

HPV self-sampling for cervical cancer screening: engaging under-screened rural and remote Aboriginal women

Laurinne Campbell¹, Anne Vail¹, Georgia-Lee Pollard², Dr Jannine Bailey², Tegan Dutton², A/Prof Tracy Robinson³, Dr Sunil Jacob⁴, Rene Wykes⁵, Megan O'Connor¹, Cassandra Kelly¹, Nichole Callan¹, Kate McKay¹, Rozlyn Tiffen¹

¹Marathon Health, ²Bathurst Rural Clinical School, Western Sydney University, ³University of Canberra, ⁴Dubbo Medical and Allied Health Group, ⁵Murdi Paaki Regional Enterprise Corporation

Introduction

Cervical cancer is the second most common cancer in women and the sixth leading cause of death worldwide¹. Traditionally detected using a Pap test, screening rates using this method vary dramatically both between countries and between certain population groups within the same country¹. In Australia, the incidence of cervical cancer in Aboriginal women is more than twice that of non-Aboriginal women and their mortality rate is fourfold higher². Despite this, Aboriginal women are significantly under screened with respect to cervical cancer screening due to complex cultural and socio-economic factors that are a barrier to participation in routine Pap testing³. Given that more than half of cervical cancers occur in never-screened and under-screened women⁴, increasing the participation of Aboriginal women in cervical screening programs is crucial.

The recent discovery of Human Papilloma Virus (HPV) as the primary causative agent in most cervical cancers⁵ has opened the door to HPV testing as a means of detecting prospective cervical cancer. Current research suggests that HPV testing as a primary screening test is more sensitive than a traditional Pap test and provides better protection against cervical cancer⁶. In addition, HPV testing as a primary screening test allows for self-sampling which may overcome some of the barriers to Pap testing, including being less-obtrusive, and this may make it a more acceptable screening practice for Aboriginal women⁷. An important factor for improving Aboriginal women's uptake of cervical screening is the acceptance and support of the Aboriginal community, which as Miller⁸ maintained, will require ongoing consultation ideally via a community engagement model.

The present pilot study seeks to explore the feasibility and acceptability of HPV self-sampling as a cervical screening approach for Aboriginal women using a nurse-led community engagement approach. A secondary aim is to facilitate and strengthen connections between under-served Aboriginal communities, female Aboriginal community workers and primary health services.

Methods

This study was approved by the Aboriginal Health & Medical Research Council Ethics Committee (Approval No. 1188/16), with reciprocal approval granted by the Western Sydney University Human Research Ethics Committee (Approval No. H11837).

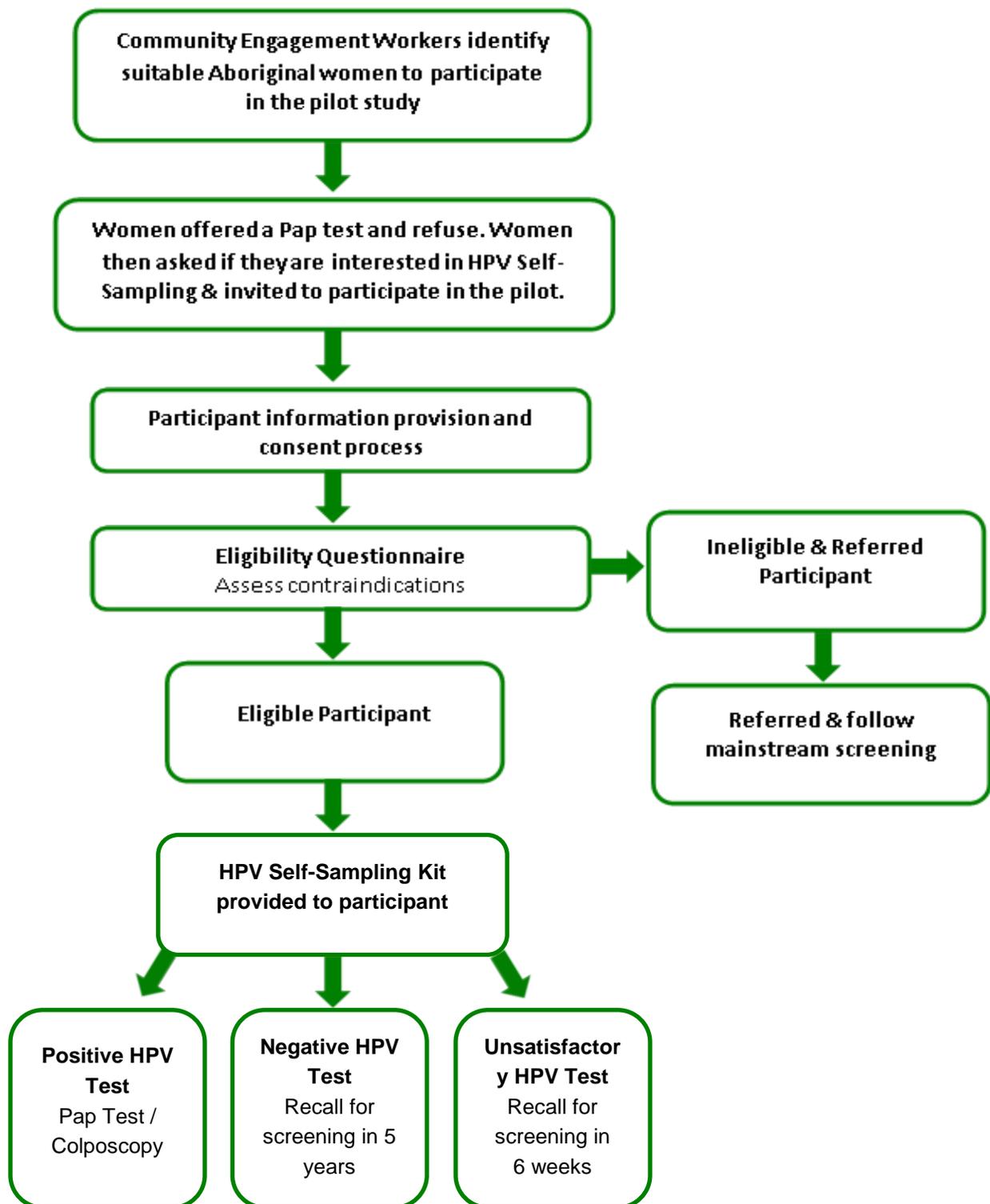
Following a comprehensive collaboration and co-creation process, eight rural centres in Western NSW agreed to participate in the study with a targeted sample size of 266 women across the eight regions. Marathon Health Primary Healthcare Nurses (PHCNs) are working alongside Local Aboriginal Land Council Community Engagement Workers (CEWs) to identify, engage with, and provide culturally appropriate education to Aboriginal women around the value of cervical cancer screening, including that of the current standard Pap test in the first instance.

Following this initial engagement and education process, the women are firstly offered assistance in procuring a regular Pap test by the CEW (Figure 1). Should they refuse the offer of a Pap, the CEW invites them to participate in the study and carries out the informed consent process. Consenting women are then assessed for eligibility for the study via an interview with the CEW. Women are considered ineligible to participate if they: do not identify as Aboriginal; are currently pregnant; are menstruating at the time of participation; have had a hysterectomy; disclose contraindications such as recent unexplained heavy bleeding or discharge; or present with medical issues that could affect their consent e.g. moderate to severe intellectual disability. In most cases, a person younger than 25 or older than 64 years of age and a person that has had a Pap test within the last 4 years are ineligible, however the lead Nurse on the project has the ability to assess each participant individually and, where necessary, allow participation. Ineligible participants are provided with relevant information on request relating to their answers from the eligibility questionnaire. Prospective participants who present with the contraindications listed above are referred to the appropriate services for treatment. Prospective participants who do not usually reside within the study communities but who wish to take part in the study are still eligible to participate, provided they meet the abovementioned eligibility criteria.

Eligible participants are invited to conduct the HPV self-sampling with the CEW providing thorough verbal instructions as well as a culturally appropriate instruction sheet complete with pictures for the participant to follow along with. The participant is shown to a private room where they can conduct their self-sample, or in some cases were able to complete the sampling in the privacy of their own home. Self-sampling kits are returned firstly to the CEW who then returns them to the nominated PHCN for that region, or are returned directly to the PHCN. Re-identifying information is retained by the PHCN to allow for follow up to occur with all participants, regardless of the outcome of their HPV test. All self-samples are sent to the Victorian Cytology Service for HPV testing, and results are forwarded to the participant via the PHCN as well as their nominated GP (or the project GP if they do not have a regular GP).

Follow-up by the PHCN includes a discussion of the results and referral information if required. Appropriate referral for follow-up services if an abnormality is detected is conducted as per Figure 1. A minimum of three attempts at contact is made by the PHCN for each participant irrespective of HPV screening results. Clarification regarding the meaning of the result is offered and assistance to referral pathways is also offered as required. At the end of this phone call, an anonymous follow-up evaluation questionnaire is administered to consenting participants by a different PHCN who was not involved in the initial collection of data and self-samples within that community, to allow participants the confidentiality and comfort to provide both positive and negative perspectives in the evaluation survey. The survey explores participant perspectives on the process and the service. It uses a combination of rated responses and open ended questions to ask the participant to respond to their experience with staff related to the project. Included are two questions regarding the self-sampling kit including instructions, three questions relating to the receiving of results process and three questions relating to their overall experience in participating in the project.

Figure 1: Screening and referral pathways



Results

Of the expected 266 sample size, 47 (18%) participants have been recruited, and data collection is complete for 23 of these participants. Data collection is ongoing and follow-up surveys are currently being completed and will be included in the final analysis. The following results are representative of the 23 participants for whom data collection is complete.

Participants are from seven communities across the study region. Age of participants ranged from 19 to 65 years. One participant completed only the final qualitative question in the follow-up survey and thus the quantitative follow-up survey findings are based on 22 respondents.

Participant feedback on the acceptability of the HPV self-sampling test

Overall, the process of distributing and collecting the HPV self-sampling test was perceived as being very positive and acceptable amongst all participants. Participants believed the process was clearly explained by the Aboriginal CEW; the HPV kit provided everything to complete the test; there were no problems in following the instructions provided; the process was simple; and they were able to ask questions and get results in a timely manner. This is supported by the following quotes:

“Very clear instructions”

“Yes had everything I required. I am a busy mother so don't want to have to sift through unnecessary readings”

It was also mentioned in the survey's comments that having the PHCN present at the recruitment and data collection phase was beneficial:

“I can't read really well but the nurse was very clear on explain the “what to do” to collect the sample, the pictures on card were good also”

“Yes it was also good having the nurse beside her (Aboriginal Community Engagement Worker) so I knew it was professional and accurate”

In response to whether participants felt that they were provided with confidentiality and privacy, on a scale of 1 (very unsatisfactory) to 5 (highly satisfactory), 86% (19) were highly satisfied, one participant was satisfied, and two were neither satisfied nor unsatisfied. Some participants did not feel comfortable handing the swab back to the PHCN at the Local Lands Council, and three participants mentioned they would prefer the swab not being handed back in a clear bag.

The majority of participants (78%; 18) thought that the test results were provided in an easy to understand format. However, the open ended comments suggest that some of these participants actually relied on the PHCN making contact with them to explain the results. This is demonstrated by the following quotes:

“Couldn't really understand the results on paper but understood the nurse clearly”

“The pathology made no sense to me but when the nurse called and discussed I understood then”

The three participants that rated the format of the results as unsatisfactory made the following comments:

“No I didn't understand them—threw the letter in the bin—made no sense to me. Need a medical degree to understand. Having the nurse call me and explain was very good”

“Didn't really understand the results. I am glad the nurse explained them to me given I need to go to see the doctor for a pap test”

“Not really—glad (the Nurse) rang to talk me through them”

All respondents would use the HPV self-sampling screening kit again and would recommend it to others. Reasons for using the test again and recommending it included:

- It is easy and simple
- It is free of pain and discomfort
- It is free
- It is quick, accessible, convenient, can be completed in the patients home, you do not have to travel to and wait at a Doctors Surgery
- It is confidential, more dignified, there is no shame, you are in charge/control of your own women’s business.

These are supported by the following quotes:

“No shame, no problems with me old man worrying about me going to the doctors and getting undressed down there”

“(I) was able to do it myself, at my pace at my place”

“I haven’t had a post-natal check since my 5th kid, I can tell you after all these babies I don’t hang around no doctors to have a fiddle around down there”

“I would recommend this service to all other women. I would much prefer to do the test myself than have a pap smear”

Outcomes of the HPV self-sampling test

Six participants (6; 26%) had never had a pap test, 10 (43%) had previously had a pap test but not within the last 4 years, 5 (22%) had received a pap test within the last 4 years, and data was unknown/missing for 2 participants.

Four (4; 17%) of the 23 participants tested ‘positive – high risk other’, one result was invalid, one result has not yet been received, and the remaining 17 were negative. Of the four positive tests, two participants had never had a pap smear and two had previously had a pap smear, but not in the last 4 years. All four participants were under 40 years of age and from different communities.

Two of the four women that tested positive explained the importance of the HPV self-sampling test, particularly as they indicated that it was unlikely that they would have had a pap test in the near future and thus would not have found out they had a positive result. Further, while they were unhappy about having further testing via a pap test, their comments appeared to demonstrate the importance of completing further testing:

“About time this became available. I have to now go and have a pap test because the HPV SS results have come back as a positive—wished I didn’t—wished the HPV SS was able to totally replace the pap test—the world would be a better place for us women when we get to manage our own women’s business”

“Doing the test myself was the best part. I don’t like anyone snooping around down there. If I didn’t do this swab I would not have been alerted positive result—may have been too late if I got around to do the pap test—this may have saved my life”

Discussion

Whilst data collection is ongoing and less than 50% of results have been presented in this paper, it is clear that overall there are positive comments about the process of the HPV self-sampling test, the staff involved and the test itself. The findings demonstrate that the test is accessible, culturally appropriate, easy, dignified, and free of shame. Notably, it supports Aboriginal women to be in control of their own private, or women's, business.

Of particular importance was that the four women who tested positive on the HPV test had not ever had a pap test or had not had one completed in the previous four years. The qualitative responses also indicated that two of the participants had not envisaged having a pap test in the near future. These early results suggest that the HPV self-sampling approach is able to achieve the aim of engaging never screened or under screened Aboriginal women in cervical cancer screening at the outset. More importantly, they appear to be remaining engaged with follow up, even if it means a trip to their GP to have a Pap smear for confirmation.

This study is also demonstrating the importance of having the PHCN involved in the entire process of the HPV self-sampling testing, particularly to explain results and facilitate any necessary referrals and follow-up appointments, especially given that the test results were not easy to understand by some of the participants. The nurse-led community engagement approach adopted here seems to be well accepted and applauded by the community. The breaking down of barriers relating to distance from mainstream services and knowledge and understanding of the process that this approach has enabled is a strength of the model.

At the completion of this pilot, we aim to have developed a model created with and for Aboriginal women. Further, it is anticipated that the results of this study will contribute to the work of others who are trialling the use of self-sampling and will inform the National Cervical Screening Program (May 2017), specifically in relation to Aboriginal women.

Policy recommendation

In rolling out the new National Cervical Screening Program, it is recommended that consideration be given to supporting evidence based programs (such as that reported in this paper) which seek to improve the uptake of HPV self-sampling in under-screened communities and regions.

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Presenter

Ms Laurinne Campbell has an extensive background in rural and remote nursing in primary health care and mental health, being a registered nurse and social worker. She also holds a Family Planning NSW Well Women's Certificate and a Certificate IV in Work Place Training and Assessment. Laurinne lives and works in western NSW communities as a Primary Health Care Nurse for Marathon Health. Her personal exposure of living in the bush has shaped her professional work giving her first-hand experience in navigating the tyranny of distance in accessing services systems. Laurinne's interests include access and equity in accessing health and mental health services in rural and remote communities specifically for women; and developing opportunities in promoting innovative and timely cancer screening.