV in front of my husband and my two boys. That's really uncomfortable" (FG 3).

As one participant noted, self-testing is convenient and removes the need for appointments as it is essentially available 24/7. The lack of a clinic appointment also meant that participants felt that they would no longer need to make themselves 'presentable' and more importantly: "...you wouldn't need to get dressed...yeah, you wouldn't need to be presentable to go to the doctor. Yeah - and you could do it whenever you wanted and you would be comfortable; you wouldn't need to use transport, drive...there's so many advantages...providing that the instructions were clear. Yeah, I mean it's 24/7, you know, midnight you could be like: oh, I'm going to do my test" (FG 1).

On the other hand, some participants said that they were still undecided, although willing to give it a try; they would prefer self-testing at a clinic with a professional. In addition, some of the participants preferred having the self-test at the clinic because it avoids the need to figure out how to get the samples to a laboratory safely and in a timely manner, at no cost to the clients. Indeed, the self-test being free was very important to participants.

In relation to accessing the testing kits, the consensus was that it would be an advantage to have a variety of options given that situations differ across individuals. These include participants having the option of doing it while visiting the doctor for unrelated issues and 'dropping it off' to them at the same time, whereas others preferred a text to alert them to collect the kits – as they do with prescriptions – or kits to be collected and returned via courier pack through the Post Shop.

The participants also suggested that there should be options around how they were informed that they were due for screening. For example: "I prefer leaving it to the system because sometimes I forget when is this due. But I think if the system automatically alerts you, then that's good. I'm okay with that" (FG3).

Enthusiasm for an HPV self-test

In general, participants were eager for self-testing to be included in the NCSP soon, including a call for a recommendation that the Ministry of Health proceed with rolling out self-testing for HPV: "*I can't wait for the new device to come so we can just use it every three years instead of me really [being] behind with my test*" (FG 7). Some women felt that the fact that self-testing had not already been introduced in Aotearoa New Zealand showed a lack of government commitment. The assumption was that the government were not willing to invest the necessary money. This caused frustration because of the lives that could be saved through increased screening rates.

The participants' enthusiasm was accompanied by a need for the promotion and implementation of self-testing to include a 'collective' approach consistent with a Pasifika viewpoint: "...make it more catchy and you know, like a group of some people coming together and then bang, you give them all those informations and stuff...if that could be done as a collective thing with other Pacific Island people...I'm sure that would work" (FG 2).

One of the most frequently suggested enablers to increasing screening rates is consistent with the idea of promoting self-testing through the Pasifika collective approach; that is, to normalise the relevant conversation by working with Pasifika communities to remove the stigma around sexual health: "we have a very colonised view of what medicine is and...this is a way...to re-own what actually in the old days would have been a natural thing — which is where women gather, where they you know, gain education, knowledge and that this should be part of it...that we would talk about together as women and this should be brought into that fold and made very normal within a Pacific world-view" (FG 5).

There was consensus on the need for clear instructions on all aspects of the programme that address clients' concerns and potentially conflicting information. It was noted that the instructions should include how the testing kits will be delivered and how the samples to be tested will be dropped off or collected. Substantial community education – especially to address low health-literacy – about interpreting the test results and the next steps after receiving results was also considered important, with community education needing to be conveyed in a form that Pasifika women understand, and in appropriate Pasifika languages. The information must not be full of jargon: "...my key frustration with [my General Practitioner's health app] is that it puts absolute medical jargon in the result, so the lab test results comes through and it's just all these numbers. It means nothing to me. There's no context around what does that result mean" (FG 3).

The participants also had some concerns about the testing device itself, with some feeling worried after hearing stories about them, but for some this changed when they saw the actual device: "...when I look at that [device] I'm like: oh that's not too bad" (FG I); although another participant thought that: "...visually it's confronting seeing the [Delphi Screener]" (FG 3). There was consensus that the cotton swab looked non-threatening.

Discussion

Our research suggests that the barriers to Pasifika women participating in HPV self-testing are multi-level and interacting. We identified five main themes around barriers and potential facilitators of HPV self-testing in Pasifika women:

- Perceptions and knowledge of cervical-cancer screening. Knowledge about cervical cancer and screening varied considerably amongst the participants, with some never having heard about cervical-cancer screening and some being unaware of exactly what the screening looks for and what the follow-up procedures may involve.
- Challenges to engaging in organized cervical screening. The main challenges that were raised were: i) personal privacy and confidentiality, because the Pasifika healthcare workforce is very small and general-practice waiting rooms are 'public'; and ii) time management, involving time off work, arranging childcare, etc. Which was more important varied by stage of life pre- vs. post-children.
- Perceptions of self-testing for HPV and challenges women face when deciding to self-test. Views were generally positive as self-testing addresses concerns with privacy and convenience and was considered culturally acceptable. There was consensus around the need for adequate, consistent, and accurate accessible information to boost the confidence of

women undertaking self-testing. Also, consensus on the need for a well organised reminder, delivery, collection, and follow-up system.

- Enthusiasm for an HPV self-test. In general, the participants were eager for self-testing to be included in the NCSP soon. This was accompanied by the need for the promotion and implementation of self-testing to include a collective/ community approach consistent with Pasifika world views.
- Information and communication. In general, the participating women felt that there was not enough accessible information about cervical-cancer screening and that communication about their results and what would happen next was not always very clear. Consensus was in favour of substantial community education to address low health literacy, conveyed in a form that Pasifika women understand and in appropriate Pasifika languages.

The need for information that is comprehensive, accessible, timely, accurate, and culturally appropriate cuts across the identified themes in order for HPV selftesting to be successful for Pasifika women. The fact that some of the participants did not know anything about screening until their participation in the focus group is concerning and needs to be addressed. Similarly, some participants described self-testing as scary (regarding the self-testing devices) after hearing stories from other people, but later thought "oh, that's not too bad" (FG1) after seeing some devices for themselves, which demonstrates the need for active promotion of accurate information in a timely manner. The participants, in turn, have called for better client-friendly information to give them the confidence that they are performing the self-tests correctly, as well as to ensure that they receive the results of the test in a form they understand. There was consensus that one-size does not fit all and that women should be given options about how to receive/collect the device, where to do the test, how to return the test, and how to find out about the results.

The Pasifika culture of caring for other people is expressed through the participants' preference for a collective approach to screening. Pasifika women often suggest that going for screening as a group would make them feel more comfortable than going on their own. This also has the advantage that any negative perceptions around cervical-cancer screening will not be focused on just one person.

Our findings that Pasifika women generally find selftesting acceptable are in accordance with the limited previous research focussed on cervical-cancer screening in New Zealand Pasifika women.^{15–17} Our results show: i) the importance of adequate and appropriate information; ii) the role of women within families (usually putting their own health needs last); iii) that socioeconomic capacity matters (cervical screening is expensive); iv) and that the cultural context of information and service delivery are critical in addressing barriers as well as facilitating the uptake of HPV-self sampling. In terms of cultural context for example, health messages through personal contacts have been argued to be more effective as opposed to pamphlets and posters sprinkled around surgeries⁸ or images of reproductive body parts on TV in front of Pacific families' living rooms. These findings are consistent with previous research among Pasifika^{6,21} and Māori women²² on cervical screening more generally.

Strengths and limitations

The main strengths of our study were the Pasifika lens on the advancement of Pasifika health and the nature of the focus groups, which allowed the conversation to be framed by the research questions but steered by the women themselves. The sample size, convenience sample, and single region for participant recruitment for our study limit its generalisability. Future research could seek the views of gender-diverse Pasifika, since HPV self-testing has been found to be acceptable for transmasculine individuals internationally.²³ HPV selftesting may also help to address barriers to cervical screening for people with comorbid conditions and disabled people²⁴; these could also be explored among Pasifika.

Overall, the women who participated in the study were enthusiastic about HPV self-testing for cervicalcancer screening. Some of the women were initially somewhat hesitant about the idea but became willing to try it once they had had the opportunity to discuss it, had had their questions and concerns addressed, and were able to see the testing devices.

Implementation of self-testing in Aotearoa New Zealand should be accompanied by readily accessible, clear information about the entire process, using culturally appropriate tailored educational campaigns in multiple languages.

Contributors

Brewer, N - conceptualisation, funding acquisition, study design, project administration, data collection, data interpretation, writing - original draft, and writing – review & editing. Foliaki, S - conceptualisation, study design, project administration, data collection, data analysis, data interpretation, writing - original draft, and writing – review & editing. Gray, M - data analysis, data interpretation. Potter, JD - conceptualisation, study design, data interpretation, writing – review & editing, and supervision. Douwes, J - conceptualisation, study design, data interpretation, writing – review & editing, and supervision.

Data sharing statement

As a result of ethics requirements around confidentiality, we are unable to share data.

Declaration of interests

The authors declare that they have no conflicts of interest.

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Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j. lanwpc.2022.100551.

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