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

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Mrs Anne Vail RN, MN
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

Western NSW

- Gwabegar
- Coonamble
- Baradine
- Gulargambone
- Nyngan
- Warren
- Gilgandra
- Trangie

www.marathonhealth.com.au
Developing Culturally Appropriate Materials

**BEFORE**

**HOW TO TAKE A VAGINAL SWAB**

1. **WHAT DOES THE KIT CONTAIN?**
   - A cotton swab in a plastic tube
   - A plastic resealable bag
   - Pathology information form
   - A prepaid post envelope

2. **SWAB**
   - Remove the swab out of the plastic tube, just pull and pull.
   - If possible, avoid taking the sample during your menstrual period.

3. **POSITION**
   - Lie down on your back in a comfortable position as shown above while holding the swab in your hand.

4. **WHAT IF I MAKE A MISTAKE?**
   - It can be inserted with the wrong sample.

5. **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 inner back wall for 3-4 inches (7-10 cm), hold the length of a finger. This is similar to how you would insert a tampon.

6. **TAKING THE SAMPLE CONTINUE:**
   - Rotate the swab gently for 10-30 seconds. There should be no pain or discomfort.

**INSTRUCTIONS**

**HOW TO PACK & POST THE SAMPLE**

1. **RETURN TO PLASTIC TUBE:**
   - Place the swab into the plastic tube
   - Tighten the cap onto the tube
   - Examine for any rejection of this kit.

2. **COMPLETE FORM AND CHECK LABEL:**
   - Fill out the Pathology information form and check the details. Ensure you write the date of the collection.

3. **PACKAGING:**
   - Place the plastic tube into the resealable bag
   - Send via registered mail to the following address:

**POST:**

1. **IN AUSTRALIAN Post**:
   - 19250 0299

4. **WHAT TO DO IF YOU ARE PREGNANT:**
   - Do not collect the sample if you are pregnant.

**AFTER**

**HOW TO TAKE A VAGINAL SWAB**

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**INSTRUCTIONS**

**HOW TO PACK & RETURN THE SAMPLE**

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   - Place the swab into the plastic tube
   - Tighten the cap onto the tube
   - Examine for any rejection of this kit.

2. **COMPLETE FORM AND CHECK LABEL:**
   - Fill out the Pathology information form and check the details. Ensure you write the date of the collection.

3. **PACKAGING:**
   - Place the plastic tube into the resealable bag
   - Send via registered mail to the following address:

**POST:**

1. **IN AUSTRALIAN Post**:
   - 02.8626.5200
   - AND SPEAK TO A PRIMARY HEALTHCARE PROVIDER

**IMPORTANT INFORMATION**

- Your swab should be returned by hand 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 menstrual period.
Screening & Referral Pathways

1. Identification of Participant
2. Eligibility Screening
3. Self-Sampling Collection & Testing
4. Sending away for pathology
5. Communication of results/Referral Pathways
6. Re-Screening
Current Results
## Sample

<table>
<thead>
<tr>
<th>No.</th>
<th>Target</th>
<th>HPV tests distributed</th>
<th>HPV tests returned</th>
<th>Ineligible</th>
<th>Total</th>
<th>Follow up survey completed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>266</td>
<td>58 (22%)</td>
<td>57 (21%)</td>
<td>3</td>
<td>54 (20%)</td>
<td>39 (72%)</td>
</tr>
</tbody>
</table>
Follow up survey

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

<table>
<thead>
<tr>
<th></th>
<th>Total Positive</th>
<th>Positive 16/18</th>
<th>Positive Other</th>
<th>Invalid</th>
<th>Result not received</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never had a pap test</td>
<td>6 (15%)</td>
<td>1 (3%)</td>
<td>5 (13%)</td>
<td>5 (13%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Not had a pap test in prev. 4 yrs</td>
<td>85% (2 missing)</td>
<td>23% (2 missing)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

"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


Thank you

Any questions, please contact:
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Anne Vail
Marathon Health, Dubbo Office
anne.vail@marathonhealth.com.au
Sample size calculations based on 2011 Census data and 2011-13 NSW Pap Registry data

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