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**Community-based approaches to support primary care to raise awareness and improve Indigenous participation in bowel cancer screening**

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## **BACKGROUND**

### ***Bowel Cancer and Bowel Cancer Screening in Australia***

Australia experiences one of the highest rates of bowel cancer in the world. It is the second leading cause of cancer-related death and kills over 4,000 Australian each year. Bowel cancer has a pre-symptomatic stage which can be detected before it has spread with much improved outcomes, making it amenable to early detection through bowel cancer screening which has been shown in randomised trials to be an effective population health intervention. Australia is one of a few countries which has implemented a formal, government-funded, population-based colorectal cancer (CRC) screening program<sup>1</sup>.

In 2006, Australia began rolling out a National Bowel Cancer Screening Program (NBCSP) using the Faecal Occult Blood Test (FOBT) to reduce incidence and mortality from bowel cancer through early identification and prompt treatment<sup>2</sup>. Screening test kits are mailed to eligible program participants following identification based upon enrolment in Medicare. Kits must be completed by individuals at home by taking samples of two bowel motions within three days and then mailed back to a pathology laboratory for testing. No cost is incurred to the person doing the screening and results are sent back to the participant and to their nominated GP. Participants with a positive FOBT are advised to discuss the result with their doctor, who will generally refer them for further investigations, usually a colonoscopy. Australia is in the process of implementing biennial screening in the National Bowel Cancer Screening Program.

Data on the benefits of population-based bowel cancer screening in Australia is beginning to emerge. A recent AIHW report compared the mortality outcomes and cancer characteristics for two populations: those invited to screen in the NBCSP in 2006–2008, and those of a similar age who had not been invited to screen in that time period. Of the 2006–2008 bowel cancer diagnoses in these two groups, non-invitees were found to have a 15% higher risk of dying from bowel cancer than NBCSP invitees, and bowel cancers diagnosed in non-invitees were more likely to be at a more-advanced stage<sup>3</sup>. These outcomes demonstrate that the NBCSP is contributing to reducing morbidity and mortality from bowel cancer in Australia. The report findings also suggest that the screening test has a high degree of accuracy.

### ***Bowel Cancer and Bowel Cancer Screening in Indigenous Australians***

While mortality from bowel cancer in the general population has declined in recent years, the situation among Aboriginal and Torres Strait Islander (hereafter Indigenous) Australians has not improved as would be expected, consistent with Indigenous outcomes from cancer overall. Despite a lower incidence than that of the non-Indigenous population, bowel cancer is the third most common cancer after lung and breast in Indigenous women and after lung and prostate in Indigenous men, accounting for about 10% and 9% of all cancers respectively<sup>1</sup>. Indigenous Australians experience significantly lower survival rates compared to non-Indigenous people following a diagnosis of bowel cancer, with diagnosis more commonly occurring at an advanced stage when prognosis is poor. Poorer compliance with follow-up and treatment contribute to poorer outcomes<sup>2</sup>. Lower participation in cancer screening, avoidance of care-seeking for symptoms and reluctance or barriers to accessing treatment are all thought to affect outcomes<sup>2, 4, 5</sup>.

The current bowel cancer screening uptake by Indigenous status reveals that Indigenous Australians are significantly less likely to participate in screening than the non-Indigenous population. Age-standardised incidence rates in 2002-2004 suggested that the rate of bowel cancer in Indigenous Australians were about half that of the non-Indigenous population (39.7 vs 76.4 per 100,000 in males and 36.6 vs 52.4 in females). The most recent figures released by AIHW have continued to show that the proportion of participants who identified as Indigenous in the NBCSP was consistently lower across all age and sex groups than the comparable proportion who identified as Indigenous in the 2011 Census<sup>6</sup>. Only 0.6% of the eligible population who participated identified as Indigenous, compared with 1.5% of those in the target age groups identifying as being Indigenous at the time of the 2011 Census<sup>3</sup>.

Other concerns are that Indigenous people are significantly less likely to complete the FOBT correctly and those returning tests have higher FOBT positivity rates. For example, in the 2008 report, those participants who identified as Indigenous had a higher positivity rate (10.6%) than those who reported as non-Indigenous (7.4%) or those who did not state their Indigenous status (9.5%). Indigenous status is associated with many

other risk factors for NBCSP under-screening: living in a remote or very remote area and lower socio-economic status (SES). Those in the most disadvantaged quintile of the population, that in which Indigenous Australians are disproportionately represented, are significantly less likely to follow up a positive result with their GP<sup>2</sup>.

The poor participation of Indigenous Australians in bowel cancer screening is a result of multiple factors: fatalistic and negative attitudes towards cancer; misconceptions about risk and susceptibility; the absence of family history or symptoms or cancer; lack of familiarity with the concept of screening and its implications; the embarrassment and unpleasant nature of the test; lack of confidence and low self-efficacy in carrying out the test; language and communication barriers; lack of support from health workers; absence of a physicians' recommendation; lack of knowledge of bowel cancer and screening options; shame and embarrassment with regard to discussing the options with family members; absence of suitable home environment to carry out the test<sup>7-9</sup>.

### **Policy Issue**

A critical analysis of Australia's NBCSP in 2010 identified multiple characteristics of the program that could inadvertently exclude and impact on participation by Indigenous people and other ethnic minorities.<sup>9</sup> The design of the screening programs creates significant barriers for Indigenous Australians participation in CRC screening. Organisational and structural characteristics of the NBCSP that may exclude participation by Indigenous and other disadvantaged populations include:

- Medicare enrolment recruitment;
- postal route of FOBT screening kit distribution;
- dependency on GPs in managing patients with a positive test;
- the specified target age group;
- recording of Indigenous status;
- issues such as privacy, storage and test viability;
- literacy requirements;
- the nature of the screening test; and
- other barriers to compliance with follow-up and treatment.

The analysis opened discussion of the need for policy and program changes so that a more equitable and accessible program for all Australians is developed. Modifications to the program were recommended to facilitate access to and participation by Indigenous and other minority populations.

Bipartisan commitment to "Closing the Gap" between Indigenous and non-Indigenous life expectancy demands that attention be given to how this situation might be improved. Improving uptake and outcomes after bowel cancer screening offers opportunities to reduce these substantial disparities.

In response to this and other contextual changes, a national pilot is planned to deliver the NBCSP to Indigenous Australians through Indigenous primary health care services. The pilot seeks to embed bowel cancer screening in primary care delivery through GP, nurse and Aboriginal Health Worker offer of screening, based on trials undertaken in South Australia, Queensland, the Northern Territory and Victoria between 2008 and 2010.

In this context, a literature review was conducted to identify community-based best-practice approaches/models (education processes/ resources) that are used to support the primary health care setting to raise awareness of cancer screening and engage participation in screening in Indigenous communities. This review explores the approaches that have been trialled or implemented in the community and/or primary care settings in other developed countries with Indigenous and/or underserved populations (Australia/ New Zealand/ Canada and USA) and explores their success.

## **METHODS**

The study was approved by the University of Western Australia Human Research Ethics Committee (UWA Ethics Approval Number RA/4/1/6985). Two strategies have been used to address the above-mentioned research questions: (1) a literature review and (2) interviews with key stakeholders who have been engaged in delivering cancer-related education/messages and cancer screening in Indigenous communities in Australia.

### **1. Literature Review**

The key guiding research question was to identify community-based best practice approaches/models of educational processes used in the primary care setting to raise awareness of cancer screening or to engage participation in cancer screening in Indigenous and other under-served communities internationally.

The search strategy is described in Appendix 1 and focussed on cancer screening services in community and/or primary health care setting for Indigenous and/ or other under-served populations. Twenty six studies that included an explicit statement regarding the effectiveness of approaches or strategies were selected for critical appraisal.

### **2. Consultation with Key Stakeholders**

Semi-structured interviews were undertaken by telephone or meeting with nominated key stakeholders or organisations working in cancer screening with Indigenous Australians. Interviews aimed at obtaining stakeholders' perspectives into the process of the policy development, implementation and outcomes of the NBCSP to date.

Participants interviewed were employees of the following organisations:

- Cancer Australia: community based approaches for breast and cervical screening;
- Cancer Council South Australia: Indigenous cancer resources, and GP/health worker support;
- Cancer Council WA and WA Health: Indigenous cancer resources and community projects;
- Hume Regional and Integrated Cancer Service: Let's Yarn about cancer project;
- NSW Cancer Institute: The Aboriginal Cancer Partnership Project;
- Derbarl Yerrigan Aboriginal Health Service

Interviews lasted for about an hour, were audiotaped and transcribed verbatim. Content was analysed thematically to identify key areas of success and suggestions/ recommendations.

Six interviews encompassing nine participants were conducted between July and October, 2014. All participants were women; one interview was conducted face-to-face and all others were done over telephone as the participants were from other states in Australia. Five of the participants were directly linked to screening programs in different organisations, and the rest were at the policy level.

## **WHAT DOES THE EVIDENCE SAY?**

Although there is literature that describes barriers to cancer screening in minority and underserved groups and interventions to reduce disparities in cancer outcomes, studies that have focused on Indigenous people are limited. A recent systematic review reported that most interventions have occurred in the USA, with few high quality intervention studies reported from Australia; only a handful of intervention studies have adopted community-based approaches targeting CRC screening in Australia, only one of which was labelled as methodologically robust<sup>10</sup>.

Literature that has highlighted key innovative approaches and strategies to engage community to support the primary healthcare setting/ services that may work in increasing uptake of CRC and other cancer screening services is summarised in Table 1.

**Table 1: Effectiveness of strategies and models used/trialled reported in the literature to promote cancer screening in populations of low socio-economic status**

Models/ Strategies as Described in the Literature	Description of strategies	Level of evidence of effectiveness	
		Breast and cervical screening	Bowel screening
Client Reminder	Mail-based using printed materials, letter, postcard, etc or non-mail based using interactive tools, telephone, text messages	Strong <sup>11</sup>	Sufficient <sup>10-12</sup>
Small Media	Video/ printed materials, e.g., letters, brochures, flyers, newsletters	Strong <sup>11</sup>	Strong <sup>11, 13-15</sup>
Navigator-model	Support persons assist patients in the community setting and facilitate their access to health services	Considerable evidence <sup>16-19</sup>	Considerable evidence <sup>20-23</sup>
Health Services-Community Partnership		Considerable evidence <sup>16-19, 24</sup>	Considerable evidence <sup>10, 13, 14, 25-28</sup>
Multicomponent intervention	Combining one or more of the above-mentioned strategies	Considerable evidence <sup>11</sup> Need further research	Considerable evidence <sup>11, 27, 29-33</sup> Need further research
Education One-on-one education	Information conveyed by phone or in-person by health professionals, lay health advisors, navigators in the primary health care settings or in other community settings	Considerable evidence <sup>11, 34-36</sup>	Insufficient evidence <sup>11, 39, 40</sup>
Group education	conducted by health professionals or by trained laypeople or by role models	Insufficient evidence <sup>11, 37, 38</sup>	Insufficient evidence <sup>11, 28, 41, 42</sup>
Primary Healthcare Services-based Interventions	Work with the healthcare services, with the physicians, automated information system, etc.	Insufficient evidence <sup>43</sup>	Targeted and tailored interventions increased colorectal cancer screening Need further research <sup>44-48</sup>
Client Incentives	Rewards, such as vouchers, cash, coupons, etc.	Insufficient Used with other strategies <sup>11</sup>	Insufficient Used with other strategies <sup>11</sup>
Special events	Observed day, fair, cultural event, special day, health fairs, parties	Insufficient evidence when used alone <sup>49-51</sup>	Insufficient evidence when used alone <sup>49, 51</sup>
Mass Media	TV, radio, newspaper, magazines, billboards, etc used in campaigns	Insufficient when used alone <sup>11, 52</sup> Mainly used to promote messages	Insufficient evidence <sup>48, 53, 54</sup>
Web-based Promotion	Health promotion messages disseminated via websites, can be interactive as well	Evidence is minimal	Evidence is minimal <sup>55</sup>

\* The information in this table is based upon Baron, R. C., et al. (2008). "Client-Directed Interventions to Increase Community Demand for Breast, Cervical, and Colorectal Cancer Screening: A Systematic Review." *American Journal of Preventive Medicine* **15**: s34-s55, supplemented by additional publications.

Strategies that have been reported in the literature and which were suggested by the interview participants are described below. The literature has reported several useful effective strategies. Sending reminders to the clients within the health care settings that they are due or late for their screening and use of small media in promoting screening had the strongest evidence. It is also clear that working effectively in partnership across multiple stakeholder organisations can result in improved systems and screening uptake. Considerable evidence is available about the use of effective and meaningful partnerships between the health services and community collaborators.

## Strategies that have strong evidence of success

### 1. Patient Reminders [mail-based using printed materials, letter, postcards etc or non-mail based using interactive tools, telephone, text messages and so on]

Effective interventions using client reminders have been implemented in the US, Canada, the UK and Australia, in populations of low to mixed or middle-class background for promoting breast, cervical and colorectal screening, and found strong evidence of effectiveness in increasing breast and cervical screening. Sufficient evidence was obtained to conclude that this strategy can increase colorectal cancer screening by FOBT<sup>11</sup>. Only one Australian intervention study has targeted CRC screening among lower socio-economic groups with two different multi-component interventions<sup>12</sup>. (Intervention 1: Patient decision aid comprising paper-based interactive booklet and DVD with a question prompt list and Intervention 2: patient decision aid comprising paper-based interactive booklet and DVD without a question prompt list). The intervention led paradoxically to a significantly lower uptake of screening interventions (59%) and control (75%)\* group. However, the decision aid increased the proportion of participants who made an informed choice, from 12% in the control group to 34% in the decision aid group (22% difference, 95%CI 15% to 29%; P<0.001). Participants who received the decision aid showed higher levels of knowledge than the controls. More participants in the decision aid group had no decisional conflict about the screening decision compared with the controls (51% v 38%; P=0.02)<sup>12</sup>.

### 2. Small Media [Video/ printed materials, e.g., letters, brochures, flyers, newsletters]

In the literature, small media has been found to have increased breast, cervical and colorectal cancer screening. According to Baron (2008), this finding should apply across a range of settings and populations<sup>11</sup>. 'Small media' refers to materials that convey educational and motivational information to promote cancer screening in target populations and that can be distributed from health services or at other community-settings<sup>11</sup>. Baron and colleagues identified 19 well-designed studies that targeted breast cancer screening, 12 studies that focused on cervical screening and 7 studies promoting bowel cancer screening by FOBT that had used small media to promote screening.

Culturally respectful holistic approach combining both families and communities should be adopted in developing and delivering resources. Resources where cultural values, beliefs and behaviours are affirmed; resources that are built upon to provide context and meaning for health messaging; use community role-modelling have been proved to be effective. Uptake of resources was improved when they were presented in an engaging and entertaining way, used plain and simple languages and used humour in presenting information. An approach that can give people the opportunity to make informed choices is also very crucial. However, a study conducted in Western Australia concluded that simply creating and widely distributing a good resource was insufficient for ensuring the delivery of health education to Aboriginal people and that the provision of training or workshopping a health educational resource is crucial<sup>56</sup>. Intended users require awareness of the underlying problem, adequate time for and specific training in implementation of the tool, and there needs to be adequate human and financial capacity for health promotion with education not seen as solely the responsibility of Aboriginal staff. Education requires dedicated personnel for bowel cancer community education as has occurred with breast and cervical cancer screening programs.

Makoul et al., (2009) described a multimedia patient education program on CRC screening designed specifically for the Hispanic/Latino community and developed with input from community members<sup>14</sup>. It significantly increased knowledge of anatomy and key terms (such as polyp) of primary screening options (FOBT, flexible sigmoidoscopy, colonoscopy), and risk information as well as willingness to consider screening (p<.001 for all). However, the effects on actual screening behaviour were not determined. The authors concluded that despite promising results for engaging a difficult-to-reach audience, the multimedia program served as a priming mechanism to prepare patients for discussions of CRC screening but should not be considered a stand-alone intervention or a substitute for communication with physicians.

In a study to evaluate the effectiveness of a culturally relevant intervention on knowledge of colorectal cancer and participation in FOBT among African American community elders, Powe et al reported a significantly

greater increase in their knowledge of colorectal cancer over time and being more likely to participate in FOBT at the end of the 12-month period. The authors concluded that similar strategies could be implemented in community settings and by health care agencies to inform elders about colorectal cancer<sup>57</sup>.

To evaluate the impact of educational intervention on the health behaviour process, patient knowledge and compliance with colorectal cancer screening in the average-risk population, 158 participants (aged 50–79 years) were randomly assigned either to watch a non-medical video or a colorectal cancer educational video<sup>15</sup>. Participants were assessed before and after watching the experimental or control videotape. Finally, participants received a FOBT kit and were requested to use and return it within two weeks. Participants in the video-based intervention group showed significant improvement in knowledge of colorectal cancer scores ( $P < 0.001$ ) and decreased barrier scores. The intervention group returned significantly more FOBT than controls (69.6% vs. 54.4%,  $P = 0.035$ ). The intervention had a positive effect on modifying attitudes and intention to take part in screening<sup>15</sup>.

## Strategies that have considerable evidence of success

### 1. Navigator Model [Support persons support patients in the community setting and facilitate their access to health services]

Considerable evidence is available that shows the effectiveness of the navigator-model. The development of person-centred models of care is critical to improving outcomes and particularly for Indigenous and other marginalised, underserved people with cancer and their families. Navigators are those support persons who can support patients in community settings as well as help them accessing the health service. For screening and early intervention studies, navigators are trained to provide information regarding the importance of screening and early detection of cancer and adherence to guideline, strategies to overcome barriers to obtaining cancer screening and follow-up care, and reinforcement for scheduling and keeping appointments and so on as has been described in a few studies<sup>16, 17, 35, 20, 22, 58</sup>. Statistically significant associations were found between having received Navigator-led intervention and reporting a rescreening mammogram for all racial/ethnic groups ( $p < 0.05$ )<sup>16, 17, 35</sup>. Over a 9-month period, intervention patients were more likely to undergo CRC screening than control patients (27% vs. 12% for any CRC screening,  $p < 0.001$ ; 21% vs. 10% for colonoscopy completion,  $p < 0.001$ ). Another culturally tailored RCT to increase CRC screening, primarily using colonoscopy, among low income and non-English speaking patients found that patients with in-person contact with the navigators were more likely to have CRC screening than patients with only phone contact<sup>22</sup>.

### 2. Health Services-Community Partnership

Successful, effective and meaningful partnership between health services and the community collaborators brings positive outcomes and was highlighted as important by the interview participants as well as in the literature. This is one of the key prerequisites to any program designed for marginalised communities. One participant described how they have been trying to collaborate and work with local organisations:

*“We don't have ongoing funding as such. That's where we try and link in with some of the other organisations that might be able to provide that education as part of their role. We have some ongoing projects. We're going to be working with our Medicare local around some bowel cancer screening.... We will be doing ongoing things and we're hoping that the links that have been set up with the liaison officers or the community health, and breast screening or Bowel Cancer Australia will continue on and they'll know then who to contact if they want to have further education sessions.”* (Primary health provider)

A community-based grant program<sup>25</sup> for building partnership between health systems and their community partners in implementing new CRC screening events for underserved populations was trialled in Wisconsin, the USA. A high level of community partner participation in planning and implementation of the program contributed to the success. The program reported the following outcomes:

- iFOBT kits widely distributed to underserved communities
- Increased CRC screening in the underserved populations

- Strengthened partnerships between health systems and local organisations
- Higher participation, higher rates of return on screening tests, and better survey ratings from community partners
- Events with more balanced clinical-community partnerships yielded better outcomes

As per their experience, the strategies that worked well were:

- A high level of community partners' participation in planning, designing and implementing the program delivery events
- Health service and community partners had mutual understanding on how each other works
- Clear roles and responsibilities delineated among the partners from the beginning
- Return rates for test kits were higher when supported by follow-up calls and incentives, such as grocery or gas gift card or cash
- Budgeting adequate staff time to follow up on positive screening tests
- Database created by external evaluator as part of the project made it easier for health systems to track the distribution and return of screening test kits
- New and productive linkages between health systems and community partners

An Australian collaborative research study, guided by an Indigenous state-wide reference group and with an Indigenous researcher as a frontrunner, resulted in major changes at the policy level in Queensland Australia in cervical cancer screening undertaken in Queensland. Extensive community consultations occurred before the project was started; sufficient funds were allocated to appoint and engage an Aboriginal researcher; clear protocols were established for researchers to work with the communities; cultural protocols were maintained during the implementation of the program; the strategic plan was developed with advice from the reference group. As a key outcome from the research, Indigenous nurse practitioners were trained to work with mobile health services introducing breast and cervical screening along with other health services. Although it is difficult to judge the impact of this project on cancer outcome, the whole process of engaging communities managed to achieve a substantial realignment of services to meet the needs of Indigenous women<sup>24</sup>.

### **3. Multicomponent Interventions [Combining one or more strategies]**

Evidence of effectiveness also exists for combining one or more strategies. Multicomponent interventions often are more practical for promoting screening and other health promotion messages among community stakeholders, and have been trialled widely. Evidence from a systematic review<sup>11</sup> on the effectiveness of client-directed interventions that were intended to increase community demand for screening indicated that screening for breast cancer (mammography) and cervical cancer (Pap test) was effectively increased by the use of client reminders, small media, and one-on-one education. Screening for colorectal cancer by FOBT was increased by the use of client reminders and small media. Other studies also found modest improvements as a result of multicomponent interventions where culturally and linguistically adapted interventions were utilised in the communities<sup>29, 30, 27, 32, 57, 59</sup>.

### **4. Education**

Low public awareness is one of the key barriers for cancer screening participation; so different materials have been produced to raise awareness and educate people about cancer screening<sup>15</sup>. Moreover, studies consistently report that the beliefs, attitudes and knowledge of ethnically diverse groups towards cancer and cancer screening need to be considered when devising strategies for improving screening uptake<sup>6-8</sup>. Thus, several educational strategies on cancer have been developed, designed specifically targeting these population groups (either group-based or one-on-one; by health professionals or by trained lay health advisors; in the community or within local health services or in home environment settings) in order to address the knowledge gap. Studies have found that just offering free screening programs without education and/or face-to-face intervention does not increase utilisation of services in under-utilised communities<sup>60</sup>.



**One-on-one Education:** [Information conveyed by phone or in-person by health professionals, lay health advisors, navigators in the primary health care settings or in other community settings]

Baron and colleagues (2008) after extensive literature review concluded that one-on-one education increases breast and cervical cancer screening across a broad range of settings and populations but that there was insufficient evidence to determine the effectiveness of this strategy in increasing colorectal cancer screening<sup>11</sup>.

One research study found that one-on-one health education at a woman's home by a trained lay health educator and including verbal, print and videotape information resulted in women having more knowledge about Pap Smears and undergoing screening. Individualised health education produced slightly higher levels of change in knowledge and intention toward obtaining Pap smears than mass media campaigns and group-based education programs<sup>36</sup>. Dignan and colleagues tested the relative effectiveness of a navigator one-on-one education intervention delivered face-to-face or by telephone to urban Native American women; however, they found no difference between those two techniques<sup>61</sup>. Two randomised controlled trials (RCT) were conducted in the US to test and evaluate a clinic-based, culturally and linguistically appropriate colorectal cancer screening intervention using a Health Educator to promote FOBT screening<sup>39</sup> and to assess the impact of intensive patient education on compliance with FOBT testing<sup>40</sup> - one among Chinese patients and the other among primary care clinics at the VA New York Harbor Healthcare System in New York City). Both interventions had a strong effect on FOBT completion and uptake of FOBT after six months. The completion rate was 69.5% for the intervention group and 27.6% for the control group for the first study. Intensive patient education significantly improved patient compliance with FOBT.

**Group Education:** [usually conducted by health professionals or by trained laypeople or by role models]

Baron et al., in their review, concluded, "There is insufficient evidence to determine the effectiveness of group education in increasing screening for breast, cervical, and colorectal cancer due to inconclusive findings for breast cancer; too few studies with inconsistent findings for cervical cancer; and inconsistent findings among multiple intervention arms in the only study for colorectal cancer"<sup>11</sup>. However, Weinrich, et al., (1993) reported increased colorectal cancer screening after using elderly educators among socioeconomically disadvantaged older persons<sup>41</sup>. The importance of enabling and utilising community resources, support systems and building partnership with the community stakeholders has been recognised<sup>62</sup>.

Interventions led by lay health advisors (LHA) are also influential to health promotion, straddling a variety of health topics and communities<sup>28, 38, 42</sup>, and useful for hard-to-reach and minority populations. Exchange of social support forms the basis of this approach, and support involving LHAs ultimately builds the competence of the community by increasing peoples' active participation, involvement in decision-making and problem-solving<sup>28, 38, 63-65</sup>. The LHA models recognise broader social factors as determinants of health, and adhere to the principle of holistic approaches to health and health care<sup>63</sup>.

Culturally appropriate basic education about cancer, prevention and screening was identified as a need by the interview participants. They also stressed the importance of on-going support being provided after the education sessions,

*"... the conversation and then the ongoing support that's needed. I think too, with a lot of people, not just Aboriginal people, it's not just explaining the kit and walking away. There needs to be that follow-up and some people are a bit shy to pop it in the post box. You can say to them, well, bring it back to the health service, we'll mail it for you. Just some support strategies like that that help follow through with process."*

Participants highlighted that ongoing support is needed by staff at primary health care facilities to follow-up on the participants if they do not return the kits or if they come up with abnormal results. Participants also emphasised the need for positive health messages to be circulated around screening and cancer.

## Strategies with insufficient evidence in the literature

Other strategies that have been employed and reported in the literature to increase participation in screening, such as client incentives, mass media, primary healthcare service-based interventions<sup>44-46</sup>, web-based promotion<sup>55</sup>, organising special events such as observed day, fair, cultural event, health fairs, parties<sup>49, 50</sup> are not supported by enough evidence. Mass media has mainly been used along with one or more other strategies<sup>52</sup>. Baron et al. (2008) found no studies of mass media used alone to increase breast or colorectal cancer screening. Evidence of success in using mass media health campaigns has varied because of the difficulty in evaluating their effectiveness. Studies identified that the development process involving the target audience in designing, making and launching of mass media campaign can be a valuable catalyst for effectiveness. The use of humour in several of the TV advertisements has proved to be highly effective in creating conversations and discussion among people<sup>13, 52</sup> and compelling, real-life stories have also worked effectively<sup>52</sup>.

Although significant evidence was not found in the literature to show the effectiveness of working with local primary health care services, interview participants highly commended this strategy.

### 1. Engagement with Aboriginal Community Controlled Health Services (ACCHS) or Local Primary Health Care Services [Working with the healthcare services, with the physicians, automated information system, etc.]

Several interventions worked very closely with local primary health care services to help them restructure their patient monitoring system and provide them with other supports to incorporate and improve monitoring of cancer screening from their services, mainly in the USA<sup>47, 48, 66</sup>. To determine whether targeted and tailored interventions can increase screening use, Myers, et al., (2007) conducted an RCT. Multivariate analyses demonstrated that older age, education, past cancer screening, screening preference, response efficacy, social support and influence, and exposure to study interventions were positive predictors of screening. Having worries and concerns about screening were found to be a significant negative predictor. Targeted and tailored interventions were found to increase colorectal cancer screening use. However, additional research is needed to determine how to increase the effect of such interventions in primary care.

Interview participants emphasised the need for engagement with the local health services to promote and to undertake bowel cancer screening. However, they also embarked on how local ACCHS are under pressure and overburdened with lots of expectations; thus, if they have to perform properly and effectively, they need to be supported further with resources and ongoing investment. Interviewees commented that it was unrealistic to think that any program will be a priority for an organisation if they do not receive funding for the execution of the program. It was also considered important to get a good grasp of what the objectives of each Indigenous health service are. For example, one participant clarified, *“if they’ve got a primary focus around tobacco or healthy [lifestyle] - physical activity and nutrition, then that’s [screening] going to be really hard to slot in.”*

Another service provider added,

*“we’ve had experience where we wanted to work with particular ACCHS, but sometimes if the timings are not right - sometimes within that ACCHS there might be some political family business going on and sometimes it’s hard to know about that. I think there have been times when we’ve funded an ACCHS and the project just hasn’t even got off the ground, because they are dealing with their own issues internally. Sometimes it leads to quite a bit of work establishing how ready that ACCHS is to actually enable to participate in a program around cancer screening. Sometimes the timing is just not right, so while we might desperately want to work with this ACCHS because it’s geographically right for us, sometimes it’s better to work in a different region and come back to that region, perhaps, in a year or two times, when, hopefully things have been settled and we can approach them.”*

However, the approach needs to be ‘whole-of-practice-based’ so that the program can be implemented systematically and comprehensively, and staff are well-supported. Another suggestion was to incorporate the screening within the regular health check-ups as services receive funding for regular well person checks for their patients. It was emphasised that services building a relationship with Indigenous patients and families

was important for the successful execution of any program. Aboriginal Liaison Officers should be consulted wherever possible before planning and designing any strategy to implement bowel cancer screening within the communities.

Participants also highlighted the complexity of moving forward with the screening program within the Indigenous communities, commenting that ACCHS may not be the ideal place for all Indigenous people, and that not all Indigenous people will access ACCHS. There was seen to be a risk of missing a segment of the target population if the program did not liaise with other local health services. One participant explained,

*“Because, the other thing to be conscious of is, not all Aboriginal people go to Aboriginal health services. It could even be a consideration to get the local - I don’t know what sort of approach it is in terms of how big the regions are they’re looking to fund, but ensuring there’s also some buy-in from the local general health service, or mainstream health service, or even the hospital, if there is a dedicated Aboriginal health worker within the hospital sector as well....”*

Participants interviewed from Victoria, Australia mentioned about the UnderScreened Recruitment Program that has been funded by the Department of Health that aims to increase cancer screening knowledge, awareness and participation across breast, bowel and cervical cancer in Aboriginal and Torres Strait Islander communities, in culturally and linguistically diverse communities and low socio economic communities. That initiative will open up the opportunities to trial joint screening messages (including breast, bowel and cervical cancer screening messages) for these communities. If it works in Victoria, that can be rolled out nationally. Table 2 summarises some of the strategies and models that have been trialled and/or were recommended by the interview participants.

**Table 2: Strategies and models that have been trialled or suggested by the interview participants to promote cancer screening in Aboriginal and Torres Strait Islander people in Australia**

<b>Models/ Strategies</b>	<b>What works/ What is needed</b>
1. Engagement with ACCHS or local Primary Health Care Services	<ul style="list-style-type: none"> <li><i>i. On-going support and investment</i></li> <li><i>ii. Whole-of-practice-based approach</i></li> <li><i>iii. Incorporated into regular health check-ups</i></li> <li><i>iv. Relationship-building</i></li> <li><i>v. Be mindful about the capacity, priorities and internal issues of health services</i></li> <li><i>vi. Opportunistic screening</i></li> <li><i>vii. ACCHS may not always be an ideal place</i></li> </ul>
2. Program Design	<ul style="list-style-type: none"> <li><i>i. Flexibility within the program</i></li> <li><i>ii. Long-term commitment</i></li> <li><i>iii. Multiple strategies for dissemination of kits should be employed</i></li> <li><i>iv. On-going, long-term funding</i> <ul style="list-style-type: none"> <li><i>a. Funding provided to ACCHS may or may not work</i></li> <li><i>b. Other incentives to the participants can also be trialled</i></li> <li><i>c. Phased approach to funding</i></li> </ul> </li> <li><i>v. Dedicated and trained Staff</i></li> </ul>
3. Education to Community Members	<ul style="list-style-type: none"> <li><i>i. Basic education about cancer, prevention and screening</i></li> <li><i>ii. Needs to be culturally appropriate</i></li> <li><i>iii. On-going support should be continued even after the completion of education sessions</i></li> </ul>
4. Engagement with Indigenous Communities	<ul style="list-style-type: none"> <li><i>i. Kits delivered by a respected and trusted Indigenous person within the community</i></li> <li><i>ii. Listening to the needs and preferences of the communities is very important</i></li> <li><i>iii. Utilisation of the already existed programs or resources</i></li> <li><i>iv. Trust and Relationship building</i></li> <li><i>v. Special day can be organised or utilised to promote screening and messages</i></li> <li><i>vi. Target specific services to promote messages</i></li> </ul>

5. Indigenous-friendly resources	<ul style="list-style-type: none"> <li><i>i. Adapted to the context</i></li> <li><i>ii. Easy-to-understand</i></li> <li><i>iii. Health messages should be positively portrayed</i></li> <li><i>iv. Appropriate context-specific dissemination strategy should be designed</i></li> </ul>
6. Partnership with other organisations	<ul style="list-style-type: none"> <li><i>i. Partnership works better because Indigenous organisations know their communities well whereas cancer-specific organisations have expertise in cancer</i></li> </ul>

\*This table is derived from information given by the interview participants. Please see the Appendix 2 for detailed quotes and direct comments from the participants supporting these strategies and models.

## CONCLUSIONS AND RECOMMENDATIONS

It has been clear from both the review of the existing literature on screening among the disadvantaged population in Australia, New Zealand, the USA and Canada and from the interviews that establishment of an effective system-based approach is critical to improve bowel cancer screening uptake for disadvantaged communities. If the approach of distributing FOBT kits through primary health care services is to be adopted, then the question becomes what can be learned from the literature about the best approaches to supporting primary health services promote the uptake of bowel cancer screening.

A culturally-tailored program that will have room for education, information sharing, proper explanation about a screening test, that is long-term, adequately-funded, community-consulted and partnered is needed for the marginalised communities, such as Indigenous Australians. The literature has shown the importance of individuals being given adequate health information so that they are able to make their own decision about participation. Interview participants highlighted the significance of engagement of Aboriginal Health Workers in the communities or Aboriginal Liaison Officers (where available) in planning, consultation and delivery of a screening program.

The current structure of the bowel cancer screening program in Australia does not fit with above-mentioned criteria. Sending FOBT kits directly to people in Indigenous communities has not been an effective delivery mechanism because of several reasons: the test itself is sensitive in nature; many Indigenous people are not familiar with the test at all; stigma and negative beliefs about cancer itself; no assistance from health professionals in orienting the test to the participants, in administering and following up with the participants; lack of availability of culturally appropriate instruction manuals and so on. Both the literature review and stakeholders interview have indicated kits should be distributed by the local health services and can be immersed amongst other regular health check-ups. Patient administration systems need to be linked with the program so that follow-up using patient reminder system can be effectively administered to ensure screening uptake. Regular record keeping and data collection within health services is also crucial as that will help ensure a consistent reporting mechanism. Dedicated funding and ‘a whole of service’ approach are also critical.

There is diversity in geographic, administrative, capacity, historical and funding arrangements for the Indigenous communities around Australia; thus the programs targeting the delivery of bowel cancer screening kits should also have variations. A ‘one size fits all’ approach may not work for these diverse communities. The opportunity to listen to key people in the Indigenous cancer, prevention and screening space allowed us to draw a picture about which seemed most favourable to delivery of a successful program. It is acknowledged that many factors impact upon program achievements.

Contextually-tailored models that incorporate local community input into screening services, which consider and address local cultural practices and health beliefs work better than pre-designed, top-down approaches that are often used to improve screening in the community-context. Community-based interventions are usually well-accepted and well-participated by the community members<sup>67</sup>. Bowel cancer screening delivery needs to be supplemented by promoting early education on cancer and related topics among community members in a non-threatening environment. Without adequate, culturally appropriate educational opportunities, people in the community will not have an adequate level of understanding about the

importance of screening; thus may not take advantage of the program. Both the literature and the stakeholder interviews indicated that community-based best practice approaches/ models that work in raising awareness of cancer screening and engaging participation in screening in Indigenous/ underserved communities include:

- community based workshops,
- gender-specific small group education,
- the use of community champions/ lay health workers,
- utilising respected elders, peer education sessions,
- storytelling,
- Aboriginal Health Worker education sessions (either one-on-one or small groups),
- mobile vans,
- mailed-based interventions,
- the use of patient navigators,
- pre-notification of strategy interventions

Community-based approaches (awareness-raising, education, expectation of people to be self-responsible, etc) and primary health care model are two different approaches, and for Indigenous people it would be difficult to implement one ignoring the other. Interview participants highlighted that these two models need to complement each other. Thus a program should be developed that addresses both the community needs in terms of raising awareness, knowledge base, changing/ shifting beliefs but the execution of the actual program (delivery of bowel cancer screening kits) should be delivered and monitored through the primary health care services. More concrete suggestions (summarised from the literature and the stakeholder interviews) are discussed below:

- Culturally appropriate education opportunities should supplement the screening program. Several papers have concluded that even free screening programs without education and/or face-to-face intervention do not increase utilisation of services in under-utilised communities.
- A dedicated funded education and resource person who is knowledgeable about the program and has a good understanding about the community is a key ingredient for success. Context-specific, long-term, dedicated personnel to carry on the program within a primary care setting or community clinics would be beneficial and also crucial to continue with community trust.
- Community-based, adapted, participatory approaches based on consultations work well for the underserved, marginalised communities (details in Table 2).
- Consultation needs to occur with stakeholders, including public health practitioners and other local service providers, to ensure the most effective use of existing local resources and that the resources are used in an appropriate and sustainable manner for the benefit of Indigenous people.
- Cultural appropriateness and cultural safety should be central and underpinning characteristics of the program
- Culturally suitable resources (audio-visual, pictorial) should supplement the delivery of kits.
- Mixed approaches where multiple strategies are used to deliver screening should be adopted.
- Indigenous-friendly resources need to have community-input; easy and plain language resources need to be used if the target audience is from lower socio-economic background.

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## Appendix 1

### The literature search strategy

The literature search strategy comprised the following components:

A multi-database search for peer-reviewed journal articles with terms (subject heading, title, abstract and/or keyword) pertinent to Indigenous Australians, Cancer and Primary Health Care was conducted. Databases searched were Ovid, Medline, Embase, CINAHL-Plus and Informit. The search was restricted to English language articles. Publication date was limited from 1990 to current. The search syntax was modified (as were subject headings, if applicable) according to the requirements of each electronic database. The generic structure of the search strategy was:

#### **Cancer [& related]**

(cancer OR cancers OR cancer\* OR malignancy OR malignancies OR tumor\* OR tumour\* OR neoplas\* OR carcinom\* OR sarcom\* OR lymphom\* OR leukem\* OR leukaem\* OR melanoma\* OR mesothelioma\*)

#### **Indigenous [& related]**

(oceanic ancestry group [mh] OR health services, indigenous [mh] OR american native continental ancestry group [mh] OR indigenous OR indigene\* OR aborigin\* OR "torres strait islander" OR maori\* OR polynesian\* OR "pacific peoples" OR "native american" OR "native americans" OR "first nations" OR inuit\* OR eskimo\* OR alaskan\* OR "american indian" OR "american indians" OR "native canadian" OR "native canadians" OR metis)

#### **Primary health care [& related]**

(primary health care [mesh] OR general practice [mesh] OR general practice\* OR primary care OR primary health care OR community controlled OR aboriginal medical service\* OR aboriginal health service\* OR comprehensive health care [mesh] OR )

A Google Scholar supplementary search was undertaken to identify any peer-reviewed articles that had been overlooked in the electronic databases searches.

Additional articles previously known to the researchers or identified in citation snowballing were added.

Retrieved references were stored in a reference library (EndNote® Version X5). The original four database search retrieved n=247 articles (Medline=189; Embase=36; CINAHL=18; Informit=5). After cleaning up the RIS (.txt) file, these references were automatically imported into EndNote (with 7 duplicates automatically removed, i.e. EndNote recognised 243 references—the 5 Informit references were missing). Duplicates were identified and discarded by automated searching supplemented with a manual check. 'Clearly non-relevant' articles were identified on review of title/abstract.

All remaining article titles/abstracts (N=243) were reviewed. Those containing evidence of effectiveness of cancer screening services in community and/or primary health care setting for Indigenous and/ or other under-served populations (N=115) were read more carefully for any explicit mention about the effectiveness. Pre-specified characteristics of these articles were entered into a spreadsheet. Among the relevant studies, those that included explicit statement regarding the effectiveness of any approaches or strategies (N=26) were selected for critical appraisal.

## Appendix 2

### Box 1. Themes came out from the key informant interviews

#### A. Engagement with ACCHS or Local Primary Health Care Services: What is needed

##### **i) On-going support and investment is crucial**

*"I think it has been proven that they can do it, but they require support and investment and ongoing investment to support them to do that and an acknowledgement that there are real competing health priorities for ACCHOs, particularly in the clinic health space and that, historically, cancer and cancer screening have sat outside of clinic health and that there are quite complicated pathways depending on location and type of cancer and many different people involved in that space. I think that yes, is my short answer, but it definitely should be supported further with resources and support."*

*"it needs to be resourced appropriately. It's not going to be a priority for the ACCHOs that aren't receiving funding for it. In fact, that's kind of like their incentive to be involved in this space and if they're not funded for it, it's not going to be a priority."*

##### **ii) Whole-of-practice-based approach**

*"... it really needs to be a whole-of-practice-based approach, from the receptionist to the practice manager to the actual staff delivering the screening service itself."*

##### **iii) Incorporated into regular health check-ups**

*"if some health services are giving a financial incentive for people to actually do the health check, it would be great to see bowel cancer screening included..."*

*"we've trained up the BreastScreen receptionist, the radiographer, the pap nurse, all about key messages around bowel cancer screening, so while they're doing the pap test, they can talk to the Aboriginal woman about the benefits of bowel cancer screening, just as they should also be talking about STI, or whatever else it might be. We feel it's an appropriate time to be talking about cancer screening as a whole - it's great that you've had a pap test here today. I've noticed that you're turning 50, have you thought about bowel cancer screening? Do you know there's a national program? This just helps pre-empt it."*

##### **iv) Relationship-building is important**

*"One thing I did forget to mention was with our Medicare local – (name), they have a couple of Aboriginal liaison officers up there. So we linked in with them from the start as well. So they promoted through their organisation as well. So that was a good way to also link in the primary health. Community health, we had links through the nurses there as well. So that was another really good way just to have that connection because they are the people that are actually working with those communities. That was a really good link for us."*

##### **v) Capacity, priorities and internal issues**

*"it's just really important to get a really good grasp of what the objectives of each Aboriginal health service is. So, going in and if they've got a primary focus around tobacco or healthy - physical activity and nutrition, then that's going to be really hard to slot in, perhaps a screening and prevention message, particularly, if they're working with more youth, or childhood services.*

*So I think it's about really doing quite a bit of investigation as to what the key priorities are for that ACCHS, so this doesn't come out of left field."*

*"we've had experience where we've wanted to work with particular ACCHS, but sometimes if the timings not right - sometimes within that ACCHS there might be some political family business going on and sometimes it's hard to know about that. I think there have been times when we've funded an ACCHS and the project just hasn't even got off the ground, because they are dealing with their own issues internally. Sometimes it leads to quite a bit of work establishing how ready that is ACCHS to actually enable to actually participate in a program around cancer screening. Sometimes the timing is*

*just not right, so while we might desperately want to work with this ACCHS because it's geographically - area is right for us, sometimes it's better to work in a different region and come back to that region, perhaps, in a year or two times, when, hopefully things have been settled and we can approach them."*

**vi) Opportunistic Screening**

*"They looked at opportunistic screening as well, so scanning daily appointments to see who might benefit from messages around bowel cancer screening."*

**vii) ACCHS may not always be an ideal place**

*"Our group may not mix with another group. Finding a neutral - if you're wanting to run a program finding a neutral place, don't go to the Aboriginal Organisation if half the town don't go there, go to the football club or community centre."*

*"... if you were trying to run a bowel screening program we actually have the Aboriginal Health Service but there's also another service called [name of a community health service], many people - Aboriginal people may go to [the name of the service] and not go to the Aboriginal Health Service and vice versa.... don't assume that all Aboriginal people go to the Aboriginal Health Service because they don't. That's an assumption that I thought that most people would have used that but they don't."*

**B. Program Design: What works**

**i) Flexibility within the program**

*"So where the community is smaller and more localised, rather than the message being testing of 52 to [unclear] 55, that you actually talk about bowel cancer screening for the ages of 50-plus."*

*"what works over there certainly won't work over here in Albury. Be open and transparent, don't be judgmental."*

*"You might have a women's group and again we've just started that here, is women just sit around weaving or they're sewing or they're knitting but at the same time you've got - like if [name of a speaker] comes out, she's talking but they're actually listening but they're focusing on what they're doing, they're not actually looking at you with eye contact but they're taking in what you're saying and it makes it a little less threatening I suppose. So just be mindful that - try and be flexible, think outside the square."*

**ii) Long-term commitment**

*"It's disappointing that - I'm sure they see it as disappointing too, but, like Nisha said, it takes so much time to build the trust and to build a relationship with the ACCHOs. Then to say, well, look, we actually need a final report produced in - and I know, with that pilot back in 2010, it was a six-month-timeframe, it was tiny and way too short."*

*"we shouldn't be funding projects with such short timeframes."*

*"that's why, looking at cancer screening rather than just bowel, I guess we can be working with these ACCHOs and be quite confident we're there for the long-term, not just for a short-term project that's just about one cancer screening program. But, we're there to talk to them and to work with them on all three cancer screening programs. I think that's why, with the UnderScreen program, it is a new approach and it will be very interesting to see whether we can get some good outcomes from it."*

**iii) Multiple strategies should be employed**

*"It's not like a one-size-fits all. If the kit can be accessed by the community in multiple ways, whether it's by the Aboriginal health service having them available, whether it's the Aboriginal health worker handing them out, but still making it available by the mail too for those that's suitable for."*

## **C. Education to Community Members**

### **i) Basic education about cancer, prevention and screening**

*"the Aboriginal liaison officers also were involved with the women's health nurse at [the name of the place] and they did a Pap screening clinic, they ran some education again. They were able to meet the women's health nurse to begin with, just in a very informal session and once they'd received that education and were a bit more familiar and comfortable about what would happen, then the clinics were open to them and then they attended the clinic. So they were also able to put their name down at the time of that education if they would like the women's health nurse to follow up with them at a later time, or just to explain more about what would happen."*

*"I know they got quite a few women screened through that way as well for the Pap screening. With the bowel cancer, we ran some sessions this year. We involved Bowel Cancer Australia and we have an educator from there come down. But again, we probably should've targeted more specific - we had the more educating for the general community."*

*"We went through those - we contacted those community health nurses first and then they linked us in with those populations. They were able to bring the community in and we were able to bring the breast screen or breast care nurses in and they ran the education. We also have interpreters as well for those particular groups that were organised through the community health for us. They were able to translate the information that was being provided in the education sessions."*

*"I suppose one thing that came across and this is through all the communities, not just the Aboriginal community, was that the kits, quite often they receive them, so there's a lot of money spent on sending out the kit, but the people then, they don't know what to do with them. Generally, I'd assume it's because they're not aware of what to do with them. They would actually throw them out or they would put them aside and they never get used."*

### **ii) It needs to be culturally appropriate**

*"we did target men's and women's Aboriginal groups in some screening education and we gave them information about screening through those sessions. So again, we targeted a specific men's business, and women's business. That was again probably a better way to bring them all to get that information and education across to them."*

### **iii) On-going support even after the education sessions**

*"... the conversation and then the ongoing support that's needed. I think too, with a lot of people, not just Aboriginal people, it's not just explaining the kit and walking away. There needs to be that follow-up and some people are a bit shy to pop it in the post box. You can say to them, well, bring it back to the health service, we'll mail it for you. Just some support strategies like that that help follow through with process."*

## **D. Funding**

### **i) Funding provided to ACCHS**

*"... providing funding - as we know the ACCHOs of those, they're so busy with so many health and welfare issues that I think they do need to be fairly financially funded to actually be involved in bowel cancer screening"*

*"One of those was it definitely works, obviously, by funding the ACCHOs to actually have a focus on bowel cancer screening and encouraging their community to screen, but we can't just fund them and walk away."*

### **ii) Other incentives**

*"financial incentive full stop... the breast screen bus is located - it might even be there at the time. Anyway, I guess that's an incentive for women to be informed about cancer screening. So that element of incentive, whether it's financial, or if it's making sure there's child-care available, or having a lunch or a pamper day, it definitely seems to resonate well with the community."*

**iii) Phased approach to funding**

*“from a funder’s point of view, it’s probably important to almost have a phased approach as well. So, rather than allocating the whole amount of funding in one hit, just to ensure that, as a funding body you’re happy with the outcomes that are being met, but being fully clear about the commitment at the onset, but just being smart about how it’s actually allocated. A phased approach would probably work quite well with the Aboriginal community as well.”*

**E. Engagement with Aboriginal Communities**

**i) Kits delivered by a respected and trusted Aboriginal person within the community**

*“We definitely hear that loud and clear from the community, that to receive the kits by a respected and trusted Aboriginal person is of far more benefit than just receiving the kit in the mail with a very government-worded invitation letter.”*

*“we’ve used well-known community members to be our champions. We’ve developed some resources that have a woman who has had bowel cancer and survived bowel cancer and she’s also the CEO of our peak Aboriginal Community Controlled Organisations of ACCHO. ... She’s a very well respected woman in the community in Victoria and by having her endorsement, her face and picture on the brochure and on the poster, that’s been really well received by the community. So, definitely using kind of those community champions has been successful for us.”*

*“it was about a high profile person in the Aboriginal community. Some people use footballers and some people use different things but we had the opportunity to engage with [name of a prominent figure] and we were able to get him to become - to do that DVD.”*

**ii) Listening is very important**

*“... important if they're wanting a project to work that you do it right from the start and if you're ringing and getting people's comments they should take those things on board and don't go out sort of assuming that you know best. Just listen, I guess is another thing but listen to the workers that are already there because they know their community.”*

*“so if anyone comes into any area they need to engage with the right people to - you know, to talk about what the project is about and that might not be just one meeting, that could be two or three meetings. It could take quite a while and it's very important to sit back and listen and take on board what the workers are telling you or what the community is telling you.”*

**iii) Utilisation of existing programs or resources**

*“tap into things that are already there, that are already established. Engage with them, find a contact person and then between you set up a community meeting and there you address the meeting to tell them who you are and what you're after.”*

*“If you've got Aboriginal health services or organisations that employ Aboriginal health workers use them. They're your first point because don't reinvent things that are already there, just tap into them.”*

**iv) Trust and Relationship building**

*“even the engagement process is an initiative in itself, if you like, a way of raising awareness.”*

*“it takes long-time to build relationships and trust with Aboriginal communities, especially in the bowel cancer, cancer screening space, more specifically. So that lead time and that engagement and trust building is something that we do and we do well and think it’s really important for the project...”*

*“They have to be comfortable enough you've got to build up a rapport and rapport and trust takes a long time to build. That's why you're better off going in employing or working with Aboriginal health workers that know the community. So you've got to take the time, never assume that you know what's best. What works in one community doesn't work in another, so that's another thing that you need to*

*be mindful of.”*

**v) Special day**

*“recently we've just finished some Well Women workshops which was about ensuring that people know about breast screening and from what I've seen ... the best way to approach it is to hold an event that has some fun - a fun event but in that fun event there's screening happening at the same time.”*

*“some of the barriers are you need to look at the time of day that you run things. Transport is always an issue. There are certain days that you wouldn't run it or you can run it if you know that there is a program happening on that day.”*

**vi) Target specific services**

*“The same with cervical cancer screening, they didn't - no actually, with one of the sessions with cervical cancer screening again, they targeted a local childcare centre for the workers, for the staff there. If they wanted to have Pap screens done at that time, they actually did them at the time of the education session. But there was a couple of health nurses and they set up to be able to do that at that time. But then they also organised clinics too that they can attend if they didn't want to have it done on the day.”*

*“specific with targeting groups and the different communities around this area particularly because we have quite a big population. There is quite a few different organisation or places that we could target to do that education, to inform them about”*

**F. Dedicated and Trained Staff**

*“my first thing would be that they need to employ an Aboriginal project or whatever title they give them, that is known in each of those communities that they're targeting. Whether or not they are a person that's well known in the community or they're an Aboriginal health worker or they've got some standing or trust I guess in their community that they live. So that would be my first thing that would go on that list and then that makes it easier for you then to come in because you've already got that person that knows the community.”*

*“it should be a cervical screening worker or a bowel worker - it should be funding a position around cancer screening and making sure there are targets.”*

*“... obviously support the health worker who was in charge of the project at the health service... just want to reiterate the importance of having the health worker and the nurse involved in bowel cancer and having the space to be able to dedicate time and resources to that, because it was a significant investment for them”*

*“Aboriginal health workers are actually quite pivotal to helping get the message out there and - but in our projects we've actually provided education to health workers to upskill them about cancer because it's not part of their curriculum.”*

**G. Aboriginal-friendly resources**

**i) Adapted to the context**

*“... we've obviously developed a number of resources, so both information-based brochures for the community, but then also training resources for Aboriginal health workers who are working directly with the community. With that, we've always engaged with Aboriginal artists to commission art work and we've always ensured that it's a female artist and a Victorian-based artist. That's really important for the community to be aware of that.”*

*“an apron which looks at the reproductive organs for females and - just like that using Aboriginal artwork. That's been quite an effective way to reach local communities.”*

*“if you look at the national - first of all, the letter that gets sent and the instruction sheet that's included, it's definitely not very culturally appropriate. Again, it's been quite well received by the*

community, that having instructions and introduction letters that are adapted for them is definitely far better than the government speak that comes with the national kit in the mail.”

“The specific resources like the ATSI specific resources - we just made sure that we had those Aboriginal specific resources available, that when we sent out anything, that they had those identifiers on them. So that the community were aware that it was for them. I think that's been really important being able to access those resources that the organisations have made actually specific for the Aboriginal community.”

**ii) Easy-to-understand**

“... we obviously use our general information brochures and try and translate that into more simple English where possible.”

**iii) Positive health message**

“There was discussion of making sure health messages are framed positively: this test is easy; and it can save your life.”

“Anecdotally, we're hearing ... Aboriginal communities have very limited awareness of bowel cancer and bowel cancer screening. Their awareness of bowel cancer is that their community is getting it at a very late stage and mortality rates are high. So we're battling a fatalistic understanding of cancer and cancer screening and really trying to balance that with pushing a positive cancer screening message in what's a difficult situation for those communities that have other really pressing needs.”

**iv) Appropriate dissemination strategy**

“... cinema under stars... that's where we showed the DVD first. So we had a good viewing for that and again it made all those people aware of the signs and symptoms. We spoke. So it was a good introduction and so from that I guess we had other services or workers asking us about the DVD, so then we were actually promoting it to other places because they wanted copies of it. So it was distributed out. We had a link that was sent out as well so - on our website and it's also the Lung Foundation of Australia have actually distributed it widely through the link.”

**H. Partnership with other organisations**

“We don't have ongoing funding as such. That's where we try and link in with some of the other organisations that might be able to provide that education as part of their role. We have some ongoing projects. We're going to be working with our Medicare local around some bowel cancer screening.... We will be doing ongoing things and we're hoping that the links that have been set up with the liaison officers or the community health, and breast screening or Bowel Cancer Australia will sort of continue on and they'll know then who to contact if they want to have further education sessions.”

“we're not educators ourselves here, we facilitate their education. We involved organisations like BreastScreen Victoria, the breast care nurses, local breast care nurses. We had the women's health nurse at the hospital who would do the cervical screening, cervical or Pap screening. We had Bowel Cancer Australia involved with educating for the bowel cancer education.”

“I think by involving either state Cancer Councils to be involved in projects like this, we can be the support people for them. We can be the one knocking on their door and ... helping them in any way we can and whether that's trying to keep this project front-of-mind, which I think is very important, but also offering suggestions and our expertise that we've had from our experiences, too.”

“I think it needs intense support every step of the way. It's giving them a call every week, every two weeks, seeing how they're going. There're several key success factors: visiting, going out and just having a really informal chat and talking to them about it. It really makes a massive difference.”



*"I was just going to say, it could almost be like a consortium-type arrangement. Because, the other thing to be conscious of is, not all Aboriginal people go to Aboriginal health services. It could even be a consideration to get the local - I don't know what sort of approach it is in terms of how big the regions are they're looking to fund, but ensuring there's also some buy-in from the local general health service, or mainstream health service, or even the hospital, if there is a dedicated Aboriginal health worker within the hospital sector as well.... What works is when they are the arms and legs for us to reach the community, to engage the community and organisations like the Cancer Council remain there supporting them, holding their backs with specific information around cancer screening expertise and knowledge. They don't have to know everything, but we're there to support them to do their job."*

*"... you have the best of both. [Name of the person] knows the cancer stuff and I know the Aboriginal community, so together we deliver some good programs but again it's tapping into whatever sort of programs and things that are happening out there."*

## **I. Innovative Approaches**

### **i) New program**

*"the UnderScreened Recruitment program has been funded by the Department of Health, so the Victorian Government, for three years, from 2014 to 2016. It aims to increase cancer screening knowledge, awareness and participation across breast, bowel and cervical cancer in Aboriginal and Torres Strait Islander communities, in culturally and linguistically diverse communities and low socio economic communities."*

*"the project is really still in partnership development stage, so the Aboriginal aspect of the project. So, we'll be looking at working with the metropolitan community in Melbourne, which has the largest population of Aboriginal people here and also, in Bendigo. So to look at different models though, to look at different involvement, different partners and different communities."*

*"one of the aims of the project is to look at whether joint screening messages - so breast, bowel and cervical cancer screening messages - to test whether joint screening messages are going to work for these communities... So it's looking at where we can draw on what already works and what's going to work for specific communities best is what we can then roll out state-wide."*

### **ii) Success stories**

*"we were funded by the State Government to do this - we developed specific HPV resources; a brochure, a fact sheet, and poster. But then we also contracted an Aboriginal woman, who again, was well known in the community. We contracted her to literally visit every single Aboriginal health service in Victoria ... 25 of them. So over a period of a month or two, she just hopped in her car, very informal visit to health services, obviously used the networks and contacts she had and basically, informally spoke to anyone she could on the day that she was there. So whether she had the reception, any GPs, any Aboriginal health services, she put up the posters, she chatted to them all about what HPV immunisation was, because it was very new. She spoke to them how there was a catch-up program up to the age of 26 and really just talked about the benefits of it. So, it was coming from an Aboriginal person who they knew."*