



# **Women's Cancer Screening Program Consumer Research**

## **Project completion report**

*Report on the barriers and enablers for participation in cervical  
and breast screening by eligible women residing in the north  
coast region.  
Suggestions for local services.*

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**June 2018**



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## **1 Acknowledgements**

The researchers wish to sincerely acknowledge and thank the women from the Port Macquarie, Tweed Heads, Richmond Valley, Coffs Harbour, Woolgoolga, Ulong, Lismore and Casino communities who participated in the focus group discussions and interviews and shared their stories about this important and challenging women's health issue.

## **2 Background**

Four out of ten women living in the North Coast region are overdue to be screened for breast and cervical cancer, or have never screened. Aboriginal women are less likely to screen for these types of cancers. They are also more likely to die from these cancers than non-Aboriginal women. Participation of Aboriginal women in Lismore in the BreastScreen program in 2014-2015 was considerably lower (46%) than total Lismore women's participation (60%). Women generally residing in Lismore on the north coast have low cervical screening participation rates.<sup>1, 2</sup>

Early detection of cancer is key to survival as it offers women the best chance of effective treatment. For this reason, regular screening by women in the target age groups for breast and cervical cancer is vital. However there are cultural, social, level of education, geographical location, health provider and personal factors that can influence women's cancer screening participation rates.<sup>3, 4</sup>

### **2.1 Women's Cancer Screening Collaborative**

The Women's Cancer Screening Collaborative (WCSC) is delivered through the North Coast Primary Health Network (NCPHN). The WCSC involves 23 local health agencies, located between Port Macquarie and Tweed Heads, in collaborative efforts over the period September 2016 to June 2018.

The WCSC seeks to increase eligible NSW north coast women's participation rates in screening programs for breast cancer and cervical cancer. This will be achieved through the provision of structured, clinician-led general practice quality improvement and health literacy interventions.

## **3 Women's Cancer Screening Collaborative Consumer research**

In 2017 the WCSC was awarded funding by the Cancer Institute NSW to support a consumer research project. The consumer research project was undertaken over the period August 2017 – May 2018. A consultant from Carroll Communications was commissioned to support the WCSC to implement the research. This support included developing the methodology, research tools, supporting ethics approval processes, providing fieldworker team training, undertaking data analysis and synthesis and final reporting. The consultant also undertook two key informant interviews to supplement the research in one research site.

### **3.1 Aim of the Women's Cancer Screening Collaborative Consumer research**

The WCSC Consumer Research aims to explore the personal, social and cultural barriers and enablers for women in the NSW north coast region for participating in breast and cervical screening. The information gathered from the research will support WCSC participating agencies build at-risk women's engagement in screening.

### **3.2 Research objectives**

The research objectives for WCSC consumer research project are:

1. To provide a rapid assessment of the barriers and enablers for participation in cervical and breast screening for eligible women residing in four communities in the north coast region. They are Port Macquarie, Tweed Heads, Coffs Harbour and Lismore;
2. To develop simple, easy to read research summaries that participating services and BreastScreen can use to build at-risk women's engagement in breast and cervical cancer screening programs in these communities; and
3. To contribute to the development of NCPHN staff and stakeholders capacity to understand and undertake qualitative health research.

### **3.3 Research target group**

WCSC participating health services examined local patient data to identify women they believed most at risk of under-screening in their practice. The at-risk groups prioritised by practices were then confirmed during a series of workshops conducted by the WCSC in July 2017.

Four research site locations for the WCSC consumer research project were identified together with the following site-specific target groups:

1. *Port Macquarie site:*
  - (1) Women of eligible screening age for breast and cervical screening programs;
2. *Coffs Harbour site:*
  - (1) Women of eligible screening age for breast and cervical screening programs residing in the Ulong community.
  - (2) Women of Indian heritage and of eligible screening age for breast and cervical screening programs.
3. *Tweed Heads site:*
  - (1) Women with a disability and of eligible screening age for breast and cervical screening programs.
4. *Lismore site:*
  - (1) Women who identify as being Aboriginal and of eligible screening age for breast and cervical screening programs.

### **3.4 Research approach**

The WCSC Consumer Research adopted a participatory approach using a rapid assessment research (RAR) methodology. RAR is evidence-based intensive, team-based qualitative research involving a cyclical process of data collection, review and analysis to quickly gather insights of a situation from the 'insiders' perspective<sup>5</sup>. Information about internal and external factors influencing women's participation in breast and cervical screening gathered from previous research studies, was also used to support the data analysis stages and interpretations.

### **3.5 Research methodology**

The research methodology included a mix of focus group discussions and semi-structured interviews. The research generally included women in the following age segments within the age range of 30-69 years:

- Women 30-39 years;
- Women 40-49 years
- Women 50-59 years;
- Women 60-69 years; and
- Women 55-65 years.

The research methodology included further segmentation by breast and cervical screening behaviour (never/underscreened and regular screeners). The ‘regular screeners’ groups were included in order to explore facilitators (personal, practitioner and service) for their screening behaviour.

The research methodology and implementation also involved the following:

- Where possible, women who had had a hysterectomy were excluded from groups that focussed on participation in cervical screening;
- Where it was not possible to recruit for the same screening behaviour for both BreastScreen and cervical screening programs, the default inclusion/exclusion criteria used was screening behaviour for BreastScreen;
- A screening instrument was used for selecting participants for group discussions to ensure potential participants meet the specification set for each group and were confident to participate in discussing issues in a group;
- Other research tools included discussion guides (varied according to screening behaviour group and the nature of group participants), note-taker forms, research information sheet, consent forms, check lists, reflection sheets and participant and stakeholder questionnaires;
- Groups were recorded for the purpose of verification of information, to assist with reporting and to capture valuable quotes;
- Stimulus materials such as posters/pamphlets was included to facilitate discussions;
- At the conclusion of the group discussions and interviews, the participants were provided with a promotional sample bag containing information about cervical and breast screening and local services and support;
- A 15-minute Q&A session was also provided at the end of each focus group. This provided information about issues and queries about screening and other relevant health issues that were raised by group participants. This session was facilitated by members of the fieldworker team;
- Fieldworker teams for each site comprised a team leader and 1-2 facilitators and 1-2 note-takers;
- A program of semi-structured interviews was designed to reach women with a disability. Interviews were also conducted with key informants within the disability sector; and
- Focus groups involving women of Indian heritage were supported by a translator.

## **4 Research fieldworker team**

Local personnel of the North Coast Primary Health Network and WCSC partners formed the research fieldworker team. They undertook the implementation of the research including participant recruitment, facilitation of focus group discussions and interviews, note-taking and data analysis.

### **4.1 Fieldworker team training**

A half-day fieldworker team training workshop was conducted at the commencement of the research in each of the four sites. The training session was designed to support each fieldwork team to implement the research at their site. Each workshop was tailored to the specific research focus and methodology for each site (focus group discussion or semi structured interviews).

Each workshop was facilitated either by the consultant (Tweed Heads and Lismore sites) or the senior project leader of the WCSC (Port Macquarie and Coffs Harbour sites) with a training power point and notes provided. Workshop participants were the local personnel forming the research site fieldwork team. Workshops were practical in design providing participants with a briefing on the research and an overview of the use of qualitative methodologies and practical sessions for using the research tools, applying basic techniques in interviewing/group facilitation and undertaking thematic analyses.

## **5 Ethics approval**

The Human Research Ethics Committee at Southern Cross University and the Ethics Committee of the Aboriginal Health and Medical Research Council granted ethical approval for the research project.

## **6 Implementation of the research**

The breakdown of research groups and interviews implemented in each site is presented in Table 1.

<b>Table 1: Focus groups and interviews</b>			
<b>Site 1: Port Macquarie (September 2017)</b>			
<b>Group number</b>	<b>Age segment</b>	<b>Screening behaviour</b>	<b>Number of participants</b>
1	Women 50-59 years	Regular screeners <sup>A</sup> (Breast screening & Cervical screening)  <sup>A</sup> Never/under screeners were the primary target for the research with this age segment, however recruitment was only able to enlist regular screeners in the focus group discussions.	6
2	Women 30-40 years	Lapsed screeners <sup>B</sup> (Cervical screening)  <sup>B</sup> Never/under cervical screeners were the primary target for the research with this age segment, however recruitment was only able to enlist lapsed screening women to the focus group discussions.	3
<b>Site 2: Coffs Harbour (October 2017)</b>			
<b>Group Number</b>	<b>Age segment</b>	<b>Screening behaviour</b>	<b>Number of participants</b>
3 (Woolgoolga community)	Women of Indian heritage 50-59 years	Regular screeners (Breast screening & Cervical screening)	5
4 (Woolgoolga community)	Women of Indian heritage 40-60 years	Never/ under screeners <sup>C</sup> (Breast screening & Cervical screening)  <sup>C</sup> Some participants were outside the eligible age for participation in the BreastScreen program.	6
5 (Ulong community)	Women 50-59 years	Regular screeners <sup>D</sup> (Breast screening & Cervical screening)  <sup>D</sup> Never/under screeners were the primary target for the research in Ulong with this age segment, however recruitment was only able to enlist regular screeners in the focus group discussions.	5

<b>Site 3: Lismore / Casino (May 2018)</b>			
<b>Group number</b>	<b>Age segment</b>	<b>Screening behaviour</b>	<b>Number of participants</b>
6	Women who identify as Aboriginal  30-60 years	Regular screeners <sup>E</sup>  (Breast screening &  Cervical screening)  <sup>E</sup> Never/under screeners were the primary target for the research in Lismore/Casino with this age segment, however recruitment was only able to enlist regular screeners in the focus group discussions.	8
7	Women who identify as Aboriginal  30-40 years	Regular screeners <sup>F</sup>  (Cervical screening)  <sup>F</sup> Never/under screeners were the primary target for the research in Lismore/Casino with this age segment, however recruitment was only able to enlist regular screeners in the focus group discussions.	5
<b>Site 4: Tweed Heads research site including Richmond Valley (February 2018)</b>			
	<b>Age segment</b>	<b>Screening behaviour</b>	<b>Number of interviews</b>
<b>Interviews</b>	Women 50-59 years	Never/under/lapsed screeners  (Breast screening &  Cervical screening <sup>E</sup> )  <sup>E</sup> Two participants had had a hysterectomy and were not participating in cervical screening.	5
	Women 30-40 years	Never/under/lapsed screeners (Cervical screening)	1
	Representatives of disability and mental health services		2

## 7 Analysis

The research team undertook an analysis of the data collected from the focus group discussions to systematically categorise pieces of content within the data set (field notes and group recordings) into themes. This first analysis stage involved a preliminary examination of their field notes and the development of theme names. Brief descriptions were then allocated to each theme name. Templates were developed to assist the fieldworker teams with this analysis. Data was then analysed further using the templates to clarify theme similarities and to refine the themes. The consultant then undertook the final analysis and synthesis processes to develop a set of key ‘barriers’ and ‘enablers’ themes and suggestions for local services.

Additional literature was used to support the data analyses and interpretations for two of the research:

1. Barriers and enablers for women with a disability (Tweed Heads)<sup>i</sup>; and
2. Barriers and enablers for women who identify as Aboriginal (Lismore/Casino)<sup>ii</sup>.

## 8 Findings

The research found a range of barriers and enablers for women’s participation in breast and cervical screening programs. A number of themes were found to be common across all research sites. These included the following:

1. *Common barrier themes:*
  - Low personal priority of screening for breast and/or cervical cancer;
  - Being time poor;
  - Access to local services including transport, cost, a gender-preferred practitioner and service opening hours;
  - Male GP/health practitioner;
  - Lack of GP reminder;
  - Negative past experiences of screening;
  - Negative contact experiences with health practitioners or health services;
  - Lack of trust in health practitioner;
  - Low knowledge, awareness or understanding of screening, its purpose and procedures;
  - Scepticism with efficacy of screening; and
  - Failure to update contact details for postal reminders.
2. *Common enabler themes*
  - Screening for early detection of disease;
  - Reminders and prompts from GP;
  - Having a female GP;
  - Access to a women’s health centre;
  - Assistance with transport to services; and

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<sup>i</sup> Johnson K, Strong R, Hillier L, Pitts M. Screened Out: Women with Disabilities and Preventive Health. *Scandinavian Journal of Disability Research*. 2006;8(2-3):150-60

<sup>ii</sup> Pilkington et al. (2017) Perspectives of Aboriginal women on participation in mammographic screening: a step towards improving services. *BMC Public Health*;17:697

- Community-based promotions, local campaign efforts and settings-based education programs to improve knowledge.

Attachments 1-4 provide short research summary reports for each research site.

## 9 Lessons learnt

Discussions with and feedback from the fieldworker teams identified a number of research challenges. These were mainly concerned with difficulties with the recruitment processes resulting in a lesser number of focus groups than originally outlined in the research methodology. It is recommended that future similar research projects ensure adequate time is allocated to brief key local services and groups in the community about the research, its purpose and importance in order to generate their support with recruitment efforts.

As well, whilst a training session was provided to each fieldworker team prior to the implementation of the research in each site, it is recommended that where possible additional time is allowed for fieldworker team members to practice group facilitation using the discussion guide/s. This will assist team members to become familiar and comfortable with these types of research tools and thereby support the creation of a relaxed group session and group discussion. Conducting a number of practice sessions is also valuable when a group discussion guide is comprehensive and covering a range of issues, and where the use of prompting techniques is required.

Some specific challenges encountered by the research with special population groups were:

### 1. *Women of Indian heritage*

#### *Challenges*

- Difficulty with recruitment of women of Indian heritage owing to long working hours and home duties; and
- Language and communication with women in the groups.

#### *Adjustments/solutions*

- Targeting of religious days/events to engage with women in focus group sessions; and
- Use of a translator to support the group facilitation and validation of fieldworker notes from the group discussions.

### 2. *Women with a disability*

#### *Challenges*

- Lack of capacity within services to assist recruitment processes;
- Potential participants were not favourable to participating in groups;
- Saturation of information from the NDIS at the same time and its impact of services to read the research information;
- Last minute cancellations;
- Research topic regarded as too personal or beyond the scope some services; and
- Email considered an ineffective method for seeking service support with recruitment.

#### *Adjustments/solutions*

- Seek assistance beyond disability services such as through community-based support groups, alliances and key individuals;

- Change research methodology from group discussions to personal interviews;
- Face-to-face and phone contact rather than email;
- Visits to explain about the WCSC, the research to support recruitment where time permitted; and
- Use of key informants in interview program to supplement research.

### 3. *Women who identify as Aboriginal Challenges*

- Venue being noisy;
- Broad age range of participants recruited resulted in younger age women participating in discussions with older aged women. This may have hindered younger women's responses in the discussion groups;
- This also meant that younger women (outside the screening age for breast screening) were in the discussions around breast cancer and screening issues; and
- Small numbers of women over 50 years recruited to the research.

#### *Adjustments/solutions*

- The women accepted the noisy environment.
- Future research should explore alternate methodologies such as 'yarning circles' conducted in communities and involving women of similar age. This methodology may also be more successful in reaching women who are less likely to participate in these screening programs due to their living circumstances (living in rural locations or on the missions).

## 10 References

<sup>1</sup> North Coast Primary Health Network. Women's Cancer Screening Collaborative. Breast Cancer Screening. Available at: <http://ncphn.org.au/wcsc/breast-cancer-screening/>

<sup>2</sup> North Coast Primary Health Network. Women's Cancer Screening Collaborative. Cervical Cancer Screening. Available at: <http://ncphn.org.au/wcsc/cervical-cancer-screening/>

<sup>3</sup> Olesen SC, Butterworth P, Jacomb P, Tait RJ. Personal factors influence use of cervical cancer screening services: epidemiological survey and linked administrative data address the limitations of previous research. *BMC Health Services Research*. 2012;12 (1):34.

<sup>4</sup> Nicola Scott, Samantha Raheb, Pippa Rendel. Cancer Institute NSW (Australia). Factors affecting the participation of lapsed and never screened women in BreastScreen NSW. Behavioural Research in Cancer Control Conference 2015. Available at: <https://www.cancercouncil.com.au/bccc2015/2015-program/day-2/factors-affecting-the-participation-of-lapsed-and-never-screened-women-in-breastscreen-nsw/#ElpU2rS4Z55EHOYH.99>

<sup>5</sup> J. Beebe. RAP — Rapid Assessment Process. RAP Alta Mira Press, Walnut Creek, CA (2000)

## **Attachment 1 – Port Macquarie Research Summary Report**



# **Women's Cancer Screening Program Consumer Research**

## **Site summary report – Port Macquarie**

*Report on the barriers and enablers for participation in cervical  
and breast screening by eligible women residing in Port  
Macquarie.  
Suggested actions for local services.*

**Prepared by:**

**Bev Carroll**

**Director**

**November 2017**



## 1 Acknowledgements

The researchers wish to sincerely thank the women from the Port Macquarie community who participated in the focus group discussions and shared their stories about this important and challenging women's health issue.

## 2 Aim of the Women's Cancer Screening Collaborative Consumer research

The Women's Cancer Screening Collaborative (WCSC) Consumer Research aims to explore personal, social and cultural barriers and enablers for women in the NSW north coast region for participating in breast and cervical screening. The information gathered from this research will support WCSC participating agencies to build at-risk women's engagement in screening.

The focus of the research in Port Macquarie was women of eligible screening age for breast and cervical screening programs.

## 3 Research approach for the Port Macquarie site

The WCSC Consumer Research adopted a participatory approach. Local personnel of the North Coast Primary Health Network and WCSC partners formed the research fieldworker team and undertook focus group implementation, participant recruitment, facilitation of group discussions, note-taking and data analysis.

A content analysis of the data collected from the focus group discussions was undertaken to identify themes and their descriptors. Information from other Australian research studies about women's participation in breast and cervical screening was used to support data analyses and interpretations.

## 4 Focus groups

Two focus groups were conducted with women in Port Macquarie in September 2017 (see Table 1).

<b>Age segment</b>	<b>Screening behaviour</b>	<b>Number of FGD Participants</b>
Women 50-59 years	Regular screeners* (Breast screening & Cervical screening) <small>*Whilst never/under screeners were the target for the research, recruitment was only able to enlist regular screeners in the focus group discussions.</small>	6
Women 30-40 years	Lapsed screeners** (Cervical screening) <small>** While never/under cervical screeners were the target for the research, recruitment was only able to enlist lapsed screening women to the focus group discussions.</small>	3

## 5 Key findings – Women residing in Port Macquarie

Barriers and enablers for women residing in Port Macquarie for participating in local breast and cervical screening are presented in Appendix 2 and Appendix 3.

It should be noted that:

- Themes for breast and cervical screening were identified from the discussions with regular breast and cervical screening women and lapsed cervical screeners; and
- Barriers were focussed on issues that may or have delayed regular screening.

Key findings are:

- Avoiding cancer (early detection) and particularly secondary cancers was a key motivating factor for the women.  
*“...do it for peace of mind”*
- The prospect of cancer spreading to other parts of the body (due to not detecting it in the breast or cervix early) was highly concerning for these women.  
*“You just have to do it....give yourself every chance”*
- Older-aged women believed that getting cancer would place a considerable burden on their lives and their families. This included economically, because of the perceived high cost associated with cancer treatments.
- Avoiding getting cancer through regular breast and cervical screening was considered their responsibility as a woman (to self), a mother (to family) and a partner (relationship).
- Reminders and invitation letters from government screening programs were highly regarded and important facilitators for prompting screening.
- Younger women expressed less urgency in maintaining regular cervical screening and cervical screening was not a high priority for them.
- For some young women, it was felt that this was due to little awareness or discussion about cervical cancer amongst their friends, peers and within the community generally.
- These women felt that compared to breast cancer, very few people talk about cervical cancer, it was less ‘visible’ in terms of community promotions, media coverage and special health or charity event days.
- Other younger-aged women reported having a GP whom they could trust, was paramount to their decision to have a Pap smear test.
- Not having a regular GP or no GP at all impacted on young women’s cervical screening behaviour due to their reliance on a GP to remind about screening.
- A number of themes were common for both the breast and cervical screening programs.

## **6 Suggested actions for improving women's participation in breast and cervical screening in Port Macquarie**

A list of suggested actions for addressing some of the issues identified by the research has been prepared. It should be noted that these suggestions are broad. The final design, development, implementation and evaluation of future strategies should involve local service staff, health practitioners, key community influencers and local women.

(1) Support statewide campaigns promoting screening and early detection through local initiatives.

- Conduct a small-scale research project to identify relevant community and social settings, outlets and events that have potential to reach and engage women in Port Macquarie in breast and cervical screening education activities.
- It is suggested that these efforts prioritise settings for increasing exposure of statewide cervical screening campaign messages, local information and for generating community discussion about cervical cancer and cervical screening among young women.
- Inform local health workers and other relevant individuals in the community about statewide breast and cervical screening campaigns, messages and resources.
- Support local health workers and other relevant individuals in the community to extend the promotion of these campaigns through locally targeted activities.
- Support local initiatives that are designed to reach eligible women and inform about the Renewal.

(2) Produce a '*local health services guide for women*' in Port Macquarie.

- The guide should include information about local women's health services, BreastScreen and Pap test providers, services personnel and health providers available, contact details and access information (opening hours, group bookings, parking and transport).
- Dissemination strategies should include health care settings such as health clinics, medical practices, community health services, health food stores, wellness centres and pharmacy outlets.
- Other relevant social and community settings should also be targeted including relevant settings identified through the abovementioned research (see 1. above).
- The guide could also be disseminated and promoted during health awareness weeks/months for breast and cervical cancer.
- The guide should be designed to enable regular updating.

(3) Promote processes for updating BreastScreen and NSW Pap Register contact details.

- Develop and disseminate information to local women that promotes the importance of updating personal contact details held by the BreastScreen program and the NSW Pap Test Register.

- Dissemination strategies include a range of outlets including GP practices and health clinics as well as other suitable social and cultural networks and services (see 1. above).

(4) Conduct regular visits to General Practice clinics and medical centres.

- Regularly visit GP clinics and other medical centres to:
  - Assess reminder systems for breast and cervical screening;
  - Facilitate the dissemination of breast and cervical screening promotional materials and handouts;
  - Encourage the display of posters and information sheets in waiting rooms and clinics; and
  - Provide information to practice staff and GPs about the importance of updating contact details with BreastScreen and the NSW Pap Test Register. This includes providing information about how to change contact details, the upcoming changes to National Cervical Screening Program under the Renewal and prompting clients to talk about screening with their GP.

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## 7 References

1. North Coast Primary Health Network. Women's Cancer Screening Collaborative Handbook. Available at: <http://ncphn.org.au/wcsc/wp-content/uploads/2017/03/20170306-WCSC-handbook.pdf>
2. Woolcott Research. Research Report Campaign Developmental Research for Breast Screening Prepared for: Australian Government Department of Health. March 2014. Available at: [http://health.gov.au/internet/screening/publishing.nsf/Content/D2F8355B3C9C3107CA257E1A007D9F71/\\$File/Breast%20Screening%20Developmental%20Report.docx](http://health.gov.au/internet/screening/publishing.nsf/Content/D2F8355B3C9C3107CA257E1A007D9F71/$File/Breast%20Screening%20Developmental%20Report.docx)
3. Queensland Cervical Screening Program Cancer Screening Services Branch. Manual for Authorised Pap smear providers. February 2012. Available at: [https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0030/147468/qh-gdl-939.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0030/147468/qh-gdl-939.pdf)

## 8 Appendix 1: Barriers and enablers for women for participating in breast screening in Port Macquarie

i. Barriers for Port Macquarie women for participating in breast screening	
Theme	Descriptors
<i>Client-based</i>	
Not top of mind	<ul style="list-style-type: none"> <li>• Having to think about screening and making an appointment were common reasons for putting off or delaying breast screening.</li> </ul>
Limited knowledge	<ul style="list-style-type: none"> <li>• Women exhibited limited knowledge about breast cancer, its causes and screening for the disease.</li> <li>• Lack of knowledge also included how to do self-checks and what a lump might feel like.</li> </ul>
Not updating contact details	<ul style="list-style-type: none"> <li>• Some women reported moving house and not receiving reminders and invitations from BreastScreen.</li> </ul>
No GP	<ul style="list-style-type: none"> <li>• Some women, who had recently moved to Port Macquarie, reported not having a GP.</li> </ul>
Painful procedure	<ul style="list-style-type: none"> <li>• Some women found the screening test painful due to breast size.</li> </ul>
Scepticism about efficacy of screening	<ul style="list-style-type: none"> <li>• Some women questioned the reliability of the screening test particularly for women with dense breast tissue.</li> </ul>
<i>Access</i>	

Parking	<ul style="list-style-type: none"> <li>Some women reported parking at the fixed BreastScreen site (at the hospital) was difficult and limited.</li> </ul>
<b><i>General Practitioner/healthcare provider</i></b>	
Lack of information	<ul style="list-style-type: none"> <li>Most women reported that their GP did not talk about breast cancer or about screening.</li> </ul>
No systematic reminder	<ul style="list-style-type: none"> <li>Women reported that their GP did not remind them when their breast screening was due.</li> </ul>
Gender	<ul style="list-style-type: none"> <li>Some women mentioned a preference for a female GP in terms of talking about breast cancer and screening issues.</li> </ul>
Short appointment time	<ul style="list-style-type: none"> <li>Women stated that their time with the GP was limited and insufficient time was available to them to talk about breast screening.</li> </ul>
<b><i>Community</i></b>	
Limited campaign exposure	<ul style="list-style-type: none"> <li>Women reported low awareness of breast screening campaign messages in the community.</li> </ul>
<b>ii. Enablers for Port Macquarie women for participating in breast screening</b>	
<b>Theme</b>	<b>Descriptor</b>
<b><i>Client-based</i></b>	

Taking 'preventative' action	<ul style="list-style-type: none"> <li>• Women's beliefs about the seriousness of getting cancer, its impact on women's lives and their family and the perceived high prevalence of the disease, reinforced the notion of screening for 'peace of mind'.</li> <li>• Women strongly believed that, if detected early, breast cancer can be successfully treated and other cancers may be prevented.</li> <li>• Taking action and attending BreastScreen to prevent getting breast cancer was a key trigger for most women for rescreening.</li> <li>• Regular breast screening was important for women who rarely doing breast self-checks.</li> </ul>
Confidence in self-checks	<ul style="list-style-type: none"> <li>• Education about (1) how to do breast self-checks correctly; and (2) what a lump would feel like, was considered important for prompting women to do self-checks.</li> </ul>
Family / friend with breast cancer	<ul style="list-style-type: none"> <li>• Women who reported they had a family member or knew someone who had breast cancer were motivated to participate in regular screening.</li> </ul>
<b><i>GP/primary care provider</i></b>	
Reminders	<ul style="list-style-type: none"> <li>• GP-prompted reminders including asking eligible women clients about the BreastScreen invitation letter, reinforced the importance of screening and prompting rescreening.</li> </ul>
<b><i>Service/systems - based</i></b>	
Reminders/invitation letters	<ul style="list-style-type: none"> <li>• Receiving the letters and invitations from BreastScreen was very important for these women for reminding to screen and for prompting action (making an appointment).</li> </ul>
Change of address/contact details information	<ul style="list-style-type: none"> <li>• Dissemination of information about how to update contact and address details held by BreastScreen to facilitate the reminder and invitation systems, would be useful for those women who change address often or are new to Port Macquarie.</li> </ul>

Service staff/efficient appointments	<ul style="list-style-type: none"> <li>• Some women preferred service staff to be female owing to the nature of the screening procedure, having to undress and expose their breasts.</li> <li>• Friendly, welcoming staff, efficient appointment times and easy booking systems were highly regarded.</li> </ul>
Text messaging	<ul style="list-style-type: none"> <li>• Text messaging as a reminder system was considered a useful addition to the mail-out reminder system to prompt booking an appointment.</li> </ul>
Stickers/calendar reminders	<ul style="list-style-type: none"> <li>• Resources such as stickers or other appropriate calendar reminders were suggested as useful prompts for making an appointment.</li> </ul>
<b><i>Education</i></b>	
Campaigns/media coverage	<ul style="list-style-type: none"> <li>• Localising mass media campaigns that inform about breast cancer and encourage and promote breast screening could positively influence local women’s participation.</li> <li>• Using social media could broaden the reach of campaigns and promote local breast cancer and breast screening information.</li> <li>• Potential appealing and motivating images and messages were: <ul style="list-style-type: none"> <li>○ ‘<i>screening is free</i>’, ‘<i>peace of mind</i>’; and</li> <li>○ Using images that portray groups of women of different ages and culture within the target age group.</li> </ul> </li> </ul>
Community-based education	<ul style="list-style-type: none"> <li>• Enlisting the support of local celebrities, appealing and high profile individuals and breast cancer champions in local promotions can provide the local community with valuable role models.</li> <li>• This can also legitimise the delivery of health information and support statewide campaign efforts.</li> </ul>

Settings-based promotions/displays	<ul style="list-style-type: none"><li>• Displaying posters and providing information about breast cancer and breast screening in a range of social, cultural and workplace settings would increase awareness and remind women to screen.</li></ul>
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## 9 Appendix 2: Barriers and enablers for Port Macquarie women for participating in cervical screening.

i. Barriers for Port Macquarie women for participating in cervical screening	
Theme	Descriptor
<i>Client-based</i>	
Out of date contact details	<ul style="list-style-type: none"> <li>Women who often changed address, reported not receiving reminders and invitations from the NSW Pap Register.</li> </ul>
Not proactive - <i>self</i>	<ul style="list-style-type: none"> <li>Women relied on their GP to remind them, rather than themselves.  <i>"...if he doesn't [remind me] I don't think about it."</i></li> </ul>
Not proactive – <i>no GP</i>	<ul style="list-style-type: none"> <li>Delaying or forgetting to book an appointment was particularly the case for those women who currently do not have a regular GP or hadn't found a GP they would trust to perform the test.  <i>"....proactive now myself [because I don't have a GP] ....and I hate to say that I don't [screen]"</i></li> </ul>
Low priority - <i>not important to me</i>	<ul style="list-style-type: none"> <li>Having a Pap test was not a high priority for some women.  <i>"Life [gets in the way] – don't think about it, not on my radar"</i></li> </ul>

<p>Low priority - <i>no cues to screen</i></p>	<ul style="list-style-type: none"> <li>• Women reported there was a lack of cues for screening. These included hearing about cervical cancer, other women getting cervical cancer and exposure to cervical screening messages.</li> </ul> <p><i>“I know it’s important, but I don’t think about it....not prominent in my thoughts, I don’t know why – whether it is because of my age [early 30’s] .....”</i></p> <p><i>“I don’t know many incidences of it around me....touch wood – not really something I’ve got much exposure to so I’m not ... It’s not at the forefront of my mind...”</i></p>
<p>Limited knowledge</p>	<ul style="list-style-type: none"> <li>• Women generally had limited knowledge of cervical cancer, HPV, its causes, at-risk groups and screening for the disease.</li> </ul>
<p>Not personally relevant</p>	<ul style="list-style-type: none"> <li>• The women expressed a belief that cervical cancer was not particularly relevant to them. This related to their understanding that it was a sexually transmitted disease or they were too young to get the disease.</li> </ul> <p><i>“don’t connect with HPV, STDs....that’s not me”</i></p>
<p>No ‘trusted’ GP</p>	<ul style="list-style-type: none"> <li>• Not having a GP (due to being new to community) or not finding a doctor they trusted to conduct their Pap smear test, impacted on some women’s opportunity to have their scheduled Pap test.</li> </ul> <p><i>“I need to find a GP I trust... then I’ll do it.”</i></p> <p><i>“I don’t have a GP...difficult to go to someone I don’t know. I need to feel comfortable, trust them.”</i></p>
<p>Not prepared</p>	<ul style="list-style-type: none"> <li>• Women offered a Pap test spontaneously during an appointment (unplanned) was not viewed positively.</li> <li>• Being unprepared for a Pap test related to personal hygiene preparations (waxing, washing, clean underwear, menstruation) and being prepared mentally.</li> </ul>

Fear	<ul style="list-style-type: none"> <li>• Fear and dislike of the Pap test was expressed by some women.</li> <li>• Fear was strongly associated with being diagnosed with cancer of the cervix.</li> </ul> <p>“...if you don't know, it doesn't bother you!”</p>
Threat to confidentiality/being judged	<ul style="list-style-type: none"> <li>• Some women felt that younger women may avoid talking to their GP about having a Pap smear for fear of disclosure of information about their sexual activity and for being judged.</li> </ul>
Negative attitudes	<ul style="list-style-type: none"> <li>• Negative attitudes to having a Pap smear test and the associated internal examination were expressed.</li> <li>• Women used the following descriptive terms for the procedure:  It's ... <i>'invasive', 'degrading', 'unpleasant', 'gross' and 'discomfort'</i>.</li> <li>• Some women described it as <i>'too long'</i> and <i>'very medical'</i>.</li> </ul>
<b><i>Access</i></b>	
Hours of operation	<ul style="list-style-type: none"> <li>• Some women reported that women's health centres had limited hours of operation which hindered access to screening services after work.</li> </ul>
<b><i>General Practitioner/health provider</i></b>	
Gender	<ul style="list-style-type: none"> <li>• Some women preferred a female GP for women's health and screening procedures such as the Pap test.</li> <li>• Some women felt that this was an important issue for young women who were new to screening.</li> </ul>
No available GP/GP booked up	<ul style="list-style-type: none"> <li>• Some women reported that GPs in the community were not taking new clients.</li> <li>• Other women reported difficulties and delays in obtaining an appointment with their GP.</li> </ul>

No systematic reminder	<ul style="list-style-type: none"> <li>Women reported that their GP did not remind them when their Pap smear test was due.</li> </ul> <p><i>“Our vet is better [at reminding] than the GP!”</i></p>
<b><i>Service/system - based</i></b>	
No reminder	<ul style="list-style-type: none"> <li>Women reported that not receiving reminders from the Pap Register.</li> <li>This was mainly related to change of contact details/moved house.</li> </ul>
Cost	<ul style="list-style-type: none"> <li>Some women mentioned the costs related to having the Pap smear test if their practice did not bulk bill.</li> </ul>
<b><i>Community</i></b>	
Low awareness/discussion in community	<ul style="list-style-type: none"> <li>Women felt that there was little in the community that prompted them to think about cervical screening.</li> <li>Younger-aged women in particular felt that there was little or no discussion about cervical cancer amongst their friends, peers and in the community.</li> </ul> <p><i>“People don’t say as much as they do about breast cancer...hear about it [breast cancer] more than cervical cancer – not as big a killer.”</i></p> <p><i>“Read somewhere it kills many women...that’s news to me!”</i></p>
<b>ii. Enablers for Port Macquarie women for participating in cervical screening</b>	
<b>Theme</b>	<b>Descriptor</b>

<i>Client -based</i>	
Early detection - peace of mind	<ul style="list-style-type: none"> <li>• Women felt that cervical cancer was very serious and would be very impactful on their lives.</li> <li>• Early detection was considered highly important for treating the disease successfully and for stopping it spreading to other sites where successful treatments may not be possible.</li> <li>• Women felt the Pap test was a necessary test that had to be done regardless of how you felt about it.</li> <li>• Women commonly referred to screening for '<i>peace of mind</i>'.</li> </ul>
Being informed	<ul style="list-style-type: none"> <li>• Being informed about cervical cancer, its prevalence in the community and the Pap test was important for women.</li> <li>• Information about changes to the Pap test (The Renewal) was important.</li> </ul>
<i>GP/Health provider</i>	
Confidence/trust	<ul style="list-style-type: none"> <li>• Having confidence in a GP to perform the Pap smear test procedure correctly so the disease would be detected early.</li> <li>• This was very important in relation to women's choice of GP and particularly those new to Port Macquarie.</li> <li>• Women referred to the provider's technique and the importance of having the procedure explained to them, being encouraged to relax and having their privacy respected.</li> </ul>
Reminders	<ul style="list-style-type: none"> <li>• Some women felt the GP reminding them (repeatedly) when their Pap test is due, facilitated booking an appointment to have the test.</li> </ul>
Gender of GP	<ul style="list-style-type: none"> <li>• For some women, having a female GP was considered an important enabler for having a Pap test especially for younger women.</li> </ul>

Change of contact/address details	<ul style="list-style-type: none"> <li>• Awareness of the procedures for updating contacting details on the NSW Pap Register would be beneficial for women who move frequently or were new to the Port Macquarie community.</li> </ul>
Access	<ul style="list-style-type: none"> <li>• Women felt that increasing opening hours for appointments with GPs or other women's health providers would be helpful for busy working women.</li> </ul>
Sharing medical information	<ul style="list-style-type: none"> <li>• Transferring client medical information between GPs was deemed useful for women who move frequently or were new to Port Macquarie</li> </ul>
<i>Service/system</i>	
Reminder letters	<ul style="list-style-type: none"> <li>• Women considered the reminder letters were important for prompting them to have a Pap test.</li> </ul>
Change of contact/address details	<ul style="list-style-type: none"> <li>• Awareness of the procedures for updating contacting details on the NSW Pap Register would be beneficial for women who move frequently or were new to Port Macquarie.</li> </ul>
Women's health clinic	<ul style="list-style-type: none"> <li>• Some women considered women's health clinics that provide Pap smear test services would be a valuable alternative service to seeing a GP.</li> <li>• The women felt that practitioners at a women's clinic would be better skilled and experienced in the procedure (because it was their core business).</li> <li>• Information about options for women for having Pap tests in the community or nearby was important. This included information about available providers and women's health services, provider- gender information, availability and booking and billing processes.</li> </ul>
One-stop shop	<ul style="list-style-type: none"> <li>• Some women were interested in attending a well women's health clinic where all women's health checks including Pap tests could be performed.</li> </ul>
Centralised medical records system	<ul style="list-style-type: none"> <li>• Some women were supportive of medical systems that enable centralised medical records to facilitate the exchange of client health and medical information between medical services and women's clinics.</li> </ul>

Stickers/calendar/SMS reminders	<ul style="list-style-type: none"> <li>Resources such as stickers or other appropriate calendar reminders and SMS text messages were suggested as useful prompts for making a screening appointment.</li> </ul>
<b><i>Education</i></b>	
Campaigns	<ul style="list-style-type: none"> <li>Hearing about the prevalence of cervical cancer in the community was considered important by some women.</li> <li>Conducting mass media campaigns that encourage and promote cervical screening can positively influence participation.</li> <li>Messages and images that promote '<i>peace of mind</i>' and diversity of age and culture were considered important by the women.</li> </ul>
<b><i>Community</i></b>	
Community-based education	<ul style="list-style-type: none"> <li>Strategies that use local celebrities, appealing and high profile individuals and cervical cancer champions in local promotions were mentioned by women.</li> <li>These individuals could act as role models, support the delivery of relevant health information and supplement statewide campaign efforts with activities in the local community.</li> </ul>
Media coverage	<ul style="list-style-type: none"> <li>Increasing local media coverage and discussion about cervical cancer and cervical screening could assist to normalise cervical screening.</li> </ul>



## **Attachment 2 – Coffs Harbour Research Summary report**



# **Women's Cancer Screening Program Consumer Research**

## **Site summary report – Coffs Harbour**

*Report on the barriers and enablers for participation in cervical  
and breast screening by eligible local women of Indian heritage  
and women residing in Ulong.  
Suggested actions for local services.*

**Prepared by:**

**Bev Carroll**

**Director**

**November 2017**



## 1 Acknowledgements

The researchers wish to sincerely thank the women from the Woolgoolga and Ulong communities who participated in the focus group discussions and shared their stories about this important and challenging women's health issue.

## 2 Aim of the Women's Cancer Screening Collaborative Consumer research

The Women's Cancer Screening Collaborative (WCSC) Consumer Research aims to explore personal, social and cultural barriers and enablers for women in the NSW north coast region for participating in breast and cervical screening. The information gathered from this research will support WCSC participating agencies to build at-risk women's engagement in screening.

The focus of the research in the Coffs Harbour site was women of Indian heritage and women residing in the small community of Ulong, who were within the eligible screening age for breast and cervical screening programs.

## 3 Research approach

The WCSC Consumer Research adopted a participatory approach. Local personnel of the North Coast Primary Health Network and WCSC partners formed the research fieldworker team and undertook focus group implementation, participant recruitment, facilitation of group discussions, note-taking and data analysis.

A content analysis of the data collected from the focus group discussions was undertaken to identify themes and their descriptors. Information from other Australian research studies about women's participation in breast and cervical screening was used to support data analyses and interpretations.

## 4 Focus groups

Three focus groups were conducted with women in Coffs Harbour in October 2017 (see Table 1).

<b>Age segment</b>	<b>Screening behaviour</b>	<b>Number of FGD Participants</b>
Women of Indian heritage 50-59 years	Regular screeners (Breast screening & Cervical screening)	5
Women of Indian heritage 40-60 years	Never/ under screeners <sup>A</sup> (Breast screening & Cervical screening)	6

<b>Age segment</b>	<b>Screening behaviour</b>	<b>Number of FGD Participants</b>
	<sup>A</sup> Some participants were outside the eligible age for participation in the BreastScreen program.	
Women (Ulong) 50-59 years	Regular screeners <sup>B</sup> (Breast screening & Cervical screening)  <sup>B</sup> Whilst never/under screeners were the target for the research in Ulong, recruitment was only able to enlist regular screeners in the focus group discussions.	5

## 5 Key findings – Women of Indian heritage

Barriers and enablers for participating in breast and cervical screening for women of Indian heritage are presented in Appendix 1 and Appendix 2.

It should be noted that:

- The focus group discussions involved only women from the Sikh community in Woolgoolga
- The ‘barrier’ themes were mainly identified from the discussions with never or under screening women who were on 457 visas;
- The discussions with regular screening women provided some insights regarding women in their community who were not regularly screening;
- The ‘enabler’ themes were mainly identified from the discussions with regular screening women; and
- Some limited information regarding ‘enablers’ for screening was also identified from the discussions with never/under screening women.

Key findings are:

- The concept of ‘good health’ was considered an individual’s responsibility. Diet, exercise and having a stress free lifestyle were key contributing factors for a healthy (happy) life.
- There were strong negative emotions expressed at the prospect of getting breast and cervical cancers. However, the women were optimistic that if caught early, both types of cancers could be successfully treated.
- Poor knowledge and awareness of cervical and breast cancer and screening for these cancers, were primary reasons for women not participating in screening programs.
- Poor knowledge was found regarding:
  - The causes of cervical and breast cancers;
  - Screening procedures; and
  - Local services available for screening.
- The early detection of breast cancer and cervical cancer was the primary motivation for women’s regular participation in the breast and cervical screening programs.

- The high regard the women held for: (1) the Australian Government (for participation in the BreastScreen program) and (2) GPs (for participation in cervical screening) were other notable enablers for their screening participation.
- Some barriers and enablers were common for both breast and cervical screening programs.

## **6 Suggested actions for improving participation in breast and cervical screening by women of Indian heritage**

A list of suggested actions for addressing some of the issues identified by the research has been prepared. It should be noted that these suggestions are broad. The final design, development, implementation and evaluation of future strategies should involve local service staff, health practitioners, community leaders and local women of Indian heritage.

(1) Instigate a local cancer screening marketing and recruitment project for women of Indian heritage.

- Establish a local community-based project that aims to:
  - Improve local women's knowledge about breast and cervical cancer and screening for these diseases; and
  - Raise awareness of breast and cervical screening services available in the local community.
- Suggested activities include community-based education and communication strategies and the development and dissemination of materials and resources that are tailored to appeal to women of Indian heritage within the screening target ages.
- The *Pink Sari Project* (supported by the Cancer Institute NSW to improve participation rates of Indian and Sri Lankan women in breast screening) provides a valuable case study example.
- The *Pink Sari Project* could usefully guide the design of a similar locally-branded screening program (incorporating both breast and cervical screening).

(2) Establish a community partnership.

- Form a community partnership to support the abovementioned local community-based project.
- The formation of partnerships within local communities can take time to develop and maintain, but can build valuable sustainability for activities.
- Some suggestions for membership of the community partnership include:
  - Local community champions such as doctors, community and religious leaders of Indian heritage;
  - Local women who have survived breast cancer and other volunteer women (e.g. women of Indian heritage who regularly screen); and
  - Representatives of women's health services and the local BreastScreen service.

(3) Make resources for women of Indian heritage available.

- Produce and disseminate resources in Hindi and Punjabi language that inform about breast and cervical screening services in the community.
- These resources should include information about the availability of female nurse practitioners to conduct Pap tests.
- Resources could be disseminated and promoted during health awareness weeks/months for breast and cervical cancer.
- They could also support special local projects instigated during these health events that target women of Indian heritage residing in Coffs Harbour.

(4) Offer a community transport service for cancer screening.

- Investigate options for a community transport support service for cancer screening.
- This service could support local women of Indian heritage to attend group appointments at the fixed BreastScreen site and medical appointments for a Pap test on set days.
- Aligning the service to special group booking days, would enable local women of Indian heritage to attend BreastScreen and women's health clinics together.
- This service could be offered annually such as during down-times in farm work.

(5) Conduct cultural competency assessments of local primary health care services.

- Undertake an assessment of local screening services such as BreastScreen and medical practices and women's health clinics for cultural competency.
- This assessment should include factors such as the level of cultural understanding, knowledge and skills among staff and the availability of translators to meet the needs of local women of Indian heritage.

## **7 Key findings – Women residing in Ulong**

Barriers and enablers for women residing in Ulong for participating in local breast and cervical screening are presented in Appendix 3 and Appendix 4.

It should be noted that:

- Themes for breast and cervical screening were identified from the discussions with regular breast and cervical screening women; and
- Barriers were focussed on issues that may or have delayed regular screening.

Key findings are:

- There were strong negative emotions expressed at the prospect of getting breast or cervical cancers. However, the women were optimistic that if caught early, both types of cancers could be successfully treated (though they were less optimistic about survival from cervical cancer).

- Most women reported delaying screening due to having negative attitudes towards screening. These attitudes related to:
  - Screening considered an ‘inconvenience’ or a disruption to their daily life, requiring considerable planning and preparation;
  - The location and availability of the BreastScreen service and GP access; and
  - Previous negative past cancer screening experiences.
- Another key barrier for regularly screening was limited knowledge about breast and cervical cancer.
- In many instances cancer knowledge was generated from anecdotal stories and feedback about health care advice provided by family, friends or other community members.
- The efficacy and safety of breast and cervical screening tests was also questioned by some women.
- The women considered early detection of breast cancer and cervical cancer the primary motivation for their regular participation in the breast and cervical screening programs.
- The women welcomed the prompts and reminder letters and invitations from screening services.
- Hearing about others getting these types of cancers, and especially breast cancer was also a significant prompt for the women to screen.
- A number of themes were common for both the breast and cervical screening programs.

## **8 Suggested actions for improving Ulong women’s participation in breast and cervical screening**

A list of suggested actions for addressing some of the issues identified by the research has been prepared. It should be noted that these suggestions are broad. The final design, development, implementation and evaluation of future strategies should involve local service staff, health practitioners, key community influencers and local women.

1. Instigate a regular women’s health forum.
  - In collaboration with the local community, local GPs, women’s health services and health educators, instigate a regular women’s health forum.
  - The forum should be conducted within the community.
  - The forum could support and enable opportunities for local women and particularly more isolated women to regularly meet and discuss women’s health and cancer screening programs.
  - Useful discussion topics include:
    - The prevalence and incidence of breast and cervical cancers in the community;
    - Breast and cervical cancer risks factors;
    - Screening ages for breast and cervical screening;
    - Screening issues for older women;

- The safety and efficacy of breast and cervical screening tests;
  - Local breast and cervical screening services in the community;
  - Personal strategies for improving women's experience of the a Pap test; and
  - Changes to the National Cervical Screening Program (the Renewal).
  - Investigate the feasibility of incorporating well-women's health checks in these health forum days.
  - Breast and cervical cancer awareness months, breast and cervical cancer events and health weeks would be appropriate occasions for scheduling forum meetings and wellness days.
2. Localise statewide cancer screening campaigns.
- Conduct a small-scale research project to identify relevant community and social settings, outlets and events that have potential to reach and engage women in Ulong in breast and cervical screening awareness-raising activities.
  - Inform local health workers and other relevant individuals in the community about statewide breast and cervical screening campaigns, messages and resources.
  - Support these local health workers and other key community leaders and champions in the Ulong community, to extend the promotion of these campaigns through targeted activities that can reach local women.
3. Produce a '*local health services guide for women*' in Coffs Harbour and surrounding communities such as Ulong.
- The guide should include information about:
    - Local women's health services, BreastScreen and Pap test providers;
    - Services personnel and available health providers;
    - Contact details; and
    - Access information (opening hours, group bookings, parking and transport).
  - Dissemination strategies should include a range of health care settings such as health clinics, medical practices, community health services, health food stores, wellness centres and pharmacy outlets.
  - Other relevant social and community settings should also be targeted including relevant settings identified through the abovementioned research (see 2. above).
  - The guide could also be disseminated and promoted during health awareness weeks/months for breast and cervical cancer.
  - The guide should be designed to enable regular updating.
4. Conduct regular visits to GP clinics and medical centres.
- Regularly visits to GP clinics and other medical centres in Coffs Harbour and surrounding communities such as Ulong to:
    - Assess reminder systems for breast and cervical screening;
    - Facilitate the dissemination of breast and cervical screening promotional materials and handouts; and

- Encourage the display of posters and information sheets in waiting rooms and clinics.
- 

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## 10 Appendix 1: Barriers and enablers for women of Indian heritage for participating in breast screening

i. Barriers for women of Indian heritage for participating in breast screening.	
Themes	Descriptors
<i>Client-based</i>	
Low knowledge	<ul style="list-style-type: none"> <li>• Women exhibited very low levels of knowledge about breast cancer, its causes and screening procedures for the disease.</li> <li>• There was considerable misinformation about breast cancer shared by the women.</li> </ul>
Fear	<ul style="list-style-type: none"> <li>• Fear was strongly associated with being diagnosed with cancer and fear of having to endure cancer treatments.</li> <li>• Whilst the women had low levels of knowledge about the screening process, fear was associated with getting a cancer diagnosis.</li> </ul> <p><i>“....say your prays you don’t get it!”</i></p>
Time poor	<ul style="list-style-type: none"> <li>• Women reported that they were very time poor, had busy lives involved in farm work, family/child minding responsibilities and commitments to their community.</li> </ul>
Lack of motivation	<ul style="list-style-type: none"> <li>• Breast screening for some women was not a high priority in terms of their use of available time.</li> </ul> <p><i>“Low motivation – they are thinking that they are just waiting for it to happen and then they will do something about it.”</i></p>
Age	<ul style="list-style-type: none"> <li>• For older women, age appeared to influence motivation to continue to participate in breast screening.</li> <li>• Older women, who were reliant on public transport, were less motivated to continue to participate in breast screening.</li> </ul>
Not regularly seeing a GP	<ul style="list-style-type: none"> <li>• Some women reported that they treated themselves with home-based remedies.</li> <li>• Seeking medical assistance would only be undertaken if the women’s home-based treatments were not working.</li> <li>• Opportunities to discuss breast screening with GPs were subsequently limited.</li> </ul>

Not relevant	<ul style="list-style-type: none"> <li>• Some women reported that they felt they were very fit and had healthy diets.</li> <li>• These factors were considered important for a healthy and happy life.</li> <li>• Some women did not consider themselves sick.</li> <li>• Participation in screening tests (or having any tests) was considered unnecessary if there were no signs or symptoms of being unwell.</li> </ul>
<b><i>Access</i></b>	
Limited available transport support	<ul style="list-style-type: none"> <li>• Some women did not drive and were reliant on others to drive them to the service.</li> </ul> <p><i>“The ones who don’t screen – they need the bus – wouldn’t make the trip. They have to travel.... they have to get someone to take them.”</i></p>
<b><i>General Practitioner/Health Provider</i></b>	
Lack of mention	<ul style="list-style-type: none"> <li>• Some women reported that their GP did not talk about breast cancer or about the importance of screening and where to access screening.</li> </ul>
No systematic reminder	<ul style="list-style-type: none"> <li>• While some women reported that their GP did not remind them when their breast screening was due, they considered this was acceptable as GPs were important and busy community members.</li> <li>• They believed the reminder system was the responsibility of the BreastScreen service.</li> </ul>
<b><i>Service/system - based</i></b>	
No reminders	<ul style="list-style-type: none"> <li>• Women (those on 457 visas) reported that they did not received any letters or reminders about screening.</li> </ul>
Low awareness in community	<ul style="list-style-type: none"> <li>• Women talked about not aware of any promotion of the BreastScreen service in the community.</li> <li>• This included promotions that disseminate information about the service, what happens at the service, where it was located and how appointments are made.</li> </ul>
No more ‘pink’ bus	<ul style="list-style-type: none"> <li>• The women reported that the BreastScreen bus no longer came to the community. Women were required to go to the fixed site at the Base Hospital.</li> <li>• The women felt that this change in the local BreastScreen service and the lack of visibility of the ‘pink’ bus in the community meant women were no longer prompted to think about breast screening.</li> </ul>

ii. Enablers for women of Indian heritage for participating in breast screening.	
Themes	Descriptors
<i>Client-based</i>	
Take control – <i>be proactive</i>	<ul style="list-style-type: none"> <li>• Women considered breast (or any cancer) to be very serious and highly impactful on their lives.</li> <li>• Early detection was important for successfully treating the disease.</li> <li>• Women felt breast screening was a necessary procedure that had to be done regardless of how you felt about it.</li> <li>• Women regularly mentioned screening provided ‘<i>peace of mind</i>’, and allowed women to move on with their lives.</li> </ul> <p><i>“Just have to get it over and done with!”</i></p>
Positive attitude - <i>compliance</i>	<ul style="list-style-type: none"> <li>• Regular screening women displayed positive attitudes to the BreastScreen service because it was a government program.</li> <li>• Some women overlooked any discomfort from the procedure as they considered it a necessary screening test.</li> </ul> <p><i>“They’re not deliberately rough - they have to do what they have to do!”</i></p>
Family history	<ul style="list-style-type: none"> <li>• Women who reported they had a family member who had breast cancer, were motivated to regularly breast screen.</li> </ul>
Community life	<ul style="list-style-type: none"> <li>• Women living in a close knit community were aware of issues with other women.</li> <li>• Hearing about a community member having breast cancer and its impact on their family/life motivated some women to regularly breast screen.</li> </ul>
<i>Service/systems - based</i>	
Reminders/invitation letters	<ul style="list-style-type: none"> <li>• Receiving the letter from BreastScreen inviting them to screen was considered very important for reminding them that they were due for screening.</li> </ul>

High regard of service	<ul style="list-style-type: none"> <li>• Many women reported having positive experiences at the service.</li> <li>• This included friendly and welcoming staff and time-efficient appointments.</li> </ul>
After-hours service	<ul style="list-style-type: none"> <li>• Access to the service after work hours was considered important for working women and especially those women requiring childminding.</li> </ul>
BreastScreen van	<ul style="list-style-type: none"> <li>• The presence of a BreastScreen van in the community in previous years reminded women about screening and provided them the opportunity and convenience to screen.</li> </ul> <p><i>“The bus! – there is no excuse!”</i></p>
Gender of service staff	<ul style="list-style-type: none"> <li>• Women preferred service staff to be female owing to the nature of the screening procedure, having to undress and expose their breasts.</li> </ul>
Screening service information	<ul style="list-style-type: none"> <li>• Women mentioned the need for information about the service especially those newly arrived in the community.</li> <li>• Information needs included: what you have to do to participate, where to go, any costs, how to make an appointment and what happens in your appointment.</li> </ul>
<b><i>Education</i></b>	
Campaigns	<ul style="list-style-type: none"> <li>• Conducting mass media campaigns that encourage and promote breast screening can positively influence participation.</li> </ul> <p><i>“....they drum it into you to do it!”</i></p>
Community-based women’s health group sessions	<ul style="list-style-type: none"> <li>• Bringing role models, local champions and health educators to the community was considered beneficial for increasing awareness and interest in breast screening and to build self-efficacy among local women of Indian heritage.</li> </ul>

## 11 Appendix 2: Barriers and enablers for women of Indian heritage for participating in cervical screening

i. Barriers for women of Indian heritage for participating in cervical screening.	
Themes	Descriptors
<i>Client-based</i>	
Poor knowledge	<ul style="list-style-type: none"> <li>• Women exhibited low levels of knowledge about cervical cancer, HPV, its causes and screening for the disease, and particularly age eligibility for the screening program.</li> <li>• There was considerable misinformation about the causes of cervical cancer shared by the women.</li> </ul>
Time poor	<ul style="list-style-type: none"> <li>• Women reported that they were time poor, had busy lives involving farm work and family/child minding responsibilities and commitments to their community.</li> <li>• Work was considered a higher priority in terms of their use of time.</li> </ul>
Fear	<ul style="list-style-type: none"> <li>• Fear was associated with low levels of knowledge about cervical cancer and cervical screening.</li> <li>• Fear included: the screening test (Pap test), what it entailed, who performed it and where they would have to go to have it.</li> <li>• Fear was also associated with being diagnosed with cancer of the cervix.</li> </ul>
Pain	<ul style="list-style-type: none"> <li>• Women referred to the physical discomfort of having a Pap smear test and described pain associated with the Pap smear.</li> </ul> <p><i>“It’s hurts a little – bloody hell, why do I have to go through it”</i></p>

Not regularly seeing a GP	<ul style="list-style-type: none"> <li>• Some women reported that they treated themselves with home-based remedies.</li> <li>• Seeking medical assistance would only be undertaken if the women's home-based treatments were not working.</li> <li>• Opportunities to discuss cervical screening with GPs were subsequently limited.</li> </ul>
<b><i>Access</i></b>	
Limited available transport support	<ul style="list-style-type: none"> <li>• Some women did not drive and were reliant on others to drive them to a medical appointment.</li> </ul>
Too expensive	<ul style="list-style-type: none"> <li>• There was a perception that the test would cost a lot of money as it was considered a medical procedure.</li> </ul>
<b><i>General Practitioner/Health Provider</i></b>	
Gender	<ul style="list-style-type: none"> <li>• Some women preferred a female GP for women's health and screening procedures such as the Pap smear test.</li> </ul>
Lack of mention	<ul style="list-style-type: none"> <li>• Women reported that their GP did not talk about cervical screening or remind about having a Pap test.</li> <li>• Women of Indian heritage may be reluctant to raise it with their GP owing to the trust and high regard they had for their GP.</li> </ul>
Language	<ul style="list-style-type: none"> <li>• Having a provider who did not speak Punjabi or Hindi was a barrier for women who could not speak English.</li> </ul>
<b><i>Service/system - based</i></b>	
Limited knowledge - local screening services	<ul style="list-style-type: none"> <li>• Women displayed poor knowledge of local cervical screening services available.</li> <li>• This includes information about where to get screened, how often and costs associated with screening.</li> <li>• Related to this was poor-low awareness of what happens after screening in terms of results of screening.</li> <li>• Women were not aware that female nurse practitioners were available to provide cervical screening.</li> </ul>

No systematic reminder	<ul style="list-style-type: none"> <li>Women reported that they did not receive letters reminding about cervical screening.</li> </ul>
<b>Community</b>	
Lack of education and information in community	<ul style="list-style-type: none"> <li>Some women reported low recall of hearing about cervical cancer and screening within the local community.</li> </ul>
<b>ii. Enablers for women of Indian heritage for participating in cervical screening.</b>	
<b>Themes</b>	<b>Descriptors</b>
<b>Client -based</b>	
Take control	<ul style="list-style-type: none"> <li>Women felt that cancer was very serious and would be very impactful on their lives.</li> <li>Early detection was considered highly important for successfully treating the disease.</li> <li>Women felt the Pap test was a necessary test that had to be done regardless of how you felt about it.</li> </ul> <p><i>“Just want to get it done – bite the bullet and get it done!”</i></p> <ul style="list-style-type: none"> <li>Women regularly referred to ‘<i>peace of mind</i>’, and screening (whilst unpleasant) allows women to ‘<i>move on with their lives.</i>’</li> </ul>
Language - <i>English</i>	<ul style="list-style-type: none"> <li>Having English language skills was considered necessary for understanding the purpose of having a Pap test and what it entails.</li> </ul>
<b>GP/Health provider</b>	
High regard/status	<ul style="list-style-type: none"> <li>Women regarded GPs highly and complied with their advice accordingly.</li> </ul> <p><i>“You do what they tell you!”</i></p>

Reminders	<ul style="list-style-type: none"> <li>• Many women stated that GP reminders facilitated booking another appointment to have the test.</li> </ul>
Gender	<ul style="list-style-type: none"> <li>• Some women of Indian heritage (regular screeners) were not concerned with the gender of a GP as they considered the test an important procedure and beneficial to detecting cancer early.</li> </ul> <p><i>“We’ve given birth in front of a man. It’s important to do it!”</i></p>
Gender of GP – <i>being female GP</i>	<ul style="list-style-type: none"> <li>• For some women, the gender of the GP was considered an important enabler for having a Pap test especially those women who have never been screened.</li> </ul>
Language – <i>Punjabi/Hindi</i>	<ul style="list-style-type: none"> <li>• Having a provider who spoke Punjabi or Hindi was considered important for women who could not speak English.</li> </ul>
<b><i>Service/system - based</i></b>	
Reminder letters	<ul style="list-style-type: none"> <li>• Women felt that the reminder letters were important for prompting them to have a Pap test.</li> <li>• Receiving a letter from the government reinforced the importance of cervical screening for women to avoid getting cancer.</li> </ul>
<b><i>Education</i></b>	
Campaigns	<ul style="list-style-type: none"> <li>• Obtaining information about the prevalence of cervical cancer in the community was considered important.</li> <li>• Conducting mass media campaigns that encourage and promote cervical screening could positively influence participation by women of Indian heritage.</li> </ul>
Community-based women’s health group sessions	<ul style="list-style-type: none"> <li>• Bringing role models, local champions and health educators to the community could increase awareness and interest in cervical screening and build self-efficacy.</li> <li>• Conducting well women’s checks at specific times of the year when work/farm life is less demanding on personal time, could address certain access issues for some women of Indian heritage.</li> </ul>

Resources - language	<ul style="list-style-type: none"><li>• The availability of language-specific information was important for non-English speaking women for improving their understanding about:<ul style="list-style-type: none"><li>○ Cervical cancer;</li><li>○ Risks of getting cervical cancer; and</li><li>○ Prevention of the cervical cancer.</li></ul></li></ul>
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## 12 Appendix 3: Barriers and enablers for Ulong women for participating in breast screening.

i. Barriers for Ulong women for participating in breast screening.	
Themes	Descriptors
<i>Client-based</i>	
Low motivation - <i>Inconvenience</i>	<ul style="list-style-type: none"> <li>• Putting off or delaying screening was commonly reported.</li> <li>• This was due to having to think about it, making an appointment, cancelling the appointment and the implications of that i.e. having to do it all again.</li> </ul> <p><i>“Too busy, lifestyle....You’ve got to make time... just too much else going on in life/my day’</i></p> <p><i>‘It’s very hard when there is so much going on in your life.’</i></p>
Low motivation - <i>Not a priority</i>	<ul style="list-style-type: none"> <li>• Breast screening for some women was not at the top of their priority list in terms of how they chose to spend their day.</li> </ul>
Painful procedure	<ul style="list-style-type: none"> <li>• Some women found the screening test painful due to breast size.</li> </ul> <p><i>“It’s not an easy test and straightforward...not like having blood pressure”</i></p> <p><i>‘It’s unpleasant so you put it off.’</i></p>
Limited knowledge	<ul style="list-style-type: none"> <li>• Women exhibited limited knowledge about breast cancer, its causes and screening for the disease.</li> <li>• Some information was based on their recall of past medical advice.</li> <li>• There was misinformation about breast cancer shared by the women that was based on anecdotal stories from family, friends and other community members.</li> </ul>

<p>Personal belief</p>	<ul style="list-style-type: none"> <li>• Some women held suspicious attitudes regarding health care, treatments and screening procedures.</li> <li>• These women were particularly sceptical of the efficacy of screening tests.</li> <li>• This challenged personal motivation and decision-making when it was time for them to re-screen.</li> </ul> <p><i>“I know some women who had them regularly and ending up finding the lump themselves.”</i></p> <p><i>“....and those women who get a positive result and then find out there isn’t nothing...put through all that stress!”</i></p> <p><i>“ ....how will you know you’ll get a correct result?”</i></p>
<p>Negative attitudes to service -past experience</p>	<ul style="list-style-type: none"> <li>• Some women reported negative experiences in the past with breast screening such as prolonged pain after screening which deterred them from making their appointment.</li> <li>• Other negative past experiences related to past contact with a BreastScreen service (not the Coffs Harbour service).</li> </ul>
<p>No current GP</p>	<ul style="list-style-type: none"> <li>• Some women mentioned they did not currently have a GP.</li> </ul>
<p><b>Access</b></p>	
<p>No BreastScreen van in community</p>	<ul style="list-style-type: none"> <li>• The BreastScreen bus does not come to the community.</li> <li>• This reinforced the ‘<i>inconvenience</i>’ of screening for some women.</li> </ul>
<p>Distance to BreastScreen site</p>	<ul style="list-style-type: none"> <li>• Women were required to drive for one-hour to the fixed site at the Base Hospital.</li> <li>• The women exhibited some resentment regarding the distance to the fixed site.</li> <li>• This reinforced the attitude that screening was an inconvenience and a disruption to daily life, commitments and routines.</li> </ul> <p><i>“You can’t just drop in... you have to drive an hour...”</i></p>

	<i>"I reckon if the women at Coffs Harbour had to drive to Grafton, they wouldn't go as regularly!"</i>
<b>General Practitioner/Health Provider</b>	
Lack of information	<ul style="list-style-type: none"> <li>Some women who had a GP reported that their GP did not talk about breast cancer and where to access screening.</li> </ul>
No systematic reminder	<ul style="list-style-type: none"> <li>Some women who had a GP reported that their GP did not remind them when their breast screening was due.</li> </ul>
<b>Service/system -based</b>	
Lack of information in community	<ul style="list-style-type: none"> <li>Some women (new to the community) expressed limited knowledge and awareness about the local BreastScreen service.</li> <li>They reported a lack of local information about the service including where it was located.</li> </ul>
<b>ii. Enablers for Ulong women for participating in breast screening.</b>	
<b>Themes</b>	<b>Descriptors</b>
<b>Client-based</b>	
Taking 'preventative' action	<ul style="list-style-type: none"> <li>The women's beliefs about the seriousness of getting cancer, its impact on women's lives and their family and the perceived high prevalence of the disease, reinforced the notion of screening for 'peace of mind'.</li> </ul> <p><i>"...you hear so many women get it, so just have to do it...prevent it!"</i></p> <ul style="list-style-type: none"> <li>Attending BreastScreen addressed personal concerns for women rarely doing breast self-examinations.</li> </ul>

	<ul style="list-style-type: none"> <li>• Strong beliefs that breast cancer can be successfully treated if detected early were highly motivating for these women.</li> </ul>
Family / friend with breast cancer	<ul style="list-style-type: none"> <li>• Women who reported they had a family member or knew someone who had breast cancer were motivated to participate in regular screening.</li> </ul>
Community life	<ul style="list-style-type: none"> <li>• Women living in a close knit community were aware of and discussed other women's health issues.</li> <li>• Hearing about a community member having breast cancer and its impact on their family/life motivated some women to regularly participate in breast screening.</li> </ul>
<b><i>Service/system - based</i></b>	
Reminders/invitation letters	<ul style="list-style-type: none"> <li>• Receiving the invitation letters from BreastScreen was very important for reminding women when screening was due.</li> </ul>
High regard of service	<ul style="list-style-type: none"> <li>• Most women mentioned positive experiences at the service.</li> <li>• This included friendly and welcoming staff who took time to explain the procedure and were gentle in their approach.</li> <li>• Short waiting times were also highly regarded by these women and addressed concerns about time away from their homes.</li> </ul>
Gender of service staff	<ul style="list-style-type: none"> <li>• Women preferred service staff to be female owing to the nature of the screening procedure, having to undress and expose their breasts.</li> </ul>

Group bookings	<ul style="list-style-type: none"> <li>• The group block booking system was considered favourably as it would enable women to travel together for appointments, provide support and to share time together.</li> </ul>
BreastScreen van	<ul style="list-style-type: none"> <li>• Women felt that the presence of a BreastScreen van in the community would remind women about screening.</li> <li>• It would also address concerns about the inconvenience of having to leave the community to go to the fixed site.</li> </ul>
Information	<ul style="list-style-type: none"> <li>• Women felt information about the BreastScreen service in Coffs Harbour including contact details, location and instructions for parking would be very useful for planning purposes.</li> </ul>
<b><i>Education</i></b>	
Community-based women's health group sessions	<ul style="list-style-type: none"> <li>• Regular women's health discussion group meetings within the community could increase awareness and interest in breast screening, to build self-efficacy and support breast screening participation.</li> <li>• Regular meetings that involved health service personnel, educators and practitioners were considered important for validating health information.</li> </ul>
Campaigns/media coverage	<ul style="list-style-type: none"> <li>• Conducting mass media campaigns that encourage and promote breast screening could positively influence women's participation in screening.</li> </ul>

### 13 Appendix 4: Barriers and enablers for Ulong women for participating in cervical screening.

i. Barriers for Ulong women for participating in cervical screening.	
Themes	Descriptors
<i>Client-based</i>	
Fear and denial	<ul style="list-style-type: none"> <li>• Fear and dislike of the Pap test was expressed by some women. This included:               <ul style="list-style-type: none"> <li>○ Fear of the screening test (Pap test) and that it could damage the cervix and cause lesions;</li> <li>○ Discomfort, pain, and feeling vulnerable;</li> <li>○ The test being too invasiveness; and</li> <li>○ Fear of being diagnosed with cancer of the cervix.</li> </ul> </li> </ul>
Not prepared	<ul style="list-style-type: none"> <li>• Having a Pap test required planning and preparation.</li> <li>• Women offered a Pap test spontaneously during an appointment (unplanned) was not viewed positively. Being unprepared for a Pap test related to personal hygiene preparations (waxing, washing, clean underwear, menstruation) and being prepared mentally.</li> </ul>
Low motivation - <i>Inconvenience</i>	<ul style="list-style-type: none"> <li>• This was due to having to think about it, making an appointment and consequences of cancelling the appointment (having to do it all again).</li> </ul>
Low motivation – <i>not a priority</i>	<ul style="list-style-type: none"> <li>• Having a Pap test was not a high priority for some women in terms of how they chose to spend their day.</li> </ul>
Low motivation - <i>poor well-being</i>	<ul style="list-style-type: none"> <li>• Women delayed having a Pap test during times when they were experiencing poor well-being or periods of low mood.</li> </ul>

Menopause	<ul style="list-style-type: none"> <li>• Older women found having a Pap test uncomfortable and painful as a consequence of menopause.</li> </ul>
Not having a GP	<ul style="list-style-type: none"> <li>• Not having a GP (due to being new to community or not finding a suitable female doctor) impacted on women's opportunity to have their scheduled Pap test.</li> </ul>
Limited knowledge	<ul style="list-style-type: none"> <li>• Women generally had limited of knowledge about cervical cancer, HPV, its causes, high-risk groups and screening for the disease.</li> <li>• Stress, negative sexual experiences and the Pap test itself were top of mind as causes of cervical cancer.</li> </ul>
Personal belief	<ul style="list-style-type: none"> <li>• Suspicious attitudes regarding health care, treatment and screening procedures and scepticism about Pap tests challenged personal motivation and decision-making when it was time to re-screen.</li> </ul>
<b><i>Access</i></b>	
Distance to GP/health services	<ul style="list-style-type: none"> <li>• Most women talked about having to travel out of the community to see their GP and the inconvenience that it entailed in terms of time away from home.</li> </ul>
<b><i>General Practitioner/Health Provider</i></b>	
Gender	<ul style="list-style-type: none"> <li>• Some women preferred a female GP for women's health and screening procedures such as the Pap test.</li> </ul>
Negative past GP experience	<ul style="list-style-type: none"> <li>• Negative past experiences included: <ul style="list-style-type: none"> <li>○ Lack of GP explanation about the procedure;</li> <li>○ Lack of GP understanding of the woman;</li> <li>○ Perceived GP judgemental attitudes towards a woman's sexual history (particularly when younger);</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ GP not sharing a holistic attitude to health; and</li> <li>○ Feeling being rushed during GP appointment.</li> </ul>
<b><i>Service/system - based</i></b>	
Long waiting lists for appointments	<ul style="list-style-type: none"> <li>● Appointments at women's health centres were in high demand and had to be booked well ahead.</li> </ul>
Preference for female health provider	<ul style="list-style-type: none"> <li>● Women were not aware that female nurse practitioners were available to provide cervical screening.</li> </ul>
<b>ii. Enablers for Ulong women for participating in cervical screening.</b>	
<b>Themes</b>	<b>Descriptors</b>
<b><i>Client -based</i></b>	
Take control	<ul style="list-style-type: none"> <li>● Women felt that cervical cancer was very serious and would be very impactful on their lives and especially the lives of younger women.</li> <li>● Early detection was considered highly important for treating the disease successfully.</li> <li>● Women felt the Pap test was a necessary test that had to be done regardless of how you felt about it.</li> <li>● Women regularly referred to '<i>peace of mind</i>', and considered screening (whilst unpleasant) necessary.</li> </ul>
Age	<ul style="list-style-type: none"> <li>● Older women have more time available to have their Pap tests.</li> <li>● Post-menopausal women were considered less stressed and more amenable to having the Pap test.</li> </ul>
Knowledge and awareness of test	<ul style="list-style-type: none"> <li>● Being informed about the Pap test and knowing what it will entail was important for women.</li> <li>● This also includes changes to the Pap test (The Renewal).</li> </ul>

<b><i>GP/Health provider</i></b>	
Respectful manner	<ul style="list-style-type: none"> <li>• Women mentioned the following GP-related enablers: <ul style="list-style-type: none"> <li>○ Respectful communication and behaviour;</li> <li>○ Technique and having the procedure explained to them through the appointment;</li> <li>○ Being encouraged to relax; and</li> <li>○ Having women's privacy respected.</li> </ul> </li> </ul>
Reminders	<ul style="list-style-type: none"> <li>• Many women felt the GP reminding them (repeatedly) when their Pap test is due facilitated their booking an appointment to have the test.</li> </ul>
Gender of GP	<ul style="list-style-type: none"> <li>• For some women, having a female GP was considered an important enabler for having a Pap test.</li> <li>• Having a female GP was considered especially important for younger women (e.g. their daughters).</li> <li>• Having a female GP was also important for those women who had had a negative experience previously with a male practitioner.</li> </ul>
<b><i>Service/system - based</i></b>	
Reminder letters	<ul style="list-style-type: none"> <li>• Women considered the reminder letters were important for prompting them to have a Pap test.</li> </ul>
Information about options available	<ul style="list-style-type: none"> <li>• Information about service options available for women in the community for having Pap tests was important.</li> <li>• This included information about available providers and women's health services, provider-gender information, service hours, booking and billing processes.</li> </ul>
<b><i>Education</i></b>	
Information	<ul style="list-style-type: none"> <li>• Obtaining information about the prevalence of cervical cancer and about cervical screening and its efficacy was considered important.</li> </ul>

Campaigns	<ul style="list-style-type: none"> <li>• Conducting mass media campaigns that encourage and promote cervical screening can positively influence participation.</li> <li>• Messages and images that promote '<i>peace of mind</i>' and diversity of age and culture were considered important.</li> </ul>
Community-based women's health group sessions	<ul style="list-style-type: none"> <li>• Bringing health educators to the community to conduct 'health information' days could increase awareness and interest in cervical screening among women in the community.</li> <li>• Involving local community leaders, role models and champions could build self-efficacy.</li> <li>• Aligning these visits to well women's checks that include having a Pap test could address personal access barriers.</li> </ul>
<b><i>Community</i></b>	
Transport	<ul style="list-style-type: none"> <li>• Improvements to local transport and infrastructure in rural towns was raised as important for women for accessing health services.</li> </ul>

## **Attachment 3 – Tweed Heads Research Summary Report**



## **Women’s Cancer Screening Program Consumer Research**

### **Site summary report – Tweed Heads\***

\* Research participants included women and key stakeholders from the Tweed Heads and Richmond Valley areas.

*Report on the barriers and enablers for eligible women living with a disability for participating in cervical and breast screening in Tweed Heads.  
Suggested actions for local services.*

**Prepared by:**

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## **1 Acknowledgements**

The researchers wish to sincerely thank the women from the Tweed Heads and Richmond Valley communities and local staff members who participated in the interview program, sharing their stories about this important and challenging women's health issue.

## **2 Aim of the Women's Cancer Screening Collaborative Consumer research**

The Women's Cancer Screening Collaborative (WCSC) Consumer Research aims to explore the personal, social and cultural barriers and enablers for participating in breast and cervical screening for women in the NSW north coast region. The information gathered from this research will support WCSC participating agencies to build at-risk women's engagement in screening.

## **3 Research focus for the Tweed Heads site**

The focus of the research for the Tweed Heads site was participation in breast and cervical screening by eligible women living with a disability and women with a mental health issue. Due to the challenges of recruiting this special population segment to the research project, research participants included women and key stakeholders from the Tweed Heads and Richmond Valley areas.

## **4 Research approach**

The WCSC Consumer Research adopted a participatory approach. Local staff from the North Coast Primary Health Network formed the research fieldworker team. They undertook the implementation of the interview program including the recruitment of participants, facilitation of interviews, note-taking and data analysis.

A content analysis of the data collected from the interviews was undertaken to identify themes and descriptors. Information from other relevant Australian research studies was used to support the data analyses and interpretations.

## **5 Interview program**

Two key informant interviews were conducted with representatives of local disability and mental health services in October 2017. Four telephone and two face-to-face interviews were conducted with women living with a disability from the Tweed Heads and Richmond Valley communities in February 2018 (see Table 1).

<b>Table 1: Interviews conducted for the Tweed Heads research site (including Richmond Valley community women)</b>		
<b>Age segment</b>	<b>Screening behaviour</b>	<b>Number of interviews</b>
Women 50-59 years	Never/under/lapsed screeners (Breast screening & Cervical screening*) <small>* 2 participants had had a hysterectomy and were not participating in cervical screening.</small>	5
Women 30-40 years	Never/under/lapsed screeners (Cervical screening)	1
Representatives of disability and mental health services		2

## **6 Key findings – Women living with a disability (Tweed Heads and Richmond Valley communities)**

The barriers and enablers for women living with a disability for participating in breast and cervical screening are presented in Appendix 1 and Appendix 2.

Key findings are:

- A woman’s disability adds another layer to personal, cultural and social barriers to breast and cervical screening commonly experienced by women.
- Attitudes towards breast and cervical screening may also be impacted by:
  - Previous past experiences of physical and sexual abuse; and
  - Negative experiences and contact with the medical profession and screening services staff.
- Living with and managing life with a disability was the primary focus for many women in terms of prioritising health-associated actions.
- Poor to limited knowledge about breast and cervical cancer and screening programs was found. This included poor knowledge of:
  - The causes of cervical and breast cancers;
  - Risks of getting these cancers; and
  - Screening procedures and accessible services available in their community.
- For some women, contact with GPs mainly focused on the care and ongoing treatment associated with the woman’s specific health issue.
- There was little recall or mention of GPs discussing or reminding women about breast or cervical screening. Recall of receiving reminder letters from screening services such as BreastScreen was also found to be low.
- The attitudes of carers and family members may influence some women’s perceptions of the risks of getting breast and cervical cancer and their motivation to participate in screening programs.
- A range of access issues were found to strongly influence participation in screening. These included:

- Physical and structural issues associated with the premises of local medical practices and services;
- The design of breast screening equipment;
- Access to suitable transport and transport cost;
- Costs associated with screening;
- The duration and lack of flexibility of screening appointment times; and
- An absence of trained service/practice staff to support, encourage and assist women living with a disability with screening.
- Attendance at screening services was considered challenging for some women requiring complex thinking and organisation.
- The early detection of breast cancer and cervical cancer to enable treatment was the primary motivation for participation in screening programs.
- The inclusion of women living with a disability in cancer screening education programs and campaigns was considered important for improving the personal relevance of cancer screening messages for these women.
- Adjustments to medical practices, screening services and screening equipment were important for improving participation in screening.
- A number of themes were found to be common for both the breast and cervical screening programs.

## **7 Suggested actions for improving participation in breast and cervical screening by women living with a disability**

A list of suggested actions for addressing some of the issues identified by the research has been prepared. It should be noted that these suggestions are broad. The final design, development, implementation and evaluation of future strategies should involve local service staff, health practitioners, community leaders and local women living with a disability.

- (5) Conduct a program of visits to General Practice clinics, medical centres and screening services to assess, develop or modify *Disability Plans*.
- Visits to local GP clinics, other medical centres and screening services should involve meetings with practice and service managers and staff to:
    - Assess physical and structural issues that may affect access for women with a disability;
    - Discuss training for practice staff and GPs that covers communicating with and supporting clients who have a disability; and
    - Facilitate the display of posters and information resources about breast and cervical cancer and screening programs in waiting rooms and clinics that include images of women with a disability.
  - Involve women living with a disability in these visits, feedback processes and the implementation of a service's Disability Plan.

(6) Produce a '*local health services guide for women with a disability*'.

- The guide should be specific to women living with a disability and include information about:
  - Local accessible women's health services including BreastScreen and Pap test providers, service personnel and health providers available, contact details and access information (opening hours, costs, group bookings, physical access details such as ramps, parking and transport); and
  - The availability of female nurse practitioners to conduct Pap tests and suitable screening equipment that can be adjusted to accommodate the needs of women in wheelchairs or those women with restricted body or limb movement.
- Dissemination strategies for the *Guide* should include health care settings such as health clinics, medical practices, community health services and pharmacy outlets. Other relevant social and community settings such as disability support agencies should also be targeted.
- The *Guide* could also be disseminated and promoted during health awareness weeks/months for breast and cervical cancer through targeted activities involving disability agencies.
- The guide should be designed in a range of accessible formats and to enable regular updating.

(7) Conduct education and training sessions for local GPs, practice staff and screening service personnel.

- Education, training and resources could usefully improve medical practitioners' and screening services staff's understanding of issues for women living a disability and build skills in relation to:
  - Talking to women living with a disability about breast and cervical cancer and screening procedures; and
  - Addressing any fears or concerns women may have about screening procedures.
- Produce a *Desktop Tool* for health practitioners that supports them to:
  - Talk about breast and cervical cancer and screening programs;
  - Ask and remind about screening; and
  - Provide referral information for women to accessible breast and cervical screening services.

(8) Develop breast and cervical cancer and screening education and information resources for women with a disability.

- Examine available breast and cervical cancer and screening education and information materials for their appeal and relevancy for women living with a disability. It may be useful to contact screening services in other jurisdictions about any available resources that could be included.

- Conduct focus group discussions and/or interviews with women with a disability and key informants to explore the design and development of resources in a range of appropriate reading and presentation formats.
- Ensure women living with a disability are portrayed in images in any new education and information resources.
- Utilise a range of health, social and cultural settings to disseminate breast and cervical cancer and screening education and information resources to reach women living with a disability, carers and family members.

(9) Undertake local promotions to reach women living with a disability.

- Work with local disability agencies and health services to conduct promotions during health awareness weeks/months for breast and cervical cancer. These local promotions could support:
  - The dissemination of breast and cervical cancer and screening education and information resources to this special population group; and
  - Women living with a disability to access and participate in women’s health discussion sessions and talks aimed at increasing their awareness of breast and cervical cancer and screening programs available in their local community.
- Utilise local champions in community promotions aimed at encouraging participation in cancer screening programs by women living with a disability.
  - These women can share their own stories about breast and cervical screening. Examples of suitable women include local Paralympians or other local sportswomen living with a disability, local disability advocates and celebrities.

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## 8 References

1. North Coast Primary Health Network. Women’s Cancer Screening Collaborative Handbook. Available at: <http://ncphn.org.au/wcsc/wp-content/uploads/2017/03/20170306-WCSC-handbook.pdf>
2. Johnson K, Strong R, Hillier L, Pitts M. Screened Out: Women with Disabilities and Preventive Health. *Scandinavian Journal of Disability Research*. 2006;8(2-3):150-60

## 9 Appendix 1: Barriers and enablers for women living with a disability for participating in breast screening (Tweed Heads and Richmond Valley communities)

i. Barriers for women living with a disability for participating in breast screening (Tweed Heads and Richmond Valley communities)	
Theme	Descriptors
<i>Client-based</i>	
Low priority/too hard	<ul style="list-style-type: none"> <li>Some women felt that cancer screening was a low priority for them. <i>“It’s not important to me to do it...I have so much wrong with me, with my disability, but I just think I have so much else that could wipe me out before breast cancer gets me”.</i></li> <li>Some women felt overwhelmed by the organisation and logistics of screening. This impacted on their motivation to screen. <i>“It means a lot of organisation mentally, can I go, how will I do it, who can help me, will I be physically able to do it .... The logistics become quite large ....there’s the bus, I have to ring and make sure the bus on my route at that time is accessible.”</i></li> </ul>
Negative past experience/s	<ul style="list-style-type: none"> <li>This includes past childhood or adult sexual abuse.</li> <li>Weary about talking about intimate women’s health issues.</li> <li>Negative past experiences with the medical profession, practice and service staff.</li> <li>Some women perceive GPs, health practitioners and practice staff having negative attitudes towards people living with a disability and a lack of understanding or experience with people living with a disability.</li> </ul>

	<p><i>“...they assume you are mentally unwell...They talk slowly and loudly...It’s only the eyes that don’t work! It puts you off.”</i></p> <p><i>“I wasn’t treated with the same respect...”</i></p>
Health condition	<ul style="list-style-type: none"> <li>• A mental health condition can impact on motivation to think about screening and opportunities to discuss screening with GP</li> <li>• Certain mental health illnesses can cause delusional thoughts and reinforce existing fears about screening such as fear of radiation from screening machines.</li> <li>• Some behaviours may be disruptive to screening procedures.</li> <li>• Feeling ‘well’ can vary day to day.</li> <li>• Time spent at medical appointments.</li> </ul> <p><i>“I’m so over going to medical appointments”.</i></p>
Limited knowledge	<ul style="list-style-type: none"> <li>• Low literacy and limited capacity to understand and interpret information about breast and cervical cancer and screening programs.</li> <li>• Women who are blind or with hearing impairment may experience limited access to information about breast screening.</li> <li>• Health information about breast cancer and screening programs available deemed not relevant to them (by self or others including carers, family members and health practitioners);</li> <li>• Some women may not read information about breast cancer and screening because it does not include images or other information that they consider relevant.</li> </ul>
Living context	<ul style="list-style-type: none"> <li>• Some women living with a disability have limited contact with other women or people who may provide information about women’s health issues such as screening.</li> <li>• Some women with an intellectual disability may have limited choices about where they live and this may impact on their access to information and services.</li> </ul>
No fixed address	<ul style="list-style-type: none"> <li>• Some women regularly move house or don’t have a fixed address. These women may not receive reminders and invitations from BreastScreen.</li> </ul>

Attitudes of family/carer	<ul style="list-style-type: none"> <li>• Carer/family may consider breast screening not a priority for the woman.</li> <li>• Carer/family may have limited knowledge about breast cancer and breast screening.</li> <li>• Attitudes of carers and family members may influence some women's beliefs about their risks of getting breast cancer and the relevancy of screening programs.</li> </ul>
Limited contact with GP	<ul style="list-style-type: none"> <li>• Some women with a mental health issue may not regularly visit a GP.</li> <li>• GP contact may only be related to the management of their mental health issue.</li> <li>• Contact with GPs may focus mainly on the management of their disability rather than on women's health issues. This may result in a lack of mention of cancer screening programs by GPs or referral to other services that are less familiar to the woman.</li> </ul>
<b><i>Access (not specific to BreastScreen)</i></b>	
<i>Access - physical</i>	<ul style="list-style-type: none"> <li>• Some women may not have access to mobile coverage to make appointments for breast screening.</li> <li>• Service may not be suitable for women in a wheel chair in terms of size of scanning rooms, height of doorways and change room/area size and capacity.</li> <li>• Service may not be accessible for women who are blind.</li> <li>• Service may have dog restrictions and this may limit access for women with a guide dog.</li> <li>• Distance from home and limited transport options may restrict some women's access to a breast screen service.</li> <li>• Cost of transport to a breast screen service may pose difficulties for some women.</li> </ul>
<i>Access - equipment</i>	<ul style="list-style-type: none"> <li>• Screening equipment may not be adjustable to suit wheelchairs.</li> <li>• Screening equipment may pose difficulties for women with restricted limb movement or have suffered limb loss or live with chronic pain.</li> </ul>

<i>Service (not specific to BreastScreen)</i>	
Staff	<ul style="list-style-type: none"> <li>• Staff may not be trained or have experience in assisting women with a disability. This includes assistance with dressing, positioning and explaining procedures in an appropriate manner.</li> <li>• Lack of staff understanding that a client may require assistance with the screening procedure may impact on women's experience with breast screening.</li> <li>• More appropriate equipment that is not generally set-up may not be used owing to low awareness or lack of time by staff to set up.</li> </ul>
Appointments	<ul style="list-style-type: none"> <li>• The duration of screening appointment times makes some women feel they will be rushed.</li> <li>• A lack of flexibility around available appointment times may hinder the presence of a carer or other support person at the woman's appointment.</li> </ul>
Reminders	<ul style="list-style-type: none"> <li>• Women reported not receiving reminder letters or any communications from breast screening services.</li> </ul>
<i>General Practitioner/healthcare provider</i>	
Lack of offer of information	<ul style="list-style-type: none"> <li>• Some women reported that their GP does not talk about breast cancer, screening or screening services.</li> </ul>
No reminders/follow up	<ul style="list-style-type: none"> <li>• Women reported that their GP did not remind them about breast screening.</li> </ul>
High turnover	<ul style="list-style-type: none"> <li>• There may a high turnover of GPs. This can impact on the development of the client/GP relationship.</li> </ul>
Culture of practice	<ul style="list-style-type: none"> <li>• The GP practice may not have developed or implemented a disability plan.</li> </ul>

Gender	<ul style="list-style-type: none"> <li>Some women reported that they preferred to talk to a female GP about breast cancer and the screening process.</li> </ul>
Low level of GP screening knowledge	<ul style="list-style-type: none"> <li>Some GPs may not have sufficient knowledge of the breast screening process. This may limit their ability to support and reassure women with a disability who may be fearful of screening.</li> </ul>
<b>Community</b>	
Lack of accessible educational material.	<ul style="list-style-type: none"> <li>Lack of relevant and appealing information, education and communication materials about breast cancer and screening.</li> <li>Available breast cancer and screening information may not be presented in an accessible format such as for women with low literacy or women who are blind or visually impaired.</li> </ul>
<b>ii. Enablers for women living with a disability for participating in breast screening (Tweed Heads and Richmond Valley communities)</b>	
<b>Theme</b>	<b>Descriptor</b>
<b>Client-based</b>	
Taking 'preventative' action	<ul style="list-style-type: none"> <li>Women's beliefs about the seriousness of getting cancer and its impact on women's lives and their family reinforced the notion of screening for '<i>peace of mind</i>'.</li> <li>Women strongly believed that, if detected early, breast cancer can be successfully treated.</li> </ul> <p><i>"I need to know I am clear of breast cancer or have it so I can have treatment for it early so you're clear!"</i></p>
Stable mental health	<ul style="list-style-type: none"> <li>Women with a mental health illness whose condition is stable, may be more amenable to discussing breast cancer and breast screening with a health practitioner.</li> </ul>

Improved awareness and knowledge about screening and screening services.	<ul style="list-style-type: none"> <li>Information that is accessible for all women is important for improving women's screening knowledge, their understanding of the screening services and processes and their motivation to participate in breast screening.</li> </ul>
Support person	<ul style="list-style-type: none"> <li>Women with disability may benefit from being encouraged to attend breast screening with a trusted support person.</li> <li>A support person could reinforce and encourage participation on the day as well as provide assistance with: <ul style="list-style-type: none"> <li>Transport;</li> <li>The booking procedures and screening preparation tasks;</li> <li>Interpreting instructions for screening; and</li> <li>Reading and interpreting information about screening results.</li> </ul> </li> </ul>
<i>GP/primary care provider</i>	
Education	<ul style="list-style-type: none"> <li>GP education programs that focus on improving GPs understanding of personal and physical needs of women with disability could increase opportunities for clients and GPs to discuss breast screening.</li> <li>The development of a <i>GP reading-aide or tool</i> that summarises key information about breast cancer and screening and available accessible services could usefully support GPs in their consultations with eligible women.</li> </ul>
Practice Disability Plan	<ul style="list-style-type: none"> <li>A <i>practice disability plan</i> would support GP practices and medical clinics to provide for the needs of patients with disabilities.</li> <li>Issues to be addressed by the <i>Plan</i> should include: the need for ramps, doorway widths, accessible toilet facilities, adequate space in waiting rooms and consultation rooms, staff training, height of beds and presence of hoists.</li> </ul>
<i>Service/systems – based</i>	
Reminders/invitation letters	<ul style="list-style-type: none"> <li>Receiving letters and invitations from BreastScreen are very important for all women for reminding to screen and for prompting action (making an appointment).</li> </ul>

	<ul style="list-style-type: none"> <li>• Dissemination of information about how to update contact and address details held by BreastScreen to facilitate the reminder and invitation systems, would be useful for those women who change address often or are new to the community.</li> </ul>
Service Disability Plan	<ul style="list-style-type: none"> <li>• A <i>service disability plan</i> would support breast screening services to provide for the needs of patients with disabilities.</li> <li>• Issues to be addressed by the <i>Plan</i> should include: physical issues such as ramps, doorway widths, toilet facilities, space in waiting rooms and consultation rooms as well as issues related to staff training, the screening procedures and equipment.</li> </ul>
Support staff/volunteers	<ul style="list-style-type: none"> <li>• Designated trained support staff or rostered volunteer women who are available at screening services could assist some women who require support and help with having a breast screen.</li> </ul>
Feedback	<ul style="list-style-type: none"> <li>• Ensuring there are client feedback mechanisms in place so all female health consumers have the opportunity to offer comments and suggestions for service improvements.</li> </ul>
Improvements in the design in screening equipment.	<ul style="list-style-type: none"> <li>• Improvements in the design of screening equipment (such as to accommodate a wheel chair) would support women with a range of physical disabilities to participate in screening.</li> </ul>
Group bookings	<ul style="list-style-type: none"> <li>• Group appointments may facilitate screening by women with a disability.</li> </ul>
Staff training	<ul style="list-style-type: none"> <li>• Staff training in disability issues can enable an inclusive health service.</li> <li>• Key issues for training programs include: <ul style="list-style-type: none"> <li>○ Communications, so all women are respectfully and sensitively managed through the screening procedure;</li> <li>○ Understanding the physical and mental health issues and needs that can impact on a woman's screening experience; and</li> <li>○ Strategies that staff can use to ensure an inclusive service.</li> </ul> </li> <li>• Engaging women living with a disability in the design and implementation of training programs is important.</li> </ul>

<i>Education</i>	
Community-based education	<ul style="list-style-type: none"> <li>• Producing information materials that are accessible for women with a disability (including women with low literacy or women who are blind or visually impaired) may improve knowledge and motivate women to screen.</li> <li>• This includes information in a range of formats (Braille and clear, plain English with graphics, video and sound tapes).</li> <li>• Producing information, education and communication materials promoting breast screening that include images of women living with a disability may make breast screening more personally relevant.</li> <li>• Recruit and engage high profile or appealing local champions in education and promotional programs.</li> </ul>
Settings-based promotions/displays	<ul style="list-style-type: none"> <li>• Displaying posters and providing information about breast cancer and breast screening in a range of social, cultural and workplace settings builds awareness and reminds women to screen.</li> <li>• Conducting information sessions in a range of settings would increase opportunities for women living with a disability to discuss women's health issues such as breast cancer.</li> </ul>
Broaden dissemination of information resources	<ul style="list-style-type: none"> <li>• Disseminating information, education and communication materials through a broad range of outlets within the general community that includes images of women living with a disability is important.</li> <li>• This would contribute to the normalisation of breast screening by women (regardless of health or life circumstances).</li> <li>• Disseminate information about breast cancer and breast screening for women living with a disability through a range of outlets that will reach carers and /or other family members. Outlets could include those associated with carer payments and the NDIS.</li> </ul>

## 10 Appendix 2: Barriers and enablers for women with a disability for participating in cervical screening (Tweed Heads and Richmond Valley communities)

i. Barriers for women living with a disability for participating in cervical screening (Tweed Heads and Richmond Valley communities)	
Theme	Descriptors
<i>Client-based</i>	
Low priority	<ul style="list-style-type: none"> <li>For many women, other life and personal health issues associated with their disability are a higher priority.</li> </ul>
Not relevant	<ul style="list-style-type: none"> <li>Some women may not consider information about cervical screening relevant to them because they are not sexually active.</li> </ul>
Negative past experience/s	<ul style="list-style-type: none"> <li>Negative experiences include past childhood or adult sexual abuse.</li> <li>Weary about talking about more intimate women's health issues.</li> <li>Negative past experiences with the medical profession.</li> <li>Some women perceive GPs, health practitioners and practice staff having negative attitudes towards people living with a disability and a lack of understanding or experience with people living with a disability.</li> </ul>
Health condition	<ul style="list-style-type: none"> <li>A mental health condition can impact on motivation to think about screening and opportunities to discuss screening with a GP.</li> <li>Some mental health behaviours may be disruptive and hamper the cervical screening procedure.</li> </ul>

<p>Low understanding or knowledge of cervical screening</p>	<ul style="list-style-type: none"> <li>• Women with intellectual disability may have difficulties in understanding written information about cervical screening.</li> <li>• Women who are blind or with a visual or hearing impairment may experience limited access to information about cervical screening.</li> <li>• Some women may not read information about cervical cancer and screening because it does not include images or other information that they consider relevant.</li> </ul>
<p>Isolated living</p>	<ul style="list-style-type: none"> <li>• Some women with disability have limited contact with other women or people who may provide information about women’s health issues such as cervical screening.</li> <li>• Some women with an intellectual disability may have limited choices about where they live and this may impact on their access to information and services.</li> </ul>
<p>No fixed address</p>	<ul style="list-style-type: none"> <li>• Some women regularly move house or don’t have a fixed address. These women may not receive reminders and invitations from the NSW Pap Register.</li> </ul>
<p>Attitudes of family/carer</p>	<ul style="list-style-type: none"> <li>• Carer/family may consider cervical screening not a priority or not relevant for the woman.</li> <li>• Carer/family may have limited knowledge about cervical cancer and cervical screening.</li> </ul>
<p>Limited contact with GP</p>	<ul style="list-style-type: none"> <li>• Some women with a mental health issue may not regularly visit a GP.</li> <li>• GP contact may only occur for the management of their mental health or disability health issue.</li> </ul>
<p><b><i>Access</i></b></p>	
<p><i>Access - physical</i></p>	<ul style="list-style-type: none"> <li>• Some women may not have access to mobile coverage to make appointments for cervical screening.</li> <li>• GP clinics and women’s health services may not be suitable for women in a wheel chair.</li> </ul> <p style="text-align: center;"><i>“The only thing stopping me is the bed!”</i></p> <ul style="list-style-type: none"> <li>• GP clinics and women’s health services may not be accessible for women who are blind.</li> <li>• GP clinics and women’s health services may have dog restrictions and this may limit access for women with a guide dog.</li> <li>• Distance to GP clinics and women’s health services and limited transport options may restrict some women’s access to cervical screening services.</li> <li>• Cost of transport to GP clinics and women’s health services may pose difficulties for some women.</li> </ul>

<p><i>Access – procedure</i></p>	<ul style="list-style-type: none"> <li>• Examination beds may not be moveable or adjustable to accommodate certain physical disabilities.</li> <li>• Consultation rooms and examination beds may not be fitted out with hoists or other equipment necessary to assist women in wheelchairs.</li> <li>• The procedure may be problematic for women who live with chronic pain.</li> <li>• Additional clinic staff may not be available to assist the client in preparing to have a Pap smear test.</li> </ul>
<p><b><i>Practice/service-related</i></b></p>	
<p><i>Staff</i></p>	<ul style="list-style-type: none"> <li>• Staff may not be trained or have required experience in assisting women with disability.</li> <li>• This includes identifying women who may need assistance, assisting women with making appointments, during waiting periods and with undressing.</li> </ul>
<p><i>Attitudes</i></p>	<ul style="list-style-type: none"> <li>• Discriminatory or dismissive attitudes of health professionals that focus on women’s disability rather than the whole woman can impact on women’s screening opportunities and experiences.</li> </ul>
<p><i>Cost</i></p>	<ul style="list-style-type: none"> <li>• GP clinics and women’s health services may have insufficient budgets for purchasing additional equipment that could assist some women with a disability to have a Pap smear test.</li> <li>• Cost for longer appointment times may inhibit some women’s access to Pap smear tests.</li> </ul>
<p><b><i>General Practitioner/healthcare provider</i></b></p>	
<p>Lack of information /reminders</p>	<ul style="list-style-type: none"> <li>• GP may not talk about cervical cancer, Pap smear tests or other women’s health issues with women with disability. <p style="text-align: center;"><i>“I have never been asked about my sexual health by any GP.”</i></p> </li> <li>• GP may not remind or have systems in place for routinely reminding women about cervical screening. <p style="text-align: center;"><i>“My GP always asks me when I had my last blood test but not when I had my last pap smear.”</i></p> </li> </ul>

High turnover	<ul style="list-style-type: none"> <li>• There may be a high turnover of GPs. This can impact on the development of the client/GP relationship.</li> </ul>
Culture of practice	<ul style="list-style-type: none"> <li>• The GP practice may not have developed or implemented a disability plan.</li> </ul>
Limited choice of GP	<ul style="list-style-type: none"> <li>• The choice of GP (including gender-based provider choices) or women's services may be limited due to low numbers of accessible medical practices, clinics and services in local area.</li> </ul>
Inexperience in disability care	<ul style="list-style-type: none"> <li>• Some GPs may have limited training and experience in caring and treating women with a disability.</li> </ul>
Gender	<ul style="list-style-type: none"> <li>• Some women may prefer a female GP in terms of talking about cervical cancer and screening procedures.</li> </ul>
Limited appointment time	<ul style="list-style-type: none"> <li>• Cervical screening for some women with a disability may require additional appointment time which may not be readily available at their GP practice.</li> </ul>
<b>ii. Enablers for women living with a disability for participating in cervical screening (Tweed Heads and Richmond Valley communities)</b>	
<b>Theme</b>	<b>Descriptor</b>
<i>Client-based</i>	
Stable mental health	<ul style="list-style-type: none"> <li>• Women with a mental health illness and whose condition is stable, may be more amenable to discussing cervical cancer and screening with a health practitioner.</li> </ul>

Improved awareness and knowledge about screening	<ul style="list-style-type: none"> <li>Information that is accessible for all women is important for improving women's screening knowledge and their motivation to participate in cervical screening.</li> </ul>
Support person	<ul style="list-style-type: none"> <li>Women living with a disability may benefit from being encouraged to attend cervical screening with a support person.</li> <li>A support person could reinforce and encourage participation on the day as well as provide assistance with: <ul style="list-style-type: none"> <li>Transport to the screening appointment;</li> <li>Undertaking the booking procedures and screening preparation tasks;</li> <li>Reading and interpreting instructions for screening; and</li> <li>Reading and interpreting information about screening results.</li> </ul> </li> </ul>
<b><i>GP/primary care provider</i></b>	
Education	<ul style="list-style-type: none"> <li>GP education programs that focus on improving GPs understanding of personal and physical needs of women living with a disability could increase opportunities for clients and GPs to discuss cervical screening.</li> <li>The development of <i>GP reading-aide or tool</i> that summarises key information and advice about cervical cancer and screening could usefully guide GP consultations with eligible women regarding cervical screening.</li> </ul>
<b><i>Practice/service –systems-based</i></b>	
Reminders/invitation letters	<ul style="list-style-type: none"> <li>Receiving the letters and invitations from the NSW Pap Register are very important for all women for reminding to screen and for prompting action (making an appointment).</li> <li>Dissemination of information about how to update contact and address details held by the NSW Pap Register to facilitate the reminder and invitation systems, would be useful for those women who change address often or are new to the community.</li> </ul>

Practice Disability Plan	<ul style="list-style-type: none"> <li>• A <i>practice disability plan</i> would support GP practices and medical clinics to provide for the needs of patients with disabilities.</li> <li>• Issues to be addressed by the <i>Plan</i> should include: the need for ramps, doorway widths, accessible toilet facilities, adequate space in waiting rooms and consultation rooms, staff training, height of beds and presence of hoists.</li> </ul> <p style="text-align: center;"><i>“A bed that lowers, that would good or a hoist that will get me on the bed – it’s the biggest enabler for a [wheelchair] woman!”</i></p>
Group bookings	<ul style="list-style-type: none"> <li>• Group appointments at women’s health clinics may facilitate screening by women living with a disability.</li> </ul>
Support staff/volunteers	<ul style="list-style-type: none"> <li>• Designated trained support staff or rostered volunteer women who are available at GP practices and medical clinics, could assist women who require additional support and help with having a Pap smear test.</li> </ul>
Staff training	<ul style="list-style-type: none"> <li>• Staff training to improve their understanding of disability issues can build and enable an inclusive health service.</li> <li>• Key issues include: <ul style="list-style-type: none"> <li>○ Communication, to ensure all women are respectfully and sensitively managed through the screening procedure;</li> <li>○ Understanding the physical and mental health issues and needs that can impact on a woman’s screening experience; and</li> <li>○ Strategies that staff can use to ensure an inclusive service.</li> </ul> </li> <li>• Recruiting women with a range of disabilities in training programs to have input in the design and implementation of training programs is important.</li> </ul>
Well-women’s sessions	<ul style="list-style-type: none"> <li>• Well-women’s sessions for women with a disability would provide opportunities for women to raise and discuss personal issues regarding screening.</li> <li>• Well-women’s sessions would enable the dissemination of information about accessible local practices and clinics providing cervical screening services.</li> </ul>

Feedback	<ul style="list-style-type: none"> <li>• Ensuring all health consumers have the opportunity to provide feedback on the service and to offer suggestions for service improvements.</li> </ul>
<i>Education</i>	
Community-based education	<ul style="list-style-type: none"> <li>• Producing information materials that are accessible for women with a disability.</li> <li>• This includes information in a range of formats (Braille and clear, plain English with graphics, video and sound tapes).</li> <li>• Recruit and engage high profile or appealing local champions in education and promotional programs.</li> </ul>
Settings-based promotions/displays	<ul style="list-style-type: none"> <li>• Displaying posters and providing information about cervical cancer and cervical screening in a range of relevant social, cultural and workplace settings builds awareness and reminds women to screen.</li> <li>• Conducting information sessions about cervical cancer and screening in a range of setting, would increase the opportunity for women living with a disability to discuss women's health issues, improve their knowledge of cervical cancer and awareness of preventive actions such as cervical screening.</li> </ul>
Broad dissemination of education resources	<ul style="list-style-type: none"> <li>• Disseminating information, education and communication materials through a broad range outlets within the general community that includes images of women living with a disability is important.</li> <li>• This would contribute to the normalisation of cervical screening by women (regardless of health or life circumstances).</li> <li>• Disseminate information about cervical cancer and cervical screening for women living with a disability through a range of outlets that will reach carers and /or other family members. Outlets could include those associated with carer payments and the NDIS.</li> </ul>



## **Attachment 4 – Lismore Research Site Summary Report**



# **Women's Cancer Screening Program Consumer Research**

## **Site summary report – Lismore/Casino**

*Report on the barriers and enablers for participation in cervical  
and breast screening by eligible local women who identify as  
Aboriginal.*

*Suggested actions for local services.*

**Prepared by:**

**Bev Carroll**

**Director**

**June 2018**



## 1 Acknowledgements

The researchers wish to sincerely thank the women from the Lismore and Casino communities who participated in the focus group discussions and shared their stories about this important and challenging women's health issue.

## 2 Aim of the Women's Cancer Screening Collaborative Consumer research

The Women's Cancer Screening Collaborative (WCSC) Consumer Research aims to explore personal, social and cultural barriers and enablers for women in the NSW north coast region for participating in breast and cervical screening. The information gathered from this research will support WCSC participating agencies to build at-risk women's engagement in screening programs.

The focus of the research in the Lismore/Casino site was women who identify as Aboriginal and of eligible screening age for breast and cervical screening programs.

## 3 Research approach

The WCSC Consumer Research adopted a participatory approach. Local personnel of the North Coast Primary Health Network and WCSC partners formed the research fieldworker team. They undertook focus group implementation, participant recruitment, facilitation of group discussions, note-taking and preliminary data analysis.

A content analysis of the data collected from the focus group discussions was undertaken to identify themes and their descriptors. Information from other Australian research studies about women's participation in breast and cervical screening was used to support data analyses and interpretations.

## 4 Focus groups

Two focus groups were conducted with women in Casino and Lismore (see Table 1).

<b>Age segment</b>	<b>Screening behaviour</b>	<b>Number of FGD Participants</b>
Women who identify as Aboriginal 30-60 years	Regular screeners (Breast screening &/or Cervical screening)	8
Women who identify as Aboriginal 30-40 years	Regular screeners (Cervical screening)	5

## 5 Key findings

Barriers and enablers for participating in breast and cervical screening programs for women who identify as Aboriginal are presented in Appendix 1 and Appendix 2.

It should be noted that:

- The research team was unable to recruit women who were never/under screeners within the project timeframe;
- Therefore the two focus groups involved only women who were regularly participating in breast and/or cervical screening programs;
- The discussions explored reasons why women in their community may not regularly participate in screening;
- One focus group, regular breast and cervical screeners, included women across a wide age range (30-60 years). This may have impacted on younger-aged participants' responses; and
- This also meant that younger women (outside the screening age for breast screening) were in the focus group discussions around breast cancer and screening issues

Key findings are:

- The women expressed strong negative emotions at the prospect of getting breast and cervical cancers. However, the women were optimistic that if caught early, both types of cancers could be successfully treated.
- Poor knowledge and awareness of cervical and breast cancer and screening for these cancers, were suggested as the primary reasons for other women (and especially younger-aged women) to not participate in screening programs.
- Poor knowledge was found amongst the participants even though the women were regular screeners. This related to:
  - The causes of cervical and breast cancers;
  - The reasons for screening; and
  - The screening process and eligibility.
- Family and being healthy for your family were important motivators for their participation in breast and cervical cancer screening programs.
- The early detection of breast and cervical cancers (through screening) was strongly associated with beliefs regarding cancer survival.
- Instigating targeted education efforts at the local community level to dispel myths about breast and cervical cancer and screening was considered important for empowering women to make informed decisions about their screening opportunities.
- Improving access to women's health services and transport were also mentioned as enablers for improving breast and cervical screening participation rates.
- Some barriers and enablers were common for both breast and cervical screening programs.

- Barriers and enablers identified were consistent with findings from a recent Western Australia study<sup>1</sup> that had a similar research focus.

## **6 Suggested actions for improving participation in breast and cervical screening by women who identify as Aboriginal**

A list of suggested actions for addressing some of the issues identified by the research has been prepared. It should be noted that these suggestions are broad. The final design, development, implementation and evaluation of future strategies should involve local service staff, health practitioners, community leaders and local community women.

### (1) Establish community partnerships.

- Form community partnerships to support local community-based efforts.
- The formation of partnerships within local communities can take time to develop and maintain, but can build valuable sustainability for activities.
- Some suggestions for membership of the community partnerships include:
  - Local community champions such as community elders and AMS personnel;
  - Local community women who have survived breast cancer and other volunteer women (e.g. women who regularly screen); and
  - Representatives of women's health services and the local BreastScreen service.

### (2) Instigate regular women's health workshops.

In collaboration with the local community partnerships, Aboriginal Medical Service, local GPs, women's health services and health educators, conduct regular women's health workshops. These workshops should:

- Be conducted within the communities;
- Support and enable opportunities for local women of different ages to regularly meet and discuss women's health and cancer screening programs;
- Involve female health workers and cancer screening service providers and other relevant health personnel who can inform and educate about cervical and breast cancers and screening programs.
- Useful discussion topics for these workshops include:
  - The prevalence and incidence of breast and cervical cancers in the community;
  - Breast and cervical cancer risks factors;
  - Screening ages for breast and cervical screening;
  - Local breast and cervical screening services in the community;
  - Personal strategies for improving women's experience of the a Pap test;
  - HPV;
  - Self-collection cervical screening tests; and

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<sup>1</sup> Pilkington et al. (2017) Perspectives of Aboriginal women on participation in mammographic screening: a step towards improving services. *BMC Public Health*;17:69

- Changes to the National Cervical Screening Program (the Renewal).
  - Investigate the feasibility of incorporating well-women's health checks including Pap tests and group BreastScreen appointments in association with these health workshop sessions.
  - Breast and cervical cancer awareness months, breast and cervical cancer events and health weeks would be appropriate occasions for scheduling workshops and for conducting wellness days.
- (3) Disseminate culturally appropriate information, education and promotional resources.
- Produce and disseminate culturally appropriate education materials that inform about screening and local breast and cervical screening services.
  - These resources should include information about the availability of female GPs and nurse practitioners to conduct Pap tests.
  - Resources could be disseminated and promoted through the health workshops and during health awareness weeks/months for breast and cervical cancer.
  - They could also support special local projects instigated during these health events that target Aboriginal women.
- (4) Offer a community transport service for cancer screening.
- Investigate options for a community transport support service for Aboriginal women to attend cancer screening appointments.
  - This service could support local community women to attend group appointments at BreastScreen and medical/clinic appointments for a Pap test on set days.
  - Aligning the service to special group booking days, would enable local women to attend BreastScreen and women's health clinics together.
  - Explore feasibility of a support person (Aboriginal Health Worker, counsellor or nurse) to accompany the women to the appointments and assist them with screening.
- (5) Conduct cultural competency assessments of local primary health care services.
- Undertake an assessment of local screening services such as BreastScreen and local medical practices and women's health clinics for cultural competency.
  - This assessment should include factors such as the level of cultural understanding, knowledge and skills among staff for meeting the needs of local Aboriginal women.
  - Examine services' access to appropriate personnel who would be available to support Aboriginal women with screening such as with answering any questions, explaining the procedure, assisting with preparation for screening and as a chaperone where only a male doctor is available.
- (6) Localise statewide cancer screening campaigns.

- Conduct a small-scale research project to identify relevant community and social settings, outlets and events that have potential to reach and engage Aboriginal women in breast and cervical screening awareness-raising activities.
- Inform local Aboriginal health workers and other relevant community members about statewide breast and cervical screening campaigns, messages and resources.
- Support these local health workers and other key community leaders and champions, to extend the promotion of these campaigns through targeted activities that can reach local Aboriginal women.

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## 7 References

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4. Pilkington et al. (2017) Perspectives of Aboriginal women on participation in mammographic screening: a step towards improving services. BMC Public Health;17:697

## 8 Appendix 1: Barriers and enablers for women who identify as being Aboriginal for participating in breast screening

i. Barriers for women who identify as being Aboriginal for participating in breast screening.	
Themes	Descriptors
<i>Client-based</i>	
Low knowledge	<ul style="list-style-type: none"> <li>• Women exhibited very low levels of knowledge about breast cancer, its causes and screening for the disease.</li> <li>• There was considerable misinformation about breast cancer shared by the women.</li> <li>• The women reported a general lack of information available to women in their community and especially information for younger community women.</li> </ul>
Shame* * The concept of “shame” as used by Aboriginal English speakers is broader than the non-Aboriginal use of the word. It extends to include embarrassment in certain situations and self-consciousness often due to attention (for positive or negative reasons) rather than as the result of an action by the individual. [Pilkington et al. 2017]	<ul style="list-style-type: none"> <li>• Women associated the breast screening process with ‘shame’ and feelings of vulnerability. They disliked the notion that others would see them going to screening, or having to remove clothing and others seeing you naked.</li> </ul> <p><i>“People make fun of you, degrade you, when you are getting on the bus”</i></p> <ul style="list-style-type: none"> <li>• Some women mentioned feeling vulnerable as a result of being physically exposed during the screening process.</li> <li>• Some women also mentioned they didn’t like other people touching their body.</li> </ul>
Fear of results	<ul style="list-style-type: none"> <li>• Fear was strongly associated with being diagnosed with cancer and the fear of not surviving the disease.</li> <li>• Some women mentioned other family members had been diagnosed with breast cancer and exhibited a fatalistic attitude towards getting the disease themselves.</li> <li>• For this reason, they felt that some women may avoid having a mammogram because they feared finding out that they may also have breast cancer.</li> </ul>

Concern about confidentiality	<ul style="list-style-type: none"> <li>• Some women expressed concern about confidentiality during a screening appointment.</li> <li>• These women were concerned about others knowing about their business, being overheard by others in the waiting room and health practitioners discussing their business with other community or family members.</li> </ul>
Low priority	<ul style="list-style-type: none"> <li>• The women felt that for some women in the community, breast screening was not a high priority.</li> <li>• This was expressed as ‘<i>too busy</i>’ and ‘<i>other things just come up in the day</i>’.</li> <li>• Some women also mentioned women forgetting to turn up to a screening appointment.</li> </ul>
Dislike procedure	<ul style="list-style-type: none"> <li>• Some women reported that they found the procedure uncomfortable and unpleasant.</li> <li>• Some women mentioned having issues with the machines owing to their height and the coldness of the machine/screening equipment.</li> </ul>
<b><i>General Practitioner/Health Practitioner</i></b>	
Lack of mention	<ul style="list-style-type: none"> <li>• Many women reported that their GP did not talk about or provide any information about breast cancer or about the importance of screening and where to access screening.</li> </ul>
No systematic reminder	<ul style="list-style-type: none"> <li>• Some women reported that their GP did not remind them when their breast screen was due.</li> </ul>
GP attitudes	<ul style="list-style-type: none"> <li>• Some women expressed a dislike of GPs and a lack of trust in them.</li> </ul> <p><i>“[GP] talks down to you...doesn’t treat you like a person...just another number....doesn’t like Indigenous people!”</i></p>
<b><i>Service/system - based</i></b>	
Lack of awareness in community	<ul style="list-style-type: none"> <li>• The women reported there were women in their community who were not aware of the BreastScreen service.</li> </ul>
<b><i>Access</i></b>	
Transport	<ul style="list-style-type: none"> <li>• The women reported that transport to and from health services such as BreastScreen was difficult for some women and especially those living in rural locations and on the missions.</li> <li>• These women rely on other family members to drive them to the service or medical appointments.</li> </ul>

ii. Enablers for women who identify as being Aboriginal for participating in breast screening.	
Themes	Descriptors
<i>Client-based</i>	
Take control – <i>be proactive</i>	<ul style="list-style-type: none"> <li>• Women considered breast (or any cancer) to be very serious and highly impactful on their lives.</li> <li>• Early detection was considered important for successfully treating the disease.</li> <li>• The women felt breast screening was a necessary procedure that had to be done regardless of how you felt about it.</li> <li>• The women regularly mentioned screening provided ‘<i>peace of mind</i>’.</li> </ul> <p>“<i>You want to know whether you got it or not...want to be around for your children and your children’s children.</i>”</p> <p>“<i>It’s better to be safe than sorry!</i>”</p>
Family history	<ul style="list-style-type: none"> <li>• Women who reported they had a family member who had breast cancer, were motivated to regularly breast screen so they can catch the disease early.</li> </ul>
<i>Service/systems - based</i>	
Reminders/invitation letters	<ul style="list-style-type: none"> <li>• Receiving the letter from BreastScreen inviting them to screen was considered very important for reminding them when they were due for screening.</li> </ul>
Presence of a counsellor/support person	<ul style="list-style-type: none"> <li>• The presence of a support person, counsellor or Aboriginal Health Worker at the BreastScreen appointment was suggested as a helpful strategy to improve women’s experience at the service.</li> <li>• They felt there are many women who feared the screening process because they don’t understand it.</li> <li>• A counsellor or other support person (female) would assist to allay these fears by explaining the process, helping them with preparing for screening and to answer any questions or concerns they may have.</li> <li>• The women also thought this would address any cultural concerns women may have regarding male health practitioners/radiographers.</li> </ul>

BreastScreen service information	<ul style="list-style-type: none"> <li>• Women mentioned the need for more education and information about the BreastScreen service for women in the community.</li> <li>• Information needs included: what you have to do to participate, where to go, costs, how to make an appointment, what happens at your appointment and who can help you.</li> </ul>
<b><i>GP/Health Clinic</i></b>	
Reminders/inform about breast cancer screening	<ul style="list-style-type: none"> <li>• The women highlighted the importance of GPs and other health practitioners reminding women clients about breast screening.</li> <li>• Some women mentioned their GP had a computerised reminder system that provided regular reminders to women clients.</li> <li>• The women suggested the need for GPs and other health practitioners to talk about breast cancer, risks and screening programs with their female clients.</li> </ul>
Cultural competence	<ul style="list-style-type: none"> <li>• Cultural competence is a key strategy for reducing inequalities in healthcare access and the quality and effectiveness of care received.</li> <li>• Local cultural competency programs that target health services, agencies and clinics can improve staff interactions with Aboriginal clients and thereby improve the client's healthcare experience.</li> <li>• These programs support the establishment of 'safe' healthcare environments for Aboriginal female clients and their engagement in discussions about breast cancer and screening programs with healthcare service providers.</li> </ul>
<b><i>Education</i></b>	
Community education workshops	<ul style="list-style-type: none"> <li>• The women suggested workshops in the local community would improve women's knowledge and understanding about breast cancer and breast screening.</li> <li>• Workshops were also considered important to allay fears and concerns about confidentiality.</li> <li>• The women suggested Aboriginal health or community health workers should lead workshop discussions and activities.</li> <li>• Workshops should also include fun activities that encourage the women to return for future workshop sessions.</li> <li>• Workshops that include making appointments, taking women to BreastScreen appointments together may be useful.</li> <li>• The involvement of respected community women in the workshops was also considered important.</li> <li>• Using local language at education sessions was recommended.</li> </ul>

	<ul style="list-style-type: none"> <li>• These workshops were considered very important for the women living on the missions or in more remote communities.</li> </ul>
Health materials	<ul style="list-style-type: none"> <li>• The women emphasised the need for clear and simple messages about BreastScreen and for the inclusion of Aboriginal women in posters and other promotional materials.</li> <li>• They also suggested the use of images that explain about breast screening to reach women with limited literacy skills.</li> </ul>
Role models and advocates	<ul style="list-style-type: none"> <li>• Bringing role models, local champions and health educators to the community was considered beneficial for increasing awareness and interest in breast screening and to build self-efficacy among community women.</li> <li>• The women mentioned the importance of elders (women) who can encourage community women to go to appointments and attend education sessions.</li> </ul> <p><i>“They need to say if she can do it, I can do it...”</i></p>
<b>Access</b>	
Transport	<ul style="list-style-type: none"> <li>• The women suggested the need for improvements in transport especially for the women living on the missions.</li> <li>• They suggested the transport/buses be available in the community on certain days to take the women to appointments. They also suggested the elders would have an important role to play in encouraging the women to use the bus service.</li> </ul>

## 9 Appendix 2: Barriers and enablers for women who identify as being Aboriginal for participating in cervical screening

i. Barriers for women who identify as being Aboriginal for participating in cervical screening.	
Themes	Descriptors
<i>Client-based</i>	
Low level of knowledge	<ul style="list-style-type: none"> <li>• Women exhibited low levels of knowledge about cervical cancer, HPV, its causes and screening for the disease, and particularly age eligibility for the screening program.</li> <li>• There was considerable misinformation about the causes of cervical cancer shared by the women.</li> <li>• The women felt that low levels of knowledge was especially prevalent among the younger women in the community.</li> </ul>
<p><b>Shame*</b></p> <p>* The concept of “shame” as used by Aboriginal English speakers is broader than the non-Aboriginal use of the word. It extends to include embarrassment in certain situations and self-consciousness often due to attention (for positive or negative reasons) rather than as the result of an action by the individual.</p> <p>[Ref: Pilkington et al. 2017]</p>	<ul style="list-style-type: none"> <li>• Women associated the cervical screening process with ‘shame’ and feelings of vulnerability. They disliked the notion of having to remove clothes and others (especially male GPs) seeing the women naked.</li> <li>• Some women mentioned feeling vulnerable as a result of being physically exposed during the screening process.</li> <li>• Some women also mentioned they didn’t like people touching their body.</li> </ul> <p><i>“I get very uncomfortable when I have to open my legs up for somebody...very uncomfortable”</i></p> <p><i>“I don’t like people touching your privates”</i></p> <ul style="list-style-type: none"> <li>• The women stated that some women would also be embarrassed if they were found to have a STD.</li> </ul>

<p>Low priority/forget</p>	<ul style="list-style-type: none"> <li>Some women stated that many women just forget to turn up for screening appointments as other things come up during their day.</li> </ul> <p><i>“Life gets in the way!...your day just gets filled up with other things”</i></p> <ul style="list-style-type: none"> <li>Similarly, the women felt that cervical cancer screening was a low priority for some women because of not having any symptoms. Therefore, many women just don’t think about it.</li> </ul>
<p>Fear</p>	<ul style="list-style-type: none"> <li>Fear was associated with low levels of knowledge about cervical cancer and cervical screening.</li> <li>Fear was also associated with hearing other women talk about their experience with having a Pap test.</li> </ul>
<p>Not prepared</p>	<ul style="list-style-type: none"> <li>Women offered a Pap test spontaneously during an appointment (unplanned) was not viewed positively especially if they were menstruating or were pregnant.</li> </ul>
<p>Pain</p>	<ul style="list-style-type: none"> <li>Women referred to the physical discomfort of having a Pap smear test and described pain associated with the Pap smear.</li> </ul> <p><i>“I’m scared of the tool...”</i></p>
<p>Not regularly seeing a GP</p>	<ul style="list-style-type: none"> <li>The women reported some women have limited opportunities to discuss cervical screening with GPs as they didn’t have a regular GP.</li> </ul>
<p>Concern about confidentiality</p>	<ul style="list-style-type: none"> <li>Some women expressed concern about confidentiality at medical centres and GP practices.</li> <li>These women were concerned about others knowing their business, being overheard by others in the waiting room and health practitioners discussing their business with other community or other family members.</li> </ul> <p><i>“You can hear things from outside...”</i></p>
<p><b><i>Access</i></b></p>	
<p>Limited available transport support</p>	<ul style="list-style-type: none"> <li>Some women were reliant on others to drive them to a medical appointment. These included those living in rural/remote communities and on the missions.</li> <li>The cost of transport was also mentioned as a barrier for women living in these communities.</li> </ul>

	<i>“They’re like an hour away...they only get to see someone now and then....they have to rely on others to get them to town.”</i>
Too expensive	<ul style="list-style-type: none"> <li>• There was a perception that the test would cost a lot of money as it required a longer appointment time.</li> </ul>
No local clinic	<ul style="list-style-type: none"> <li>• The women reported that there is no longer a women’s health clinic in Casino and no women’s health services for women living on the missions.</li> </ul>
<b><i>General Practitioner/Health Provider</i></b>	
Gender	<ul style="list-style-type: none"> <li>• The women preferred a female GP for women’s health and screening procedures such as the Pap smear test.</li> <li>• Some women stated that if the GP was male they would need to arrange for a chaperone to come as well.</li> </ul>
Lack of mention	<ul style="list-style-type: none"> <li>• Women reported that their GP did not talk about cervical screening or remind about having a Pap test.</li> </ul>
Communication skills	<ul style="list-style-type: none"> <li>• The women reported GPs having poor communication skills</li> </ul> <p><i>“They don’t explain things and then you have it and it hurts so many don’t go back again....they fear it.”</i></p> <ul style="list-style-type: none"> <li>• The women also highlighted concerns about GPs and other health practitioners exhibiting poor awareness of the cultural needs of women. This, they felt, hindered women’s motivation to go for medical appointments.</li> </ul>
Hard to get appointments	<ul style="list-style-type: none"> <li>• Some women expressed frustration at the difficulty of making appointments especially with a female GP.</li> <li>• Women also mention difficulties with making long appointments for having a Pap test.</li> </ul>
<b><i>Community</i></b>	

Lack of education and information in community	<ul style="list-style-type: none"> <li>Some women reported low recall of hearing about cervical cancer and screening within the local community.</li> </ul> <p><i>“The lack of information...you don’t really see anything out there...you only see something when you are in medical area...some people can’t read, so you need to get information out to them.....target the younger ones, they don’t know, they need groups like this to explain things...”</i></p>
No mention in community	<ul style="list-style-type: none"> <li>The women reported that there was very little discussion in the community about cervical cancer.</li> <li>It was considered a private women’s health issue and something that wasn’t discussed particularly with younger-aged women or girls.</li> </ul>
<b>ii. Enablers for women who identify as being Aboriginal for participating in cervical screening.</b>	
<b>Themes</b>	<b>Descriptors</b>
<i>Client -based</i>	
Take control	<ul style="list-style-type: none"> <li>Women felt that cancer was very serious and would be very impactful on their lives.</li> <li>Early detection was considered highly important for successfully treating the disease.</li> <li>Women felt the Pap test was a necessary test that had to be done regardless of how you felt about it.</li> </ul> <p><i>“First you are shy and then you get used to it...”</i></p> <p><i>“You have to get over the shame and let the doctor do what they’ve got to do!”</i></p> <ul style="list-style-type: none"> <li>Women regularly referred to ‘<i>peace of mind</i>’, and screening (whilst unpleasant) allows women to ‘<i>know everything is OK down there.</i>’</li> </ul> <p><i>“Healthy body, health mind...otherwise you would worry and that causes stress and you get ill from worrying.”</i></p>
<i>GP/Health provider</i>	
Reminders	<ul style="list-style-type: none"> <li>Many women stated that GP reminders facilitated bookings for Pap tests.</li> <li>An SMS from GPs was mentioned as being a useful reminder system.</li> </ul>

Education and information source	<ul style="list-style-type: none"> <li>The women felt that GPs had a responsibility to provide information about cervical cancer to female clients and to explain the screening procedure and the meaning of test results.</li> </ul>
Gender of GP – <i>being female GP</i>	<ul style="list-style-type: none"> <li>For some women, the gender of the GP was considered an important enabler for having a Pap test.</li> <li>This was especially highlighted for those younger-aged women who have never been screened.</li> </ul> <p><i>“It’s best to ask for a female doctor or nurse to come into the room...the young ones should be told this....that makes you feel safe.”</i></p> <p><i>“It’s got to be done in a culturally appropriate manner...having a female there!”</i></p>
Support person, counsellor & Aboriginal Health Worker	<ul style="list-style-type: none"> <li>The presence of a support person, nurse, counsellor or Aboriginal Health Worker at clinics during Pap test appointments was suggested as a helpful strategy to improve women’s experience at health clinics or services.</li> <li>The women felt there are many women who feared the screening process because they don’t understand it. A counsellor or other support person (female) would assist to allay these fears by explaining the process, helping them with preparing for screening and to answer any questions or concerns they may have.</li> </ul> <p><i>“Have a counsellor as some will panic...having a counsellor there to talk you through it...trauma in people’s lives and they don’t want to be touched...a counsellor would help them, talk to them...”</i></p>
<b><i>Service/system - based</i></b>	
Reminder letters	<ul style="list-style-type: none"> <li>Women felt that the reminder letters were important for prompting them to have a Pap test.</li> </ul>
Self-collection	<ul style="list-style-type: none"> <li>The women felt that self-collection tests would be a welcomed strategy for women who were shy about having a practitioner performing the test.</li> </ul>
<b><i>Education</i></b>	

Education programs	<ul style="list-style-type: none"> <li>• Obtaining information about cervical cancer and screening programs in the community was considered important for improving participation rates.</li> <li>• This included information about local services with female GPs or nurse practitioners providing Pap tests.</li> <li>• Information should be provided that is simple and clear and provides images that are culturally appropriate and appealing, especially for younger-aged women.</li> </ul>
Community-based women's health group sessions/workshops	<ul style="list-style-type: none"> <li>• Bringing role models, local champions and health educators to the community could increase awareness and interest in cervical screening and build self-efficacy.</li> <li>• The women suggested different workshop sessions for different age groups of women (peers and friends).</li> <li>• This would encourage women to attend and address younger women's shyness in the presence of older women or other family members (mothers/aunties/sisters) during workshop discussions and activities.</li> </ul>
<i>Access</i>	
Women's clinics/outreach services	<ul style="list-style-type: none"> <li>• The women stated that access to a women's health clinic was important for addressing fears and embarrassment about having the Pap test.</li> <li>• The women also suggested the need for outreach clinic services to reach women living in rural areas and on the missions.</li> <li>• The women believed that clinics that offer a drop-in service would facilitate participation in cervical screening.</li> <li>• The women highlighted the need for clinics being culturally competent and appropriate.</li> <li>• This was essential for Aboriginal women to comfortable and safe.</li> </ul>
Transport	<ul style="list-style-type: none"> <li>• The provision of transport was raised as important for women for accessing health services providing Pap tests.</li> </ul>