

# Sisters doing it for themselves: developing a safe and acceptable self- collection model for cervical cancer screening

Presented by :

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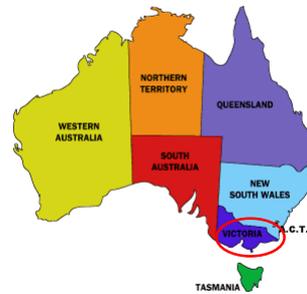
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## Pilot Project Steering Group

- Sandy Anderson, Ballarat and District Aboriginal Cooperative (BADAC)
- Professor Kerry Arabena, Chair of Indigenous Health, Melbourne University
- Emma Pakula, Ruvimbo Bako and Kate Wilkinson, Department of Health and Human Services (DHHS)
- Associate Professor Marion Saville and Dr David Hawkes, Victorian Cytology Service (VCS)
- Bernadette Suter, Cohealth
- Paul Bourke, Access Health



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## AIM:

The aim of the pilot is to increase cervical cancer screening in under-screened populations by developing an acceptable and high quality model to implement HPV self-collection in clinical settings.



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## Objectives

1. To recommend an acceptable alternative self-collection pathway for under-screened women for the purpose of Renewal
2. To develop a clinical practice approach (protocols and processes)
3. Develop resources to support the workforce to implement self collection pathways for under-screened women.
4. To prepare the workforce – Aboriginal Health Workers, practice nurses, general practitioners, allied health providers and persons performing colposcopy – ahead of Renewal.



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## Background

- Aboriginal women are 2.8 times as likely to develop invasive cervical cancer and 3.9 times as likely to die from cervical cancer
- Regular Pap-tests can prevent 90% of cervical cancers
- Indigenous women are more likely to be diagnosed with high fatality cancer and to have advanced disease when they are diagnosed.
- There are currently no national data on the screening participation of Indigenous women
- In Victoria in 2011, 50% of women diagnosed with invasive or micro-invasive cervical cancer had no known screening history
- 28% had not been screened for at least 2.5 years prior to detection



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## Cancer incidence

It is highly likely that the higher rates of cervical cancer amongst Indigenous women and the higher rates of mortality resulting from cervical cancer is linked to late detection and under-screening



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## Self sampling criteria

Self-collection for HPV testing, facilitated by a medical or nurse screening provider who also offers mainstream cervical screening, will be available to under-screened (including never-screened) women

DHHS has funded VCS and Centre for Equity, Indigenous Health Equity (Onemda) to coordinate the self sampling project

The pilot will be assessable to both vaccinated and unvaccinated women aged 27-74 years who are more than a year overdue for screening



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## Barriers for Aboriginal and Torres Strait Islander screening and treatment

These could be grouped under two broad headings:

- Societal - Structural and practical barriers to participation
- Emotional – psychological barriers to participation arising from personal experience, trauma or history

Aboriginal women find themselves in a uniquely difficult position experiencing these barriers more acutely than other non-Indigenous Australians owing to their disenfranchisement and their well-documented position of social disadvantage



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## Context for Phase 1

The pilot was run out of Ballarat and District Aboriginal Co-operative (BADAC).

BADAC is the Aboriginal Community Controlled Health Organisation for the area and has been operating since 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, attempting to address a wide range of health aspects. Currently the clinic has over 900 Aboriginal clients

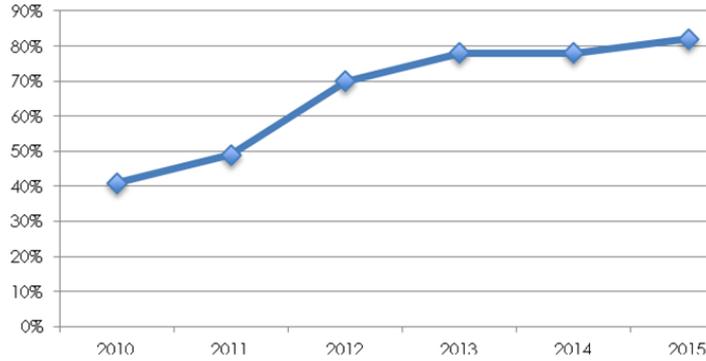


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### Baarlinjan Medical Clinic at Ballarat & District Aboriginal Cooperative



## The percentage of eligible Aboriginal women who had a Pap test recorded has risen steadily over time, from 41% in 2010 to 82% in 2015



## Community Engagement



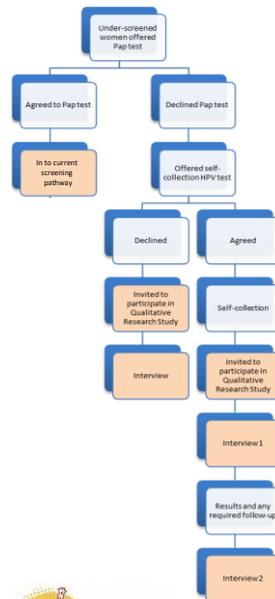
Tammy Anderson performing The Great Walls of Vagina



Tammy and I talking at the community event about speculum vs self sampling cervical screening



## Qualitative Research Study Pathway



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## BADAC findings

From the eligible women 13 women have participated in the Self Sampling HPV test

Women with a negative self sample HPV test will not require cervical screening for 5 years

Three of the 13 women have had positive other high risk HPV results and required a follow up Pap test. All with a negative result will need a repeat self sample in 12 months

Self sampling will be offered at BADAC until September 2016

Phase 2 at CoHealth and phase 3 at Access Health will start soon



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## BADAC findings

<b>Accepted</b>			<b>Declined</b>
Self-Collected	13	59%	5
Pap Test	4	18%	
<b>Total</b>	<b>17</b>	<b>77%</b>	<b>22%</b>



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## Methodology

### Participant surveys

- First survey was undertaken after women participated in self sampling
- Interviews offered to women who refused self sampling
- Second survey was undertaken once all results were finalised

### Staff surveys

- Were conducted in electronic form to all feedback on the acceptability of self sampling

### Family, friend or relative surveys

- Women were given the option to nominate a close family member, friend or relative to give provide understanding about how they felt about them being in an under screened group



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## Key Findings

### Psychological:

'BADAC, I know who to talk to there.'

### Distrust of the health system:

'I'd say that my very first Pap smear that I had done was, it was frightening obviously, it was back in the days when they used the metal clamps. I had a male doctor do it and it was done at the Alice Springs emergency department where I just had a sheet wrapped around, that's all I had. So it was very very uncomfortable. It was awful. I didn't want to go back. That was after my daughter was born, 13 years ago. Then they wanted me to do one after my son was born. I don't think I had one done till we moved down, so six or seven years. It was really really scary.'



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## Key Findings

### Distrust of the health system continued:

'Never again you're not touching me down there no more, I've had enough of you people', a clear indication of marked alienation from the health care system and from those treating her.

'To put one of them in is the most humiliating thing that could've happened to me, other than being taken from my family. That is right up there with that.

'and I put it aside, they'd say 'you haven't had a papsmear' and I'd say 'stiff shit, I'm not in here for that I'm in here for other ailments, I don't need to check about down there at the moment, nothing' I put em aside. BUT NOW, you got me every five years, I'm willing to do it every five years, that is easy.'

'Unprofessional service - I get angry with being treated inferior and just like a body not a person.'



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## Key Findings

### Discomfort and hurt:

'It's uncomfortable and I have been hurt in the past having a Pap test. I also worry about the results and the unknown. I want to be indestructible and be around forever.'

'More comfortable doing it yourself and it didn't hurt - extremely comfortable. The professionals aren't always gentle. Young people I know don't get them done because they been hurt by regular Pap test.'

'It's less invasive. Good because it gave a result. Unfortunately the result was a bit scary. Getting a result meant I had done it right. Normal Pap tests are painful for me so this test is better.'



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## Key Findings

### Embarrassment and shame:

'Yes it was ok. I liked that I didn't have people prodding me. It was much more comfortable.'

### Empowerment to overcome emotional barriers:

'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 Sandy could help if I needed assistance, but the option was that I could do it myself.'

'To be honest I've had low grade change before and I've been afraid. The tests before have hurt me.'



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## Key Findings

**Cost of healthcare as a prominent barrier:**

**Resources to access healthcare as a barrier:**

**Childcare:**

**Differing ideas or priorities of what 'looking after your health' is:**

**Lack of information and education:**

**Convenience, time, ease:**

**Importance of family and community:**

**Cultural:**

**Gender of the practitioner:**



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## Conclusion

- There was unanimous preference for self-collection over regular Pap-testing. It was clearly the preferred option for all the women interviewed for various reasons: the privacy therefore reducing embarrassment and shame, convenience, time taken, ease.
- Indigenous women require resources and support to look after their own health and to make self-collection accessible.
- This might be financial, transport, reminders, childcare, home visits, support through follow-ups.
- Indigenous women require empathetic, culturally in tune health services that build trusting relationships with their clients to dispense self-collection in its initial stages at least.
- The community is an important and valuable asset for promoting acceptability of self-collection .
- For women who have been reluctant to have Pap-tests in the past, this is an acceptable and viable option.



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