
Self-collection Pilot Project

– improving access to cervical screening for under-screened women

Evaluation Report

Developed by the University of Melbourne and Victorian Cytology Service Ltd for the Victorian Department of Health and Human Services

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- Self-collection Pilot Steering Group representatives from the Victorian Department of Health and Human Services (DHHS), Ballarat and District Aboriginal Cooperative (BADAC), the University of Melbourne's Indigenous Health Equity Unit and the Victorian Cytology Service (VCS);
- Members of the Self-collection Pilot Advisory Group;
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Executive Summary

This Evaluation Report summarises outcomes and results from the Victorian Self-collection Pilot Project – a 12 month project conducted in three health services that support women experiencing disadvantage from a range of backgrounds. The pilot was designed to assess a service model and self-collection screening pathway for cervical screening and to inform development of strategies to support self-collection of Human papillomavirus (HPV) testing as part of the renewed National Cervical Screening Program (NCSP).

The evaluation of the pilot showed that the service model tested was effective in recruiting and supporting under-screened women to undertake self-collection HPV tests, and that the project clearly met its aim and objectives. (Key evaluation findings are summarised in Appendix F.)

Each of the health services involved introduced a range of effective internal processes to engage and train staff and to support under-screened women involved in the pilot. All sites appointed a project lead who played an integral role in coordinating the project and maintaining momentum.

The offer of self-collection within a clinical setting was largely embraced by under-screened women. The pilot targeted women aged 27 -74 years, who have not screened for cervical cancer in over three years, or at all. A participation rate of 85.7% was achieved, which, combined with feedback from women in the research study component of the evaluation, demonstrated that self-collection was an acceptable and welcome alternative to a practitioner collected cervical screening test.

Of the 79 under-screened women who agreed to self-collection, 14 had oncogenic HPV detected (any type): 4 had HPV detected (16/18) and 10 had HPV detected (not 16/18). Compliance with follow-up testing was high, with 12 of the 14 women who had oncogenic HPV detected (any type) (85.7%) having since returned for a follow-up consultation and/or completed follow-up testing within 90 days of self-collection. Two high grade squamous intraepithelial lesions (HSIL) and one low grade intraepithelial lesion (LSIL) were found.

Ensuring full compliance with follow-up testing after HPV detection was a key focus, given the risk that under-screened women who have declined a Pap test in the past may have been unwilling to have a follow-up test that involved either a practitioner-assisted cervical screening test (using a speculum) or a colposcopy. Health services put additional measures in place to support women when receiving their results and during follow-up testing.

The pilot reiterated that under-screened women are likely to be experiencing multiple circumstantial and socio-cultural barriers to cervical screening that are unlikely be overcome simply by the introduction of a new test. This reinforced the need for health providers to have strong cultural competency and a good understanding of their local communities.

A range of recommendations for governments and health services to support implementation of self-collection under Renewal have been offered. They include considerations for implementation of the screening pathway and the provision of follow-up testing, as well as suggestions to assist health services embed self-collection into their usual practice. Recommendations arising from the pilot are detailed on page 33.

The experience of the pilot and the results from the research study should give policy makers and health services increased confidence that the introduction of self-collection is likely to lead to higher participation in cervical screening, and in turn, to improved health outcomes for under-screened women who may be at risk of cervical cancer.

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1 Introduction

1.1 Purpose of this Report

This Evaluation Report forms the final evaluation of the Victorian Self-collection Pilot Project – a 12 month project conducted in three health services that support women experiencing disadvantage from a range of backgrounds. The pilot was designed to assess a service model and self-collection screening pathway for cervical screening and to inform development of strategies to support self-collection of Human papillomavirus (HPV) testing as part of the renewed National Cervical Screening Program (NCSP).

The evaluation is framed around the four pilot objectives and includes results from a research study conducted with under-screened and never-screened women (referred to hereafter as under-screened women). The study assessed under-screened women's responses to self-collection and explored barriers and enablers to their participation in cervical screening.

It is hoped that findings from the Self-collection Pilot Project will be of interest to policy makers and cervical screening providers across Australia (and beyond) as cervical screening moves into a new era with additional screening options and an increased emphasis on engagement with under-screened women.

1.2 Background

As part of the renewed NCSP, due to commence in May 2017, the Medical Services Advisory Committee (MSAC) recommended that self-collection¹ for HPV testing be made available to under-screened women. This would be facilitated by a medical or nurse cervical screening provider who also offers mainstream cervical screening. The aim of the recommendation was to increase participation of under-screened women who decline to have a cervical sample collected by a health professional.

The recently released National Cervical Screening Policy specifies that self collection of a sample for cervical screening for HPV testing be available for:

- women who have never participated in the NCSP and are 30 years of age or over; or
- women who are overdue for cervical screening by two years or longer and are 30 years of age or over.²

To prepare for implementation of this recommendation, the Victorian Department of Health and Human Services (DHHS) funded a pilot project that aimed to increase cervical cancer screening in under-screened women by developing an acceptable and high quality service model for HPV testing through self-collection in clinical settings.

The pilot was implemented from November 2015 to December 2016.

1.3 Under-screened women

Most cases of cervical cancer occur in under-screened women who haven't participated in cervical screening for more than three years. In Victoria in 2011, 50% of women diagnosed with invasive or micro-invasive cervical cancer had no known screening history and 28% had not been screened for at least 2.5 years prior to detection.³

The following groups are over-represented among the under-screened:

- Women of a lower socioeconomic status;
- Women from culturally and linguistically diverse backgrounds;
- Women who identify as lesbian or bisexual or transgender men;^(4,5)

¹Also referred to as self-sampling. The two terms can be used interchangeably.

² National Cervical Screening Program Policies – self-collection policy, finalised on 27 October 2016

³ Mullins, R., Scalzo, K. and Sultana, F. 'Self-sampling for cervical screening: Could it overcome some of the barriers to the Pap test?' *Journal of Medical Screening*, 2014, vol. 21, no. 4, pp. 201-206.

⁴ Johnson, M. J., Mueller, M., Eliason, M. J., Stuart, G. and Nemeth, L. S. 'Quantitative and mixed analyses to identify factors that affect cervical cancer screening uptake among lesbian and bisexual women and transgender men', *J Clin Nurs*, 2016, vol. 25, pp 3628–3642. doi:10.1111/jocn.13414

- Women in rural/remote areas;
- Women with disabilities;
- Women who have experienced violence/abuse;
- Older women; or
- Aboriginal and Torres Strait Islander women.⁶

These broad categories include a vast array of people from incredibly diverse and often disadvantaged communities. They may include women experiencing homelessness, women who have experienced female genital cutting (FGC), women with alcohol and/or drug dependencies and women experiencing mental health issues.

The data on Aboriginal and Torres Strait Islander women (hereafter referred to as Aboriginal women) is particularly concerning. Although there is currently limited data on the cervical screening participation of Aboriginal women⁷, a study by Coory, Binns and Landon found that Aboriginal women have up to an 18% lower participation rate than non-Aboriginal women.⁸ Aboriginal women are 2.8 times as likely to develop invasive cervical cancer and 3.9 times as likely to die from cervical cancer than non-Aboriginal women.⁹ They are also less likely than non-Aboriginal women to survive five years once they are diagnosed with cervical cancer.¹⁰ It is likely that the higher incidence and mortality from cervical cancer amongst Aboriginal women is linked to under-screening and late detection of pre-cancerous lesions and infection with HPV.^{11, 12, 13, 14}

1.4 Barriers to cervical screening

There are many potential barriers that may influence a woman in her decision or ability to participate in cervical cancer screening. Studies into barriers have typically focussed on barriers to having a Pap test. They have shown barriers to include:

- Lack of information and understanding about cervical cancer, the importance of screening, or how to access screening;
- Belief that cervical cancer will not affect them;
- Fear of tests, further tests or cancer treatment;
- Bad past experiences, including pain or discomfort;
- Lack of transport and / or access to health services;
- Fear of being diagnosed with cancer, or negative beliefs about a cancer diagnosis;
- Cultural issues (related to circumstances, beliefs, background and inequities in society);
- Language issues;
- Embarrassment / awkward nature of the test;
- Reluctance to have a test taken by a practitioner they know or difficulty in accessing their provider of choice;
- Being busy or forgetting when their next Pap test is due; and

⁵ Brown, R., McNair, R., Szalacha, L., Livingston, P. and Hughes, T. 'Cancer risk factors, diagnosis and sexual identity in the Australian longitudinal study of women's health', *Women's health issues*, vol. 25, no. 5, 2015, pp. 509-516, doi: 10.1016/j.whi.2015.04.001.

⁶ PapScreen Victoria and Cancer Council Victoria (2013) *Clinical Practice Guidelines for Nurses Undertaking Cervical Screening in Victoria*, <http://www.papscreen.org.au/downloads/nurse-guidelines/nurse-pap-clinical-practice-guidelines.pdf> (accessed 5 Jan 2017)

⁷ Whop, L.J., Cunningham, J. and Condon, J.R. 'How well is the National Cervical Screening Program performing for Indigenous Australian women? Why we don't really know, and what we can and should do about it', *European Journal of Cancer Care*, 2014, vol. 23, pp. 716-72.

⁸ AIHW 2015. Cervical screening in Australia 2012-2013. Cancer series no. 93. Cat. no. CAN 91. Canberra: AIHW: 27

⁹ AIHW, Cancer Australia 2013. Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview. Cancer series 78. Cat. no. CAN 75. Canberra: AIHW: 14

¹⁰ Ibid

¹¹ Ibid

¹² Cunningham, J., Rumbold, A.R., Zhang, X. and Condon, J.R. 'Incidence, aetiology, and outcomes of cancer in Indigenous peoples in Australia', *The Lancet Oncology*, vol. 9, 2008, pp. 585-95.

¹³ Roder, D. 'Comparative cancer incidence, mortality and survival in Indigenous and non-Indigenous residents of South Australia and the Northern Territory' *Cancer Forum*, 2005, vol 29, pp. 7-9.

¹⁴ Garland, S., Condon, J., McIntyre, P., Stevens, M., Smith, D., Tabrizi, S. and the WHINURS study group, 'Human papillomavirus prevalence among indigenous and non-indigenous Australian women prior to a national HPV vaccination program' *BMC Medicine*, 2011, vol. 9, p. 104.

- Barriers associated with a disability.¹⁵

Although these barriers may have prevented some women from having regular Pap tests, it is hoped that the introduction of self-collection HPV testing as an alternative screening option may be more acceptable to under-screened women.

¹⁵ PapScreen Victoria and Cancer Council Victoria (2016) *Barriers to Screening*, <http://www.papscreen.org.au/forhealthprofessional/barrierstoscreening> (accessed 10 December 2016)

2 The Self-collection Pilot Project

2.1 Aim

- To increase cervical cancer screening in under-screened populations by developing an acceptable and high quality model to implement self-collection HPV testing in clinical settings

2.2 Objectives

- To recommend an acceptable alternative self-collection pathway for under-screened women for the purposes of Renewal;
- To develop a clinical practice approach (protocols and processes);
- Develop resources to support the workforce to implement self-collection within under-screened women; and
- To prepare the workforce —Aboriginal Health Workers, practice nurses¹⁶, general practitioners, allied health providers and persons performing colposcopy — ahead of Renewal Project design

The pilot project was designed to assess the acceptability and effectiveness of self-collection as a means of improving participation by under-screened women, and to inform development of a service model that incorporates all steps from identifying and recruiting women to the provision of results and follow-up care. It targeted both vaccinated and unvaccinated women aged 27 -74 years, who have not screened for cervical cancer in over three years, or at all.

Three Victorian health services were chosen for the pilot project which ran in two overlapping phases:

Phase	Health Service	Description
1 Nov 2015 to Nov 2016	Ballarat and District Aboriginal Cooperative (BADAC), Baarlinjan Medical Clinic (12 months)	An Aboriginal Community Controlled Health Service located in regional Victoria
2 April to Dec 2016	cohealth (2 ½ months)	A multi-site community health setting that supports a large number of women from refugee and migrant backgrounds in western Melbourne, as well as injecting drug users and women experiencing homelessness.
	Access Health (6 months)	An urban Melbourne clinic which sees a large number of women experiencing homelessness, sex workers and injecting drug users.

Table 1 – Participating health services

(See Appendix A for more information about the pilot sites.)

The health services were asked to:

- Identify and recruit under-screened women;
- Offer self-collection HPV tests in a clinical setting (for woman who declined a Pap test);
- Communicate results in a culturally appropriate manner;
- Provide/support follow-up services; and
- Offer feedback on implementation of the pathway.

Staff from BADAC were also involved in the development of the clinical pathway, pilot processes and the Resource Manual.

¹⁶ i.e. credentialed/authorised nurse cervical screening providers

2.3 Screening Pathway

Figure 1 provides a broad outline of the screening pathway, while Figure 2 details the clinical pathway.

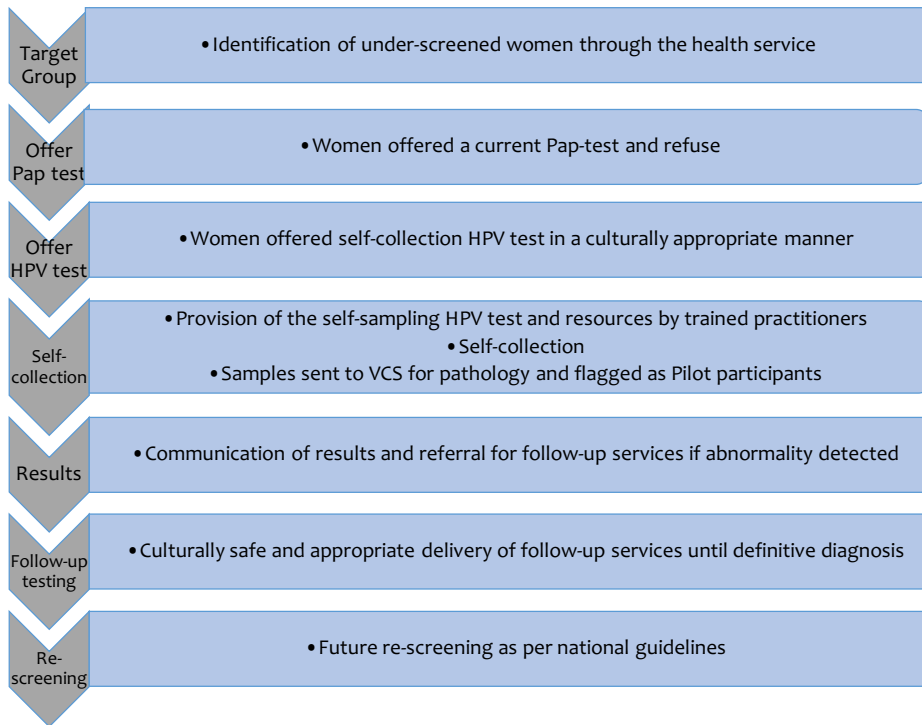


Figure 1 – Overview of the Screening Pathway

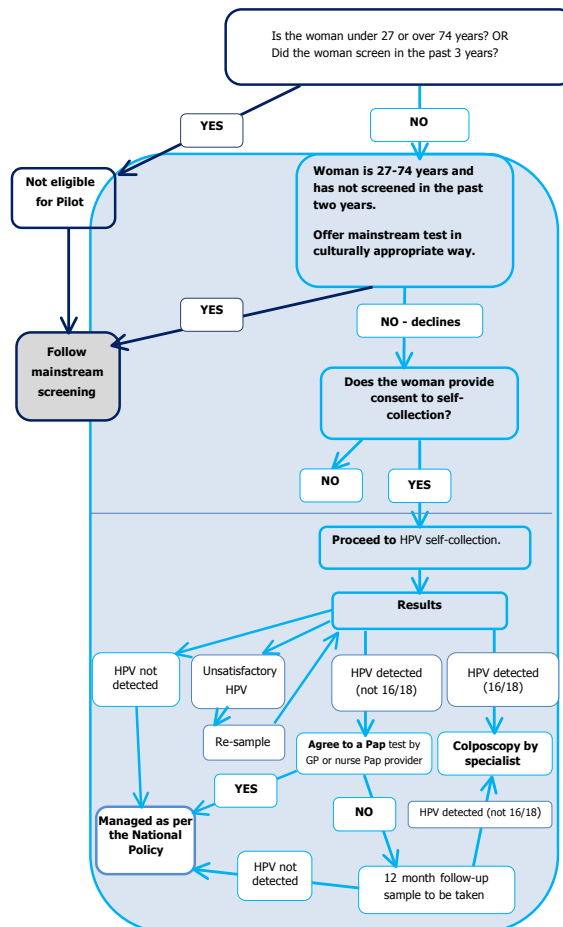


Figure 2 – Clinical Pathway

2.4 Governance

A Steering Group with representatives from DHHS, VCS, Melbourne University's Indigenous Health Equity Unit and BADAC oversaw development, implementation and assessment of the pilot.

The project was also supported by an Advisory Group made up of screening experts. The Steering Group sought specific advice and feedback around appropriate models of engagement with the Aboriginal community in Ballarat from the Victorian Aboriginal Community Controlled Health Organisation Inc. (VACCHO).

2.5 Resources

Each health service received an implementation grant to cover costs associated with workforce training, data management and reporting.

cohealth and Access Health were provided with a Resource Manual - a practical guide designed to support implementation of the pilot within health services. The manual was based on the clinical pathway processes developed at BADAC during Phase 1 of the pilot. It included information on the screening pathway, ideas for engaging staff and the community and a site preparation checklist.

Two participant resources were provided to support health professionals discuss self-collection with women:

1. How to Take Your Own HPV Test – low-text diagram explaining the procedure (Appendix B)
2. Explaining the HPV Test – plain English one-page document explaining the benefits and risks of self-collection (Appendix C)

The participant resources were translated into five languages: Amharic, Arabic, Burmese, Hakha Chin and Somali. These languages were identified during local consultations as the most appropriate for potentially under-screened women living near cohealth sites.

Oncall Interpreters and Translators was enlisted as the interpreting service for the project.

Pathology resources included self-collection swabs and containers and a modified Pathology Request Form that identified pilot participants.

A specific referral form was developed for referrals to a gynaecologist.

cohealth provided self-collection participants with a small 'pamper pack' with skin care items after they had agreed to be part of the pilot.

2.6 Laboratory and colposcopy services

All laboratory services were carried out by VCS Pathology. Participants were not charged for laboratory services.

A specialist gynaecologist from the Royal Women's Hospital, with extensive experience working with disadvantaged women, was selected as the preferred colposcopy provider for the pilot.

2.7 Implementation

2.7.1 Workforce training and engagement

A one-day Pilot Training Program was conducted before Phase 2 to prepare cohealth and Access Health staff for implementation of the pilot. The training day drew heavily on the lessons learnt by BADAC in Phase 1. It was facilitated by the project lead at BADAC, who had direct experience of the pilot, and included sessions delivered by DHHS and the Director of the Indigenous Health Equity Unit.

Each pilot site took a different approach to engaging staff in the pilot project, with the project leads taking responsibility for staff communication and training. They coordinated workforce engagement activities that included:

- Information sessions for staff;
- Training for self-collection providers;
- Staff workshops to address specific details about the project;
- Sessions at medical, nurse cervical screening provider and community advisory group meetings; and
- Distribution of pilot information via the staff intranet.

All sites adopted an ‘all of practice’ approach, but there was variation in the choice of self-collection providers at each service. At BADAC, nurse cervical screening providers, Aboriginal Health Workers and General Practitioners (GPs) were trained as self-collection providers, but in reality, most consultations with women were conducted by the Women’s Nurse (who was also the project lead) due to her existing relationships with under-screened women. At cohealth both nurse cervical screening providers and GPs conducted self-collection consultations with under-screened women. Access Health trained three of its GPs as self-collection providers. They were chosen because one ran the women’s group and the other the Aboriginal group. The Sexual Health Nurse was also involved but did not undertake any self-collection consultations.

The project leads at each site were the project drivers and maintained communication about self-collection throughout the pilot. They were the ‘go-to’ resource for all staff involved. This was a significant undertaking at all sites, but most notably at cohealth which had six of its eight health service sites involved and 28 staff engaged as potential self-collection providers (6 nurse cervical screening providers and 22 GPs).

2.7.2 Community engagement and recruitment strategies

To harness the support of local women and stakeholders, and to promote the pilot, each pilot site developed consultation, recruitment and community engagement strategies to suit their circumstances and the women who visited their health service.

Community engagement strategies are summarised in Table 2. They were based on past experiences of strategies that worked with each service’s clientele. The Resource Manual provided suggestions and background information on culturally sensitive community engagement strategies.

Pilot site	Community engagement strategies
BADAC	<p>A Community Reference Group made up of key community members and Aboriginal elders was formed as a quality control strategy. It provided feedback to the Steering Group during the planning process.</p> <p>The pilot was launched at a Koori Women’s Day in August 2015 during which the project was promoted and the community was consulted about the development of communication resources. The health day featured a performance titled ‘<i>The Great Walls of Vagina</i>’, by comedian and actor Tammy Anderson. It also included a series of short, interactive presentations to engage women around the issue of cervical screening and introduce the concept of self-collection. (See Appendix D for event photos)</p> <p>Following the Women’s Day, BADAC enlisted the support of local women to act as advocates for self-collection throughout the community.</p> <p>BADAC also included an article and fliers about the self-collection pilot in its community newsletter.</p>
cohealth	<p>With the support of its Community Participation Workers, consultations and information sessions were held with local women’s groups, under the assumption that at least some women from these groups would be under-screened and eligible for the self-collection pilot. This included two presentations to cohealth’s Community Advisory Group and 15 presentations to local multicultural women’s groups (reaching a total of 192 women), some using up to three interpreters.</p> <p>Several local agencies were engaged and received presentations about the pilot. They included WESTCasa (Centre Against Sexual Assault), Women’s Health West, the Victorian Aboriginal Health Service and the Royal District Nursing Service’s Homeless Persons Program.</p>

Access Health	Given the transient nature of its clients, and the high number of homeless women and injecting drug users, Access Health did not undertake any community engagement activities outside of its regular community engagement activities.
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Table 2 – Community engagement strategies

More personalised recruitment activities were also undertaken as summarised in Table 3. Across sites there was a combination of letters of invitation¹⁷, phone calls to under-screened women and opportunistic invitations within consultations on other health issues.

Pilot site	Recruitment strategies		
	Letters	Phone calls	Opportunistic invitations
BADAC	No	Yes	Yes
cohealth	6/10 clinics	1 clinic	Yes- all sites
Access Health	No	No	Yes

Table 3 – Recruitment strategies

¹⁷ The invitation letter reminded women that they were due for a Pap test and explained that an alternative self-collection test was available during the pilot if they made an appointment at the health service.

3 Pilot Evaluation

3.1 Methodology

To assess the pilot's service model and self-collection pathway, and to inform development of strategies to support self-collection as part of Renewal, a pilot evaluation framework was developed around the four pilot objectives. It included both quantitative and qualitative methods.

3.1.1 Quantitative Methods

Data relating to all pilot pathology was managed by VCS Pathology, whose staff tested all pathology samples and collated results. The quantitative data considered practice and pathology data to measure:

- Number of tests completed;
- Positivity rates;
- Types of HPV detected; and
- Clinical outcomes.

Each health service was responsible for monitoring data on the number of invitations distributed, the number of self-collection consultations and participation in self-collection.

Together, these data sources have been used to assess compliance with the screening pathway, to determine participation and positivity rates and to document clinical outcomes.

3.1.2 Qualitative Methods

Qualitative research was carried out by the University of Melbourne's Indigenous Health Equity Unit. It included a research study with 45 women, a staff survey with nine participants and a series of in-depth interviews with seven health professionals associated with the pilot. These methods were used to gain a deeper understanding of the experience of the pilot and responses to self-collection.

3.1.2.1 The Research Study

In the research study, participants were interviewed by a researcher using open-ended questions in a semi-structured format. The study sought to interview each woman who agreed to take a self-collection HPV test, twice: the first following completion of the test, and; the second following the woman receiving her results and undertaking any follow-up care (where relevant). The interviews aimed to measure:

- Acceptability of the self-collection HPV test;
- Acceptability and appropriateness of the service model;
- Satisfaction and intentions to screen and rescreen;
- Positive and negative risk factors around participation; and
- Cultural acceptability.

Five other women were interviewed who had declined both a Pap test and the self-collection HPV test.

An additional component of the study included four interviews with family or friends of under-screened women who agreed to take a self-collection HPV test. Women were given the option to nominate a close family member, friend or relative to complete a separate interview regarding the support they might be able to offer the participant, should she require further tests or care.

All research study participants received a \$25 giftcard in recognition of their contribution to the study.

The pilot's research study aligned with the National Health and Medical Research Council's (NHMRC's) [National Statement on Ethical Conduct in Human Research](#). Bellberry Human Research Ethics Committee (HREC) reviewed and approved the pilot in accordance with the NHMRC guidelines on 05 November 2015.

The research study collected a significant amount of information from previously under-screened women that has not been included in this report. For a full summary of findings please contact the University of Melbourne's Indigenous Health Equity Unit via iheu-admin@unimelb.edu.au.

3.1.2.2 Staff Survey

The staff survey was designed to assess the health service staff's knowledge of the pilot pathway and their professional opinions on its implementation.

3.1.2.3 In-depth Interviews

In-depth interviews with health professionals focussed on:

- Acceptability of the self-collection screening pathway;
- Appropriateness of the resources and training provided;
- Process issues particular to different health service settings; and
- Suggestions for implementation of self-collection under Renewal.

3.1.2.4 Participation

Table 4 shows participation in the three qualitative research methods.

Health service	Interviews with women - after completing self-collection	Interviews with women who declined screening	Interviews with women - after receiving results/follow-up care	Interviews with relatives/close friends	Staff on-line survey	Health Professional in-depth interviews
BADAC	12	0	8	1	1	1
cohealth	20	2	7	3	8	2
Access Health	8	3	2	0	0	2
VCS Pathology						1
Royal Women's Hospital						1
Total	40	5	17	4	9	7

Table 4 – Participation in qualitative methods

See Appendix E – Demographics of Research Study Participants.

3.2 Limitations

The pilot evaluation was limited by the following factors:

- Challenges in determining the number of eligible, under-screened women

There was variation in data on cervical screening history across health services. While BADAC had good cervical screening history records for clients, cohealth had a large number of women without a cervical screening history record. It was not known whether their patients were un-screened/under-screened, or whether they had screened at another service. This was also the case at Access Health where the transient population of clients makes comprehensive record keeping virtually impossible.

- Challenges with data collection at the practice level

Variation in the consistency of record keeping at each site posed some problems, particularly in relation to the self-collection discussions held with under-screened women. Only one of the three sites (BADAC) consistently recorded each self-collection consultation and whether women chose to have a Pap test or declined screening. Although efforts have been made to retrospectively collect this data, there is potential for the number of consultations and the number of women who chose to have a Pap test to be under-reported, affecting the accuracy of the reported participation rate. It is somewhat re-assuring, however, that the participation rates across the three sites were very similar.

- Challenges with the timing of Research Study interviews that may have impacted on participation

The Research Study faced logistical challenges in arranging interview times across multiple-sites. Ideally, the first interview would have been conducted directly following the first consultation and completion of self-collection, but with a large number of women participating opportunistically, this was not always possible. It was also difficult to encourage women to return for a second interview.

- Limited insights from women who chose not to participate

As only five women who declined to participate in self-collection agreed to be interviewed, results from the research study may be somewhat skewed towards women who engaged with the concept of self-collection.

- Limited information on colposcopy provision

As only one woman who had HPV detected (16/18) had a colposcopy during the pilot, this part of the screening pathway remained largely untested.

4 Evaluation results

4.1 Objective 1 - To recommend an acceptable alternative self-collection pathway for under-screened women for the purposes of Renewal

In assessing the acceptability of the self-collection pathway utilised during the pilot, two key questions were explored:

1. Did the Pilot lead to an increase in screening of under-screened women?
2. How acceptable was the self-collection screening pathway to health service staff and women?

4.1.1 Participation and clinical results

Quantitative data from the three sites was pooled and analysed by VCS Pathology. A summary of results is shown in Figure 3 and in Table 5.

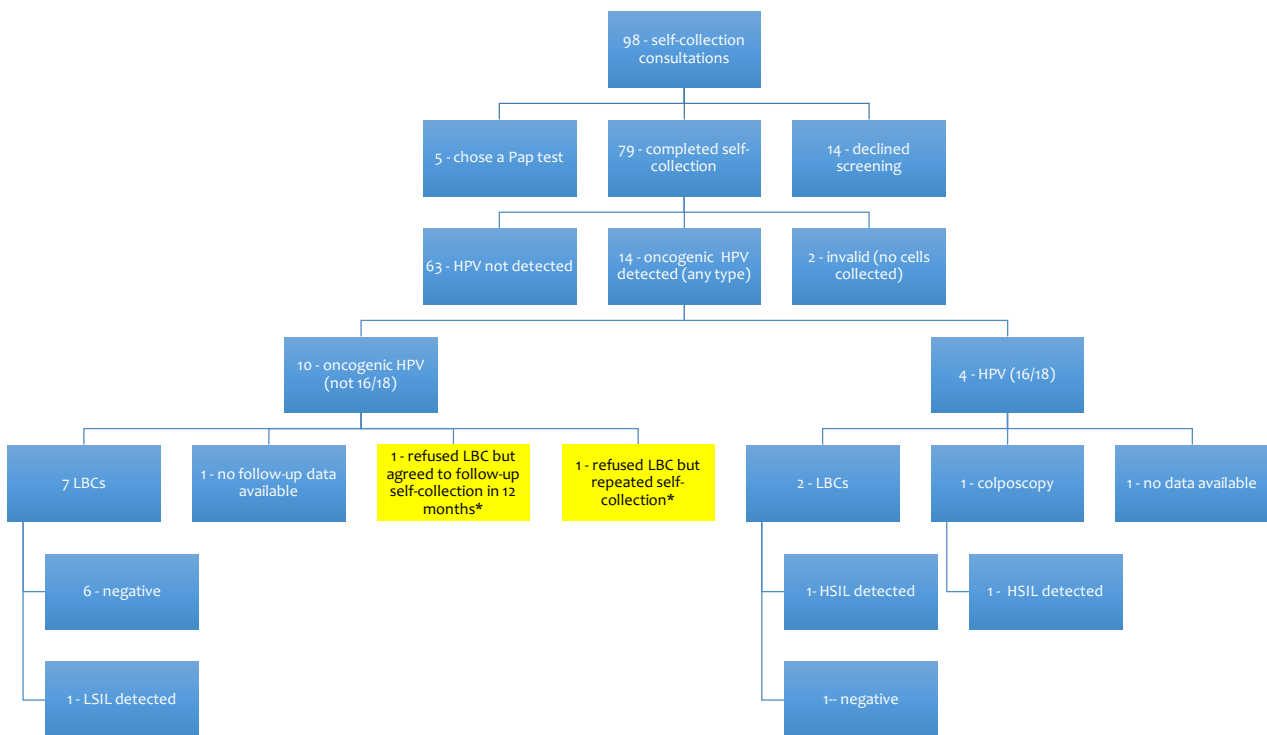


Figure 3 – Self-collection pilot clinical results

*Please note the screening pathway was modified for these participants to reduce the likelihood of them being lost to follow-up

Outcomes	BADAC	cohealth	Access Health	Total
Self-collection consultations	33	51	14	98 ¹⁸
Chose Pap test	4 ¹⁹	1	0	5
Declined screening	5	7	2	14
Agree to self-collection	24	43	12	79
Screening participation rate = Participating women (Pap test & self-collection)/ women offered self-collection within a clinical setting	28/33 84.8%	44/51 86.3%	12/14 85.7%	84/98 85.7%

Table 5 – Screening participation as at 6 Dec 2016

¹⁸ Please note there was variation in the quality of the data relating to self-collection consultations across sites, resulting in potential for this figure to be an under-estimate of the number of discussions held with under-screened women that may have led to a Pap test, self-collection or refusal to screen.

¹⁹ No abnormalities were detected in these women

4.1.1.1 Participation

Of the 98 under-screened women aged 27-74 years who were invited to participate in the pilot within a clinical setting, 84 women (85.7%)²⁰ agreed to either a Pap test or a self-collection HPV test. Although there was slight variation across sites, all achieved a participation rate of above 84%.

4.1.1.2 Results

Of the 77 valid self-collection HPV test results received, 14 women tested had oncogenic HPV detected (any type) giving an overall positivity rate of 18.2%. As the numbers are small and the data has not been segregated by age or for risk factors, the positivity rate is considered to be within the expected range for under-screened women and is in-line with similar research conducted in Australia.¹⁴

Of the women who had oncogenic HPV detected, four (28.6%) had HPV detected (16/18) and 10 (71.4%) had oncogenic HPV detected (not 16/18).

Two high grade squamous intraepithelial lesions (HSIL) and one low grade intraepithelial lesion (LSIL) were found.

'...all of these women were under or never-screened and we picked up a number of lesions in women that were obviously at intermediate to high risk. These wouldn't have been picked up otherwise.'

VCS Pathology lead

4.1.1.3 Compliance with follow-up testing

Of the 14 women who had oncogenic HPV detected, 12 women (85.7%) had returned to their practitioner for follow-up by the time this report was completed, with 10 (71.4%) having completed either LBC (9) or a colposcopy (1).

Compliance with the screening pathway within 90 days of self-collection was 87.5% and 91.6% within 180 days.

Of the 10 women who had oncogenic HPV detected (not 16/18), seven (70%) had follow-up cytology taken by their health practitioner. Two refused follow-up LBC, although one completed another self-collection HPV test and the other agreed to complete another self-collection HPV test in 12 months. There was one outstanding women in this group who had not returned for follow-up testing.

Of the four women who had HPV detected (16/18), three had returned for follow-up, with two having completed LBC and one having completed a colposcopy at the time of writing. There was one outstanding women in this group who had not returned for follow-up testing.

Overall, there were two women who had oncogenic HPV detected (any type) (14.3%) who had not returned to their practitioner for follow-up by the time this report was written, and four (28.6%) who had not completed follow-up LBC and/or colposcopy.

4.1.1.4 Invalid results

There were two invalid results from pilot participants, giving an invalid rate of 2.5%. A further three invalid results were received but were excluded from the pilot data as two were from women outside the pilot age group and one was from a women who was not under-screened. The five invalid results were received across two of the pilot sites.

In each of the invalid results no cell content was detected. It is likely that these women returned the self-collection swabs without attempting to complete the test which only requires a very small sample of cells. When contacted, these women failed to return to their health services to receive their results or complete follow-up examinations.

²⁰ We have calculated the screening participation rate as the number of under-screened women who agreed to self-collected cervical screening following an explanation from a health professional within a clinical setting. This is in-line with the aim of the pilot.

The risk of invalid results poses a reminder to health providers that some women may agree to self-collection but then decide not to complete the test. It also supports the view that laboratories should only use HPV tests that include controls that will identify acellular samples, otherwise these samples would be reported as ‘HPV not detected’, falsely reassuring the practitioner about the woman’s risk.

The screening of a woman who was not under-screened reinforces the need for health services to maintain comprehensive screening records, and to cross-check with the Cervical Screening Register where patients have given their permission.

Case Study – Implementation of self-collection in a unique Aboriginal Controlled Community Health Service

BADAC was chosen as the first pilot site as it has consistently been able to achieve high participation rates in preventative health initiatives. At 1 July 2016, the cervical screening participation rate at BADAC for active Aboriginal patients aged 20-69 who had had a Pap test in the last 3 years was 63% (49% in the last 2 years). This compared favourably to the general Victorian average of 72.6% and was well above the Victorian Aboriginal Controlled Health Organisation average.²¹

There are many factors contributing to BADAC’s success in cervical screening. They take a whole-of-practice approach to prevention and regularly telephone under-screened women to invite them to visit a practitioner. The service goes to considerable efforts to maintain complete patient screening histories, routinely seeking patients’ permission to contact screening registries to gain access to screening history records. Perhaps most significant to their ability to engage community members in cervical screening has been the determined efforts of all staff to build trust with their patients over years. The Women’s Nurse works closely with staff and community members to ensure all cervical screening initiatives are undertaken in a culturally respectful way.

The involvement of BADAC in the self-collection pilot has shown what a well-resourced, proactive health service with a strong track record in cervical screening can achieve. We acknowledge that many Aboriginal Controlled Community Health Services may not have the resources and infrastructure in place to expect the same self collection outcomes as BADAC has been able to achieve in the short-term, but that they may be achievable over time .

4.1.2 Acceptability to health service staff

The pilot project was well received by staff at each health service. All staff involved in the staff survey and in-depth interviews responded positively to self-collection, and were pleased to be able to offer under-screened women as an alternative to a practitioner collected cervical screening test.

A summary of points raised by staff showed:

- Under-screened women responded favourably to the offer of self-collection;
- Staff were able to easily incorporate the screening pathway into their usual practice, however, the pathway required frequent clarification at two sites, particularly in relation to the management of results and re-screening messages, with GPs requiring additional support in the initial stages;
- The coordinator role was very important, both in disseminating information and maintaining momentum for the pilot, noting that the role required a significant time investment;
- Some services found it challenging to confidently identify under-screened women due to the quality of their data records; and
- Cervical screening was often a low priority for under-screened women when raised during consultations; and
- Additional efforts were required to support women who had HPV detected to return for follow-up testing.

The health professionals who participated in the in-depth interviews believed that the option of self-collection had increased the number of under-screened women who participated in cervical screening at their service.

²¹ BADAC Service Improvement Project - Interim Report - Results at 30 June 2016. Available from DHHS via Ruvimbo.Bako@dhhs.vic.gov.au

4.1.3 Acceptability to women

Of the 40 women who completed a self-collection HPV test and participated in the research study, 39 (97.5%) found the self-collection test to be an acceptable option for cervical screening. Thirty-seven (92.5%) of women reported that nothing would prevent them from doing the test again in the future.

The women shared their past experiences of cervical screening with the conventional Pap test, noting a range of barriers to their previous participation that concurred with other studies into the acceptance of Pap tests.^{22, 23, 24, 25, 26} Several barriers were ones that may be overcome by the fact that self-collection HPV tests are self-administered and do not involve speculum insertion by a health practitioner. They included:

- Discomfort or pain experienced during a regular Pap examination (mentioned by 50% and 40% of women respectively). For some women, the pain or discomfort arose from a physical experience of the examination and for others it was linked to emotional trauma derived from past experiences.
- The invasiveness or intrusiveness of the Pap test (mentioned by 40% of women). This led to feelings of embarrassment, humiliation and degradation.
- Traumatic past experiences (mentioned by 32% of women). This included trauma associated with a previous Pap test, and trauma associated with experiences of sexual abuse which was triggered by the experience of a Pap test, or by the thought of one.

4.1.3.1 Enabling factors for self-collection

Women spoke positively about the self-collection HPV test, citing several reasons for its acceptability. These 'enabling' factors are summarised in Table 6.

Reasons for acceptability of self-collection	% of women reported
Autonomy and control	45%
Privacy	37.5%
Allowed/empowered women to check health	12.5%
Ease and convenience	57.5%
Time (quick test)	32.5%

Table 6 – Enabling factors – reasons for acceptability of self-collection

Self-collection enabled women to overcome barriers of pain and discomfort because it allowed the women to perform the examination by themselves. Having autonomy and control over the test meant there was little chance of pain.

'It's so much easier, it takes all the fear out of it. Like you're not going to hurt yourself, you know.'

Pilot participant

Embarrassment, humiliation and degradation were also overcome by self-collection because there was no one else present, watching or touching the woman. This was reinforced by the number of women who referred to the benefit of the privacy of the test.

²² Mullins, R., K. Scalzo and F. Sultana . (2014). "Self-sampling for cervical screening: Could it overcome some of the barriers to the Pap test?" *Journal of Medical Screening* 21(4): 201-206 202p

²³ Barata, P., Mai, V., Howlett, R., Gagliardi, A. and Stewart, D. '[Discussions about self-obtained samples for HPV testing as an alternative for cervical cancer prevention](#),' *Journal of Psychosomatic Obstetrics & Gynecology*, 2008, vol. .29, no. 4, p. 252.

²⁴ Prior, D. 'The meaning of cancer for Australian Aboriginal women; changing the focus of cancer nursing', *European Journal of Oncology Nursing*, 2009, vol. 13, no. 4, pp. 280-286.

²⁵ Cadman, L, J. Waller, L. Ashdown-Barr and A. Szarewski, 'Barriers to cervical screening in women who have experienced sexual abuse: an exploratory study', *Journal of Family Planning and Reproductive Health Care* 2012, vol. 38, pp 214–220.

²⁶ Peters, K. 'Politics and patriarchy: Barriers to health screening for socially disadvantaged women', *Contemporary Nurse*, 2012, vol. 42, no. 2, pp. 190–197.

'I wouldn't do it if someone else was going to be involved. There is an invisible lock here and I'm the only one with the key.'

'I felt like it would be really intrusive from another person. I just didn't want to do it with another person in the room, you know, I wanted to do it with the cotton bud because I could do it myself and it didn't make me feel powerless.'

Pilot participants

At the BADAC pilot site, it was noted that by allowing Aboriginal women to complete the test in their own space and in privacy, which all the women chose to do, self-collection enabled women to avoid feelings of invasion, shame and embarrassment previously experienced during cervical screening. In doing so, self-collection provided a more culturally safe alternative for cervical screening for Aboriginal women. Two Aboriginal women reported feeling empowered after completing the self-collected test on their own:

'Because of the first experience that I had, knowing that I wouldn't be put into that position again. Knowing that I could do it in the comfort of myself and then if I needed to then [the nurse] could help or the [women's' health desk staff] could help if I needed assistance, but the option was that I could do it myself.'

'It gives you a sense of control. It was comfortable as a test. I didn't have to worry about positioning my body as you would for a regular test.'

Aboriginal pilot participants

Women commented on the ease and convenience of self-collection, despite it requiring a consultation at a health service. Self-collection was considered quicker than a Pap test due to the shorter time required to perform the test, and time saved in not needing to undress, lay on a bed or get in position for the procedure.

'Much easier, peace of mind, quick result and time wise - for time poor people.'

'Because it's convenient, it's helpful. Useful. It avoids all the rigmarole of the whole hoopla. It's so much easier, it takes all the fear out of it. Like you're not going to hurt yourself, you know.'

Pilot participants

4.1.3.2 Barriers to self-collection

There were several factors affecting women's willingness to screen, often related to their circumstances, backgrounds and inequities in society. These barriers, referred to as 'circumstantial or 'socio-cultural barriers', may not be overcome simply by the introduction of self-collection. Many of the participants were experiencing multiple barriers to accessing health care which meant that cervical screening was not a high priority for them. These barriers are summarised in Table 7.

Circumstantial/socio-cultural barriers to screening	% of women reported
Not a priority or disorganisation	35%
Health issues	27.5%
Mental health issues/low self-esteem	25%
Alcohol and drug use	10%
Trust with a health practitioner	47.5 %
Fear of test results	20%
Discrimination and/or racism	40%

Table 7 – Circumstantial / socio-cultural barriers to self-collection

- Multiple issues

Twenty women (53%) reported that something was preventing them from putting their own health first. In nine of these cases the women's reasons included their mental state, 10 others were, at times, prevented due to their

physical health, whilst a few reasoned that their use of drugs or alcohol had impeded their ability to look after their health.

A significant proportion of the women interviewed came from a position of disadvantage, and were experiencing multiple vulnerabilities such as health problems, housing and financial instability and discrimination; all of which may impact on mental health. Many reported challenges to prioritising their own health – in particular preventative health care. For these women making extra appointments to visit a clinic for cervical screening was unlikely to be a priority.

A health professional from Access Health described the multiple barriers to preventative health facing their patients:

‘Due to the complex and demanding nature of the experiences of this cohort, such as frequent and lengthy episodes of homelessness and associated demands, behaviours associated with drug and alcohol addiction and the nature of street based sex work (which is often partnered with experiences of assault and sexual abuse), it is common that preventative health care is overlooked in place of responding to acute and symptomatic health problems or psycho-social problems. Illness, health assessments and screening can often only be addressed in a partial or fragmented way.’

- Mental health issues

Mental health issues were an important contributing factor for this group of under-screened women. Many of the women were anxious, depressed or had low self-esteem leading to a lack of will to prioritise their own health.

‘My mental health is not great. Being a heroin addict for 7 years, it stops you from doing anything really, sucks your soul, stops you from living.’

‘Most of the time, like I said, it depends how I’m travelling. If I’m not travelling well, I don’t care.’

Pilot participants

- Relationship and trust with a health provider (as both a barrier and an enabler)

Many of the women mentioned distrust of a health professional or health service as a reason they had not in the past, or would not engage with health care or cervical screening. Forty-seven percent of women expressed the importance of their relationship with their health provider in accessing health care, information and support. For many women, the relationship with their practitioner had been built over time and the women had a history of support from their current provider.

The theme of fear or anxiety with the health system was found in particular with Aboriginal women. Three Aboriginal women described having a lack of trust in the health care system and/or anxiety surrounding the system.

- Fear of results

Another common theme was women’s fear of the results. Twenty percent of women in the research study reported anxiety over the outcomes of a positive result. Anxiety and not wanting to know results were revealed as barriers to women looking after their own health generally.

- Discrimination and/or racism

A further barrier, highlighted for its impact on engagement with the health system more generally, was discrimination and racism. Eleven of the research study participants across all sites (28%) specifically mentioned staff’s judgement or discrimination as a barrier to accessing a health service. A further three women stated that if they could not see their own doctor they would be reluctant to attend a health service. Sixteen women (40%) responded that racism could be a barrier, of which nine (56%) were Aboriginal. Overall, 64% of the Aboriginal women interviewed said that racism would prevent them from attending a health service.

Summary of key findings – Objective 1

- There was good evidence that self-collection was an acceptable cervical screening option for many under-screened women, and that the screening pathway used during the pilot was able to be effectively implemented in a variety of health service settings.
- The active engagement of under-screened women at safe locations with health workers known to them supported the uptake of self collection.
- A screening participation rate of 85.7% was achieved for under-screened women offered self-collection within a clinical setting. This is a promising indication that self-collection under Renewal will lead to an increase in cervical screening participation for under-screened women.
- Of the 14 women who had oncogenic HPV detected (any type) four, (28.6%) either refused LBC follow-up or did not return for a follow-up consultation.
- Although the process of self-collection HPV testing will remove some of the barriers women have experienced in completing Pap tests, the circumstantial/socio-cultural barriers experienced by many under-screened women from disadvantaged backgrounds are likely to continue to be barriers to cervical screening and more broadly, to them accessing health care.

4.2 Objective 2 - To develop a clinical practice approach (protocols & processes)

In assessing pilot activities related to this objective we looked at:

- The practical appropriateness and utilisation of the clinical guidelines and pathway; and
- Clinical processes and protocols put in place –
 - at the health service level;
 - at VCS Pathology; and
 - by the colposcopy provider.

4.2.1 Screening Pathway Considerations**4.2.1.1 Compliance with follow-up**

As shown in Table 5, compliance with the screening pathway was high. Of the 14 women who had oncogenic HPV detected (any type), 12 (85.7%) have since returned for a follow-up consultation and 10 (71.4%) had completed follow-up testing.

Twenty-seven percent of the women who participated in the follow-up interview during the research study reported that they would not complete a Pap test if they had HPV detected. This was similar to the outcome of the pilot, where 28.6% of women who had oncogenic HPV detected (any type) had not completed LBC or colposcopy at the time of writing.

4.2.1.2 Invalid results

See section 4.1.1.4

4.2.1.3 Location of testing

While most women were comfortable completing the self-collection HPV test at the health service (usually in the service's toilets), a number of women expressed preference for being able to take the test home to complete. Although technical requirements for rapid returns of pathology prevent this option, home-completion with a health professional or other carer/social or community worker present may appeal to women who are experiencing more extreme trauma or anxiety and do not wish to do the test in a public area, or for women who are physically less capable of visiting a health provider. One patient at BADAC, who usually received her health care from BADAC clinic at home due to other health issues, completed self-collection during a home visit with the Women's Nurse.

4.2.1.4 Health professional understanding of the pathway

Despite there being strong compliance with the screening pathway there was mixed feedback on its application. Some health professionals found it easy to incorporate the pathway into their everyday practice, whilst others required frequent clarification on a range of issues including eligibility, pathology and data collection requirements. Some confusion at cohealth may have been due to another cervical screening project operating concurrently. Any issues related to the pathway were usually easily overcome through contact with VCS Pathology or DHHS.

The issue that remained un-resolved was the long-term cervical screening management of under-screened women who completed self-collection as part of the pilot. As they are no-longer 'under-screeners', the current guidelines exclude them from an offer of self-collection if they return for screening in five years.² This is unlikely to be acceptable to these women given their history and experience with self-collection.

4.2.2 Health service processes and protocols

Cooperation between health service staff helped the coordination and success of the project. The 'whole of practice' approach, with all staff informed, facilitated conversations about self-collection between staff, and increased the identification of eligible women who could be referred to self-collection providers.

4.2.2.1 Choice of self-collection providers

At BADAC and cohealth both nurse cervical screening providers and GPs were trained as self-collection providers. This seemed to work well although it is worth noting that the majority of self-collection consultations at BADAC were conducted by the Women's Nurse, with other clinic staff referring clients to the Women's Nurse for self-collection. At Access Health the GPs and the Sexual Health Nurse were trained as self-collection providers. While Access Health had hoped to offer the test to all eligible women opportunistically, this didn't always happen due to time constraints within consultations and higher patient priorities.

4.2.2.2 Identifying under-screened women

The PenCAT tool was used with Medical Director at two health services to carry out a clinical audit and identify under-screened and never-screened women eligible for self-collection. The patient records of eligible women were flagged and nurses phoned under-screened women to invite them to attend a consultation about self-collection. One service was unable to use the PenCAT tool to identify under-screened women as they discovered there had been a problem with their data entry practices. They therefore had to complete manual record checks before adding alerts on eligible women's records.

As with all databases, the tool is limited by the data recorded. BADAC has very comprehensive data on their patients' screening history. They routinely ask all new patients for permission to contact relevant registries to check and update their records. Although cohealth was able to identify almost 400 women who appeared to be under-screened, there were over 1500 women on their database without a screening record. It was not known whether these women had screened at another service. Access Health faced further challenges in identifying under-screened women given the highly transient nature of their patient population.

Four women involved in the research study reported to the researcher that they had had a Pap test within the last three years, despite having been offered self-collection. It is unclear whether the women did not accurately recall the date of their last screen or whether the health service's data was incorrect.

4.2.2.3 Opportunistic engagement

Each health service raised self-collection opportunistically with under-screened women when they attended the health service for another reason. In most cases this was prompted by an alert or flag on medical software.

There was general consensus that opportunistic recruitment was preferable to sending letters of invitation as letters may contain too much information or be confusing for women who speak English as a second language and can

easily be ignored. A letters strategy relies on patient addresses being current - a challenge for some health services, and staff commented that letters are slow and costly.

4.2.2.4 Communicating results

Some health services followed their usual practice in relation to the communication of test results while others modified procedures for the pilot, given the risk that women who received a result indicating that HPV had been detected may not return for follow-up testing.

As women completed their self-collection HPV test at BADAC, staff made an appointment for them to return to receive their results in two weeks, regardless of the outcome. If the women required follow-up care the nurse or doctor was present to explain everything and complete a conventional Pap test if required. This was not usual practice, but worked well during the pilot.

'All women were asked to make a return appointment because they are so hard to engage that we didn't want them to be on the end of the phone hearing that they then had to deal with another test.'

BADAC Pilot lead

At the other two health services a nurse generally phoned all women who completed a self-collection HPV test and explained their results over the phone, although there was some variation between practitioners.

Project leads took responsibility for tracking all women and following-up with their health practitioners to ensure the women completed the screening pathway. A participant tracking sheet was used to eliminate gaps and to help coordination with other staff members.

All clinics had difficulty ensuring women returned for follow-up appointments. This required extra time, effort and multiple attempts by staff to contact women to make sure women who had HPV detected returned for follow-up testing.

4.2.2.5 Patient support for follow-up testing

Staff from at least two health services were available to accompany women to colposcopy appointments if required and could provide transport. In one instance, a woman in whom HPV had been detected received a home visit from a GP and a nurse cervical screening provider and had her follow-up Pap test taken at home.

4.2.2.6 Community engagement

Two of the health services undertook community engagement activities to promote the pilot to groups of women likely to include women who were under-screened. They gave presentations about self-collection, showed the women the collection swab and answered questions, often with the support of an interpreter.

Although community presentations and health days are a labour intensive exercise and we are not able to determine whether they resulted in increased participation, staff felt they were useful in harnessing community support and raising awareness of cervical cancer and screening options. Presenters were able to answer the many questions raised by women in the audience.

'Cos I come here (to the clinic) for Womens groups, that's how I found out about it, a woman talked about it, another nurse, and I thought I'd get onto it, hey, I'd give it a go...' (The woman explained that previously she hadn't known that she had a cervix.)

Research study participant who had attended an education session

4.2.4 Pathology service processes

VCS Pathology put several processes in place to support the pilot.

The project lead at VCS Pathology acted as the single contact point for all self-collection issues. Normal laboratory practices were undertaken in terms of reporting results to practitioners. Pilot data was recorded in a separate spreadsheet.

Self-collection pathology request forms were identified with a watermark. Laboratory processing did not incur any charges for participants.

VCS Pathology prioritised the processing of self-collection HPV tests and was able to provide the results quite quickly when requested.

Unlike some laboratories, VCS is currently able to separate results for HPV 16, 18 and other high risk HPV types. This will be a requirement under Renewal and it is anticipated that all laboratories reporting cervical screening tests will be using appropriate HPV tests when the renewed NCSP commences (1 May 2017).

4.2.5 Colposcopy service processes

Although the Royal Women's Hospital and the specialist gynaecologist were prepared to support women who have HPV detected (16/18), only two women were referred to colposcopy during the pilot, and only one colposcopy was performed.

The gynaecologist agreed to see women from the pilot separately to her private patient clinic and bulk billed for services. Despite there being a specific referral form for the pilot, data was entered into the hospital's regular database which was not then able to identify women as having come through the self-collection pathway.

4.2.5.1 Colposcopy provision under Renewal

Colposcopy clinics are currently struggling to meet the demand for colposcopies, resulting in significant wait times in the public system. Demand is expected to rise in the first two years following Renewal, but then decrease in over the following three years as women transition from the two yearly screening interval to a 5 yearly screening interval.²⁷ There is also limited access to colposcopy services in rural areas. A short-term plan is needed to address access for women on the self-collection pathway in the first years of the Renewal.

'It is arguable that it is necessary to prioritise women who have followed the self-collection pathway as they are at higher risk of testing positive due to being under-screened.'

Gynaecologist involved in pilot

The gynaecologist involved in the pilot raised concerns about the provision of colposcopies under Renewal, believing that it would not be financially viable to bulk-bill women in private colposcopy rooms or to prioritise appointments with women who are on the self-collection pathway without special arrangements put in place. She suggested that the pathway may need to streamline women who have self-collected into colposcopy clinics. This would be the only way to prevent women having to potentially wait several months to see a colposcopist at a public health clinic.

Several suggestions for managing colposcopy under Renewal were offered:

- Consultations with each of the public health providers of colposcopy;
- Setting up an urgent referral system to prioritise colposcopies arising from self-collection over regular referrals;

²⁷ Smith, M., Gertig, D., Hall, M., Simms, K., Lew, J., Malloy, M., Saville, M. and Canfell, K. 'Transitioning from cytology-based screening to HPV-based screening at longer intervals: implications for resource use.' *BMC Health Services Research*, 2016, vol. 16, p. 47.

- The possibility of a specialised colposcopist for women who self-collect and have HPV detected (16/18); and/or
- Specialist colposcopists who are able to provide outreach services.

Summary of key findings – Objective 2

- Health services introduced a range of effective internal processes to support the pilot and implementation of the screening pathway ran smoothly across the three pilot sites.
- Compliance with follow-up testing was high, with 12 of the 14 women who had oncogenic HPV detected (any type) (85.7%) having since returned to their practitioner for a follow-up consultation and/or completed follow-up testing within 90 days of self-collection. Compliance with screening pathway within 180 days was 91.6%.
- Although there was some confusion with some elements of the pathway (such as the long-term screening recommendations for participating women), most issues were largely resolved during the pilot.
- Two of the health services experienced challenges in identifying their under-screened population, one because their patient record system did not have comprehensive data on women's screening history, and the other because of the transient nature of their patient population.
- Practices acknowledged that under-screened women are likely to require support as they receive their results and whilst having follow-up testing.
- VCS Pathology modified some of its services to support the pilot. The laboratory prioritised processing of self-collection test HPV tests and no charges were made to participants for laboratory services. VCS Pathology was able to distinguish results for HPV types 16, 18 and other - a requirement for cervical screening tests undertaken in the Renewal.
- Concerns were raised about the provision of colposcopy for women on the self-collection pathway under Renewal, given the long wait times in the public system and the predicted increase in demand in the early years of Renewal.

4.3 Objective 3 – To develop resources to support the workforce to implement self-collection pathways for under-screened women

Under this objective we considered feedback on the resources that were developed for women and health professionals during the pilot. They included:

- The Pilot Resource Manual;
- Resources for women (described on page 11); and
- Invitation letters.

4.3.1 Resources for health services

4.3.1.1 Resource manual

The resource manual was developed after Phase 1 and drew heavily on BADAC's experiences in implementing the pilot. It proved to be a very useful resource for Phase 2 health services. Project leads reported utilising the entire manual and self-collection providers referred to sections as required. The most useful sections were the practical ones, such as the Clinical Pathway, a table describing actions for different test results and information on pathology sample labelling. Access Health used the manual to develop their own flowchart to clarify the pathway for women.

Suggestions for improvement have been gathered and will be used in the development of a resource to support health services integrate self-collection under Renewal.

4.3.2 Resources for women

The written/visual resources used to explain self-collection and HPV were well received by women and by health professionals who found them to be *'simple, straightforward and easy to use.'*

A high number of women in the research study reported that self-collection was easy, indicating that the resources and information provided were adequate to support women to complete the test. Ninety-one percent of women who were asked said they had enough information/instructions, and 91% felt they had enough support from their health practitioner.

The translated resources that were developed for cohealth were not widely utilized. Only two women required an interpreter and printed resources in only three out of five of the languages (Amharic, Arabic and Somali) were used with women. In hindsight, other language translations may also have been more relevant. One nurse cervical screening provider suggested that visual tools to assist in explaining self-collection (including a picture of the reproductive system) were preferable to written resources.

4.3.2.1 Invitation letters (and phone calls)

Two of the three pilot sites invited under-screened women to participate in the pilot via a letter from the health service. The letters alone did not appear to persuade many women to make an appointment to discuss self-collection, although one doctor reported that she had several women come in with the letter to request a regular Pap test. Phone calls made an impact at BADAC where this form of communication is commonly used. A nurse cervical screening provider at cohealth reported that although she had made 10 phone calls to under-screened clients, not a single woman responded and took up self-collection from the phone call.

Summary of key findings – Objective 3

- The resources developed for the pilot were generally well received and could easily be modified to support self-collection under Renewal.
- Invitation letters were considered the least useful strategy for engaging under-screened women in self-collection, with more personal engagement strategies and opportunistic invitations preferred.

4.4 Objective 4 - To prepare the workforce — Aboriginal Health Workers, practice nurses, general practitioners, allied health providers and persons performing colposcopy — ahead of Renewal

This component of the evaluation focussed on the training program that was provided for key staff at each health service, and the initiatives they then put in place at a practice level to support pilot implementation. We were most interested in learnings that would assist services to embed self-collection options into their usual practice under Renewal. We also considered the information and support needs of under-screened women, given their relevance to workforce training and development.

4.4.1 Initial training

Feedback from the Phase 2 sites indicated that the training day gave a very useful overview of the self-collection project and how it was implemented in Phase 1. However, there was some need for more detailed workshopping and suggestions for implementing such a project in different types of health services. A later workshop held at cohealth provided this opportunity.

4.4.2 Clinical training

One of the most challenging components of the pathway was management of unsatisfactory/invalid results. While unsatisfactory results could be caused by the swab being affected by an inhibitor (e.g. lubricant in the vagina), they are more likely to mean a woman has not completed self-collection. This calls for a sensitive, understanding and

educated response from the practitioner to determine why the women may not have completed the test, and how best to proceed with cervical screening. Specific guidance is required on the management of these results.

4.4.3 Workforce engagement and support

The importance of a well-trained, well-informed, sensitive workforce was re-iterated throughout the evaluation findings. The research revealed that women's engagement with the health system was often reliant on the relationship they had with their health care professional, especially regarding such personal testing as cervical screening. Health providers who are able to develop a good rapport with their patients and know how to ask appropriate questions are more likely to engage them in cervical screening.

Project leads played an important role in preparing and supporting staff at each health service. Their hard work in driving the project, maintaining communication, overseeing pathway implementation and trouble-shooting if required, was integral to the success of the pilot.

Feedback from the project leads reinforced the benefits of early preparation. They would have preferred more lead time for information sharing and educating GPs and nurse cervical screening providers in readiness for the pilot, however, they accepted that GPs may not have been able to dedicate any additional time.

4.4.4 Women's information and support needs

Acknowledging that there may be some overlap with the previous objective, the feedback provided by under-screened women highlights important considerations for both workforce training and resource development.

Under-screened women involved in the pilot reported that they required clear, consistent information from health professionals who were sensitive to their personal needs. It was both the support and the information provided to women from their health providers that helped them to overcome their apprehensiveness with cervical screening.

The women interviewed in the research study were generally aware of the reasons for cervical screening. However, for many of the women, this was the first time in many years a health practitioner had sat down to offer them information on cervical cancer or screening.

Three of the women interviewed had negative experiences during the pilot due to their results being either poorly explained or misinterpreted or due to being given inaccurate information regarding follow-up care. For example, one woman was told to return for a Pap test despite her self-collection result showing HPV was not detected. There was also some confusion across the pilot as to the future screening recommendation for pilot participants, and whether they would continue to be offered self-collection. This resulted in some confusion and stress for a small number of women.

A common theme in the research study was women's concern that they had not completed the self-collection HPV test well enough to gain an accurate result. Whilst this did not prevent the women from completing the test, some doubted their ability to complete the test correctly. This observation may be useful for in the development of future resources that should include information on the accuracy of the test.

It is advisable that any self-collection training programs or resources for Renewal are developed in light of these observations of women's support and information needs, as well as the barriers to self-collection participation discussed under Objective 1.

Summary of key findings – Objective 4

- The health workforce required training and support to implement self-collection. It was beneficial to have a proactive project lead available to drive the project and support its implementation within each service.
- Specific guidance is required for health practitioners on the management of unsatisfactory/invalid results.
- With a significant array of issues to consider when engaging under-screened women in self-collection, the importance of a well-trained workforce is clear. Health practitioners need to be able to clearly and sensitively explain the self-collection HPV test, results and follow-up procedures to women who may have complex needs.

6 Discussion

The pilot has demonstrated that the approach taken to self-collection is likely to address barriers to cervical screening for many women, and in turn, to increase participation rates. It is to be hoped that self-collection will also contribute to more equitable access to cervical screening services. In order to achieve the potentially substantial benefits of self-collection, there are several issues that will be pertinent to Renewal.

Participation

The pilot reinforced that many of the challenges facing under-screened women are likely to impact on their participation in cervical screening. Health providers engaged in all stages of the screening pathway will require empathy, sensitivity and an understanding for the circumstantial and socio-cultural barriers faced by these women. Screening providers who have the skills and strategies for effectively engaging with under-screened women in a culturally acceptable way, and are able to build trust with their patients are likely to have success in encouraging many under-screened women to participate in self-collection.

Despite the pilot's encouraging participation rates, many under-screened women may be experiencing multiple circumstantial and socio-cultural barriers to cervical screening that are unlikely to be overcome simply by the introduction of a new test. This assumption was reinforced by the 14.8% of under-screened women who declined the offer of self-collection when it was explained to them by a clinician, feedback from women in the research study who declined self-collection and the poor response to screening invitation letters.

The engagement of Aboriginal women in the NCSP will require particular attention. Studies have revealed a fear in Aboriginal women arising from a lack of trust in treatment and an apprehension and confusion with the healthcare system generally.^{28, 29, 30} The literature demonstrates that these fears inhibit Aboriginal women's willingness to access healthcare for cancer treatment for a number of reasons. Tang and Browne argue that the Aboriginal experience of mainstream healthcare services is 'invariably embedded in the history of colonization and in current political discourses, including racializing discourses that shape policy and everyday interactions'.³¹ Logan and McIlfatrick found that this fear often results in non-attendance for Aboriginal women accessing cervical screening.³² This fear is also interlinked to the barrier of embarrassment and shame and reinforces the need for health providers to have strong cultural competency and a good understanding of their local communities. Encouragingly, the pilot showed that many under-screened Aboriginal women were receptive to self-collection when it was offered by a trusted health care professional in a supportive environment.

Preparing for Renewal

Different degrees of readiness for self-collection were highlighted across health services. Although the three health services achieved similar participation rates, there were differences in their implementation models and in the challenges they faced. Despite the enthusiasm with which health providers reflected on the pilot, it is worth noting that project leads had to continually promote the pilot within their services. This was most taxing at the largest pilot site which had a large number of staff spread over multiple locations, requiring information and support regarding issues such as pathway clarification and data collection requirements.

²⁸ Cancer Council NSW (2015) *Aboriginal Patterns of Care Project*, accessed at <<https://www.cancercouncil.com.au/aboriginalcancer/research-information-findings/apocc-project/>>, December 2016

²⁹ Shahid, S., Finn, L. and Thompson, S. 'Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting', *The Medical Journal Of Australia*, 2009, vol. 190, no. 10, pp. 574-579, p 577.

³⁰ Prior, D. 'The meaning of cancer for Australian Aboriginal women; changing the focus of cancer nursing', *European Journal of Oncology Nursing*, 2009, vol. 13, no. 4, pp. 280-286.

³¹ Tang, S. Y., and Browne, A.J. (2008) in Newman, C.E., Gray, R., Brener, L., Jackson, C., Johnson, P., Saunders, V., Harris, M., Butow, P. and Treloar, C. (2013) 'One size fits all? The discursive framing of cultural difference in health professional accounts of providing cancer care to Aboriginal people.' *Ethnicity and Health*, vol. 18, no. 4, p. 435.

³² Logan L. and McIlfatrick, S. 'Exploring women's knowledge, experiences and perceptions of cervical cancer screening in an area of social deprivation', *European Journal of Cancer Care*, 2011, vol. 20, pp. 720-727.

All health services will need to plan and prepare for Renewal. Process decisions will need to be considered and the whole practice engaged, to ensure services are Renewal-ready. For some services it may be appropriate to appoint a cervical screening provider (nurse or GP) to coordinate activities during the period of change. Other services might choose to engage a small group of staff, or the Practice Manager.

As self-collection will be offered opportunistically to eligible under-screened women, an important step in ensuring health services are Renewal-ready will be to ensure patients' cervical screening data is comprehensive and up-to-date. Two of the three pilot sites found this challenging, and there will no-doubt be many health services in the same situation.

Compliance with the screening pathway

The most notable risk with introducing self-collection is that women will be willing to complete a self-collection HPV test, but unwilling to participate in the more-invasive follow-up tests. Over a quarter of women who had HPV detected either refused LBC follow-up or did not return for a follow-up consultation. This may not be surprising given the high numbers of under-screened women experiencing disadvantage, but poses a clear risk for Renewal. The risk of non-compliance puts an onus on service providers to carefully explain HPV, the self-collection HPV test, test results and any required follow-up, and to provide the support necessary to assist women to complete follow-up testing if required. Many services have additional supports in place. Others may need to plan accordingly.

Ensuring previously under-screened or never-screened women who have oncogenic HPV detected (not 16/18) complete a 12-month follow-up test may also be a challenge. There was some indication in the pilot, albeit anecdotal, that these women may be reluctant to re-engage. At the time when early participants from BADAC who had oncogenic HPV detected (not 16/18) were due for a 12-month follow-up, there were reports of some women not responding to prompts and others cancelling appointments.

Although the screening pathway is generally clear, there are bound to be variations in how it is interpreted by service providers, and adjustments made for particular circumstances. An example of this was one of the women who had oncogenic HPV detected (not 16/18) but refused to have follow-up LBC. Her health care provider was able to convince her to complete another self-collection HPV test in 12 months. Although this has delayed a definitive result, it was considered a good compromise given the woman's circumstances.

Although not a feature of the pilot experience, with only one woman having completed a colposcopy, colposcopy provision will be an important consideration for Renewal. With current services in the public system stretched, new arrangements will be needed to fast-track under-screened women who have HPV detected (16/18) as they are more likely to be at risk of significant lesions, and potentially, harder to engage in follow-up testing.

Re-screening

The re-screening of previously under-screened women who participate in self-collection poses an important issue for Renewal. A recent self-collection study conducted in Italy showed that self-sampling can be useful to increase overall participation, but if used only once, does not seem to increase the proportion of women regularly screening.³³ Women in the pilot reported wanting to continue with self-collection in the future. As the pathway stands, this would not be an option for them unless they delayed screening for seven years. Having re-engaged these women with the NCSP via self-collection, it would seem illogical to potentially lose them if self-collection was not an option when they were next due to screen.

The experiences of the pilot and the findings of the research study provided important learnings that have led to a range of recommendations for self-collection in the NCSP.

³³ Del Mistro, A., Frayle, H., Ferro, A., Fantin, G. Altobelli, E. and Rossi, P.G. 'Efficacy of self-sampling in promoting participation to cervical cancer screening also in subsequent round' *Preventive Medicine Reports*, 2017, vol. 5, pp 166-168.

6 Recommendations

The following recommendations for Renewal have arisen from the pilot evaluation and have the support of the Steering Group. They form the basis of a best practice model for implementing self-collection. There is recognition that some approaches may not be feasible in some settings and that health service training on Renewal and resourcing will be provided by the Australian Government Department of Health.

Considerations for the screening pathway

- The screening pathway implemented in the self-collection pilot is appropriate for Renewal and delivered encouraging increases in screening participation among previously under-screened women.
- Implementation of the self-collection screening pathway requires some flexibility on an as-needs basis to increase the likelihood of under-screened women completing the pathway. For example:
 - Women who have oncogenic HPV detected (not 16/18) and decline a follow-up test with a speculum examination should be offered a second self-collection HPV test in 12 months. This could be considered part of the same screening event because the women have not received a definitive result. As this approach may delay diagnosis of abnormalities in under-screened women, it should only be an option for women who would otherwise be unlikely to complete the screening pathway, and who accept that they will need further testing if the second self-collection HPV test also shows oncogenic HPV detected (any type).
- Under-screened women who have oncogenic HPV detected (any type), and are recommended to have colposcopy regardless of their cytology result, should be managed in the same way as women from the wider screening program who have possible HSIL or HSIL findings on reflex LBC. This would see self-collection participants prioritised for colposcopy, ideally within 8 weeks.³⁴ Reasons include the likelihood of more advanced lesions in under-screened women and the potential for loss-to-follow-up with this cohort of women who may have intermittent support. The potential for psychosocial distress in this group should also be taken into consideration and additional support provided to assist women who have been referred to a gynaecologist.
- State governments should consult with colposcopy providers to ensure there is capacity within the public health system to meet demand for prioritised referrals. A short-term plan is needed to address colposcopy access for women on the self-collection pathway in the first years of Renewal. Access and capacity in rural areas should also be addressed. Suggestions include appointing a dedicated colposcopist for women who self-collect and have HPV detected (16/18) and/or appointing colposcopists who are able to provide outreach services. Self-collection participants should be identified on referral forms and on colposcopy clinic databases.
- Under-screened women who complete self-collection HPV tests should continue to be given the option of self-collection in the future without having to become two years overdue for screening on each screening round. This would see women who were initially under-screened offered a standard cervical screening test in 5 years time, and then immediately given the option of self-collection if they refuse a standard test. This should be flagged in medical software and potentially at the National Cancer Screening Register.

Health service preparation

- Health services will need to consider their options for managing the transition to Renewal and embedding HPV self-collection for under-screened women into their usual practice. Where resources are available, and where services support a high volume of under-screened women, identifying a cervical screening provider (nurse or GP) to coordinate the required changes for self-collection is recommended.

³⁴ Cancer Council Australia Cervical Cancer Screening Guidelines Working Party. National Cervical Screening Program: Guidelines for the management of screen-detected abnormalities, screening in specific populations and investigation of abnormal vaginal bleeding. Cancer Council Australia, Sydney (2016).

- A whole-of-practice approach to Renewal is recommended, with all staff adequately trained on the changes to the NCSP and self-collection. Services will need to determine which of their practitioners will provide self-collection consultations – nurse cervical screening providers, GPs or both, remembering that under-screened women are most likely to engage if they know and trust their health practitioners. Given the vulnerability of many under-screened women, special arrangements should be considered to support women as they receive their results and attend any follow-up testing.
- All health services should conduct a clinical data audit ahead of Renewal to identify their under-screened population.
- All health services should maintain comprehensive data on their patients' screening history to allow them to opportunistically offer self-collection to eligible women identified as being under-screened. Routinely seeking women's permission to contact the National Cancer Screening Register and up-date screening records has been shown to be an effective strategy for improving the integrity of screening records.
- With the transition to Renewal, medical software systems need to differentiate a provider collected HPV test from a self-collected HPV test. This may require changes at the practice level to support recall systems.
- Health practices should ensure all staff record screening offers and women's responses, and that re-screening dates are correctly and consistently recorded in their patient management systems.
- Health providers need specific training and resources on the barriers and enablers affecting under-screened women to ensure they have the skills and strategies for effective engagement. A well informed workforce will be able to offer culturally sensitive, safe and compassionate care to women who may be facing multiple hardships and are unable to prioritise cervical screening.

Laboratory preparation

- As Renewal will involve entirely new processes and a redesign of laboratory systems and data collection, planning for self-collection should be factored in early. It may be useful to identify a laboratory lead for self-collection who can coordinate service preparation and liaise with health services.

Community engagement – community organisations and Aboriginal Controlled Community Health Organisations

- Community-based activities that engage and inform local communities about changes to the NCSP with Renewal are strongly encouraged. For communities likely to include under-screened women, these will be important avenues for socialising the concept of screening, introducing self-collection and building community support. Various health and community organisations could undertake activities locally, which may include information sessions in languages other than English, women's health days and/or guest presentations at women's group meetings. It is important to ensure consistent messaging on Renewal is provided nationally and appropriate engagement and consultation with peak bodies who represent priority under-screened groups is undertaken.

Additional considerations for the Australian Government

We ask that the Department of Health considers the potential for an alternative screening pathway for Aboriginal women that sees them offered self-collection without needing to be under-screened. This should be available to all Aboriginal women who decline a conventional cervical screening test. This recommendation has been made in light of evidence from our research study which clearly showed that Aboriginal women were willing to participate in self-collection, and in acknowledgement of the low participation rates of Aboriginal women in cervical screening and the higher incidence and mortality of cervical cancer in Aboriginal women compared to non-Aboriginal women. This approach aligns with the Australian Government's willingness to explore alternative pathways for Aboriginal communities as part of the National Bowel Cancer Screening Program.

7 Conclusion

The evaluation of the Self-collection Pilot showed that the project clearly met its aim and objectives.

The offer of self-collection within a clinical setting was largely embraced by under-screened women. A participation rate of 85.7% was achieved, which, combined with feedback from women in the research study, demonstrated that self-collection was an acceptable, and welcome alternative to a practitioner collected cervical screening test. The nature of the self-collection test helped to empower women and reduced some of the barriers under-screened women had faced to participating in cervical screening in the past. The new test, together with the support and information provided to women by their health providers, helped them to overcome their apprehensiveness with cervical screening.

Health services were able to implement the screening pathway, but relied heavily on the support of their project leads. To successfully implement self-collection under Renewal, services will require training, resources and support to ensure staff are fully-briefed on the screening pathway and that quality processes and consistent data collection methods are put in place.

Ensuring full compliance with follow-up testing after HPV is detected will remain a challenge for health services. Under-screened women who have declined a Pap test in the past may be unwilling to have a follow-up test that will involve either a practitioner-assisted cervical screening test (using a speculum) or a colposcopy. It will be important for practitioners to carefully explain the implications of having HPV detected to women, and the risks in not completing follow-up testing if required. Additional measures to support women when receiving their results and during follow-up testing are recommended.

The importance of a culturally-sensitive, supportive workforce cannot be under-estimated. As under-screened women are likely to be experiencing multiple circumstantial and socio-cultural barriers to cervical screening that won't be overcome simply by the introduction of a new test, health providers need to have strong cultural competency and a good understanding of their local communities.

The pilot evaluation has led to a range of recommendations for governments and health services to support implementation of self-collection under Renewal. They include considerations for implementation of the screening pathway and suggestions for health services to assist them to embed self-collection into their usual practice.

The experience of the pilot and the results from the research study should give health services and policy makers increased confidence that the introduction of self-collection is likely to lead to higher participation in cervical screening, and in turn, to improved health outcomes for under-screened women who may be at risk of cervical cancer.

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9 Appendices

9.1 Appendix A – Pilot Sites

- Ballarat and District Aboriginal Co-operative (BADAC)

The first pilot was delivered at BADAC, the Aboriginal Community Controlled Health Organisation for the area. It opened in 1979 and provides a wide range of services to the Aboriginal community. The health arm to BADAC is Baarlinjan Medical Clinic. Baarlinjan takes a holistic approach to medicine. This site was selected as the first pilot location given the high levels of trust and relationships formed between the service, the Women's Nurse and the community. The Women's Nurse led the pilot as she had a significant understanding of the under-screened population. It should be noted that BADAC had conducted a clinical data audit preceding the pilot and knew which women were eligible thus, possibly, contributing to the high response rate.

- cohealth

Phase two of the pilot was delivered at cohealth, a community health service which provides services in north, west and inner Melbourne. The pilot was conducted at seven cohealth sites. Altogether cohealth has over 850 staff and 44 local sites and is the culmination of three community health organisations that joined together in 2014. cohealth clients are often people from marginalised communities who face multiple health disadvantages. In particular it supports people living with chronic illness, mental illness, children, Aboriginal people and Torres Strait Islander people, refugees and asylum seekers, people who experience homelessness, people with disabilities and people who have alcohol or other drug issues. cohealth services are positioned in areas with extensive public housing, a high incidence of homelessness and large numbers of new migrants. Over 110,000 people a year use cohealth services. Fifty percent of cohealth clients were born overseas.

- Access Health

Access Health is based in St Kilda, an inner-city suburb of Melbourne with high rates of sex-work, drug use and homelessness. Access Health targets people with such experiences to provide accessible, responsive primary health care that enhances health and well-being. The majority of Access Health's clients are men (only 38.1% are women). Access Health has significant relationships with the local Aboriginal and Torres Strait Islander community, with 23% of visits (230 per month) being from Aboriginal and Torres Strait Islander people.

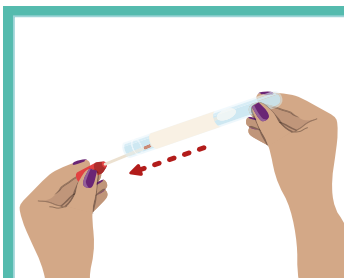
9.2 Appendix B – How to Take Your Own HPV Test



VCS Pathology

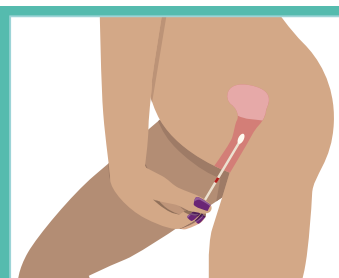
HOW TO TAKE YOUR OWN HPV TEST

SIMPLY FOLLOW THE STEP-BY-STEP INSTRUCTIONS



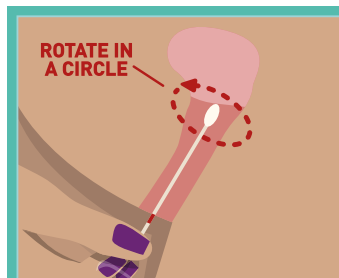
Step 1

- Lower your underwear.
- Twist the red cap and pull out the swab.
- Look at the swab and note the red mark closest to the tip.



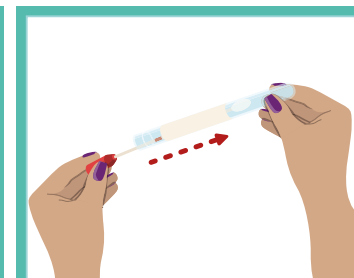
Step 2

- Get in a comfortable position.
- Insert the swab into your vagina, aiming to insert to the red mark. It may be easier to use your other hand to hold the skin of your vagina.



Step 3

- Rotate the swab gently for 10-30 seconds. It should not hurt.



Step 4

- Remove the swab, and place back in tube.

9.3 Appendix C – Explaining the HPV Test

Explaining the HPV Test

Why do I need this test?

You have been given the option of doing a human papillomavirus (HPV) test instead of the normal Pap test. Both the HPV and Pap tests help identify changes before they become cervical cancer. You can do the HPV test yourself, is more comfortable and it can give more warning about cervical cancers.

HPV is the virus that can cause cervical cancer. It is like the common cold of sexual activity, most women have it at some point in their lives.

What will the test show?

The test will show if you have HPV in your vagina or cervix. The body can clear most HPV infections. But if your body can't get rid of some types of HPV and the virus can cause changes to the cells of your cervix. If cells change and are not picked up early and treated, they can develop into cervical cancer.

How good is the test?

This test is as good as a Pap test done by a doctor or nurse.

Can I do the test wrong?

Most women do this test correctly. It's important to make sure the stick is inserted in your vagina and rotated. Remove the stick and replaced in the tube without cleaning.

Why do I need this test if I had the HPV vaccine?

The HPV vaccine only protects against the two most common types of HPV, so it's important to check for other types of HPV.

How will I get my results?

The doctor or nurse will contact you to schedule an appointment to discuss your results.

What type of follow-up will I need?

Result	Follow-up needed
You do not have HPV	Have regular cervical screening
You have HPV but not HPV types 16 or 18	You will need a Pap test by your nurse or GP and may need further follow-up
You have HPV types 16 or 18	Your doctor will refer you to a specialist for more tests

Risks

The HPV test you've taken does no physical harm. But you may have become upset or embarrassed if you find out you have an HPV infection. Remember, most women get HPV at some time in their lives.

9.4 Appendix D – Photos from BADAC’s Koori Women’s Day held in August 2015 to introduce the self-collection pilot



Aboriginal comedian and actor Tammy Anderson explains the female reproductive system.



BADAC’s Women’s Nurse, Sandy Anderson, uses an apron to explain cervical screening.



Tammy mingles with the audience of largely Aboriginal women.



Tammy and Sandy explain self-collection HPV testing.

9.5 Appendix E - Demographics of Research Study Participants

	Identifies as Aboriginal*		Born in country other than Australia		Language other than English spoken at home		Responsible for children at home	
BADAC	12	100%	0	0%	2	17%	6	50%
cohealth	1	5%	6	30%	5	25%	3	15%
Access Health	1	12.5%	0	0%	1	12.5%	2	25%
Total	14	35%	6	15%	8	20%	11	27.5%

*Women were asked if they identified as Aboriginal or Torres Strait Islander – all identified as Aboriginal.

Age	27-49		50-74	
BADAC	8	66.5%	4	33.5%
cohealth	8	40%	12	60%
Access	7	87.5%	1	12.5%
Total	23	57.5%	17	42.5%

Only one woman at cohealth and another woman at Access identified as Aboriginal. The Aboriginal woman at cohealth also identified as Stolen Generation.

Six women were born in countries other than Australia. All of these women were clients at cohealth. They were from:

- Ethiopia
- Eritrea
- Croatia
- Lebanon
- New Zealand
- England

One woman required a translator. Only two of these women (the woman from Eritrea and the woman from Ethiopia) had recently arrived in Australia and neither of these women had received a Pap test before.

9.6 Appendix F - Summary of key findings

The pilot found self-collection to be an effective tool for the recruitment and participation of under-screened women in the National Cervical Screening Program. The evaluation noted the following findings in relation to the pilot objectives:

Objective 1 - To recommend an acceptable alternative self-collection pathway for under-screened women for the purposes of Renewal

- There was good evidence that self-collection was an acceptable cervical screening option for many under-screened women, and that the screening pathway used during the pilot was able to be effectively implemented in a variety of health service settings.
- The active engagement of under-screened women at safe locations with health workers known to them supported the uptake of self collection.
- A screening participation rate of 85.7% was achieved for under-screened women offered self-collection within a clinical setting. This is a promising indication that self-collection under Renewal will lead to an increase in cervical screening participation for under-screened women.
- Of the 14 women who had oncogenic HPV detected (any type) four, (28.6%) either refused LBC follow-up or did not return for a follow-up consultation.
- Although the process of self-collection HPV testing will remove some of the barriers women have experienced in completing Pap tests, the circumstantial/socio-cultural barriers experienced by many under-screened women from disadvantaged backgrounds are likely to continue to be barriers to cervical screening and more broadly, to them accessing health care.

Objective 2 - To develop a clinical practice approach (protocols & processes)

- Health services introduced a range of effective internal processes to support the pilot and implementation of the screening pathway ran smoothly across the three pilot sites.
- Compliance with follow-up testing was high, with 12 of the 14 women who had oncogenic HPV detected (any type) (85.7%) having since returned to their practitioner for a follow-up consultation and/or completed follow-up testing within 90 days of self-collection. Compliance with screening pathway within 180 days was 91.6%.
- Although there was some confusion with some elements of the pathway (such as the long-term screening recommendations for participating women), most issues were largely resolved during the pilot.
- Two of the health services experienced challenges in identifying their under-screened population, one because their patient record system did not have comprehensive data on women's screening history, and the other because of the transient nature of their patient population.
- Practices acknowledged that under-screened women are likely to require support as they receive their results and whilst having follow-up testing.
- VCS Pathology modified some of its services to support the pilot. The laboratory prioritised processing of self-collection test HPV tests and no charges were made to participants for laboratory services. VCS Pathology was able to distinguish results for HPV types 16, 18 and other - a requirement for cervical screening tests undertaken in the Renewal.
- Concerns were raised about the provision of colposcopy for women on the self-collection pathway under Renewal, given the long wait times in the public system and the predicted increase in demand in the early years of Renewal.

Objective 3 – To develop resources to support the workforce to implement self-collection pathways for under-screened women

- The resources developed for the pilot were generally well received and could easily be modified to support self-collection under Renewal.
- Invitation letters were considered the least useful strategy for engaging under-screened women in self-collection, with more personal engagement strategies and opportunistic invitations preferred.

Objective 4 - To prepare the workforce — Aboriginal Health Workers, practice nurses, general practitioners, allied health providers and persons performing colposcopy — ahead of Renewal

- The health workforce required training and support to implement self-collection. It was beneficial to have a proactive project lead available to drive the project and support its implementation within each service.
- Specific guidance is required for health practitioners on the management of unsatisfactory/invalid results.
- With a significant array of issues to consider when engaging under-screened women in self-collection, the importance of a well-trained workforce is clear. Health practitioners need to be able to clearly and sensitively explain the self-collection HPV test, results and follow-up procedures to women who may have complex needs.