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A qualitative study

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Aboriginal and Torres Strait Islander women's views of cervical screening by self-collection: a qualitative study

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Incidence and mortality rates from cervical cancer are two and four times higher, respectively, for Aboriginal and Torres Strait Islander women compared with non-Indigenous women, despite a nationally organised cervical screening program that was introduced in 1991.¹ National screening participation data are not available from the National Cervical Screening Program (NCSP) for Aboriginal and Torres Strait Islander women, but estimates from Queensland, New South Wales and the Northern Territory range between 33.5% and 42.2% of eligible women, much lower than their non-Indigenous counterparts (55.7–59.1%).^{2–5} The disparity in participation rates, and consequent cervical cancer outcomes, indicates that the NCSP does not meet the needs of all Australian women.

Several barriers to cervical screening exist for Aboriginal and Torres Strait Islander women (similar to other Indigenous populations), which span across knowledge of cervical screening (e.g. benefits, screening process, etc) information and beliefs, access to services and health provider of choice, data and systems, and colonial legacies.⁶ Cervical screening is often viewed as Women's Business by Aboriginal and Torres Strait

Abstract

Objective: This study aimed to describe Aboriginal and Torres Strait Islander women's views of self-collection introduced in the renewed National Cervical Screening Program.

Methods: A total of 79 Aboriginal and/or Torres Strait Islander women (50 screened in previous five years, 29 under-screened) from five clinics across three Australian states/territories participated. Topics discussed were perceptions of self-collection, the instruction card and suggestions for implementing self-collection. We employed yarning (a qualitative method), which established relationships and trust between participants and researchers to facilitate culturally safe conversations. Transcripts were analysed thematically.

Results: Most women were unaware of self-collection before the yarn but found it to be an acceptable way to participate in cervical screening. Women perceived self-collection would be convenient, provide a sense of control over the screening experience, and maintain privacy and comfort. The instructions were perceived to be simple and easy to follow. Women had concerns about collecting the sample correctly and the accuracy of the sample (compared to clinician-collected samples).

Conclusions: Self-collection is acceptable to Aboriginal and Torres Strait Islander women.

Implications for public health: Given the inequitable burden of cervical cancer experienced by Aboriginal and Torres Strait Islander women, self-collection is likely to significantly improve participation and ultimately improve cervical cancer outcomes.

Key words: cervical cancer, cervical screening, self-collection, Aboriginal and Torres Strait Islander women, Aboriginal and Torres Strait Islander health

Islander women; therefore, limited access to female healthcare providers to perform screening creates a barrier for women, as does shame, fear, embarrassment, pain and invasion of privacy that Aboriginal and Torres Strait Islander women can experience

with cervical screening.^{6–10} For Aboriginal and Torres Strait Islander communities, the term *shame* has a particular meaning, which is distinct from Western conceptions of the emotion. Shame may be experienced when a person behaves in a way that

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violates collectivist, cultural or spiritual norms or is singled out – either positively or negatively.¹¹ Cervical screening is seen as Women's Business and a private and intimate procedure, causing feelings of shame among some women. These aforementioned barriers coupled with distrust of institutions caused by a colonial legacy of intergenerational trauma and experiences of racism in healthcare settings,^{6,7,9,12} require an urgent rethinking of strategies to improve safety and comfort in Aboriginal and Torres Strait Islander women's experiences of cervical screening.

In December 2017, Australia's NCSP underwent a renewal based on advances in scientific knowledge and technology. The key changes were moving from a two-yearly Papanicolaou test for women aged 18 to 69 to a five-yearly human papillomavirus (HPV) test for women aged 25 to 74, with subsequent reflex cytology of specimens that are HPV-positive.^{13,14} A highly anticipated innovation was the introduction of a self-collection option (collection of the screening specimen using a vaginal swab taken by the woman herself) for women aged 30 years or older, who are under- or never-screened (more than two years overdue or never screened at all) and who have declined clinician-collected screening.¹⁵ However, this was delayed in implementation due to unanticipated additional accreditation procedures to be completed by laboratories processing samples.¹⁶ A significant barrier to screening for some under-screened women is the embarrassment and anxiety associated with a vaginal examination by a clinician,¹⁷ however, evidence demonstrated that self-collection may reduce these barriers.¹⁸ Improving screening in under-screened women is critical, as 80% of women who are diagnosed with cervical cancer are overdue for screening or have never been screened.^{19,20}

Self-collection may provide a mechanism to overcome some barriers to participation in cervical screening while enhancing women's sense of control and empowerment.²¹ While a growing body of research suggests that Aboriginal and Torres Strait Islander women find self-collection to be acceptable in research study settings,²²⁻²⁴ self-collection has largely been underutilised in Australia.²⁵ A comprehensive understanding of the views of Aboriginal and Torres Strait Islander women regarding self-collection is needed to build and implement models that can support and maximise the uptake and benefit of self-collection. This study aimed to

explore the perspectives of Aboriginal and Torres Strait Islander women in relation to self-collection, including the benefits and their concerns, their views on the process and the instructions, and how they felt the self-collection process could be improved.

Methods

The data reported here are from a larger study entitled *Screening Matters: Aboriginal and Torres Strait Islander women's attitudes and perspectives on participation in cervical screening*. The methods and study design have been described in detail elsewhere.^{7,26} In brief, the study was conceptualised, led and conducted by Aboriginal and Torres Strait Islander women (Author 1, Author 2, Author 5). We included both screened and under- or never-screened women who were recruited from five Aboriginal and Torres Strait Islander Primary Health Care Centres (PHCC) across three Australian states/territories. Women were eligible to participate in the study if they identified as Aboriginal and/or Torres Strait Islander and were between 25 and 74 years old. Women who had a hysterectomy were excluded from the analysis.

Data reported in this paper were from all 79 eligible women who participated in the study, consisting of 50 women who had screened within the last five years, and 29 women who were classified as under-screened (either never screened, had not screened in the previous five years, or had recently screened in the past three months after an interval longer than 5 years).

Data collection

Women provided informed consent to participate in the study, completed a short demographic and health survey, then yarned with the researcher, usually individually or in a group of two. Yarning, an Indigenous research methodology and cultural form of conversation, allowed for the researcher and participant to establish a relationship built on trust and accountability, and together cover topics of interest in a relaxed and culturally safe environment. Yarning allowed the Aboriginal and Torres Strait Islander person participating in the research to speak freely and openly about their experiences.²⁷ Yarns were either audio-recorded with participants' consent or the researcher took detailed notes, and they followed a semi-structured question guide with two sections. The first section of the yarn focused on women's views toward

cervical screening (data reported elsewhere⁷). The second section, which is the focus of the current analysis, explored women's perceptions of the self-collection process and the instruction card, accompanied by visual inspection of the flocked swab and instructions used for self-collection (Figure 1). The instructions were provided by VCS Pathology, a not-for-profit public laboratory and the only laboratory accredited at the time to process self-collected specimens under the NCSP. The instructions were the standard instruction card with minor adaptations made during a Victorian pilot study of self-collection involving an Aboriginal Health Service.²³ The current version of the self-collection instruction card is available online.²⁸

Yarns with the participants were prefaced by a short description of the change to the NCSP including the introduction of the option of self-collection. At the time of the interviews (conducted between April and November 2018), the evidence suggested that self-collection had slightly lower sensitivity and specificity than a clinician-collected sample²⁹ and it was described in the interviews "... as slightly less good than if a healthcare provider did the collection". (In December 2018, a meta-analysis of previous studies found that self-collection was as reliable as a clinician-collected test, as long as a PCR-based test is used.) The instruction card and flocked swab were shown to women, followed by questions regarding women's perceptions of the instruction card, perceptions of self-collection, and preferences for how self-collection could be implemented (see Box 1 for an extract of the yarning guide relevant to the current analysis). All participants were provided with a gift voucher to reimburse them for their time and thank them for their valuable contribution.

As part of our responsibility to communities and research participants to provide accurate health promotion information, it was essential to discuss any misunderstandings and answer questions about the instructions and self-collection during the interview.³⁰ Consequently, women co-created meaning and comprehension of the instructions with the researcher as the yarn progressed.

Data analysis

Yarns were transcribed and imported into NVivo (QSR International Pty Ltd, version 11³¹) and analysed using thematic analysis.³² Aboriginal and Torres Strait Islander women researchers conducted the analysis. Author 2

developed a list of initial codes, then LJW, TLB and NL trialled the codes on three transcripts, meeting to compare the application of coding and clarify node definitions. A codebook was developed. This process was repeated on one further transcript and consensus on the coding application was achieved. TLB and NL then independently coded all remaining transcripts, meeting occasionally to discuss emerging patterns and confirm the application of codes. Both authors independently summarised all codes. LJW and TLB synthesised and organised thematic findings. The 2016 Australian Statistical Geography Standard was used to convert participant residential postcodes to three Remoteness Areas: major city, regional and remote.

Ethics approval

Ethics approval for this research was obtained from the Aboriginal Health and Medical Research Council of New South Wales (AH&MRC) Ethics Committee (1341/17), Central Australian Human Research Ethics Committee (CAHREC, CA-18-3113), Far North Queensland Human Research Ethics Committee (FNQ HREC, HREC/18/QCH/41-1218), Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (2017–2993) and Metro South Human Research Ethics Committee (MSHREC, HREC/18/QPAH/52).

Box 1: Yarning guide.	
Q1.	This is a guide to help women do a self-test. Do you think this guide does a good job of showing you how to do the self-test?
Q2.	Sometimes these pictures can be hard to understand. Are these pictures clear enough to follow what you would have to do?
Q3.	Would anything help to make understanding this guide clearer?
Q4.	Are there any parts of the pictures that women might not understand?
Q5.	Are there any parts of the pictures that women might not feel comfortable to look at?
Q6.	What do you think about this self-test?
Q7.	Underscreened women: Would you be more likely to screen if you could do it yourself? OR Screened women: Would you prefer to have a screen test if you could do it yourself?
Q8.	If yes, would you prefer to do this test at home or in the clinic?
Q9.	What information would help you decide whether you wanted to do a self-test?
Q10.	What might help you feel comfortable doing a screen test yourself?
Q11.	Does anything about a self-test worry you?

Results

Characteristics of the 79 Aboriginal and Torres Strait Islander women who participated in the Screening Matters study are reported in Table 1. Most women identified as Aboriginal (88.6%), had children (79.7%), and lived in major cities (65.8%), followed by regional cities (17.7%). Age distribution was relatively even. Twenty-four per cent were employed at a PHCC.

The qualitative analysis identified five themes: 1) self-collection is acceptable; 2) benefits of self-collection; 3) reasons for uncertainty about self-collection; 4) perceptions of instructions; and 5) suggestions for improving the process of self-collection. These are discussed below.

Self-collection is acceptable

Women generally thought self-collection was acceptable and could overcome some of the barriers relating to clinician-collected

cervical screening. When asked if they would screen using the self-collection option, both screened and under-screened women indicated that it was a positive alternative to clinician-collected samples, as reflected in a resounding “hell yeah” (P66) from one participant. Many women would try self-collection if it was offered to them and would feel comfortable collecting the sample themselves. Most under-screened women said they would try self-collection. Of those women who indicated they would not try self-collection, many self-reported that they regularly participated in screening via a clinician-collected sample.

Regardless of their opinion on whether they would try self-collection themselves, many women supported the idea of self-collection in general, emphasising that simply having two options and the ability to choose was a positive feature of the renewed program and may increase uptake of screening. Some women said that simply “just being offered it” (P16) or “knowing it’s out there” (P17) as

Figure 1: Self-collection instruction card (1a) and flocked swab (1b).

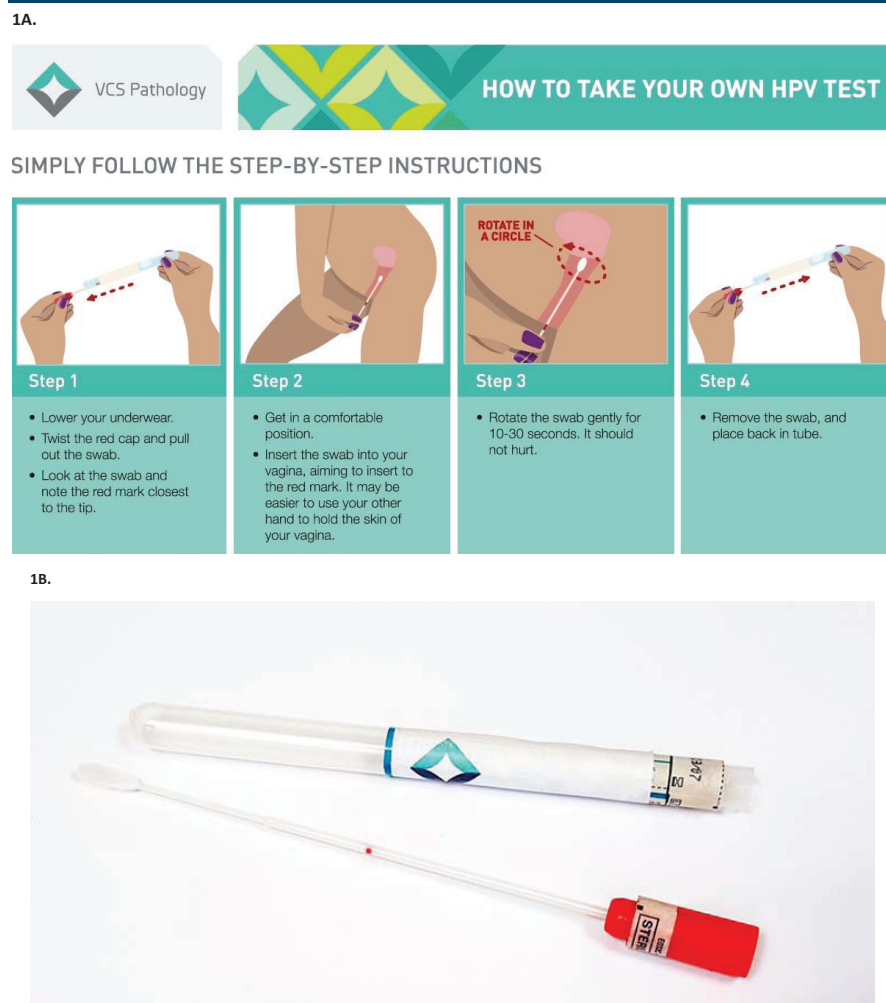


Table 1: Participant characteristics.^a

	Number of participants (n)	%
Total N = 79 ^a		
Indigenous identification		
Aboriginal	70	88.6
Torres Strait Islander or both Aboriginal and Torres Strait Islander	9	11.4
Cervical screening status		
Screened	50	63.3
Underscreened ^b	29	36.7
Age group		
25-39 years	22	27.8
40-49 years	21	26.6
50-59 years	17	21.5
60+ years	18	22.8
Had children		
Yes	63	79.7
No	15	19.0
Presence of one or more chronic disease		
Yes	48	60.8
No	30	38.0
Employed at Primary Health Care Centre		
Yes	19	24.1
No	60	75.9
Education level		
Year 12 or below	46	58.3
TAFE certificate/diploma, trade certificate	19	24.1
University	13	16.5
Marital status		
Single	31	39.2
De facto/married	33	41.8
Separated, divorced or widowed	14	17.7
Main language spoken at home		
English	61	77.2
English and an Aboriginal language	15	19.0
Missing	3	3.8
Residential postcode remoteness		
Major city	52	65.8
Inner or Outer Regional	14	17.7
Remote or Very Remote	11	13.9
Missing	2	2.5
State/Territory		
New South Wales	36	45.6
Northern Territory	11	13.9
Queensland	32	40.5
Had Human Papillomavirus (HPV) Vaccination^c		
Yes	13	16.5
No	49	62.0
Don't know	16	20.3
Number of participants per PHCC		
PHCC 1	11	13.9
PHCC 2	19	24.1
PHCC 3	13	16.5
PHCC 4	16	20.3
PHCC 5	20	25.3

Notes:

a: Figures do not necessarily sum to N=79 or 100% due to missing data. One woman did not complete the entire survey.

b: Defined as either never screened, had not screened in the previous five years or had recently screened in the past 3 months after an interval longer than 5 years.

c: Many women expressed that they were not confident about their vaccination status

PHCC: Primary Health Care Centre

an option would help support a decision to participate in screening.

I think it's good that there's another option to where you don't have to get your doctor or somebody else to do it for you. There is that option if you wanted to take it to do it yourself. I think more Pap smears would be getting done. I think more women would get tested, like checked and screen and stuff like that for cervical cancer. P17

Very few women had heard of self-collection before, and many emphasised the need for greater community awareness of its availability.

Benefits of self-collection

Women's reasons for supporting participation in self-collection centred on enhanced control, privacy, comfort and increased convenience.

Self-collection puts the woman in control of screening

Women would be inclined to try self-collection because it avoided the shame, embarrassment and discomfort surrounding the clinician-collected sample; it would "completely take away that invasion" (P56). Self-collection was seen to reduce feelings of anxiety, fear, and vulnerability felt during the clinician-collected sample because it would enhance women's sense of confidence, control and autonomy over screening. As one woman said:

... you can manage the experience [...] you can control it that little bit more. P46.

Another woman said:

I'm thinking for myself, that would be great, being able to do that yourself and give that back to the practitioner, [...] the anxiety of getting up on the bed and having someone with the light on you is sometimes, yeah, and having your legs apart and whatever. That can be daunting and obviously uncomfortable but, [...] if it was something like this [the flocked swab], that would be amazing. P20

Some women working in the participating PHCCs strongly supported the self-test for women who had experienced trauma.

Especially for those who haven't had a Pap smear and aren't willing to, because we have patients like that: "No, no, no, no," because of these really traumatic things that have happened and they're not going to do it, this would be perfect, because at least there is a – they feel like something is happening, they're having a test, and hopefully they do it right, and hopefully it comes back negative. P39

One woman spoke about self-collection as a "practice run" (P30) for the clinician-collected sample, which could build confidence in screening.

Self-collection provides privacy and comfort

Women indicated that self-collection was an easier, simpler and more physically comfortable way to collect the sample than a clinician-collected test, with a benefit being that there would be no one touching or seeing their private parts. The ability to do self-collection reduced the potential for shame because of the privacy the test would afford women.

... this is good for me; I can do it for myself, my own test, you know, like, another person don't touch you, you know, so I'm touching myself see, instead of nurse touching you, it's comfortable, you know? P79

One woman said that self-collection may be easier for her due to her concerns about her body size and not feeling comfortable on the examination table for the clinician-collected sample.

Women said that privacy was a key benefit of self-collection and should be a critical feature of the location in which they would complete the self-collection kit. Flexible options to collect the sample at home or in the clinic were discussed, with different advantages to each option (see Table 2).

Self-collection is convenient

Another reason for wanting to participate in self-collection was that it was viewed as a more convenient way to screen than a clinician-collected sample. Women noted that finding time to make an appointment and see the doctor added to the demands on already-busy women. One health worker saw benefits in self-collection in freeing up healthcare professionals' limited clinical time. She indicated she would participate in self-collection if it meant that the time allocated for her own appointment could be redirected to other clients of the PHCC.

Reasons for uncertainty about participating in self-collection

Most women's reasons for uncertainty about participating in self-collection related to perceptions that the clinician-collected sample was more accurate, proper, professional, safe and reliable. Some women simply preferred to continue to see their healthcare provider (HCP) for screening.

Table 2: Women's suggestions for improving the self-collection process for HCPS and PHCCs.

Topic	Suggestions
Increasing awareness of self-collection	<ul style="list-style-type: none"> • Raise awareness of self-collection availability as well as new 5-yearly screening interval • Provide targeted resources in different formats: a video of procedure, pamphlet with information about advantages, posters in the clinic • Encourage women to talk about self-collection and cervical screening • Deliver education and information through yarns with Aboriginal health workers, Women's groups, Women's Business clinic events or through GP • Provide education to youth about sexually transmitted infections such as HPV and sexual health • Ensure female HCPs lead awareness-raising and education activities as cervical screening is Women's Business.
Receiving a self-collection kit	<ul style="list-style-type: none"> • Provide education about where you can get the kit and whether an appointment is required • Suggestions for locations to get the kit include: at a chemist, GP, PHCC, in the mail (posted regularly in the same manner as bowel screening kits.)
Understanding how to self-collect	<ul style="list-style-type: none"> • Explain the purpose of the kit and the instructions when women receive it and answer women's questions. • Reassure women of the effectiveness of the self-collection compared to clinician-collected sample • Ensure HCPs have a demonstration swab to show to women when explaining the kit instructions. • Demonstrate and explain correct rotating motion for self-collection • Provide advice on how to know if self-collection has been completed correctly, such as expected sensations or explanations of women's anatomy. • Be prepared to answer frequently asked questions about topics including whether it is safe to collect the sample while menstruating or after sex and hand and general hygiene considerations for women when collecting the sample. • Explain self-collection in a private area where it is safe to talk about Women's Business. • Encourage women to bring a support person to help them feel comfortable during self-collection.
Location of collecting sample	<ul style="list-style-type: none"> • Implement flexible practices regarding where and when the sample is collected. No matter the location, privacy is critical. Women saw advantages of self-collection in the clinic and at home; be flexible to women's needs.
Instructions and kit	<ul style="list-style-type: none"> • Provide the option to have an HCP explain the instructions orally, as this may be preferred by some women, particularly but not exclusively those with low literacy. • Provide private, safe and confidential areas away from the gaze of men and large groups of people for viewing the instructions • Explain different options for body positioning while doing the self-collection, such as squatting, sitting, lying down, standing, especially if there are concerns about self-collection due to body size, medical conditions, being elderly or inflexible. • Explain and demonstrate how to use the red line on the swab as a guide for correct self-collection. • Make the red line on the swab and instructions bolder and brighter • Make the red line on the swab a different colour from the cap for easier visual cues. • Create versions of the instructions and images in which the woman is better representative of Aboriginal and Torres Strait Islander women and their cultures. • Create a larger text version of the instructions for women with poor eyesight • Maintain simple language with a small amount of text and big pictures in future versions of the instructions
Storing and returning self-collection kit	<ul style="list-style-type: none"> • Implement support, resources and systems for returning the kit if done outside of the clinic (including but not limited to the points below). • Provide flexible options for returning the kit. Suggestions included directly to clinic, via post (particularly for women living in remote areas), or employing staff to transport and return the self-collection sample on women's behalf. • Provide information on how to store sample (e.g., the need for temperature control). • Advertise appropriate timeframes for return • Provide reminders to return the kit

Worries about an inaccurate or incorrectly collected sample

While a large proportion of women said they would try self-collection, many women were concerned that the self-collection results could not be trusted, saying that the HCPs could be trusted to conduct screening professionally and they might collect the

sample incorrectly. Some women were worried about having to see an HCP after an invalid sample was submitted, negating some of the benefits of self-collection. The potential for injury while collecting the sample also raised concerns for some women, stating they might accidentally hurt themselves with the swab.

Clinician-collected samples viewed as more thorough

Language used to describe the clinician-collected sample implied it was a more accurate and thorough way to screen, using phrases such as the “main test” (P81), “full test” (P76), “proper way” (P12) and “doing it normal” (P84). This was also reflected in women’s sensations of the clinician-collected sample as “scraping” (P57), “cutting” (P58) or “when you have a Pap smear, they dig” (P35), which indicated to some women that a high-quality or thorough sample was being collected. Women had questions about how the self-sample would achieve the same effect, especially because a speculum was required for the clinician-collected sample and not the self-collected sample. There were perceptions that the flocked swab looked, and perhaps would feel, less “technical” than the clinician-collected sample, leading to concerns about the validity of the result.

Get it done to the most maximum thing and that's a doctor doing it. P42

Feeling safe and secure in the knowledge it's done right. P28

Concerns about physical ability to self-collect the sample

The clinician-collected sample was preferred by some women who felt they would have physical difficulty collecting the sample correctly due to body size or flexibility concerns. Some felt that due to differences in women’s body shapes and sizes, the swab would not reach the correct collection area. Often, these concerns about self-collection were held simultaneously with perceptions of the benefits, frequently leading to uncertainty around participating in self-collection.

I see the pros and I see the cons [...] My pro would be that I would be able to do it myself and no one else would see, and it would be easy and just you could do it when you wake up in the morning, you don't have to take any time off, like all that. But I think my con would be [...] even if it came back negative, I would feel like maybe I didn't do it right, [...] and it would play on my mind. It would be like, yeah, well, I don't have it. But then I would be like, I probably do because I probably didn't do that right. P39

Self-collection instructions

The self-collection kit and instructions are provided in Figure 1. The vast majority of women found the self-collection instructions

to be acceptable, saying they were simple, straightforward and easy to follow. Women liked the minimal steps involved, the emphasis on large pictures and the small amount of text using “basic lingo” (P01); it was legible with no ambiguous wording. Many women indicated they would feel confident and comfortable to do self-collection using the instructions.

I think personally for myself, it's [the instructions] right on the mark. You look at it and you think, okay, it's four simple steps. Two of those steps [the first and the last steps] are really opening and closing, the rest [step two and three] is doing your test. So, to me, there's limited steps but it's good. I wouldn't suggest anything else on it. P02

Women drew on past experiences to help make sense of the self-collection instructions. For example, women were reminded of the instructions and pictures found inside a box of tampons and this sense of familiarity was comforting. Women also compared the self-collection instructions to other experiences such as self-collected sexual health checks, vaginal swabs required during pregnancy, and vaginal creams and medications. Some reported that the concept of self-collection reminded them of the bowel cancer screening kits. These experiences provided scaffolding for women’s understanding of the self-collection concept and helped women to process the instructions.

Most women found the images to be tactfully presented and not exceedingly graphic. The illustrated images made it less confronting than anatomically detailed and realistic pictures (although one woman wanted more anatomically correct and detailed pictures). Women noted that viewing the instructions and images would need to be done in a private, safe and confidential area, away from the gaze of men and large groups of people. Some women said other women may feel shame viewing the swab being inserted in the images; indeed, one woman felt immediately uncomfortable. Focusing on the text reduced her discomfort. Other women said some Elders may feel shame looking at images.

Women’s main concern about the instructions was knowing how far to insert the swab, which was linked to fears that they would not collect the sample correctly or would harm themselves. To many women, the red line on the swab and the instruction card was not immediately obvious at first glance, and many commented that both needed to be bigger and bolder. There was also confusion about

which red part of the swab the instructions referred to, as both the cap and the insertion line were red. Women suggested that these could be different colours. Finally, many women questioned the functionality of the red line, saying that it would be impossible for them to physically see if they had “inserted to the red line” as the instructions directed:

We've all got rubber necks, have we? P11

Nonetheless, many women’s concerns abated the longer they spent reading the instructions and yarning about them with the researcher. Many women expressed that they understood the instructions more fully after viewing the actual flocked swab in conjunction with the picture of the swab on the instructions.

Women did not regard the instructions as a standalone guide to self-collection, with many indicating further information is needed about steps preceding and following the images on the instruction card. More information was said to be particularly needed about where and how women could undertake self-collection (see Table 2).

Suggestions for improving the process of self-collection

Aboriginal and Torres Strait Islander women made several suggestions of ways to improve self-collection, which are outlined in more detail in Table 2. Suggestions mostly centred on ensuring the process was clear and well understood. This included where and how women received a self-collection kit and how they returned it. Women had suggestions about the location of where they would do a self-collect test and differing advantages of a woman doing it in the clinic compared with at home. Other suggestions were more focused on the instructions about the actual process of self-collection, for example, improved visibility of the red line that indicates where the swab should be inserted to.

There were several suggestions about increasing awareness and availability of self-collection. Despite self-collection being available for at least five months at the time of the yarn, most women had not heard about it prior to their research participation, except for one woman who had completed screening via self-collection. Many women expressed a need for increased awareness of self-collection in the community, alongside general information about the purpose of the test and the new five-yearly screening interval, and reassurances about the quality

of the test compared to clinician-collected samples.

Discussion

This study explored the perspectives of Aboriginal and Torres Strait Islander women in relation to self-collection for cervical screening, including the perceived benefits and concerns, their views of the test-kit instructions, and ideas on how the self-collection process could be improved. The findings highlight that Aboriginal and Torres Strait Islander women find self-collection to be an acceptable method of screening and provide further insights into the factors needed to ensure self-collection is used effectively as a tool to improve cervical screening. The 37% of Aboriginal and Torres Strait Islander women in our sample who were under- or never-screened and engaged with a health service provide a unique and important perspective about self-collection. This is important given the disproportionate burden of cervical cancer among Aboriginal and Torres Strait Islander women,⁶ many of whom are under- or never-screened.^{2,3}

Findings from our study demonstrate that Aboriginal and Torres Strait Islander women welcomed a choice of two options for cervical screening. Among women's reasons for wanting to participate in self-collection were control, privacy, comfort and convenience. Self-collection would reduce shame, vulnerability, pain, fear, embarrassment and the invasion of privacy associated with the clinician-collected test. Self-collection was viewed as convenient and time-efficient. A key concept emerging from the yarns was that self-collection would enhance women's sense of safety and control over screening. Previous unsafe experiences of healthcare and/or having experienced trauma are known barriers to cervical screening, which increase the need for enhanced comfort and safety when screening.⁶ Self-collection has been found to be an acceptable and feasible way to overcome barriers to cervical screening among Indigenous women internationally because it supports a sense of control and bodily autonomy.³³⁻³⁷ Other Australian women have similarly reported a great sense of control from participating in self-collection.²⁵

Women's concerns about self-collection were mostly centred on views that the clinician-collected test would be more precise, proper and professional, and some women had a

preference to continue seeing their HCP for screening. This strongly related to fears that women would collect the sample incorrectly or that they would hurt themselves. Overall, our study findings were consistent with research with Aboriginal and Torres Strait Islander women^{23,24} and other Australian women^{18,25,38,39} suggesting that self-collection is acceptable, although some women still hold reservations.^{40,41} Internationally, other Indigenous women report similar benefits and concerns.^{33,34,36}

Understanding that women compare the self-collection test to the clinician-collected sample in terms of quality, accuracy and physical sensation will help HCPs to explain the differences while emphasising current evidence that self-collected samples show comparable sensitivity to clinician-collected.⁴² HCPs should also emphasise that the sample is from the vagina, not the cervix, which may be reassuring for some women.⁴³ It is important that these conversations occur with trusted HCPs, as previous research has indicated that strong relationships with HCPs are pivotal to open and positive discussion about self- or clinician-collected cervical screening.^{7,23,40}

Overall, women found the instructions to be straightforward and easy to follow, similar to previous research using low-text, diagram-focused instructions.²³ When misunderstandings arose, comments focused on the red line on the swab and the diagram (Figure 1) and often led to a discussion of concerns about collecting the sample correctly and safely. Instructions alone were not viewed as a complete guide to self-collection, and this prompted discussion of the need for flexible options regarding where, when, and how the sample was collected and explained, summarised in Table 2. Viewing the flocked swab and a demonstration of where to hold it, accompanied by oral explanations of the kit and instructions, were seen as important in helping women to understand how to collect the sample and alleviating concerns about collecting the sample correctly.

These findings are timely given the recent recommendations from the Australian Medical Services Advisory Committee (MSAC) in to expand self-collection to all eligible people with a cervix who have ever been sexually active (as opposed to only those who are overdue).⁴⁴ This expansion underscores the need for greater awareness of the option for self-collection. Despite

self-collection being available to Australian women who are overdue for screening during 2018-2019, data suggests fewer than 6000 self-collected tests were processed.⁴⁵ This was reflected in our study, as most of the women were unaware of the availability of self-collection, similarly to other Australian women.^{25,41} This is concerning given the way in which self-collection can help to overcome barriers to cervical screening. It highlights the need to ensure that clinicians are aware of self-collection and are confident in recommending it to their clientele.⁴⁶ Evidence suggests that healthcare professionals consider self-collection as a valuable option, particularly for under- and never-screened women, but they remain uncertain and hesitant about its efficacy and continue to view clinician-collected samples as the gold standard.^{25,46-48}

Despite it being highly anticipated, there were delays to the introduction of self-collection. This was largely due to the need for laboratories to conduct and have approved their own in-house validation to process self-collected samples; only one laboratory had done so in Australia when self-collection was introduced. This delay has been one of the major criticisms of the implementation of the renewed cervical screening program.¹⁶ Given the lower-than-expected uptake of self-collection, it is clear that a 'simple' policy change is not enough – it must be supported through appropriate education and awareness campaigns for health professionals and women, particularly among under- or never-screened women. It is important that information campaigns are driven by women's voices and suggestions, including those provided in Table 2.

Limitations and strengths

The strengths of the study include Indigenous leadership and the use of Indigenous research methodologies, which likely contributed to the large number of women recruited. Further, partnering with Aboriginal and Torres Strait Islander PHCCs and recruiting through these established known services and staff provided a culturally safe place for participant recruitment and yarns. We recruited many Aboriginal and Torres Strait Islander women who were under- or never-screened to participate in yarns – women who are often not represented in studies about cervical screening.

At the time of this study, self-collection was limited to never- and under-screened women

because the evidence available at the time indicated that self-collection was slightly less effective than a clinician-collected sample. However, recent evidence demonstrates that self-collection is as good as a clinician-collected test.⁴⁹ Providing information to the women about the self-collection test being slightly less effective (as previously thought) may have influenced women to favour the clinician-collected method. Despite this, many women said they would opt for self-collection, suggesting reassurance of the equivalent efficacy of self-collection to clinician-collected samples as a reason.

All women in this study were recruited through PHCC and therefore may have different views to women who are not engaged with health services. However, our large sample of women who were under- or never-screened and engaged with a health service provide a unique and important perspective about self-collection.

Conclusions

This study builds on growing evidence that Aboriginal and Torres Strait Islander women find self-collection to be an acceptable form of cervical screening. Aboriginal and Torres Strait Islander women found self-collection acceptable because it enhances control, privacy, comfort and convenience. Most women indicated that they would try self-collection, and for some, the very offer of self-collection as an option would act as a facilitator to participate in cervical screening. This study, which captures the perspectives of both screened and under- or never-screened women, speaks to the importance of implementing models to facilitate self-collection in ways that engage and support women to use self-collection and health professionals to offer it. Reducing the incidence of cervical cancer among Aboriginal and Torres Strait Islander women requires concerted efforts to improve cervical screening participation, particularly among women who are under- and never-screened. It is critical that Aboriginal and Torres Strait Islander women are supported to participate in cervical screening in a way that places them in control.

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