



WESTERN SYDNEY
UNIVERSITY



marathon
health

Women's business

A pilot of Human Papillomavirus (HPV) self-sampling of Aboriginal women from rural Western NSW communities: Evaluating a Nurse-Led Community Engagement Model

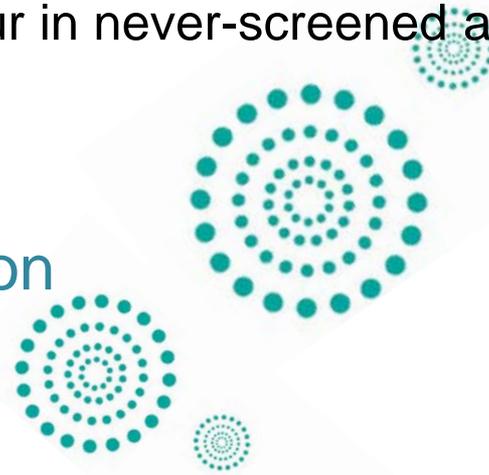
Ms Laurinne Campbell RN,BSW
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Project Rationale

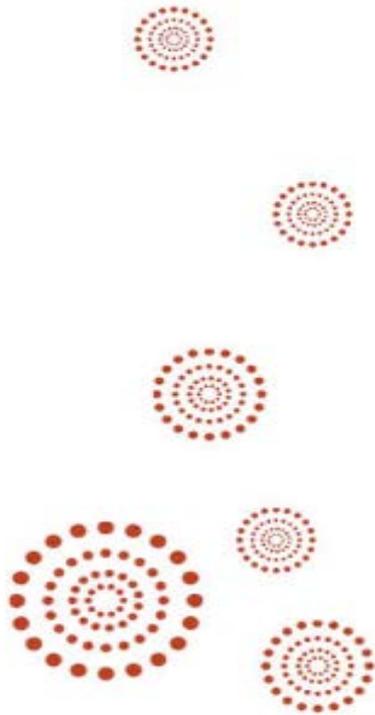
Aboriginal women and cervical cancer:

- Twice the incidence than non-Indigenous women (AIHW, 2015)
- Four times the mortality than non-Indigenous women (AIHW, 2015)
- Screening is significantly lower (DoHA, 2004)
- More than half of cervical cancers occur in never-screened and under-screened women (Sasieni et al, 1996)

Crucial to increase the participation of Aboriginal women in cervical screening Programs.



Project Aim



Assess the acceptability and feasibility of HPV Self-Sampling for Aboriginal women aged 25-64 years from eight rural and remote communities across Western NSW.





Methods



What are the barriers to accessing screening?

➤ Extensive consultation process

- Local Aboriginal Land Councils
- Murdi Paaki Regional Enterprise Corp.
- Central West & Murdi Paaki Aboriginal Women's Gathering Group
- NSW Cancer Institute
- Family Planning NSW
- Western NSW Local Health District Women's Health Nurses
- Victoria Cytology Service
- Dubbo AMS

➤ Barriers identified:

1. Shame factor
2. Pain
3. Screening not a priority in life
4. Bulk billing
5. GPs male and non-English speaking background.



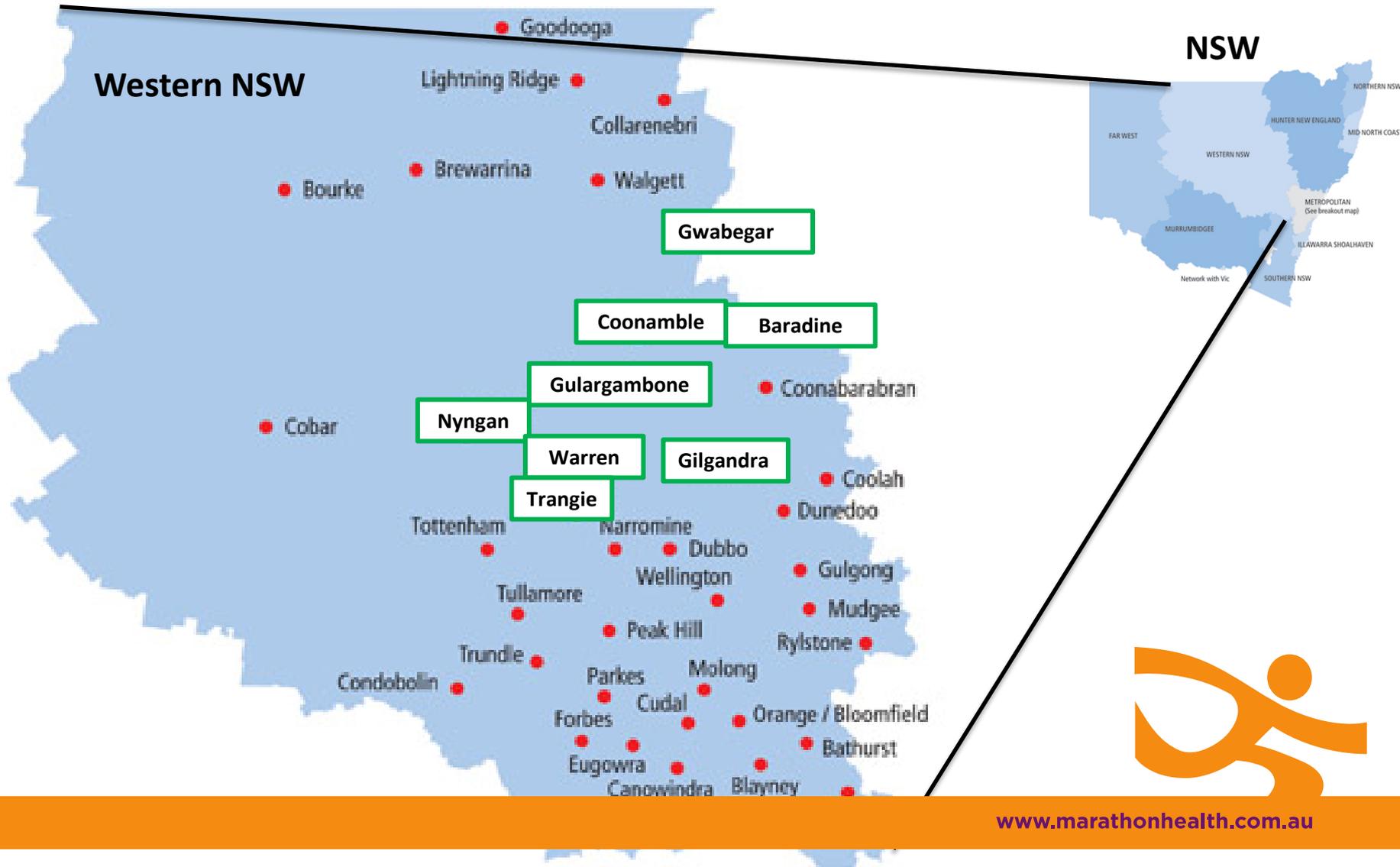
A Nurse-Led Community Engagement Model

- Partnership with the Local Aboriginal Land Councils (LALC)
- A **Primary Health Care Nurse** (PHCN) is dedicated to each community
- A female Aboriginal **Community Engagement Worker** (CEW) employed in each community to engage local Aboriginal women

Miller et al (2012)



Project Sites



Developing Culturally Appropriate Materials

BEFORE

AFTER

iPap VCS Pathology **HOW TO TAKE A VAGINAL SWAB** INSTRUCTIONS

Simply follow the step-by-step instructions below:

1

WHAT DOES THE KIT CONTAIN?

- A cotton swab in a plastic tube
- A plastic ziplock bag
- This instruction sheet
- Pathology information form
- A padded 'Reply paid' envelope

2

SWAB:

- Remove the swab out of its plastic tube, just twist and pull it
- If possible, avoid taking the sample during your monthly period

3

POSITION:

- Undress from the waist down
- Get into a comfortable position as shown above while holding the swab in your hand

4

TAKING THE SAMPLE:

- Gently spread open the folds of skin at the vaginal opening with your other hand.
- Insert the swab into your vagina directed towards your lower back about two inches (5cm), half the length of a finger. This is similar to how you would insert a tampon.

5

TAKING THE SAMPLE (CONTINUED):

- Rotate the swab gently for 10-30 seconds. There should be no pain or discomfort.

WHAT IF I MAKE A MISTAKE?

It is okay to continue with the vaginal sample if you:

- Have touched it with your fingers
- Have dropped the swab onto a dry surface

If you have inserted the swab into your vagina but are unsure if the distance is correct, please return the completed kit.

We will send another kit if we cannot get a result from your swab for any reason.

DO NOT COLLECT THE SAMPLE IF YOU ARE PREGNANT

Please call the Registry on 03 9250 0399 to request a kit to be re-sent if it:

- GETS WET/OR
- IS DAMAGED

>> Instructions overlaid on how to pack and post the sample...

marathon health VCS Pathology **HOW TO TAKE A VAGINAL SWAB** INSTRUCTIONS

Simply follow the step-by-step instructions below:

1

WHAT DOES THE KIT CONTAIN?

- A cotton swab in a plastic tube
- A plastic zip lock bag
- This instruction sheet
- Pathology information form
- A Canvas Sista Circle case

2

SWAB:

- Remove the swab out of its plastic tube, just twist and pull it
- If possible, avoid taking the sample during your monthly period

3

POSITION:

- Undress from the waist down
- Get into a comfortable position as shown above while holding the swab in your hand

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TAKING THE SAMPLE:

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- Have dropped the swab onto a dry surface

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We will send another kit if we cannot get a result from your swab for any reason.

DO NOT COLLECT THE SAMPLE IF YOU ARE PREGNANT

Please call Marathon Health Dubbo on (02) 4826 5200 if there is an issue with the swab/screening and speak with a Primary Health Care Nurse

>> Instructions overlaid on how to pack and post the sample...

iPap VCS Pathology **HOW TO PACK & POST THE SAMPLE** INSTRUCTIONS

Simply follow the step-by-step instructions below:

1

RETURN TO PLASTIC TUBE:

- Place the swab into the plastic tube
- Tightly screw the cap onto the tube
- Finish by washing your hands with soap and water

2

COMPLETE FORM AND CHECK LABEL:

- Complete the Pathology information form and check the details. Ensure you write the date of the collection.
- Check the label on the plastic tube is correct
- Your sample does not require refrigeration, even on a hot day. Just keep at room temperature.

IMPORTANT INFORMATION

- Your swab should be posted as soon as possible, preferably within 24 hours of collection
- Store the swab at room temperature until delivery
- Please read the information brochure for information on HPV and cervical cancer
- If possible, avoid taking the sample during your monthly period

3

PACKAGING:

- Place the plastic tube into the ziplock bag
- Then pack the tube and the Pathology information form into the padded reply-paid envelope
- Seal the envelope firmly

4

POST:

- Deposit the reply paid envelope into an Australian Post mail box

IF YOU REQUIRE A REPLACEMENT KIT, OR FOR MORE INFORMATION CONTACT THE VICTORIAN CERVICAL CYTOLOGY REGISTRY ON PH: 03 9250 0399

>> Instructions overlaid on how to take a vaginal swab - DO THIS FIRST...

marathon health VCS Pathology **HOW TO PACK & RETURN THE SAMPLE** INSTRUCTIONS

Simply follow the step-by-step instructions below:

1

RETURN TO PLASTIC TUBE:

- Place the swab into the plastic tube
- Tightly screw the cap onto the tube
- Finish by washing your hands with soap and water

2

COMPLETE FORM AND CHECK LABEL:

- Complete the Pathology information form and check the details. Ensure you write the date of the collection.
- Check the label on the plastic tube is correct
- Your sample does not require refrigeration, even on a hot day. Just keep at room temperature.

IMPORTANT INFORMATION

- Your swab should be returned/handed back as early as possible to the woman who gave you the kit
- Store the swab at room temperature until delivery
- Please read the information brochure for information on HPV and cervical cancer
- If possible, avoid taking the sample during your monthly period

3

PACKAGING:

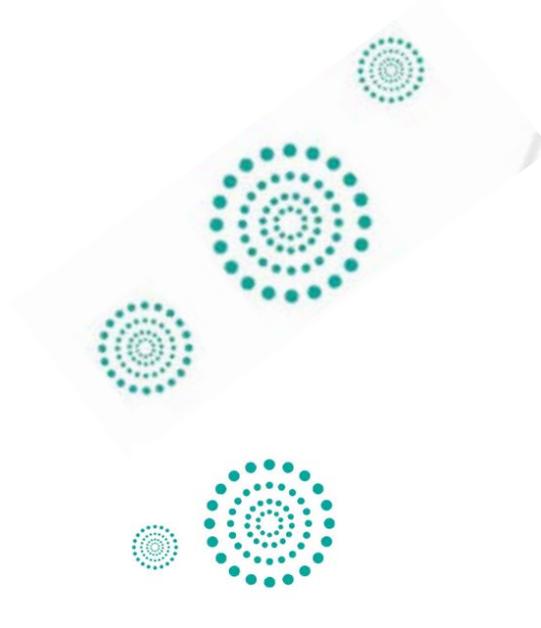
- Place the plastic tube into the ziplock bag
- Then hand the tube and the Pathology information form back to the woman who gave you the kit

4

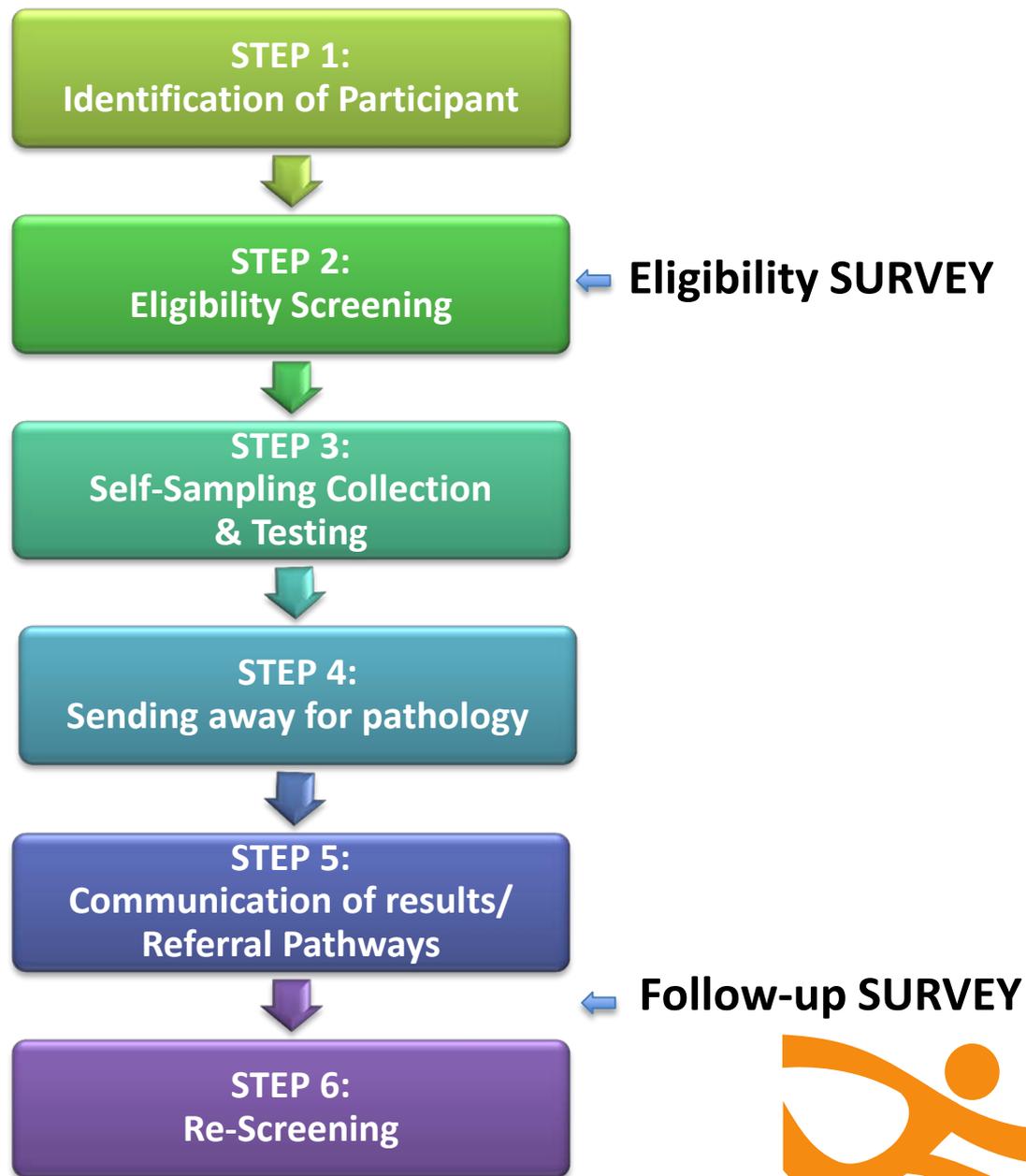
You are welcome to keep the satchel with complements of Marathon Health.

IF YOU REQUIRE A REPLACEMENT KIT, OR FOR MORE INFORMATION CONTACT MARATHON HEALTH DUBBO ON 02 6826 5200 AND SPEAK TO A PRIMARY HEALTH CARE NURSE

>> Instructions overlaid on how to take a vaginal swab - DO THIS FIRST...



Screening & Referral Pathways



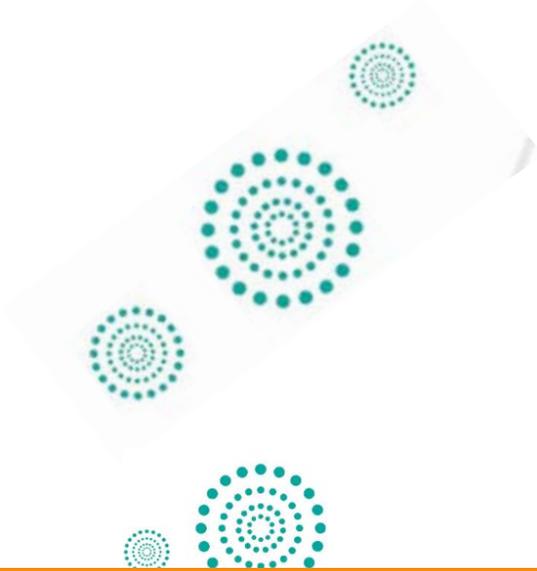
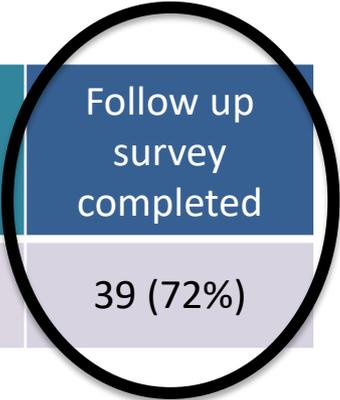


Current Results

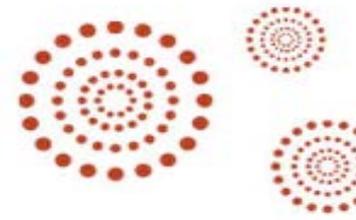


Sample

	Target	HPV tests distributed	HPV tests returned	Ineligible	Total	Follow up survey completed
No.	266	58 (22%)	57 (21%)	3	54 (20%)	39 (72%)



Follow up survey



- ✓ The Aboriginal Community Engagement Worker clearly explained the HPV self sampling process 100% very satisfied (n=37)
- ✓ The HPV self-sampling kit provided everything the participants needed to complete the test 100% very satisfied (n=38)
- ✓ Participants were able to follow the instructions provided 100% very satisfied (n=38)
- ✓ The process of the HPV Self-Sampling test was simple 100% very satisfied (n=38)
- ✓ Participants felt that they were provided with confidentiality and privacy 87% very satisfied (n=38)
- ✓ Participants received the results in a timely manner 94% Yes (n=35)
- ✓ Results were provided in an easy to understand format 74% very satisfied (n=38)
- ✓ Would participants use the HPV Self-Sampling test again? 97% Yes (n=38)
- ✓ Would participants recommend the HPV Self-Sampling test to other women? 100% yes (n=38)

Follow up survey

✓ Participants felt they were provided with confidentiality and privacy (87%)

- Not comfortable with the location of where they completed the test and/or had to hand the swab back
- Would prefer the swab not being handed back in a clear bag

“Shamed me a bit when (I) had to hand (the) swab back to the LALC in the bag which everyone could see”

✓ Results were provided in an easy to understand format (74%)

- The PHCN was able to successfully explain the results to the women over the phone.

“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”



Why would women use the test again and recommend it to others?

- Easy and simple
- Free of pain and discomfort
- Free
- Quick, accessible, convenient
- Confidential, more dignified, there is no shame, in control of own women's business





Qualitative Feedback

“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”

“Save me from having to travel to go to a doctor. Cheaper and more dignified. Now that I know that the test is real and works just fine I will be sure to keep in touch to do it this way - where I am in control of my own private business”

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



History of pap tests and HPV results

	Never had a pap test	Not had a pap test in prev. 4 yrs	Total Positive	Positive 16/18	Positive Other	Invalid	Result not received
n = 39	23% (2 missing)	85% (2 missing)	6 (15%)	1 (3%)	5 (13%)	5 (13%)	1 (3%)

“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 (about the) positive result - may have been too late if I got around to do the pap test - this may have saved my life”



Conclusions

- Has successfully engaged never screened and under screened Aboriginal women.
- Importance of having the PHCN explain results and facilitate referrals.
- The findings demonstrate that the test is accessible, culturally appropriate.
- It supports Aboriginal women to be in control of women's business.





Implications for Future Policy

We hope to contribute to the work of others who are trialling the use of self-sampling to inform the National Cervical Screening Program (December 2017) specifically in relation to Aboriginal women.



References

- Australian Institute of Health and Welfare. Cervical screening in Australia 2012-2013. Cancer series 93. Cat.no.CAN 91. Canberra: AIHW; 2015.
- Department of Health and Ageing. Principles of practice, standards and guidelines for providers of cervical screening services for Indigenous women. Canberra: DoHA; 2004.
- Sasieni PD, Cuzick J, Lynch-Farmery E. Estimating the efficacy of screening by auditing smear histories of women with and without cervical cancer. The National Co-ordinating Network for Cervical Screening Working Group. British journal of cancer. 1996;73(8):1001-5.
- Miller, J., et al. A review of community engagement in cancer control studies among Indigenous people of Australia, New Zealand, Canada and the USA. Eur J Cancer Care (Engl). 2012; 21(3): 283-295.





Thank you

Any questions, please contact:

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Acknowledgements



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**DUBBO AMS
Central West Aboriginal
Women's Gathering**

**Western NSW Local
Health District Women's
Health Nurses**



VCS



**New South Wales
Aboriginal Land Council**



Sample size calculations based on 2011 Census data and 2011-13 NSW Pap Registry data

Location	Total Females	Total Aboriginal Females	% Aboriginal Females	NS/US Females (45% of Total Females)	Target Sample Size at Each Site (20% of NS/US Females)
Baradine	165	28	17%	74.25	15
Coonamble	672	210	31%	302.4	60
Gilgandra	754	113	15%	339.3	68
Gulargambone	138	49	36%	62.1	12
Gwabegar	71	11	15%	31.95	6
Nyngan	508	73	14%	228.6	46
Trangie	272	56	21%	122.4	24
Warren	385	56	15%	173.25	35
				Total Sample	N = 266

Expected Outcomes

Developed AND PILOTED a model that has been created with and for Aboriginal women to:

- Engage women in HPV screening
- Increase awareness of HPV screening
- Assist in developing appropriate resources
- Increase knowledge and skills of CEWs
- Identify barriers and enabling factors for HPV self sampling
- Inform the National Cervical Screening Program (Dec 2017)



Other results

- Participant ages were: 24, 25, 28, 37, 38, 41 ; and were all from different communities.