

The experience of under-screened and never-screened participants using clinician-supported self-collection cervical screening within the Australian National Cervical Screening Program

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Abstract

Background: Australia has had significant successes in the prevention of cervical cancer. However, there is considerable scope for improving screening participation. In December 2017, Australia shifted from cytology to a human papillomavirus–based screening program as part of the renewed National Cervical Screening Program. This provided the opportunity to introduce a clinician-supported self-collection cervical screening pathway, which allows screening participants aged 30 years or more and who are under-screened or never-screened to screen via a self-collected human papillomavirus test.

Objective: This study aimed to explore screening participant experiences of a clinician-supported self-collection cervical screening pathway.

Methods: Interviews (n=45) were conducted with participants who had used the clinician-supported self-collection cervical screening pathway in the Australian National Cervical Screening Program between December 2017 and April 2019. Interviews were analyzed using template analysis.

Results: Under-screened and never-screened participants reported a variety of interrelated barriers to cervical screening due to the nature of the test. For these participants, self-collection was a preferable way to perform screening as it overcame various barriers, was easy to use and promoted a sense of empowerment. Participants reported that the role of their practitioner was influential in their decision to undertake cervical screening, and that the support and information provided was a key factor in their experiences of the self-collection pathway.

Conclusion: Findings support the use of a clinician-supported model of care, as an alternative screening modality in Australia's National Cervical Screening Program. As more countries consider the move from a cytology to human papillomavirus–based cervical screening program, this model may assist in greater engagement of under-screened participants.

Keywords

cervical cancer, experience, qualitative, screening, self-collection

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Introduction

Cervical cancer, which is primarily caused by persistent infection with oncogenic types of human papillomavirus (HPV), is largely a preventable disease.¹ Australia has one of the lowest rates of cervical cancer globally, currently at 6.3 cases per 100,000 women.² This can be attributed to a long-term focus on the prevention of cervical cancer, being early implementers of both a National Cervical Screening Program (NCSP) in 1991 and a National HPV Vaccination Program in 2007. The introduction of the NCSP led to a 50% reduction in cervical cancer cases and deaths.³ The successes of Australia's prevention approach to cervical cancer means that Australia is on track to meet the World Health Organization's target for the elimination (<4 cases per 100,000) of cervical cancer as a public health problem, potentially within this decade.^{4,5}

Cervical screening participation in Australia's NCSP at the recommended 2-yearly intervals peaked at a historical high of 64.8% at the end of 1999.⁶ However, since 2002, there has been a plateauing in the reduction of cases, in part influenced by the long-term declining rate of cervical screening participation,^{7,8} with 2-yearly participation between 2015/2016 recorded at 55.4%.⁹ In 2017, Australia transitioned from 2-yearly cytology screening to 5-yearly HPV-based screening. Thus, the first actual measure of 5-yearly participation in the new program will be available in December 2022. In the interim, when comparing 2-yearly screening estimates recorded between 2018 and 2019, it is evident that some populations have even lower screening participation. Screening participation for those who live in major cities, estimated at 46.9%, is 10% higher than those who live in remote locations (36.9%).¹⁰ Screening participation differs significantly by socioeconomic status, with screening participation among those from the lowest socioeconomic bracket (40.8%) significantly lower than from the highest socioeconomic bracket (52%).¹⁰ While national data are not available for other population groups, state-based estimates provide evidence that Aboriginal and Torres Strait Islander people, transgender men and gender-diverse people participate in screening much less than the general population.^{11,12} The COVID-19 pandemic has also impacted overall cervical screening participation in Australia with modeling evidence suggesting this may lead to an increase in cancer diagnoses particularly among women aged 30 to 49 years.^{13,14} Declining overall participation and substantial disparities in screening participation for under-screened groups is a cause of significant inequity as the vast majority (~75%) of cases are diagnosed in those who are not participating in screening.¹⁵ This highlights the need to consider alternative engagement strategies for under-screened groups in the current cervical screening program.

Collection of a clinician-collected cervical screening test requires women or other people with a cervix

(hereafter referred to as screening participants) to undergo a speculum examination performed by a practitioner to visualize the cervix and take a cervical sample. For people who are not screening at recommended intervals, there is a significant body of work describing the personal, practical and system-level barriers to clinician-collected cervical screening test, including embarrassment about undergoing a pelvic examination,¹⁶ cultural barriers,¹⁷ a history of trauma or sexual abuse¹⁸ or a lack of time to attend primary care for screening.¹⁹ Some of these barriers, particularly personal barriers which relate to the nature of the clinician-collected cervical screening test, can be addressed through self-collected cervical screening, where a screening participant can use a flocked swab to take their own HPV sample from their vagina.⁸ Self-collection can also increase screening participation among under- or never-screened participants. This has been demonstrated through a range of Australian and international studies, where self-collection has been found to increase screening participation in a variety of contexts and models of delivery.²⁰⁻²³

The evidence describing the superior performance of HPV-based testing over cytology in the prevention of cervical cancer informed Australia's move to a HPV-based screening program in 2017.²⁴ The NCSP now recommends 5-yearly HPV tests to eligible participants between 25 and 74 years.²⁵ This transition also provided the opportunity for the Australian NCSP to introduce an alternative self-collection cervical screening pathway for screening participants who are aged 30 years or older, under-screened by at least 2 years or have never-screened, and who decline a clinician-collected cervical screening test.²⁵ The restricted eligibility criteria for self-collection were determined before the current evidence emerged outlining equivalence in the sensitivity of self-collection versus clinician-collected samples for detecting underlying high-grade cervical disease, provided that polymerase chain reaction (PCR)-based tests are used.^{7,21} This new evidence led to the recommendation from the Australian Medical Services Advisory Committee in May 2021 to expand access to self-collection to all people eligible for cervical screening test, and not just those who are under- or never-screened.²⁶ In November 2021, the Australian Health Minister announced that universal access to self-collection would be made available on 1 July 2022.²⁷

Australia was the second country to introduce self-collection as an alternative screening pathway within an NCSP. The Netherlands has also introduced a self-collection cervical screening pathway but through a mail-out model, where participants request a self-collection kit to be sent to their homes.²⁸ Australia's program, however, is unique in that this pathway is delivered solely within primary care, meaning that eligible participants, after declining a clinician-cervical screening test, can be offered a self-collection test within a consultation with their practitioner. The reach of this strategy is potentially high given

that in the 2020–2021, 87.2% of Australian females aged over 15 saw a general practitioner.²⁹ The effectiveness of this model of care to engage under- or never-screened participants was supported by a non-randomized pilot study conducted prior to its availability in Australia, where 85.7% of participants accepted the offer of self-collection in a primary care setting, after declining a clinician-collected test.^{30,31} A clinician-supported model of care was decided upon within the Australia context in recognition of the importance of the relationship between primary care and their patients in supporting cervical screening participation. However, this model of care may not address all barriers to screening, such as limited access or time to attend primary care. Flexibility in the model to allow non-clinic-based collection as long as the participant is still supported through their provider, such as has occurred through the COVID-19 pandemic through a telehealth consultation followed by mailing of the kit, may help overcome some of these barriers. There is the potential for Australia to consider other complementary models in the future.²⁶ The clinician-supported self-collection cervical screening pathway with restricted access has now been available within the Australia's NCSP for close to 4 years (since December 2017) and universal access to self-collection will be made available on 1 July 2022.²⁷

This study aimed to identify the experience of screening participants within the self-collection pathway within the Australian NCSP. As part of a broader evaluation, we have previously reported that, while practitioners and screening participants perceived the self-collection pathway to be a highly acceptable alternative screening modality, the implementation of the pathway was limited by the restrictive eligibility criteria, limited knowledge and awareness of the pathway and uncertainty among practitioners regarding the clinical practice guidelines.³² This article further details the screening participants' experience of the self-collection cervical screening pathway and describes the perspectives of under-screened participants as to why self-collection was a suitable and acceptable method of cervical screening.

Methods

This study employed a qualitative method using semi-structured interviews with screening participants who lived in the Australian state of Victoria and had used the self-collection cervical screening pathway between the commencement of the renewed NCSP (December 2017) and April 2019 (the start of the study).

Study setting

Australian Centre for the Prevention of Cervical Cancer, which operates VCS Pathology, is a not-for-profit organization that supports equitable access to cervical screening

in Victoria, Australia, through the provision of laboratory and registry services. During the time of the study, VCS Pathology was the sole pathology provider in Australia accredited to process self-collected cervical screening samples, meaning that the entire population of screening participants who had used the self-collection pathway was known by Australian Centre for the Prevention of Cervical Cancer.

Recruitment

VCS Pathology data were used to create a purposive sampling frame of participants to be invited to the study. De-identified demographic statistics were used to estimate the proportion of self-collection users according to age (30–39 years, 40–49 years, 50+ years), history of cervical screening (overdue for screening by 2–3 years, 4–5 years, 6–9 years, 10+ years, never-screened), rurality (metropolitan, rural) and outcome of the self-collection test (HPV–, HPV+ (16/18), (HPV+ non-16/18)). Participants were included in the study if they performed a self-collection test between December 2017 and April 2019, were able to recall their experience with self-collection and were able to speak sufficient English to provide informed consent and participate in an interview. If participants were not able to provide informed consent for whatever reason or attended specific primary care sites involved in an intervention study that was concurrently operating at the time, participants were excluded.

To recruit screening participants, a two-stage opt-out process was used where VCS Pathology first sent a letter to the screening participant's practitioner. If the practitioner did not opt out their patient, then a letter was sent to the screening participant informing them of the study. At each stage, the practitioner and the screening participant were provided 14 business days to opt out from any further contact. After the opt-out periods have passed, the screening participants' contact details were provided to the researchers who then contacted the potential participants by phone to invite them to participate in an interview. Participants were offered a AUD\$50.00 gift card as an incentive to participate in the study.

Data collection

One-on-one semi-structured interviews were conducted either by phone or in-person at the participants' home by author N.C. (female researcher) who had received formal university-level qualitative research training. At the time of the study, the interviewer was in their late stage of the Master of Public Health degree, was employed as a Research Assistant at the University of Melbourne and completed this study as a component of their Master of Public Health degree. The interviewer and the study participants had no prior relationship before the commencement

of the study but participants were informed of the interviewer's reason for conducting this study.

An interview guide was developed specifically by the authorship team and steered the interview (supporting information 1) and covered themes including the participant's experience and perception of the clinician-collected cervical screening test, their experience using self-collection and their overall perception of self-collection as an alternative cervical screening modality. For participants who tested HPV+ at the time of their self-collection test, further questions were asked to understand their experience with the follow-up pathway. Prior to the commencement of interviews, the interview guide was piloted (n=2). With the permission of the participant, interviews were audio-recorded for transcription and notes were taken by the researcher during the interviews. One participant did not provide consent for the interview to be audio-recorded, so the researcher took notes during the interview and the participant confirmed the accuracy after the interview. Interviews were conducted between July and December 2019. The duration of the interviews was between 20 and 73 min with the mean duration of interviews lasting 44 min. Interviews continued until data saturation was reached, defined in this study as the point in which no new ideas or themes were being expressed by additional participants. At this point, recruitment of additional participants ceased. This was assessed by the interviewer (N.C.) and confirmed by the senior author (M.K.).

Analysis

Except for one screening participant who did not provide consent, all interviews were audio-recorded and transcribed verbatim by professional transcribers. Prior to analysis, transcripts were de-identified and cross-checked with the recording to ensure their accuracy. Participants were provided with the choice to review and revise the transcripts and to return it within 1 month of receiving the transcript. Template analysis, which is a form of thematic analysis, was used to code the data, whereby a coding framework was developed against a set of a priori themes developed prior to analysis.³³ Throughout analysis, the coding framework underwent a series of revisions to reflect the data.³³ This provided both a rigorous approach, taking into consideration the extensive literature on the experience and acceptability of self-collection in different settings, while also providing flexibility given that this study was the first to assess the experience of clinician-supported self-collection within a NCSP. The development of the initial and subsequent coding frameworks was conducted by one researcher (N.C.) who performed the coding in NVIVO-12 (QSR International, Melbourne, Australia). All revisions of the coding framework were cross-checked by another researcher for consistency (M.K.). Reiterations to the coding framework primarily

centered around the participants experience of performing self-collection and their experience through the follow-up pathway within the Australian health system. The role of the practitioner in supporting decisions around screening was a prominent theme that emerged throughout analysis. While codes related to screening participants' barriers to clinician-collected screening (i.e. negative perception of the test) and facilitators of self-collection screening (i.e. easy and preference of self-collection) were present in the initial coding framework, throughout analysis, these codes were emphasized as prominent themes. The final coding framework is provided as supplementary material 2.

Ethics approval

Ethics approval was gained from the University of Melbourne, Medicine and Dentistry Human Research Ethics Sub-committee (Ethics ID: 19540446.2). All participants provided verbal or written consent prior to the interview. Verbal consent, instead of written consent, was obtained when interviews were conducted by phone and the participant did not have the technology requirements to provide a completed written consent form prior to the interview. In these instances, a verbal consent script was read out to the participants and the interviewer obtained an audio-recording of the participant providing verbal consent.

Results

A total of 193 participants were invited to the study, 45 of whom consented to an interview (Table 1). The majority of participants (86.7%, n=39) were overdue for screening, with 13.3% (n=6) of the sample having no experience with cervical screening before their self-collection test. All the participants who self-reported that they never had a clinician-collected cervical screening test were under 40 years. Most participants received a HPV-negative result from their self-collection test (64.5%, n=29), five participants (11.1%) received a HPV- (16/18) positive test and 10 (22.2%) received a non-16/18 HPV-positive result.

Under-screened and never-screened participant's perception and barriers to clinician-collected cervical screening

All participants held a negative perception of clinician-collected cervical screening, due to the test requiring a pelvic examination with a speculum performed by a practitioner. Participants reported clinician-collected cervical screening to be "uncomfortable," "invasive" and, for some people, a physically "painful experience." For many, the thought of having a clinician-collected cervical screening test caused significant psychological distress:

Table 1. Demographic characteristics of the screening participant sample (n = 45).

Category	Variable	Number	Source population ^a
Age	Under 40 years	12 (25%)	25%
	40–49 years	10 (22%)	19%
	50–59 years	10 (22%)	22%
	60–69 years	10 (22%)	26%
	70+ years	3 (7%)	8%
Location	Metropolitan	33 (74%)	71%
	Rural	12 (27%)	29%
Ethnicity	European descent	39 (87%)	Data unknown
	Cultural and linguistically diverse	6 (11%)	
Screening history	Overdue	39 (87%)	67%
	Never-screened	6 (13%)	33%
Self-reported HPV result from self-collection test ^{b,c}	Negative for HPV	29 (65%)	88%
	Positive for HPV (16/18)	5 (11%)	4%
	Positive for HPV (other types)	10 (22%)	7%
	Inconclusive	1 (2%)	2%

HPV: human papillomavirus.

^aRefers to the population demographics for the entire population of participants (n = 1067) who had used the self-collection cervical screening pathway since the commencement of the renewed NCSP in Victoria and the 30th of April 2019 (the date of data extraction).

^bOnly conclusive self-collection test results are reported. Participants with inconclusive results were too few to stratify.

^cTo maintain the confidentiality of individuals who were contacted by the research team after the opt-out period but declined to participate in an interview, the research team did not obtain screening results from pathology. As such, self-reported results are reported for individuals who consented to participate in the study.

I was starting to have anxiety attacks, really, which surprised me, but I was getting myself really wound up about it [have a clinician-collected cervical screening test]. (Participant 15)

Screening participants reported a multitude of specific barriers to clinician-collected cervical screening with the reasons varying slightly, depending on the participant's under-screened or never-screened status. For participants who were under-screened, a history of a negative experience with either a clinician-collected cervical screening test or gynecological examination was commonly reported by participants:

Look, none of them are very comfortable, but that one was quite horrible. Yes, that was pretty horrible. I think it was probably because it was— even in the midst of my condition, but secondly, she was just a complete bitch. So, yeah, her bedside manners was shocking. (Participant 17)

On the other hand, two commonly reported barriers for screening participants who had never had a cervical screening test before were due to a history of sexual violence and a perceived lack of trust with medical practitioners to perform the test in a way that was sensitive to the participants' unique needs:

I am a survivor of childhood sexual abuse, so it's obviously extremely daunting and uncomfortable process, very vulnerable process to have to put yourself through. (Participant 8)

It is important to note that for many participants, multi-leveled and interrelated barriers to clinician-collected cervical screening were reported:

In my mind, it was the pros and cons and it was that I find it [clinician-collected cervical screening] extremely uncomfortable, potentially traumatising with someone I don't trust for a benefit I haven't researched enough to feel is worth it. (Participant 21)

Self-collection addressed reported barriers, with participants finding the self-collection process easy and preferable to clinician-collected cervical screening

While screening participants held a negative perception of clinician-collected cervical screening test, they reported that self-collection was a preferable way to undergo cervical screening for a variety of reasons. First, self-collection provided an alternative screening pathway for participants who wanted to be screened, but were restricted by significant barriers to clinician-collected cervical screening:

Overall, I wanted to have smear tests, I wanted to be screened. It was really just— It wasn't so much that I could do self-collection but more that the abilities to do self-collection got rid of some of the things that were holding me back. (Participant 16)

Second, self-collection was reported by screening participants to be a suitable and practical method, with participants stating that self-collection was easy, simple and a fast way to have a cervical screening test:

It's just so easy and just so simple. I wouldn't have that stress of going in and just laying up on the bed with my legs open. It's just so easy, so easy to do. (Participant 19)

So quick, so seamless. I took five minutes out of the doctor's consultation and it was just so easy. (Participant 6)

When participants were asked about whether they had any concerns or hesitations prior to performing the test, some participants reflected they were concerned about whether they would perform the test correctly. However, as demonstrated in the first following quote, the ease of the test mitigated participants' concern of doing the test incorrectly:

It [doing the self-collection test] was all pretty basic. It was pretty easy. I don't think there was too many challenges involved in it. It was just making sure, I suppose, that I had done it [self-collection]. Hoping that I would be able to do it properly. That was all, but as I said, it was easy and basic, which it was. (Participant 9)

For one participant who had never used a tampon previously, they expressed greater concern on whether they would be able to perform the test correctly. For this participant, receiving adequate instructions was important to assist in the individual completing self-collection:

Interviewer: Prior to performing the self-collection test, did you have any concerns or hesitations about the test?

Participant: Probably more that I might not do it properly because I don't know how my body would respond . . . you don't know what it's going to be like until you've actually done it. I think it's more, it [self-collection] was unusual for me because I don't use tampons.

Screening participants also reported that self-collection was a pain-free way to undergo cervical screening. This was especially for those who reported having a previous negative or traumatic experience with clinician-collected cervical screening:

That I didn't have to go through any pain of having a GP doing it with the gadget that causes me pain and there was no pain involved in having it [self-collection] done that way which I was really thankful for. (Participant 5)

Finally, screening participants reported that as self-collection is a self-administered test, it provided a substantially greater level of self-efficacy compared to clinician-collected cervical screening test, which further contributed to participants' positive views of self-collection:

It meant that I didn't have to be humiliated, embarrassed on top of that table, and I could do it [self-collection] privately and know that I've had a test done [cervical screening]. (Participant 12)

However, as described previously,³² a small proportion of participants who tested positive for HPV, and required

additional an additional clinician-collected cervical screening test, reported mixed acceptability of self-collection. This was not because of their experience of the self-collection test itself, but due to their experience of the follow-up pathway:

I submitted to another unwanted and very unpleasant smear [clinician-collected cervical screening test], accompanied by the same usual sources of distress. Although she meant well, she used a number of condescending platitudes and I also experienced the usual physical pain and sense of extreme indignity . . . I have made a determined commitment never to undergo another procedure [self-collection or clinician-collected test] ever again. (Participant 32)

Self-collection provided a sense of empowerment

Self-collection provided a sense of empowerment for participants.³⁴ The reasons for this were twofold. First, many participants stated that by the test being self-administered, this provided greater control of their own body and how the self-collection was performed:

I thought it was very comfortable, empowering, a better option. I thought it was, for me, driven from the point of view of the comfort of women, so pro-women . . . I don't have to be a body to which something is being done. I'm collecting it myself. (Participant 2)

You know what? Quite frankly, if she told me I had to stick a Pogo Stick up my vagina and do it myself, I would've done it. Seriously. (Participant 16)

Second, the availability of an alternative cervical screening pathway itself promoted empowerment because participants were provided the choice in testing options, rather than having to avoid cervical screening all together. This was particularly apparent for those who reported significant barriers to clinician-collected cervical screening:

For women of a particular subset I suppose, for women who have been traumatized or women that have been victims of violence, for them to know about this [self-collection] would be amazing because it might change their whole outcome, it might change their whole perception of the test. It might make them feel like—they would be empowered I think to do the test, which is something every woman needs to do to look after their own health . . . I think they would take it up if they knew that that alternative was there. (Participant 40)

Practitioners played an important role in informing participant decisions to participate in cervical screening

Practitioners' promotion of cervical screening was paramount in screening participants' consideration to participate in

screening. In cases where there was an established patient–practitioner relationship, consistent opportunistic discussions initiated by the practitioner about cervical screening reinforced the importance of screening to participants:

Every time I go there [to the practitioner], if I haven't done it [cervical screening], she reminds me. (Participant 20)

Likewise, practitioner's discussion and offer of self-collection were highly influential in screening participant's uptake of self-collection:

I responded negatively [to the practitioner's offer of clinician-collected screening] like, yeah right, I know I'm overdue but no thanks. She [practitioner] said, "How about this [self-collection] as an option" and I went, "Wow, what a great option." (Participant 14)

With my current doctor, when she suggested that there was an alternative [cervical screening modality], obviously, she suggested it [self-collection] because she knew my background and knew I hadn't had one [cervical screening test]. Yes, that all fed into her recommending that I do that [self-collection], and I went, "yes, okay. That's something I can do". (Participant 8)

Furthermore, practitioners were also key in driving participants' confidence about the self-collection pathway. Participants reported differences in the way practitioners offered self-collection and the information they provided to their patients regarding the accuracy and how to complete self-collection. For participants who felt confident about self-collection, either in terms of its effectiveness or how to complete the test, this was as a result of their practitioner's explanation and expressed confidence in self-collection:

She [practitioner] gave me enough information. I had all the information I needed that it was equal to the old method. That's all I needed to know, was the pathology would have the same sort of results from the new method. (Participant 20)

However, a smaller proportion of participants reported that their practitioners either suggested that self-collection was inferior in sensitivity to clinician-collected cervical screening test or provided limited contextual information about self-collection and how to complete the test:

She [practitioner] didn't offer much detail around it . . . I felt like it was maybe not as good as me having a Pap smear. I felt like it was a second choice basically. (Participant 23)

In these cases, this led to the participant having doubts about the effectiveness of self-collection suggesting the description and level of support provided by practitioners is influential in shaping participant's experiences of the self-collection pathway.

Discussion

This study provides the first insight to the screening participants' experiences of clinician-supported self-collection cervical screening within Australia's NCSP. We report that under-screened and never-screened participants experience a multitude of interrelated barriers to screening. For these participants, self-collection was an alternative screening modality that overcame barriers, was easy and a preferable way to undertake screening and promoted a sense of empowerment. Practitioners played a crucial role in shaping participant's experiences through the self-collection pathway. These findings provide clear evidence in favor of self-collection as an alternative screening pathway within population-based cervical screening programs and may work to address the inequity in the program for non-attendees.

Barriers to cervical screening reported by screening participants in this study were consistent with the literature. Systematic reviews highlight that pain,¹⁹ embarrassment,³⁵ finding the test invasive³⁵ and a previous negative experience with cervical screening³⁶ are barriers to cervical screening. Qualitative insights from this study provide an additional unique perspective. Barriers to cervical screening are often reported as singular restrictive impacts,³⁷ whereas this study highlights that barriers are often interconnected and multi-faceted. This understanding is critical, especially in the planning of interventions to increase participation as complex and interrelated barriers may not solely be addressed through education or patient navigation interventions that aim to improve knowledge, understanding or access to screening.

Self-collection, because the test is self-administered, has the capacity to overcome barriers to clinician-collected cervical screening. Self-collection can also increase participation among under- and never-screened participants, compared to reminder letters, demonstrating the potential impact of providing self-collection as an alternative cervical screening option within population-based screening programs.^{20,21,23} However, most of the existing literature on self-collection describes the impact of mail-out or door-to-door models of care.^{20,21,23} This study provides some of the first evidence which shows that a model of care whereby self-collection kits are provided within a primary care setting by a supporting practitioner is acceptable from the screening participants perspective. It will be important to monitor the implementation and impact of the pathway to ensure the potential of self-collection to address inequities in Australia's NCSP is achieved.

Offering self-collection cervical screening within the context of a primary care setting by a supporting practitioner has been demonstrated to lead to high uptake among under-screened participants (around 80%).^{30,31} However, despite the potential of this pathway to improve participation, its implementation in Australia has been sub-optimal. It was estimated that approximately 1 million women in

Australia would be eligible for self-collection, yet less than 6000 tests were processed in the first 2 years of self-collection being available (2018–2019).³⁸ Likewise, in the Australian state of Victoria where this study was conducted, between the commencement of the self-collection policy (1 December 2017) and 30 April 2019 (the date of our data extraction), only 1067 self-collection tests had been processed. To provide context to the scale of this, VCS Pathology, who performs approximately half of the cervical screening tests in Victoria, processed 290,000 clinician-collected tests during the same period.³² This indicates that the potential of self-collection has not been fully realized in Australia with evidence suggesting that the eligibility criteria which restricted access to only those who were 30 years or over and under and never-screened were a major barrier for practitioners in being able to offer the test opportunistically.^{32,39} In November 2021, the Australian Health Minister announced that Australia will move to a universally accessible self-collection policy meaning that all screening participants will have the choice between a self-collected or a clinician-collected cervical screening test, which may address the barriers attributed to the restricted eligibility criteria. Universal access to self-collection will be made available in Australia on 1 July 2022, and if implemented appropriately, could play a significant role in improving cervical screening participation and meeting the World Health Organization's targets for the elimination of cervical cancer as a public health program.⁵

Previous research has suggested that some screening participants have concerns about not performing the self-collection cervical screening test properly, potentially leading to an unwillingness to perform the test.^{40,41} Many of these studies, however, discuss the possibility of self-collection in a theoretical context, with participants who had not yet had the opportunity to perform the test. Our study reports experience of participants who had used self-collection. Overwhelmingly, even if participants had concerns about doing the test properly prior to self-collecting, the majority reported that the test was easy, created a sense of autonomy and provided a highly practical way to perform cervical screening. These findings are consistent with many other studies exploring acceptability among screening participants who have used self-collection,^{42,43} representing real-world experience, and highlight the need to be cautious about overstating concerns prior to implementation. Furthermore, promotion and education about self-collection cervical screening may help to both normalize self-collection as a cervical screening modality and improve participants' confidence about performing the test.⁴⁴

Self-collection promoted a sense of empowerment among participants, which is a critical finding. Empowerment, as a theoretical concept, has been suggested to be a mechanism to foster greater health literacy

and agency over one's healthcare decision-making.^{45,46} With specific reference to cervical screening, there is evidence to suggest that a sense of empowerment may lead to greater participation. Luszczynska et al.⁴⁷ found that strong empowerment beliefs promoted greater self-efficacy and autonomy over one's health and body, which in turn positively correlated with greater intention to undertake cervical screening. In an Australian study which interviewed Aboriginal and Torres Strait Islander women who identified as active cervical screeners, it was reported they saw participating in cervical screening as a way to take ownership over their own health, which in turn fostered a sense of empowerment.⁴⁸ This all suggests that by self-collection fostering a sense of empowerment, this in itself may lead to greater cervical screening participation. It will be important, however, to employ effective communication channels to ensure under- or never-screened participants know that self-collection is an available alternative.

The role of the practitioner in promoting participation in cervical screening, especially for under- and never-screened participants, has been documented in the literature.^{49–51} Shared decision-making between the practitioner and patient has been found to facilitate greater participation in numerous cancer screening initiatives including breast screening,^{52,53} colorectal cancer screening⁵⁴ and cervical screening.^{53,55,56} However, with much of the evidence supporting the impact of self-collection being developed within mail- out or door-to-door models of care where the role of practitioner is limited,^{20,21,23} there is currently a lack of evidence demonstrating the role of the practitioner in promoting uptake of self-collection cervical screening. For a clinician-supported self-collection model of care, as is employed in Australia, the role of the practitioner is paramount to engaging screening participants. Despite this, an understanding of how practitioners perceive and experience the clinician-supported self-collection model is limited. Given that the influential role of practitioners in promoting cancer screening has been demonstrated, establishing how to best mobilize the primary care workforce to use this new self-collection pathway is an urgent research priority.

Strengths and limitations

This study has clear strengths. With the study being conducted in partnership with Australian Centre for the Prevention of Cervical Cancer, which was only laboratory accredited in Australia to test self-collection samples during the study period, demographic information on the entire population of self-collection users was known. This provided the footing to develop a well-informed sampling frame, ensuring a degree of confidence that the study reflected the experience of the population of users of the self-collection pathway. Due to limitations in the available pathology data, we were not able to specifically recruit

participants from culturally and linguistically diverse or Aboriginal and Torres Strait Islander backgrounds meaning that the findings may not be representative for these priority populations, despite this study involving a small number (n=6) of participants who self-disclosed being from culturally and linguistically diverse backgrounds. Finally, only screening participants who used the self-collection cervical screening pathway were able to be included in the study. Further investigation is needed to identify the perspectives of eligible screening participants who decline the offer of self-collection to maximize the reach of self-collection.

Implications for practice and policy

While Australia and the Netherlands were the first countries to fully implement HPV-based screening programs,⁵⁷ there are a range of countries considering the transition from a cytology to HPV-based program.⁵⁸ This includes New Zealand, which recently announced that they will transition to a HPV-based screening program in 2023.⁵⁹ Doing so provides the opportunity to implement a self-collection cervical screening pathway as an alternative screening pathway. This means that this study may be of great interest to policy makers and practitioners to support the implementation of a self-collection pathway. Likewise, this study provides clear justification for the use of the clinician-supported self-collection cervical screening pathway in Australia's NCSP. This comes at an important time, as the pathway in Australia is likely to be expanded to be accessible to all women participating in cervical screening, and not just those who are under- or never-screened.²⁶

Conclusion

This study indicates that self-collection offered within a clinician-supported model of care is a suitable and empowering modality for under- or never-screened participants, many of whom would not have participated in cervical screening if a pelvic examination had been required. This study also highlights further opportunities to support the introduction of the pathway where practitioners, who are critical in driving the reach of self-collection, need to be supported and equipped with appropriate and accurate information. Further research is needed, however, to ensure culturally appropriate communication and support for specific priority groups including Aboriginal and Torres Strait Islander, culturally and linguistically diverse populations, gender and sexuality diverse individuals and those living with a disability and to identify the perspectives for under- or never-screened participants who decline the offer of self-collection. Doing so will ultimately expand the utility of the self-collection pathway within the Australian NCSP and further progress Australia's efforts to

reduce cervical cancer inequity and meet the World Health Organization's elimination targets for all.

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Author contribution(s)

Nicola S Creagh, BAdSc MPH: Data curation; Formal analysis; Investigation; Project administration; Writing—original draft; Writing—review & editing.

Claire Zammit: Investigation; Writing—review & editing.

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Supplemental material

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