

# National Indigenous Bowel Screening Pilot FINAL REPORT October 2020



Report prepared by Menzies School of Health Research

National Indigenous Bowel Screening Pilot

October 2020

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## **1. EXECUTIVE SUMMARY**

Participation in the National Bowel Cancer Screening Program (NBCSP) by Aboriginal and Torres Strait Islander peoples<sup>1</sup> is significantly lower than that of other Australians (23% versus 42% respectively).<sup>2</sup> Small scale pilot projects conducted between 2008 and 2011 showed an Alternative Pathway, through Indigenous Primary Health Care Centres, might increase Indigenous participation.

In 2015, the Australian Government funded Menzies School of Health Research (Menzies) to conduct an evidence review and undertake consultations with key stakeholders to develop resources and draft an implementation plan for a national pilot of an Alternative Pathway to bowel screening for Indigenous Australians.

The *National Indigenous Bowel Screening Pilot* (the Pilot) was conducted from 1 November 2018 to 31 October 2019. Forty-seven primary health care centres were enrolled in the Pilot. Forty-four were approved to give out NBCSP kits to their Indigenous clients; 36 gave out kits.

More than 1000 Indigenous adults in the eligible age range (50 to 74) were assessed for screening through the Alternative Pathway; 865 accepted a kit, and 390 completed the test. Fifteen of the completed tests were not valid; 53 tests were positive.

Screening participation through the Alternative Pathway (39.8%) was significantly higher than that of Indigenous people in the usual pathway (23.3%), and at a similar rate to that of non-Indigenous Australians (40.6%). Similar screening patterns for the Alternative Pathway were found even in remote areas, where barriers to screening are particularly challenging.

The Alternative Pathway also revealed greater reach into under-screened sections of the population (those who had been invited previously but not screened; those who live in areas of low socio-economic status or remote areas) than through the usual pathway.

Of those who screened through the Alternative Pathway, 70% of those who screened had been invited at least once before through the usual pathway but had never screened. The rate of return of kits for this group (previously invited but never screened) was 42% for Alternative Pathway participants, compared to 18% for all Australians through the usual pathway.

Participation by those in the lowest socio-economic group (SEG) was 47% for the Alternative Pathway compared to 37% for all Australians for the usual pathway. Amongst those from the lowest socio-economic group (SEG), those who received their kits through the Alternative Pathway screened at a significantly higher rate than those who received kits through the usual pathway.

<sup>&</sup>lt;sup>1</sup> Aboriginal and Torres Strait Islander peoples are respectfully referred to as Indigenous from here on.

<sup>&</sup>lt;sup>2</sup> Australian Institute of Health and Welfare. *National cancer screening programs participation data*. Cat. no. CAN 114. Canberra: AIHW. Viewed 02 July 2020, https://www.aihw.gov.au/reports/cancer-screening/national-cancer-screening-programs-participation

The Pilot evaluation revealed an unexpectedly high rate of positive results among Indigenous men who screened through the Alternative Pathway (19.6%), compared to Indigenous and non-Indigenous men in the usual pathway (10.6% and eight per cent respectively).<sup>3</sup> Indigenous women had similar positivity rates across both pathways (10.1% for the Alternative Pathway and 9.1% in the usual pathway), with positivity rates for Australian women overall at 5.6%.

Interviews with health centre staff and their Indigenous patients who screened showed, in combination with the screening data, that receiving a kit from a trusted health professional was a much more positive experience to receiving it through the mail and removed many of the identified barriers to screening. Patients understood why the test was important and how to collect the samples and were keen to do so. Patient adherence to correct procedures was high, with few Alternative Pathway samples found to be invalid. Those who screened through the Alternative Pathway did so much more promptly than usual pathway participants. The median number of days in which Alternative Pathway kits were returned was 13 days, compared to 34 days for the usual pathway.

NBCSP data on further assessment or diagnostic testing following a positive result was not available at the time of reporting. Interviews with health centre staff suggest that the process of offering screening to their patients has given many staff a greater investment in the entire bowel screening pathway including supporting patients who require a colonoscopy.

The Pilot outcomes suggest that – if rolled out more broadly – an Alternative Pathway could potentially close the gap between Indigenous and non-Indigenous Australians in participation in the NBCSP. The costs of offering an Alternative Pathway are not high, and expenditure on bowel screening returns a very high rate of return. Adoption of an Alternative Pathway as a permanent part of the NBCSP would also help to address inequities in the program.

However, the Pilot evaluation also highlighted technical issues that must be addressed <u>before</u> broader rollout can occur. In particular, a temporary workaround that allowed health professionals to report participation information to the NBCSP register must be replaced with a more user-friendly and direct interface with the new National Cancer Screening Register (NCSR). The workaround used during the Pilot was not acceptable to many health professionals, particularly General Practitioners, and was a barrier to the Alternative Pathway being offered. The workaround allowed health professionals to fail to follow correct procedures, while providing little opportunity to detect such errors at a system level. During the Pilot, approximately 100 kits were given out to patients but were not reported to the Register, increasing the risk that patients might not receive their results.

In mid-2019, the Department of Health agreed that Pilot health centres could continue to distribute kits beyond the Pilot and until the evaluation was complete and the Department considered its findings. More than half of the Pilot sites (N = 20) continued to give out NBCSP kits beyond the end of the Pilot, although the COVID-19 pandemic reduced their capacity to do so.

<sup>&</sup>lt;sup>3</sup> The high positivity rate for Indigenous men may be a result of the small numbers involved, where a few positive cases can make a big difference in the rate, and/or the higher rates of positivity often recorded among first-time screeners.

### 1.1 Recommendations

The National Indigenous Bowel Screening Pilot demonstrated that an Alternative Pathway for the NBCSP can close the gap between Indigenous and non-Indigenous participation in bowel screening.

It is recommended that:

- 1. The Alternative Pathway should be made available to more Indigenous Australians through Indigenous primary health care services, as widely and as rapidly as possible.
- 2. Two significant technical barriers must be addressed or resolved to ensure that broader rollout of the Alternative Pathway maintains the integrity of NCSR data and meets the required quality and safety standards for participant safety:
  - a. The online Participant Details form used to report screening activity during the Pilot is not fit for purpose to support broader rollout of the Alternative Pathway. It must be replaced with a simple and user-friendly way health centre staff to access and enter information about patients who are invited to screen, that is developed with input from those who will use it (GPs, nurses, Aboriginal and Torres Strait Islander Health Workers), trialled in situ before wider implementation, and supported with clear and concise 'how to' resources.
  - b. Systematic screening programs (like the NBCSP) around the world struggle to integrate the data of 'ad hoc' participants who screen outside the regular cycle of invitation of large cohort groups. Manual overrides of the NBCSR were carried out during the Pilot to address these issues, but this is not sustainable beyond the scale of a Pilot.
- 3. A brief co-design process involving the NBCSP Program Development Advisory Group, Primary Health Networks, Cancer Councils and Aboriginal Community Controlled Health Organisation (ACCHO) peak bodies and health centres is recommended to assist with development of program guidelines for broader rollout. For example, careful consideration should be given to how to bring health centres into the program and eligibility criteria. The Pilot worked best for health centres with a high proportion (more than 80%) of Indigenous patients, and mostly driven by Aboriginal and Torres Strait Islander Health Workers or nurses. Current or emergent programs offered by these key stakeholder groups may dovetail well with broader rollout of the Alternative Pathway.
- 4. Training and implementation support will be required to help health centres prepare to offer the Alternative Pathway, and ongoing monitoring and follow-up to ensure quality and safety requirements are met:
  - Training provided through the Pilot was effective in addressing the barriers that might prevent health centre staff from offering bowel screening to Indigenous clients and will require minimal adaption for broader rollout.
  - Implementation support: The NBCSP is a program that appears very simple but is operationally very complex. Key health centre staff need to understand it sufficiently to then develop a workable and sustainable system to embed into the health centre's routine practice. Materials used during the Pilot will need to be made more user friendly and adapted to support the implementation of Recommendation 2(a). More tailored support should be provided *before* health centres begin to offer the Alternative Pathway.

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- An ongoing program of monitoring is needed to ensure that health centre staff are recording the information required by the NBCSP for each participant. Where health centres had not systematically embedded the Alternative Pathway into routine practice, staff turnover easily lead to a breakdown of compliance. Monitoring should involve contact with health centre staff, not just filling out a form.
- Health centres with greater capacity and a systems orientation were able to implement the Alternative Pathway with minimal support. To increase uptake of the Alternative Pathway, training and implementation support should be offered flexibly so that health centres with less capacity receive the support that meets their needs.
- 5. The impact of the Alternative Pathway suggests that offering NBCSP screening through primary health care services may be of benefit to other Australians, but the Alternative Pathway should not be simply transplanted to another context. The Alternative Pathway is built on the strengths of the comprehensive primary care model promoted by ACCHOs. It was designed specifically to address the barriers or gaps that were working against greater participation by Indigenous Australians, and those that may discourage health centre staff from promoting bowel screening with their Indigenous patients. Even to roll the Alternative Pathway out to more private practices would require refinement to ensure that barriers in that setting are addressed.
- 6. The Pilot has highlighted areas of the usual pathway which could be improved. For example, the extent to which kits are sent to out of date addresses. One Pilot site recently reported receiving a delivery of 1000 usual pathway kits, addressed to individuals who must have once had a connection with the health centre. A random sample of 14 kits did not find a single kit that could be passed on to a current patient. Another opportunity for improvement might be to apply package identification and tracking, or bar coding, to help link the kit directly to its recipient. This could potentially make the Alternative Pathway much easier to deliver.

#### Limitations of this report

There are limitations in the calculation of Indigenous participation in the usual pathway, and the invitation rate for the Alternative Pathway, and as a result the participation rates for neither group is precise. See Section 8 for discussion of these limitations and how the Alternative Pathway participation rate has been calculated.

A post-Pilot round of qualitative data collection was cut short by COVID-19 shutdowns of Indigenous communities and a decision by Menzies to halt staff travel. The project team continued to carry out interviews with health centre staff by phone, although these too were suspended as clinical workloads increased in response to the pandemic. These circumstances placed some limitations on the extent to which post-Pilot data could be obtained for all sites.

### 1.2 Evaluation questions

The following tables set out the evaluation questions for the Pilot and the sections of this report in which each question is answered. A summary of the answers to each question is provided in Section 10: Findings.

#### (a) What support did health centres require to offer the Alternative Pathway?

#### Table 1.1: Evaluation questions about training and implementation support provided to Pilot health centres.

Evaluation question		Report sections
How well were [health centres] supported to implement the Alternative Pathway?		
a.	What implementation support (including training opportunities) was made available to [health centres] taking part in the Pilot? Was the implementation support provided as planned? If not, why, and how did it differ?	Sections 4.3 and 6.2
b.	What were the key barriers and enablers to providing implementation support for the Alternative Pathway?	Sections 2.3, 6.2, 10.1
c.	How effective and fit-for-purpose <sup>4</sup> were the training opportunities, resources and supporting materials?	Sections 6 and 10.1
d.	What activities or programs related to the Pilot aims were carried out by Supporting Agencies during the Pilot? Were any of these activities or programs provided directly to Pilot health centres?	Section 5 and Appendix G
e.	What support was provided to [health centres] taking part in the Alternative Pathway by the NBCSP pathology provider (Sonic Healthcare) and the Department of Human Services (during implementation and/or ongoing through the Pilot)? To what extent would this support be required	Section 4.3
	feasible or sustainable if an Alternative Pathway was rolled out more widely (with the new National Cancer Screening Register operational)?	Section 10
f.	Did [health centre] staff report increased knowledge and skills about bowel screening, and increased confidence and capability to deliver the Alternative Pathway, as a result of the training and implementation support activities? Did health centre staff view the support provided as sufficient to prepare them to offer the Alternative Pathway?	Section 6

<sup>&</sup>lt;sup>4</sup> 'Fit for purpose' was defined as whether the support provided through the Pilot addressed key knowledge and skill requirements to deliver the Alternative Pathway; barriers identified through earlier phases of the project such as lack of motivation or confidence or a shortage of suitable resources for use with Indigenous patients; and was delivered in modes that were suitable for the target audience (primary health care centre staff including Indigenous Health Workers and Practitioners, nurses and GPs).

#### (b) Did the Alternative Pathway increase screening participation?

#### Table 1.2: Evaluation questions about screening participation

Eva	aluation question	Report section
Did the Alternative Pathway achieve its objective of increasing bowel screening participation by eligible Indigenous Australians (aged 50-74 years, who may or may not have done a previous bowel cancer screening test)?		
a.	To what extent did the Alternative Pathway increase screening participation rates of eligible Indigenous Australians, compared to the usual direct mail approach?	Section 8
b.	Did the diagnostic assessment rate and median time between a positive screen and diagnostic assessment (colonoscopy) for Indigenous Australians differ between the Alternative Pathway and usual direct mail approach?	Section 8 (awaiting release of AIHW data)
c.	What factors contributed to eligible Indigenous Australians participating in screening through the Alternative Pathway?	Section 9
d.	Did the proportion of Indigenous participants with inconclusive screening results differ between the Alternative Pathway and usual direct mail approach?	Section 8 (awaiting release of AIHW data)
e.	Were there any unintended consequences (positive or negative)?	Section 10

#### (c) Delivery of the Alternative Pathway by Pilot health centres

#### Table 1.3: Evaluation questions about how health centres offered the Alternative Pathway

Evaluation question	Report section
How effectively was the Alternative Pathway delivered by health services?	
How did IPHCCs incorporate bowel screening into their practice systems and processes? (i.e. how were eligible clients identified and offered screening, and how was follow-up provided?) This includes: (1) how the Alternative Pathway was implemented at the health centre (the service model used); (2) health promotion or other activities carried out by health centre staff or others, with local community members, that occur outside the health centre itself.	Section 7
What proportion of the eligible active client group of participating health centres were invited to screen?	Section 8
To what extent was the NBCSP as delivered through the Alternative Pathway manageable for IPHCC staff and managers? Were some elements of the NBCSP more/less manageable than others?	Section 7
What were the barriers and enablers for health centres in delivering the Alternative Pathway?	Section 7

#### (d) Cost-effectiveness of support

#### Table 1.4: Evaluation questions about Group A vs Group B

Evaluation question	Report section	
How cost-effective are the two variants of the Alternative Pathway?		
Was there a difference in the performance of IPHCCs in Group A (low intensity support) compared to Group B (high intensity support) in terms of the following outcomes:	Section 8	
- Screening participation rates	Section 8	
- Invitation rates	Section 8	
<ul> <li>Measures of quality (adherence to Hot Zone restrictions by IPHCCs; sample viability; proportion of invitees with a positive result who progressed to diagnostic assessment (colonoscopy)/timely diagnostic assessment.)</li> </ul>	Sections 7 and 8	
What was the extent of variation in performance between IPHCCs within either Group A or Group B? Were there common characteristics shared by IPHCCs that attained particularly high or low participation or quality outcomes, and if so, to what extent might these factors have implications for the feasibility of wider rollout of an Alternative Pathway model?	Section 8	
What was the difference in the cost of providing the low intensity compared to the high intensity level of support for IPHCCs to implement the Alternative Pathway? (These costs will not include those of setting up or evaluating the Pilot but will include the cost of ongoing support for each option, including the Quality and Safety Checklist process and any difference in use of Helplines or email contact to Menzies.)	Section 10	

### (e) Considerations for further rollout

#### Table 1.5: Evaluation questions about further rollout

Evaluation question	Report section
Based on the findings from questions 1-4, is the Alternative Pathway feasible to be rolled out further?	
What level of implementation support for [health centres] is required for the Alternative Pathway to maximize screening participation rates (initial setup and ongoing delivery)? Does the level of implementation support required vary according to health centre or environmental characteristics?	Section 1
Do [health centres] participating in the Alternative Pilot differ from other IPHCCs?	Section 5
What other considerations (including opportunities and risks) are there for a potential further roll-out?	Section 10

### 2. BACKGROUND

#### 2.1 Bowel cancer in Australia

Australia has one of the highest rates of bowel cancer in the world with around one in 23 Australians developing bowel cancer during their lifetime. Bowel cancer is one of few cancers that can be detected in its pre-cancerous stage, and if identified early, chances of survival are high. The five-year survival rate reduces significantly if bowel cancer is detected at more advanced stages (13% stage 4 compared to 99% stage 1).<sup>5</sup> Increased early diagnosis could therefore greatly improve survival and reduce mortality and morbidity.

Bowel cancer is the third-most common cancer affecting Indigenous Australians, after lung cancer and breast cancer. Indigenous Australians diagnosed with bowel cancer are less likely to survive for five years following diagnosis than non-Indigenous Australians (58% versus 67% respectively).<sup>6</sup>

#### 2.2 Bowel screening and Indigenous Australians

The National Bowel Cancer Screening Program (NBCSP) is a population-based screening program introduced in 2006 that aims to reduce the number of Australians who die or are affected by bowel cancer each year. People eligible for screening are identified through Medicare and Department of Veterans' Affairs enrolment records and are sent a kit in the mail. The test is free and, since 2019, those aged 50 to 74 are invited to screen every two years.

Screening involves an immunochemical faecal occult blood test (iFOBT), which detects microscopic amounts of blood in the faeces. These traces of blood in the faeces may indicate changes occurring in the bowel. If blood is detected, further exploration may be carried out through colonoscopy. Recent evidence indicates the NBCSP is contributing to a reduction in morbidity and mortality from bowel cancer in Australia. The NBCSP is reported to detect bowel cancers in people at an earlier stage than among people in the same age group who do not screen through the NBCSP.<sup>7</sup>

Indigenous Australians are less likely to participate in the NBSCP than non-Indigenous Australians with the most recently published estimates 23% and 43% respectively. <sup>8</sup> The calculation of Indigenous participation relies on an estimate based on Census population data. Participation in the NBCSP is calculated as the number of people who screened as a percentage of those who were invited. An invitee's Indigenous status is not known at the time of invitation – these details are only recorded if a person participates in the program

<sup>&</sup>lt;sup>5</sup> Australian Institute of Health and Welfare, *Cancer in Australia 2019*, AIHW, Canberra, 2019.

<sup>&</sup>lt;sup>6</sup> Australian Institute of Health and Welfare, *Cancer in Aboriginal & Torres Strait Islander people of Australia* [web report], AIHW, Canberra, 2019. Available from: https://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians.

<sup>&</sup>lt;sup>7</sup> Australian Institute of Health and Welfare, *Analysis of bowel cancer outcomes for the National Bowel Cancer Screening Program 2018.* Cat. no. CAN 113. Canberra, AIHW.

<sup>&</sup>lt;sup>8</sup> Australian Institute of Health and Welfare, op cit., footnote 1, p. 43, 2019.

and completes the relevant section on their Participant Details Form. As a result, the number of Indigenous people invited to screen can only be estimated. This is done by applying the percentage of those aged 50 to 74 who identified as Aboriginal and Torres Strait Islander in the four-yearly Census, to the total number of invitations sent. The Indigenous population has been increasing as a percentage of the Australian population over recent Censuses, and accordingly the estimated number of Indigenous people invited to screen, and the participation rate, has fluctuated markedly every four years.

One of the requirements of a population health screening program in Australia is that it must:

Promote equity and access to screening for the entire target population including important subgroups such as participants who are from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, people from disadvantaged groups, and people with a disability.<sup>9</sup>

In an effort to increase the participation of Indigenous Australians in the NBCSP, the Australian Government Department of Health (Health) supported several small-scale pilot projects between 2008 and 2011.<sup>10</sup> These showed that an Alternative Pathway for the NBCSP that distributed kits through Indigenous primary health care centres could potentially increase participation of Indigenous Australians.<sup>11</sup>

#### 2.3 The National Indigenous Bowel Screening Project

In 2015, the Australian Government funded Menzies School of Health Research and a consortium of collaborators<sup>12</sup> to conduct a National Indigenous Bowel Screening Project. This included:

- Developing consumer materials targeted towards Indigenous Australians aged 50 to 74 years, to provide information in a culturally appropriate manner and encourage participation in bowel screening in NBCSP in accordance with clinical guidelines.
- Developing and delivering training for IHWs, and other clinicians working in Indigenous primary health care services, to equip them to discuss bowel cancer, encourage screening in the NBCSP and understand the operational requirements of supporting a patient through the screening pathway.

<sup>&</sup>lt;sup>9</sup> Commonwealth of Australia, *Population Based Screening Framework*, prepared by the Clinical Principal Committee, Standing Committee on Screening, Canberra, 2018.

<sup>&</sup>lt;sup>10</sup> Queensland Health, *Alternative service delivery model in regional and remote Indigenous communities*, report to the Australian Government, prepared by Queensland Bowel Cancer Screening Program, Brisbane, 2010 State Government Victoria. *Piloting service delivery model with Aboriginal communities in Victoria for the National Bowel Cancer Screening Program*, report prepared by Cancer Prevention Centre and Cancer Council Victoria, Melbourne, 2010; S Flak, D Scrimgeour & D Roder, *Alternative pathways bowel cancer screening of the Aboriginal population in South Australia – An evaluation*, report to the Australian Government, Adelaide, 2011; NT Department of Health, *NT Bowel Cancer Screening Trial: Aboriginal and Torres Strait Islander Alternate Service Delivery Model*, report to the Australian Government, prepared by NT Bowel Cancer Screening Program, Darwin, 2011; Loddon Mallee Murray Medicare Local. *General Practices supporting screening for bowel cancer project: Final report*. Bendigo, 2015.

<sup>&</sup>lt;sup>11</sup> Health used the term 'Indigenous Primary Health Care Centres' to refer to health centres that it directly funded to provide primary care services to Indigenous Australians. These centres usually had a majority of Indigenous patients, and most, but not all, were Aboriginal Community Controlled Health Organisations (ACCHOs). A substantial proportion of these centres were run by state or territory health services.

<sup>&</sup>lt;sup>12</sup> The original Menzies consortium that tendered for this project is listed in Appendix A.

• Supporting Indigenous primary health care services to participate in a national pilot of an alternative bowel screening pathway for Indigenous Australians.

As shown in Figure 2.1 each stage of the project built on the work of the previous stage. Phase One gathered data and evidence that would inform the development, in Phase Two, of patient educational materials, a training program and resources, and a draft implementation plan for the Pilot. The patient resources, training materials and implementation plan developed in Phase Two were essential tools for the Pilot to be carried out in Phase Three.



### Figure 2.1: Logic model showing the pathway to intended outcomes of the National Indigenous Bowel Screening Project.

The project timeframe was initially three years and was originally scheduled to coincide with the introduction of the new National Cancer Screening Register (NCSR) in 2017. Implementation of the NCSR was delayed, with the bowel screening component introduced in November 2019 and the provider portal yet to be implemented (as at June 2020). These delays had a significant impact on the Pilot, extending the overall project to five years.

#### Stakeholder engagement

Stakeholder engagement was embedded throughout the entire project. The evidence – based approach applied by the Menzies project team assumed that improvements in Indigenous health were more likely to be achieved if:

• Indigenous people were involved throughout the process of planning, developing and implementing policies, programs, services and projects that would affect them.

- Evidence about effective programs or practices were contextualised with the input of Indigenous people, and other key stakeholders, to ensure that policy, programs, services and projects were appropriate, feasible, effective and sustainable, and led to improved health care and, ultimately, improved health outcomes.
- Stakeholder groups including the Indigenous primary health care sector; Indigenous health professionals; Indigenous people eligible to take part in the program; individuals, families and carers of Indigenous people affected by bowel cancer; cancer councils; IHWs and practitioners; nurses; GPs; the Department of Health; state and territory health services were involved in the development of the model for an Alternative Pathway for the NBCSP for Indigenous Australians.

Three consultative committees were established to ensure meaningful engagement with stakeholders:

- 1. Project Advisory Committee (PAC): consisted of eleven members who provided timely, high level advice and included representation from patients, policy makers, primary health care, GPs, IHWs, government and Aboriginal Community Controlled Health Organisations.
- 2. Education and Training Reference Group (ETRG): consisted of ten members who guided identification, assessment, adaptation and development of bowel screening resources for Indigenous patients, and training and materials for primary health care staff to promote and facilitate participation in the Alternative Pathway.
- 3. Implementation Planning Group (IPG): was established to plan a feasible implementation for the national Pilot. However, the IPG wound down as it became difficult to address the local concerns of the many stakeholder groups and because the roll out of the Pilot was delayed due to the NCSR.

Input from these groups was crucial for maintaining a focus on key issues, barriers and enablers, and for highlighting the diversity of settings, services and populations across the jurisdictions and regions in which the Pilot was likely to be conducted.

Members of the PAC and ETRG are listed in Appendix A.

#### Barriers and enablers to screening

Phase One of the National Indigenous Bowel Screening Project provided an opportunity to strengthen the evidence base upon which to develop a feasible Alternative Pathway model. Consultations carried out in 2015-2016 expanded on the published literature, prioritising the expert knowledge and lived experience of those who might be inviting patients to screen and those who might do the test.

The project approach was informed by the Promoting Action on Research Implementation in Health Services (PARIHS) Framework which, in its early publication in 2004 set out a simple formula for better understanding and planning implementation processes.<sup>13</sup> That is, the effective implementation is a product of the degree

<sup>&</sup>lt;sup>13</sup> J Rycroft-Malone, The PARIHS framework—a framework for guiding the implementation of evidence-based practice Journal of nursing care quality 19 (4), 297-304. 2004.

of 'fit' between evidence (or an intervention), context and facilitation (the way in which the intervention or evidence is introduced). The consultations aimed to identify where there was a lack of fit between the NBCSP and Indigenous Australians eligible to screen; the barriers to screening; and identifying ways in which those barriers might be mitigated or smoothed out to allow for a better fit.

Many of the barriers identified during Phase One of the project related to the nature of the bowel screening test itself, and the way the usual pathway was offered to eligible participants. Key barriers included:

- The likelihood that many Indigenous people would not receive the NBCSP kit through the usual Pathway because it is mailed out.
- Limited investment in promoting the NBCSP through campaigns directed at Indigenous audiences, despite well documented and widespread lack of awareness about bowel cancer and misunderstandings about bowel screening among Indigenous Australians.
- The appearance of the packaging containing the test kit.<sup>14</sup>
- The nature of the test, which involves handling faeces.
- The need to provide two samples and keep them cool, which may require the samples to be placed in a refrigerator.

The Phase One consultations identified some enablers that could mediate the impact of the barriers described above. These included:

- Making the packaging of the test to look less clinical by using Indigenous designs and colours, reducing the prominence of government identifiers.
- Modifying the instructions and content to be more user friendly.
- Boosting the role of the primary health care sector in promoting and supporting the participation of Indigenous patients in the NBCSP.
  - Invitees may be more receptive to the kit if it came from a trusted source who could explain why it is important and how to use it.
  - Local distribution of kits could overcome the barriers with the mail out model.
  - Offering kits through health centres could improve follow up for those who returned a positive test. The usual pathway relies on invitees including the details of their doctor or health service on the Participant Information Form. Greater integration of bowel screening with routine primary care could improve the likelihood of follow up with colonoscopy.
- Fears about the use of faeces, or cultural protocols that might inhibit communication about bowel screening between, for example, young female IHWs (IHWs) and older men could be mediated by the involvement of a non-Indigenous person (male or female as appropriate) rather than an IHW.

<sup>&</sup>lt;sup>14</sup> At the time of the consultations, the kit was in its previous iteration, a more boxlike package than the envelope type packaging adopted in 2019.

#### Training needs analysis

The Department of Health had requested the training component of the project would:

Develop and deliver training for IHWs (IHWs) and other clinicians working in Indigenous primary health care services, to equip them to discuss bowel cancer, encourage screening in the NBCSP and understand the operational requirements of supporting a patient through the screening pathway.

The consultations in Phase One of the project identified the skills and knowledge that IHWs felt they needed to confidently encourage Indigenous patients to take part in bowel screening<sup>15</sup>.

The training needs of IHWs clustered around three main outcome areas:

- Increased awareness about bowel cancer and the value of bowel screening, so that practitioners could recognise the important role they have in relation to screening.
- Increasing practitioner's confidence to engage with patients about bowel screening. This included knowledge about bowel screening, the test kit and bowel cancer, and the knowledge, skills and techniques to talk with patients, 'take away the shame', and motivate them to do the test (practical knowledge for doing).
- Knowledge of specific procedures as implemented at the PHC centre (practical information/knowledge for doing, site specific on-the-job).

The consultations identified similar training needs for nurses and GPs, although the emphasis and delivery style might be different. For example, all the professional groups (GPs, nurses, IHWs) needed to understand more about the how the NBCSP worked. This was because the primary health care sector was not involved in the process at all, except at the point of the GP assessment following a positive result.

While some health centres had been using pathology FOBT kits (non-NBCSP) to run de facto bowel screening for patients, and some health professionals understood the NBCSP and its barriers well, many health professionals had misperceptions about how it worked<sup>16</sup>.

The key training need identified for doctors was motivational. They needed to understand that bowel screening for Indigenous people was important, that they had a role in promoting it, and, for some, confidence to talk to their patients about it. There were already a range of NBCSP resources available for GPs and nurses, which did not need to be duplicated.

<sup>&</sup>lt;sup>15</sup> Menzies School of Health Research, *National Indigenous Bowel Screening Pilot: Report on development and testing of training materials for primary health care practitioners*, unpublished report to the Australian Government, Canberra, 2016.

<sup>&</sup>lt;sup>16</sup> In its Quality Statement for the NBCSP data for 2016-2018, the AIHW points out that 'while the concept of participation in the NBCSP is easy to interpret, the NBCSP screening pathway and other concepts and statistical calculations are more complex and may be confusing to some users.' AIHW, *National Bowel Cancer Screening Program screening data for 2016–2018: Quality Statement*, AIHW, Canberra, 2019.

As part of the Phase One consultations, 210 people completed an online survey about bowel screening in December 2015. Of the 210 respondents, 124 respondents identified as Indigenous (Aboriginal, Torres Strait Islander, or Aboriginal and Torres Strait Islander). Indigenous and non-Indigenous respondents worked for a range of organisations, including state/territory and federal governments (43%), ACCHOS (25%), non-government organisations (22%), primary health care networks (9%), ACCHO peak body (7%), general practice (3%), and aged care services (3%).

Survey respondents identified a strong preference for training embedded into workplace practice, so workplace systems and information resources provided ready access to reinforce both knowledge and behaviours.

The needs analysis in Phase One concluded that training for primary health care professionals should:

- For all health professional groups (GPs, nurses and IHWs)
  - address the need to have information about bowel screening (symptoms, referral pathways, etc) at hand, through provision of online and hard copy resources (hard copy: a flip card describing the key information)
  - incorporate bowel screening reminders or triggers into health service practice by, for example: increased emphasis in adult/older person health checks, and/or through the clinical information system
  - include motivational messages about the importance of bowel screening for Indigenous patients and the role of primary health care professionals in promoting screening through the NBCSP, through posters, social media and consumer resources, as well as training materials.
- For IHWs, additional training should be available to address their expressed need for knowledge about bowel cancer and the bowel screening program; with a focus on building confidence to talk with their patients about bowel screening.

Training should be available through a half to one-day face-to-face workshop, with the same content available in an online module, or content slides that could be delivered locally or via a webinar.

### 3. THE NATIONAL INDIGENOUS BOWEL SCREENING PILOT

#### 3.1 Pilot aims

The *National Indigenous Bowel Screening Pilot* (the Pilot) ran from 1 November 2018 to 31 October 2019. The primary aim of the Pilot was to test whether an Alternative Pathway for the NBCSP via primary health care centres would increase screening participation rates for eligible Indigenous Australians, compared with those invited via the usual NBCSP direct mail approach.<sup>17</sup> A secondary aim of the Pilot was to explore whether the level of support provided to participating health centres affected their implementation of the Alternative Pathway and, therefore, screening participation rates.

#### **3.2 The Alternative Pathway**

The Alternative Pathway offered another option for Indigenous people to engage with the NBCSP. In the Alternative Pathway, primary health care centres promoted the NBCSP to their eligible Indigenous patients, distributed NBCSP screening kits, and supported patients to participate in bowel screening. Health centres were given the flexibility to incorporate bowel screening into their practice to suit their local circumstances and were encouraged to embed NBCSP bowel screening as routine practice.

The Alternative Pathway was not intended to replace the NBCSP's usual mail-out pathway, but to offer a more user-friendly way of engaging with the program. Patients at participating health centres could still complete their screening through the usual pathway if they had received a kit through the mail. Unless a patient completed a test through the Alternative Pathway, they would continue to receive invitations to screen through the usual pathway.

#### **3.3 Administration of the Alternative Pathway**

#### **Online Participant Details Form**

Delays in completion of the NCSR meant a temporary workaround was needed for administration of the Alternative Pathway. The Department of Health worked with the then Department of Human Services (DHS) and Menzies to develop and test a secure online SmartForm by which primary health care practitioners could provide information to the NBCSP.

<sup>&</sup>lt;sup>17</sup> To clarify the use of terms, the *Alternative Pathway* is the model of offering NBCSP screening to Indigenous patients through primary health care centres; the Pilot is the testing of that model carried out with 47 participating health centres between 1 November 2018 and 31 October 2019. The National Indigenous Bowel Screening Project is the broader five-year project that included consultations, development of the Alternative Pathway model and training and resources to support it, and delivery of the Pilot.

The Participant Details (Health Centre Initiated) Form – allowed practitioners to report to the DHS by completing Part A of the Form for each client invited to screen, and then to print the whole Form (Part A and Part B) for any client who agreed to accept a screening kit. The Form was included when the samples were returned for testing to the NBCSP's contract pathology provider (Sonic Healthcare).

The DHS set up a National Indigenous Bowel Screening Pilot Helpline to liaise with Pilot health centres about the SmartForm or any other issues related to clients and the Register.

#### **Bowel Screening Kits**

The kits given out by participating health centres were the same as those used in the usual pathway, with the addition of a colourful sticker applied to the front of the kit. The sticker featured Indigenous design work and messaging that had been tested through focus groups across the country and found to resonate with Indigenous people in the eligible age group<sup>18</sup>.

Sonic Healthcare distributed NBCSP kits to Pilot health centres. An initial supply of kits (provided in lots of 30, 60 or 90 – depending on size) was sent to health centres once Menzies notified Sonic Healthcare that the centre had completed the Pilot's quality and safety process. Sonic Healthcare held a supply of NBCSP kits and Pilot stickers at their warehouse and applied the stickers for an initial shipment to a health centre; subsequent shipments would have the stickers supplied but not adhered.

For health centres located in hot zones, the kits were supplied when hot zone restrictions ended. Health centres ordered additional kits from Sonic Healthcare by emailing the health centre name, address, contact person and number of kits required to be sent.

#### **Patient results**

All NBCSP samples were tested at one of three Sonic Healthcare labs. Samples received through the Alternative Pathway were tested in the same way as any other NBCSP sample. However, for Alternative Pathway samples, Sonic Healthcare would mail results to both the patient and participating health centre.

Under the Usual Pathway, Sonic Healthcare would positive or negative results to the nominated healthcare provider. For the Alternative Pathway, all results were copied to the health centre, whether positive, negative, inconclusive or no result. If the Participant Details Form was not received with the sample, or by the time the sample was tested, Sonic Healthcare would need to contact the NBCSR to find out where to return the results.

<sup>&</sup>lt;sup>18</sup>Menzies School of Health Research, *Talking about bowel screening with Aboriginal and Torres Strait Islander consumers: Report on testing of resources for use by primary health care practitioners,* Unpublished report to the Australian Government Department of Health, 2016.

#### 3.4 Support for health centres to offer the Alternative Pathway

Menzies conducted the Pilot as a cluster randomised clinical trial (RCT), with health centres randomised to receive different levels of support as they prepared to offer the Alternative Pathway. Centres were randomly selected to receive either low intensity support (Group A) or high intensity support (Group B).

The provision of support to health centres was important to the likely success of the Alternative Pathway, as consultations prior to the Pilot had shown that many primary health care practitioners had limited knowledge of how the NBCSP functioned, and that many lacked the confidence to raise bowel screening with their clients.<sup>19</sup> Training was identified as a way of creating a better 'fit' between the NBCSP and the primary health care sector, although it was also clear that health centres would need help with the implementation of the Alternative Pathway (planning how to introduce bowel screening in their local context.)

However, there were concerns within the Department of Health that the costs of providing support to health centres might reduce the cost-effectiveness of an Alternative Pathway. The Menzies project team proposed the RCT to compare two different levels of support to understand more about what was required to prepare health centres adequately to offer the Alternative Pathway.

#### Low intensity support

Health centres randomised to Group A received the low intensity model of support, which consisted of the following:

- An implementation manual (*The Alternative Pathway in your Health Centre: A guide to getting started*), which included information necessary to implement the Alternative Pathway and participate in the Pilot, NBCSP requirements, strategies for preparing for the Pilot and information on how to access forms and support lines.
- Resources raising awareness about bowel cancer, bowel screening and the NBCSP, and for talking with Indigenous patients about bowel screening and the NBCSP (posters, postcards, music videos about bowel screening, a flip chart, brochures, demonstration kits).
- Training materials to help health centre staff prepare themselves to offer the Alternative Pathway, including an online training module, information sheets and motivational posters for staff, and links to online content from other stakeholders (webinars and a four-part video about bowel screening).
- Access to the Menzies Bowel Screening Helpline.

<sup>&</sup>lt;sup>19</sup> Menzies School of Health Research, *Phase One Report*, unpublished report to the Australian Government, Canberra, 2016.

#### High intensity support

Health centres randomised to Group B received the same resources as Group A, and staff were also offered implementation planning and face-to-face training / in-service sessions (on site at health centre).

#### NBCSP support

In addition to the support provided through the Pilot, all participating health centres (Group A and Group B) had access to materials and services provided through the NBCSP. Most of these materials and services were available as part of the usual pathway and included:

- NBCSP iFOBT kits (for distribution to clients)
- NBCSP information booklets (about the program)
- NBCSP home test kit instruction brochure.
- Access to program helplines:
  - The National Bowel Cancer Screening Program Information Line (part of the Program's business as usual support services).
  - The National Bowel Cancer Screening Program Health Provider Hotline (to the program's pathology provider, also part of the Program's business as usual support).
  - A National Pilot Support Officer in the DHS who assisted with interaction between the program Register and participating health centres. This function was not part of the business as usual support but was set up to provide extra capacity around the existing Register during the Pilot, given the limited capacity of the NBCSR to support the Pilot requirement.

#### 3.5 Evaluation

#### Aim and objectives

The Department of Health had planned an independent evaluation of the Pilot, but with Menzies proposing an RCT around the Pilot it was apparent that a separate evaluation would involve significant duplication of effort and costs. Instead, the evaluation was carried out as collaboration between Menzies and the Department of Health.

An Evaluation Advisory Committee was established to review the evaluation plan and provide independent and expert advice to the Department of Health in relation to the evaluation conduct and findings. This report is therefore the draft report of the project and of the evaluation.

As a Pilot, a key focus of the evaluation was to assess whether and how the Alternative Pathway could be rolled out more widely. The objectives of the evaluation were to:

 Understand the extent to which the Alternative Pathway was acceptable to Indigenous primary health care centres (IPHCCs) as a means to encourage participation in the NBCSP by eligible Indigenous people (IPHCC patients who are Indigenous and aged 50-74 years, who may or may not have done a previous bowel cancer screening test).

- 2. Understand key factors (enablers and barriers) in the implementation of the Alternative Pathway by IPHCCs.
- 3. Measure the effectiveness of the Alternative Pathway in increasing screening participation rates amongst eligible Indigenous people (IPHCC patients who are Indigenous and aged 50-74 years, who may or may not have done a previous bowel cancer screening test).
- 4. Compare the screening participation rates, quality outcomes and costs of the two support variants of the Alternative Pathway (intervention Groups A and B).
- 5. Consider the feasibility of wider rollout of the Alternative Pathway.

The impact (if any) on screening participation rates was the key outcome measure of the evaluation.

Data on screening activity, provided by the DHS and the Australian Institute of Health and Welfare (AIHW), would be triangulated with qualitative insights about the acceptability of the Alternative Pathway (to health centre staff, and to eligible Indigenous patients), and its feasibility and sustainability for continuation or wider implementation.

## 4. IMPLEMENTING THE PILOT

#### 4.1 Recruitment of health centres

#### Health centre eligibility

To be eligible to take part in the Pilot, IPHCCs (Indigenous primary health care centres) needed to:

- 1. Have at least fifty (50) Aboriginal and Torres Strait Islander patients in the eligible age group for the NBCSP (aged 50 to 74), who were active patients under the NACCHO/RACGP definition.
- 2. Deliver at least some primary health care services to Aboriginal and Torres Strait Islander people, have capacity to support the Alternative Pathway, and have access to a GP who could assess patients who received a positive result and refer on to further diagnostic testing if required.

An IPHCC was defined as:

- A primary health care centre (PHCC) with a majority Indigenous patient population; or,
- A PHCC that did not have a <u>majority</u> of Indigenous patients, but at least 50 Indigenous patients aged 50 to 74 years and wished to make improving Indigenous participation in bowel screening an organisational priority.

IPHCCs could include:

- Aboriginal Community Controlled Organisations (ACCHOs)
- PHCCs run by state or territory health services
- Private or corporate general practices

#### **Recruitment and selection**

Applications for the Pilot opened on 20 June and closed on 27 July 2018. A total of 68 applications were received from primary health care centres. A number of these health centres delivered services across multiple sites. After investigation and discussions, a final number of 72 individual applicant sites were identified.

Of the 72 applicant sites: 62 met the eligibility criteria, eight (8) did not meet eligibility criteria and two (2) withdrew, as illustrated in Figure 4.1. Fifty health centres required for the Pilot were selected from the 62 eligible sites according to their distribution by remoteness and jurisdiction, and a partial randomisation process using computer software. Twelve eligible health centres that were not selected into the original 50 Pilot sites were waitlisted in case any of the selected sites withdrew.

Of the 50 health centres initially selected, 11 later withdrew. As a result, all the eligible applicants were able to be offered a place in the Pilot, although four chose not to accept the invitation. Eight of the withdrawn sites were replaced, bringing the total possible number of participating sites to 47.



### Figure 4.1: Flowchart of health centre assessment, selection and enrolment for the National Indigenous Bowel Screening Pilot, 7 June 2019

#### 4.2 Formal enrolment of health centres

All required ethics and governance approvals needed to be in place for health centres to be formally enrolled in the Pilot. The project had approval from its institutional ethics committee, the Human Research Ethics Committee (HREC) of the Northern Territory Department of Health and Menzies School of Health Research, prior to inviting health centres to apply to take part in the Pilot. The project received approval from all of the HRECs listed in Figure 4.2, was approved by the Kimberley Aboriginal Research Planning Forum, and negotiated clinical trial research contracts as required by three state and territory health services.

#### Figure 4.2: Human Research Ethics Committees that approved the Pilot.

#### Human Research Ethics Committee approvals for the Pilot

- HREC of the Northern Territory Department of Health and Menzies School of Health Research (HREC reference #2017-2717)
- Aboriginal Health & Medical Research Council NSW (HREC reference #1247/17)
- Aboriginal Health Research Ethics Committee SA (HREC reference #04-17-711)
- Western Australian Aboriginal Health Ethics Committee (HREC reference #763)
- Central Australian HREC (HREC reference #CA-18-3274)
- Western Australian Country Health Service (HREC reference #RGS1395)
- Metro South Health Service District HREC (HREC reference #HREC/2018/QMS/47840)

Once enrolled, health centres were randomised to one of two Groups (A or B), to receive differing levels of support in implementing the Pilot. Randomisation was carried out on a regional basis, once approvals were completed for all the health centres in the same region (e.g. South Australia – Remote). The eventual distribution of sites was as shown in Figure 4.3.



Figure 4.3: Distribution of Pilot health centres, June 2019

Note: Orange = Health centres in Group A (low intensity support); Blue = Health centres in Group B (high intensity support).

#### 4.3 Implementation support and training made available to health centres

#### Implementation support

Health centres were offered considerable flexibility in how they chose to offer the Alternative Pathway. One of the strongest messages from stakeholders during development of the Alternative Pathway model was that 'one size couldn't fit all', referring to the diversity of Indigenous communities, health services and even jurisdictional systems in which it would be implemented. The Alternative Pathway model was, therefore, designed around the concept of a 'hard core, soft periphery'<sup>20</sup>, where the hard core, or 'irreducible elements', of an innovation offer little flexibility, and the soft periphery allows for local adaption<sup>21</sup>.

The hard core of the Alternative Pathway comprised of the compliance requirements of the NBCSP and the Department of Health, aimed at maintaining patient safety and data integrity. The soft periphery or 'fuzzy' area of the innovation was that health centres could choose how, when, where and by whom patients would be invited to screen. This gave participating health centres the flexibility to incorporate bowel screening into their practice to suit their local circumstances. However, because of the lack of familiarity of most primary health care professionals with the NBCSP, and the freshly created administrative requirements of the Alternative Pathway, site coordinators needed guidance to plan for and implement the Alternative Pathway at their health centre. Furthermore, the plan for offering the Alternative Pathway needed to be conveyed to other staff, through training, meetings or other organisational communications.

The key components of implementation support made available to site coordinators (and/or other managers or champions) were:

• The Alternative Pathway at your health centre: A manual for getting started, which included strategies for preparing to offer the Alternative Pathway; the requirements of the NBCSP and how to access forms and support lines. This manual was 58 pages including appendices and was provided to site coordinators electronically with the letter confirming the health centre's formal enrolment in the Pilot. Several hard copies were included in the box of resources sent to the centre, and the manual was also available online at www.indigenousbowelscreening.com.au.

<sup>&</sup>lt;sup>20</sup> Greenhalgh TRG, MacFarlane F, Bate P, Kyriakidou O. Diffusion of Innovations in Service Organisations: Systematic Review and Recommendations. The Milbank Quarterly. 2004, 82 (4): 581-629. 10.1111/j.0887-378X.2004.00325.x.

<sup>&</sup>lt;sup>21</sup> This is a characteristic of innovations that can enable a better 'fit' between the innovation and the context in which it is to be used, and had been seen as a useful attribute for application in Indigenous primary health care centres, as for example in KL Gardner, M Dowden and S Togni, Understanding uptake of continuous quality improvement in Indigenous primary health care: lessons from a multi-site case study of the Audit and Best Practice for Chronic Disease project, Implementation Science, 5, 21, 2010. https://doi.org/10.1186/1748-5908-5-21

- A Quality and Safety Checklist, to be completed to a satisfactory standard before a health centre was authorised to be sent NBCSP kits to distribute. The QSC was designed to assist site coordinators understand the requirements of the NBCSP and to encourage planning to introduce, deliver and manage risks around the Alternative Pathway at their health centre. The QSC set out six critical quality and safety issues that might represent risks for health centres, their staff and/or patients arising from the delivery of the NBCSP through the Alternative Pathway. Topics included: management of kits and samples; staff skills and managing capability in the face of staff turnover; barriers that clients may face in doing the test; recording patient invitations and participation; managing patient follow-up (i.e. timely access to colonoscopy), and privacy and confidentiality issues. More detail about the QSC can be found in Appendix D.
- Training sessions that could be used to workshop implementation plans or focus on issues around implementing the Alternative Pathway (see section describing the sessions menu]
- *Menzies Bowel Screening Helpline*, by phone or email (bowelscreening@menzies.edu.au).

#### Training

The needs analysis carried out during Phase One of the project identified two training requirements for health centre staff:

- 1. Semi-formal training (workshop and online module) with a focus on increasing knowledge about bowel screening and bowel cancer, specifically for IHWs.
- 2. Provision of information for day-to-day use about offering screening through the Alternative Pathway, including basic procedures to be followed to meet the NBCSP requirements and the health centre's local procedures (dependent on local implementation planning).

As outlined above, the implementation manual provided the procedural information needed to meet NBCSP requirements and assess clients for screening. Within the manual was a checklist for talking with patients and a flowchart of how the Alternative Pathway interacted with the NBCSP and its Register. Unfortunately, a handy version for day-today use by health professionals as they offered the Alternative Pathway was not produced. <sup>22</sup>

The delivery of training for the Pilot was via the online module and face-to-face workshops, with IHWs as the intended audience. As outlined in Section 3, Group A (low intensity support) received access to the online training module. Group B (high intensity support), had access to the online module and additional face-to-

<sup>&</sup>lt;sup>22</sup> This small but important resource was overlooked among all the details to be worked through when, after months of delays around the NCSR, the Department of Health decided to proceed with the Pilot before rather than after the NBCSP transitioned to the NCSR. The decision set a finite end date, and therefore a definite start date, before which a completely new set of administrative procedures for the Pilot needed to be developed, concurrent with Menzies updating all the health centre and research materials in order to rollout the Pilot as a clinical trial.

face training. Training was not compulsory before centres could start giving out kits. Each health centre implemented the Alternative Pathway to suit their local setting, so the implementation planning involved in the QSC was more important than generic training.

#### Online training module

The online module was available for all Pilot health centres to provide staff with the knowledge, skills and confidence to offer the Alternative Pathway to Indigenous patients. It was designed to take approximately one hour to complete.

Topics within the online training module included:

- Information about bowel cancer and bowel cancer screening; including risk factors for bowel cancer; bowel cancer treatment; incidence, survival and screening participation rates; as well as the risks and benefits of screening
- Information about the National Bowel Cancer Screening Program and the Alternative Pathway
- Information on talking about bowel screening with Indigenous people (clinical and social aspects)
- Information on assessing a person's suitability for screening
- Understanding test results; GP assessment; and referral to colonoscopy.

The online training module included animations, music videos, and short quizzes to test participant knowledge and learning as they completed the module sections. While designed primarily for IHWs, the training module could also be used by other health professionals. The one-hour module allowed flexibility for users to learn independently, at a time and location that was convenient. It could also be completed by a small group to provide opportunities for group discussion.

The module was available for use by health centres from the 28 November 2018 and accessible through the Alternative Pathway website <u>www.indigenousbowelscreen.com.au</u>). To log in, training participants needed to go through two layers of passwords – one on the Alternative Pathway pages, and one to enter the learning management system that housed the online module. Prior to this health centres had access to an equivalent module for the usual pathway.

#### Face-to-face training

Health centres randomised into Group B (high intensity support) also had access to face-to-face training. Group B health centres were notified through their letter of enrolment that they were entitled to a visit from the Menzies Project Team to deliver on-site training and provide help, if requested, with planning their implementation of the Alternative Pathway.

A Site Training Menu (Table 4.1) was provided for health centres to select and plan training sessions that best suited their needs.

#### Table 4.1 Site visit session menu offered to Group B health centres

Site visit sessions available		
<ol> <li>An introduction to the National Indigenous Bowel Screening Pilot (30 minutes)</li> </ol>	<ol> <li>Understanding bowel cancer and bowel screening (45 minutes)</li> </ol>	
<ul> <li>A general overview of the Pilot. Suitable for all health centre staff; for example, could be presented at a staff meeting. The session includes: <ul> <li>About the National Bowel Cancer Screening Program (NBCSP)</li> <li>Barriers to bowel screening for Indigenous Australians</li> <li>Offering an Alternative Pathway to bowel screening: What it means for your health centre</li> <li>Materials and other support available</li> </ul> </li> </ul>	<ul> <li>Designed for Indigenous Health Workers and includes:</li> <li>Basic information about bowel cancer and bowel screening</li> <li>Signs and symptoms of bowel cancer</li> <li>Risk factors for bowel cancer</li> <li>Treatment</li> </ul>	
3. Preparing patients to do the test (45 minutes)	<ol> <li>The Alternative Pathway – Managing quality and safety (60 minutes)</li> </ol>	
<ul> <li>Suitable for staff who will be talking with patients about bowel screening and includes:</li> <li>Resources available for talking with patients about bowel screening</li> <li>Getting to know the test kit</li> <li>What patients need to know to complete a viable test</li> <li>What patients need to know about results and follow up</li> <li>Starting the conversation and some key messages</li> <li>What if my patient doesn't want to screen?</li> <li>Helpline information for patients</li> </ul>	<ul> <li>This session focuses on preparing the health centre to offer the Alternative Pathway and to manage quality and safety issues. Suitable for clinical and administrative staff, it includes:</li> <li>Management of kits and samples</li> <li>Identifying eligible patients</li> <li>Who is not suitable for screening?</li> <li>The essential admin: Participant Details form</li> <li>After the test: Results, follow up, colonoscopy</li> <li>Helpline information</li> </ul>	
5. Your choice: A facilitated discussion about offering the Alternative Pathway (20-45 minutes)		
An opportunity to workshop how you offer the Alternative Pathway to best meet the needs of your patients, drawing on the local knowledge and expertise of health centre staff and the Menzies Project		

Team's knowledge of the NBCSP. You can use this as an opportunity to focus on your Quality and Safety Checklist; or talk about community awareness activity and culturally respectful approaches for talking with clients about bowel screening.

Face-to-face sessions were designed to address a specific training need of differing groups of health professionals. The target audience for each session was specified in the menu, and sessions could be repeated several times during the visit in order to allow more staff to access training. Health centres were also encouraged to involve board members and/or local elders. Representatives from local organisations

such as state or territory screening services, cancer councils, PHNs or ACCHO peak bodies were invited to attend the sessions, if the health centre was comfortable with this arrangement.<sup>23</sup>

#### Websites

Menzies built and hosted a website for the project: <u>www.indigenousbowelscreen.com.au</u>, which supported two different audiences. It served as an information and resource hub for health centres involved in the Pilot and it also provided pages for the public. Families and communities wanting to know more about bowel cancer and bowel screening, as well as primary health care professionals (doctors, nurses, IHWs) who were not involved in the Pilot but who wanted to learn more about promoting the NBCSP with eligible clients, could access the public pages.

Information for Pilot health centres was in a password protected section of the website (Pilot Resources), accessible only to health centres involved in the Pilot. This section of the website provided access to electronic copies of the implementation manual, QSC, online learning module, checklist for talking with patients, a short animation showing how to do the test, a link to the online Participant Details Form, a hardcopy version of the Participant Details SmartForm and a list of key contacts to assist with the Pilot.

Health centres were also directed to the NBCSP website at cancerscreening.gov.au where there is an extensive range of information and resources to support the program.

#### **Telephone helplines**

During the Pilot, health centres also had access to three telephone helplines to support their operations in implementing and delivering the Pilot. Each helpline provided a specific aspect of support (e.g. answering questions about the NBCSP Register and Participant Details Form). A 'Contact Us' page was set up on <u>www.indigenousbowelscreen.com.au</u> as an additional means to contact Menzies Site Support. The Helplines were also highlighted in face-to-face and online training.

#### Changes to planned training and implementation support

The Pilot protocol originally included plans for two points of follow up contact from the site support officer to Group B sites, and workshops held at regional centres where staff from several participating health centres could come together. Neither of these components of the implementation and training support were proceeded with.

<sup>&</sup>lt;sup>23</sup> These stakeholder groups (state or territory screening services, cancer councils, PHNs and ACCHO peak bodies) were identified as critical collaborators for the long-term success of an Alternative Pathway. Within the project they were designated *Supporting Agencies* and actively engaged throughout the broader National Indigenous Bowel Screening Project. See Appendix G for further information about the role and activities of Supporting Agencies.

Extensive contact with site coordinators about the QSC meant that any additional follow up by the site support officer would have no discernible effect on the level of support provided. In addition, health centre managers were reluctant to release their staff for onsite training, and it seemed impractical to offer the same set of health centres (Group B) a regional workshop which would take them away from work for a longer period.

#### Support provided by DHS and Sonic Healthcare

The Pilot could only have taken place as it did with support from DHS and Sonic Healthcare. DHS provided the National Pilot Support Officer and was the interface between the NBCSP and health centres. Sonic Healthcare distributed kits to Pilot health centres, received and tested samples that were returned (as for the usual Pathway), and mailed results to health centres and patients who had screened.

Both organisations provided important input to the process of re-shaping the way that health centres would interact administratively with the NBCSP after the Department of Health decided to carry out the Pilot before, rather than after, the NBCSP transitioned to the NCSR.

'When [Menzies] ... and Health started planning (the Pilot) for the NCSR there was a whole lot of assumptions that you had to make and you had to plan for, about how different aspects were going to work and what was possible and not possible. And then when it was switched to fit in the DHS space [to be run through the old Register instead of the NCSR], there's a different set of assumptions that have to be overlaid on that. Something that is simple but has such a big impact is being able to change someone's addresses because that's not how the DHS Register design was first endorsed by Health, so it was, 'How do we get around the fact that we know that someone is likely to have a different address and the requirements that were beyond all of our control, how do we work within those to get it to work?'

DHS closely monitored the Pilot screening activity using a manual process of recording data and directly overseeing contact with health centres. This oversight allowed identification of any problems and capacity to quickly troubleshoot cases or improve systems.

The DHS National Pilot Support Officer received Participant Details Forms (Part A) online and by fax from health centres and would liaise with health centres over any problems with the forms. Examples of the problems that could occur included health centres filling out a hard copy of the form on double-sided paper but faxing only one side of the pages. If faxes weren't sent immediately, the samples could arrive for testing before Part A of the form did. In addition, if a patient had forgotten to include their copy of the Participant Details form with the samples, as frequently occurred, the sample would be treated as from an unknown source and not recognised as part of the Pilot.

DHS also fielded general questions from participating health centres, including some who asked how they got paid for filling out the forms (they did not); and entered data about screening participants into the Register. One aspect of the Register that was an uneasy fit with the Alternative Pathway was that the Register identified cohorts of individuals invited at the same time and did not easily accommodate people being invited to screen outside of those cycles.

Once a health centre was approved to distribute kits, Menzies would notify DHS and Sonic Healthcare (and the Department of Health) via email, providing the health centre's name, address and a contact person to receive the kits. Sonic Healthcare had a supply of NBCSP kits and the colourful Indigenous Bowel Screening stickers (designed for the Pilot) and would adhere the stickers to kits prior to sending.

To order additional NBCSP kits, health centres would email Sonic Healthcare providing the same information (health centre name, address, contact person), plus the number of kits required to be sent. From the second lot of kits sent out, the stickers were supplied with the kits, but not adhered.

Upon receiving completed kits from an Alternative Pathway screening participant, the samples were tested and all results (positive, negative, no result or inconclusive) sent to both the patient and health centre (participating in the Pilot) by mail.

On a number of occasions, Sonic Healthcare reported, screening participants did not enclose the Participant Details Form with their samples, and if a health centre had not submitted Part A of the form, Sonic Healthcare could have difficulty identifying which health centre the results should be sent to.

To reduce the impact of hot zone restrictions and enable some health centres to give out kits over a longer period, Sonic Healthcare supplied Menzies with a list of six pathology collection centres that were located near Pilot sites in hot zones. These collection centres may have been able to support Pilot health centres in returning samples to one of the three Sonic Healthcare labs that conduct NBCSP testing. Each health centre was sent an email explaining this possibility. As far as the evaluation has been able to determine, only two health centres tried to make such an arrangement and in neither case was an arrangement possible.

### 5. RESULTS: CHARACTERISTICS OF PARTICIPATING HEALTH CENTRES

#### 5.1 Overview

This section describes the characteristics of the 47 Pilot health centres and, where data are available, compares them to Indigenous primary health care centres that reported in the 2016-17 Online Services Report (OSR).<sup>24</sup>

The Evaluation Plan emphasised the need to understand the extent to which Pilot health centres were representative of Indigenous primary health care centres more broadly, in order to consider the generalisability of Pilot findings and potential for wider uptake of an Alternative Pathway.

The OSR summarises the annual activities of around 200 organisations funded by the Department of Health's Indigenous Health Division to deliver primary health care, maternal and child health care, social and emotional wellbeing and drug and alcohol services for Indigenous Australians. A total of 198 organisations contributed to the 2017-2018 OSR, although not all centres reported on all variables.

As shown in figures 5.1, 5.2 and 5.3 below, Pilot health centres were more likely to be in Queensland, in more urban and regional geographical areas and slightly more likely to be Aboriginal Community Controlled Health Organisations.

This profile of the Pilot sites could be explained by a number of factors including competing priorities for health centres and/or communities; the eligibility criteria of the Pilot (at least 50 Indigenous clients aged 50-74; ability to ensure samples were stored and transported at cool temperatures and tested in a timely manner; hot zone restriction affecting central and northern parts of Australia; perceived or actual barriers to client interest or willingness to complete a screening test; and actual or perceived barriers to timely access to diagnostic colonoscopy for those who receive a positive iFOBT result.<sup>25</sup>

The under-representation of NT, remote and small health centres in the Pilot may also be explained to some extent by the relatively high representation of these centres in the OSR. With approximately 10% of Australia's Indigenous population, the NT had more OSR centres (n=56) than any other state. Nearest in number was NSW, with 43 health centres and 32% of the Indigenous population.<sup>26</sup>

<sup>&</sup>lt;sup>24</sup> Australian Institute of Health and Welfare 2018. Aboriginal and Torres Strait Islander health organisations: Online Services Report—key results 2016–17. Aboriginal and Torres Strait Islander health services report no. 9. Cat no. IHW 196. Canberra: AIHW.

<sup>&</sup>lt;sup>25</sup> These were all factors identified as potential barriers to screening in the pre-Pilot consultations (Menzies School of Health Research 2016. Phase One Report. Unpublished report to the Australian Government Department of Health).

<sup>&</sup>lt;sup>26</sup> Australian Institute of Health and Welfare 2018. Aboriginal and Torres Strait Islander health organisations: Online Services Report—key results 2016–17.

OSR centres in the NT were also more likely to be small, with about two-thirds of them small remote health centres run by the NT Government.

#### Jurisdiction

Pilot health centres were distributed in similar proportions to OSR health centres across NSW, Victoria, WA and SA (Figure 5.1). The proportion of Pilot sites from Queensland and Tasmania was higher than OSR centres; and in the Northern Territory, markedly lower as discussed above. To some extent these variations may reflect differences in whether health centres were counted as single or multi-sites in the OSR and the Pilot.

In Queensland and Tasmania, for example, there were several health centres counted in the Pilot as separate health centres, but which were counted as a single multi-site organisation in the OSR.

The location of the Menzies Pilot project team in Brisbane may also have influenced the high proportion of Pilot sites in Queensland, with long-standing relationships between individuals and organisations involved in Indigenous health and Indigenous cancer issues.





Source: National Indigenous Bowel Screening Pilot – Health Centre Profile and Australian Institute of Health and Welfare 2018. Aboriginal and Torres Strait Islander Health Organisations: Online Services Report – Key results 2017-18.

#### Remoteness

A higher proportion of Pilot health centres were from major cities and inner and outer regional areas than those reported in the OSR, as illustrated in Figure 5.2. Remote and Very Remote regions are under-represented in the Pilot sample.



#### Figure 5.2: Pilot health centres (June 2019) and OSR health centres (2017-2018), by classified level of remoteness.

Source: National Indigenous Bowel Screening Pilot – Health Centre Profile and Australian Institute of Health and Welfare 2018. Aboriginal and Torres Strait Islander Health Organisations: Online Services Report – Key results 2017-18. Postcodes provided by Pilot applicants were converted to Australian Standard Geographical Classification (ASGC) Remoteness Areas.

#### Type of organisation

Most Pilot health centres (77%) were Aboriginal Community Controlled Health Organisations (ACCHOs), similar to those who reported to the OSR (71%). The proportion of Pilot sites that were state or territory government services was around half that of the OSR (13% compared to 24%). The major difference was that while eight per cent of Pilot sites were private practices (GP owned), the OSR report did not include any GP owned services.


Figure 5.3: Distribution of Pilot health centres (June 2019) and OSR health centres (2017-18), by governance/organisation type.

Source: National Indigenous Bowel Screening Pilot – Health Centre Profile and Australian Institute of Health and Welfare 2018. Aboriginal and Torres Strait Islander Health Organisations: Online Services Report – Key results 2017-18.

#### **Patient numbers**

Of the 47 health centres enrolled in the Pilot, 46 reported total patient numbers.<sup>27</sup> Total patient numbers ranged from just under 600, to more than 15,000, with an average of 3436 patients per health centre.

These total patient numbers included both Indigenous and non-Indigenous patients.<sup>28</sup> The four private practices enrolled in the Pilot each averaged nearly 6000 patients in total, but fewer than 10% of these were identified as Indigenous.

Nearly 80% of health centres however had a majority of Indigenous patients, as shown in Table 5.1 below. Several ACCHOs –in regional and remote areas – also had a low ratio of Indigenous to non-Indigenous patients.

<sup>&</sup>lt;sup>27</sup> Health centres reported patient numbers in the Health Centre Profile (at the start of the Pilot) and in the Health Centre Report (collected between August and October 2019).

<sup>&</sup>lt;sup>28</sup> However, screening through the Alternative Pathway was offered only to Indigenous patients aged 50-74.

% of total patients who identified as Indigenous	Health centres (N= 46)	
	n	%
0-25%	5	11
>25%-50%	5	11
>50%-75%	4	9
>75%-100%	32	70
Total	46	100

#### Table 5.1: Percentage of Indigenous patients at Pilot health centres

Note: One health centre was excluded from these data as no patient numbers were reported.

The total number of Indigenous people reported as patients across all health centres (N=46) was more than 100,000. A much smaller proportion (n = 17,963, almost 18%) were in the NBCSP eligible age range of 50 to 74 years. The average number of eligible Indigenous patients per health centre was 390; individual health centre numbers ranged from 40 to 2356.

#### Size

The OSR determines health centre size by the number of individual clients receiving services at a health centre in the reporting year, grouped as shown in Figure 5.4 below as Small, Medium, Large or Very Large.

In comparison to the OSR health centres, fewer Pilot sites were classified as Small. A greater proportion of health centres in the Pilot were of Medium, Large or Very Large size.



### Figure 5.1: Distribution of Pilot (June 2019) and OSR (2016-2017) health centres by size, using Indigenous client numbers as the measure.

Note: One Pilot health centre was excluded from this analysis as they did not report total Indigenous client numbers. Source: National Indigenous Bowel Screening Pilot – Health Centre Profile 2018 and Health Centre Report 2019; and Australian Institute of Health and Welfare 2018. Aboriginal and Torres Strait Islander Health Organisations: Online Services Report – Key results 2017-18

#### Hot zones

To minimise the risk of samples being exposed to high temperatures, the NBCSP restricts the distribution of kits in areas classified as hot zones. In the usual Pathway this means kits are not sent to people who live in hot zones during months classified as having an average temperature greater than 30.4 degrees.

The intent of the hot zone policy is to reduce the likelihood of a false negative test result. Over time, heat can break down blood that may be in the sample. Information in the screening invitation letter and user instructions in the test kit and information booklet advise participants of the importance of keeping the completed kit cool and how to handle and return kits to minimise heat exposure. In locations where all months average more than 30 degrees kits are mailed in the coolest couple of months, usually around May or June.

With the Alternative Pathway, health centres were required to adhere to the hot zone policy and only distribute kits during unrestricted months, unless they could demonstrate that procedures were in place to transport samples as quickly as possible, and with minimal risk of heat exposure, to a Sonic Healthcare laboratory in Sydney, Brisbane or Perth.

Pilot health centre postcodes were matched to their corresponding hot zone classification using the NBCSP Hot Zone Catchments and Postal Allocation list<sup>29</sup>. Twenty-five Pilot health centres (55%) were not located in areas classified as hot zones. As shown in Table 5.2, the remaining 21 pilot health centres were subject to hot zone restrictions and could only distribute kits during two or three months of the Pilot.

Hot zone restrictions	No. of health centres	%
No restrictions	26	55
Hot zone affected		
1- 3 months restricted	6	13
4-6 months restricted	7	15
7-9 months restricted	3	6
> 9 months restricted	5	11
Total	47	100

Source: NBCSP Hot Zone Catchments and Postal Allocation, March 2018 and National Indigenous Bowel Screening Pilot – Health Centre Profile, June 2019.

#### Characteristics of the context in which the Pilot took place

#### **Cancer screening**

Within the Australian public health system there are three national population-based cancer screening programs – breast, bowel and cervical screening. Each service aims to reduce illness and death from their respective cancer by actively recruiting and screening eligible persons by detecting the disease early.

Each service is delivered with the cooperation and support of different levels of government (federal and state governments) as well as other government and non-government organisations such as Primary Health Networks, Cancer Councils and other charities.

The role of the Australian Government in relation to bowel screening is to deliver program management and governance, including policy development and the Register; expenditure of program funds (for example, iFOBT screening and partnership follow-up support delivered via states and territories); and Medicare Benefits Schedule (MBS) coverage for relevant colonoscopy costs.

State and territory governments have responsibility for providing care services for program participants following a positive screening test; local coordination of the program, including health system workforce and

<sup>&</sup>lt;sup>29</sup> Internal Australian Government Department of Health document.

colonoscopy capacity; as well as activities to improve the awareness of the program and increase participation and follow-up.

They also have an advisory role in program policy and management through the Standing Committee on Screening of the Community Care and Population Health Principal Committee, and the Program Delivery Advisory Group (PDAG).

Several promotional bowel screening campaigns were run in Australia during the same time as the Pilot. The Cancer Institute of NSW ran a six-month campaign called *Do the Test*, in the first half of 2019. The Australian Government funded a \$10million advertising campaign through Cancer Council Australia, which ran a mass media campaign including TV, radio, digital and social media advertising, over three separate seven-week bursts in 2019. The advertising campaign was accompanied by additional communication support from the Cancer Council, including outreach to GPs to encourage them to tell patients to do the test.<sup>30</sup>

#### Switching to a new Register

In November 2019, the NBCSP transitioned to the National Cancer Screening Register (NCSR). As discussed elsewhere in this report, this transition was initially intended to have occurred in 2017. The delay in commencement of the NCSR's bowel screening component caused significant disruption to the Pilot.

#### Supporting Agency activity

'Supporting Agencies' were a diverse group of organisations identified early in the National Indigenous Bowel Screening Project as important stakeholders and potential contributors to developing or sustaining the Alternative Pathway. They included state and territory health departments, ACCHO peak bodies, Cancer Councils, Primary Health Networks and others. In December 2019 Menzies invited Supporting Agencies located in or active near Pilot health centres to complete an activity report via an online survey. The survey aimed to identify activities that might directly or indirectly have affected health centres in the Pilot or the uptake of the usual pathway in the broader public.

The reports from these agencies indicated that there was a considerable amount of activity occurring that would promote bowel screening and strengthen the capacity of health professionals and organisations to support or promote bowel screening. Activities ranged from a touring Bowel Comedy, which visited three of the Pilot sites, to development of a co-design model for effective Aboriginal governance and engagement and a framework to oversee cancer control activities for Aboriginal people.

The full report of Supporting Agency activity is included in Appendix G.

<sup>&</sup>lt;sup>30</sup> Cancer Council Australia, *Cancer Council aims to combat nation's second biggest cancer killer - Australia's first major national campaign promoting bowel cancer screening*. Media release, 4 March 2019. www.cancer.org.au.

## 6. RESULTS: IMPACT OF IMPLEMENTATION SUPPORT AND TRAINING

#### 6.1 Overview

The Pilot Evaluation Plan asked three questions about the impact and effectiveness of the implementation support and training provided to the staff at participating health centres. These questions included:

1. How effective and fit-for-purpose were the training opportunities, resources and supporting materials?

In answering this question, 'fit for purpose' was defined as whether the support provided through the Pilot addressed key knowledge and skill requirements to deliver the Alternative Pathway; barriers identified through earlier phases of the project such as lack of motivation/confidence, or a shortage of suitable resources for use with Indigenous patients; and was delivered in modes that were suitable for the target audience (primary health care centre staff).

- 2. Did [health centre] staff report increased knowledge and skill about bowel screening, and increased confidence and capability to deliver the Alternative Pathway as a result of the training and implementation support activities?
- 3. Did [health centre] staff view the support provided as sufficient to prepare them to offer the Alternative Pathway?

All three questions were answered using data from interviews with health centre staff and a pre- and posttraining survey of staff who took part in either of the two modes of training offered through the Pilot (faceto-face training and online training).

To answer the question of effectiveness, data from DHS monthly reports of screening activity and Helpline call logs were used to identify frequently asked questions and any failures to adhere to NBCSP reporting requirements.

Also relevant to these evaluation questions is the extent to which health centres took up the opportunities for implementation support and training. In medical clinical trials, dosage is tightly controlled. In a pragmatic health services trial such as the Pilot, it was important to see what the effect would be in a real-world situation where health centres could choose whether to take up the opportunities offered. Interview data, scheduling logs, and project team member journals were used to document the uptake of implementation support and training.

As described in Section 3, health centres were randomised to either Group A or Group B to receive different levels of support in preparing to implement the Alternative Pathway. The key difference between the two groups was that Group B received access to face-to-face training and implementation support on location at the participating health centre, in addition to the online implementation support and training provided to Group A.

The following sections describe the data collection, analysis and findings from these sources, as relevant to the evaluation questions set out above.

#### 6.2 Uptake of implementation and training support

#### Uptake of Quality and Safety Checklist (QSC)

The QSC process took much longer to complete, was more challenging for health centre staff, and required a greater degree of feedback and follow-up from Menzies Site Support than was anticipated.

The QSC process was impacted by the Pilot's complex enrolment phase, requirements for randomisation and the diverse governance arrangements of health centres across regions. As a result, the commencement of sites and their invitation to complete the QSC was unintentionally staggered over the full 12 months of the Pilot. Most health centres (43/47) were invited between 1 November 2018 and 16 May 2019 (nearly 7 months).

As it became apparent that health centres found the QSC difficult to complete, the project protocol was varied to allow increased contact with sites. On average, health centres required three follow up contacts<sup>31</sup>. Most health centres received no more than six follow-up contacts before completing the QSC to a satisfactory standard. In one case, 30 contacts were made. Overall, a total of 117 follow up contacts (not including QSC feedback) were made, mostly *from* Menzies *to* health centres. Five health centres received help completing their QSC step by step, either during site visits or over the phone.

On average it took 49 days from when a health centre was sent the QSC (next steps letter) till the first QSC was returned. Once a QSC was assessed by the Menzies team, the health centre was notified if it was of a satisfactory standard or would be offered feedback on areas requiring further consideration. Feedback was provided 54 times to health centres. Sixty percent (26/44) of health centres successfully completed the QSC after two attempts; ten on the first attempt; seven on the third attempt; and one centre took four attempts.

Health centres took an average of 64 days from when the QSC was sent to them, until their QSC was approved as satisfactory. Figure 6.1 provides a visual depiction of the times of commencement and completion of the QSC by each health centre.

The QSC question that most frequently required resubmission was:

What systems will your health centre use to ensure that the Participant Details (Health Centre Initiated) form includes the patient's name, date of birth, Medicare number and contact details; is submitted for every patient who is assessed for bowel screening (not just those who are given a kit); and that each patient who accepts a kit also gets a copy of their Participant Details form (Part A and B) to be included with the samples when they are returned for testing?

<sup>&</sup>lt;sup>31</sup>'Contact' is used here to include successful and unsuccessful efforts to contact the Site Coordinator or other identified contact at a health centre. It does not include the provision of feedback on a QSC.

Other questions where further clarification was frequently required included:

- Who will be responsible for overseeing the distribution of kits?
- How will you make sure that staff have the skills, knowledge and confidence, and the time, to talk about bowel screening and the NBCSP with patients?
- How will you embed bowel screening so that it becomes part of your health centre's usual practice?

The question 'How will you manage the impact of staff turnover during the Pilot?' resulted in a large number of health centres reporting that staff turnover was 'not an issue'. This proved incorrect in most cases as follow up contact often revealed that the nominated site coordinator was no longer working at the health centre (often with no further means of contact). In those instances, it could take considerable time and discussion with the organisation to identify a new site coordinator and orient them to the Pilot.



Days between enrolment in Pilot and QSC completed

#### Figure 6.1: Time between enrolment in Pilot and completion of Quality and Safety Checklist, all health centres

Note: Health centres commenced at different times due to ethics and governance requirements that needed to be completed before a centre could be formally enrolled in the Pilot. Once the QSC was approved, health centres would receive kits in one to two weeks.

#### Uptake of face-to-face training

Once formally enrolled, health centres randomised to Group B (high intensity support, n=23) were offered training and implementation planning support during a site visit from the Menzies Project Team. Site visits were conducted with at least two trainers, usually the Site Support Officer and a part-time cancer nurse.

Site visits were planned as soon as possible after a health centre was enrolled. As mentioned earlier, training was not a pre-requisite for giving out kits, and completion of the QSC was not a prerequisite for training. Sometimes face-to-face training occurred after the QSC was complete; at other times the QSC was completed during or after the site visit.

Group B health centres were offered training sessions (shown in Figure 4.2) and site visits were scheduled through negotiation with health centres and the Menzies project team. For health centres in a hot zone, visits were organised when the hot zone period was over or almost over, to reduce the time between training and when staff could start giving out kits. Nineteen health centres from Group B received site visits over a five-month period. Four Group B sites did not receive a site visit due to the timing of their formal enrolment in the Pilot<sup>32</sup>.

Some health centres were well prepared, with highly motivated staff and a clear idea of how they would implement the Alternative Pathway. Others expected the Menzies trainers to tell them what they should do. In a few instances, sessions were conducted with no attendance or input from managers about how screening would be offered (for example, how the health centre would go about distributing kits) and with staff with little or no prior information about the Pilot. In these cases, the Menzies trainers were able to generalise about what might happen, but lack of clarity about processes made it difficult to prepare staff for the essential tasks of the Pilot.

Site visits and training sessions worked best when there was significant input from health centre managers about how the centre proposed to offer the Alternative Pathway to their patients. Another factor in the success of implementation was buy-in from a dedicated staff member to organise staff training and/or determine systems for delivery. Some sites had already appointed Pilot champions at the time of the site visit.

Although the Pilot offered flexible options for training as described above, most health centres requested the full training package (sessions 1 to 4), so as 'not to miss out' on 'essential' information. However, this request conflicted with the amount of time some health centres allocated for the delivery. The time allocated to training varied greatly, from one-hour sessions to full day training, with almost half of these centres requesting 3 or more hours of training. These conflicting requests from health centres affected what

<sup>&</sup>lt;sup>32</sup> The rationale for allowing four health centres to enrol during the final weeks of the Pilot was that the Department of Health had by then authorised Pilot sites to continue to give out kits after the Pilot finished, for a limited period. However, to do so, the health centres needed to complete the Quality and Safety Checklist (QSC). Two of the four that enrolled completed the QSC before the end of the Pilot. Menzies undertook to support the remaining two centres to complete the QSC, and as all four sites were in Group B, to deliver face-to-face training if requested. Three of the four requested training, but as these sites were all in hot zones the training did not occur before the Covid-19 pandemic which has delayed its delivery to date.

could be delivered. The Menzies trainers condensed and streamlined sessions 1, 3 and 4 into a single session covering the key details necessary to offer the Alternative Pathway, that could, if necessary, be delivered in 90 minutes.

Attendees at face-to-face sessions included nurses (n = 59), GPs (n = 54) and IHWs or IHPs (n = 39). A large number of health centre staff who described their roles or positions as 'Other' (n = 49) also attended (total registered attendees, n = 201). Despite the Menzies project team emphasising that some sessions, such as *Understanding Bowel Cancer and Bowel Screening*, were designed to address the training gaps identified by IHWs/IHPs, many health centres still had GPs attend.

When sessions were attended by a mix of health professions that included GPs, the conversation was often dominated by the GPs. When sessions were conducted without GPs in attendance, IHWs appeared more comfortable and participated more fully. These observations were added to the advice Menzies provided to health centres about scheduling training, but health centres continued to invite GPs.

On-site training occurred in a variety of settings, ranging from a spacious function room with a commercial kitchen attached, to in one case, a waiting room surrounded by patients. This affected the ability to present the content effectively and inhibited health centre staff participation.

As mentioned earlier, Menzies liaised with each health centre about whether the session could also be attended by local or regional representatives of other key stakeholder groups (such as state and territory screening services, cancer councils, PHNs, ACCHO peak bodies). This occurred at 14 of the 19 health centres who received training (11 different attendees) and attendance of these agencies assisted conversation and offered insight into local avenues of support (e.g. support available if a patient received a positive result).

#### Uptake of online training

Fewer people registered to do online training (n = 115) than face-to-face training (n = 201). The number of nurses who did the online module was similar (n = 56) to the number of nurses who attended face-to-face training (n = 59). Far fewer GPs took part in online training (n = 19, compared to n = 54 for face-to-face training). Fewer IHWs took part (n = 25 compared to n = 39). The number of people who described their role as 'Other' in the enrolment for the online module was less than a quarter of those who registered for face-to-face training.



#### Figure 6.2: Training attendees by professional role

Site Coordinators reported that approximately 30 staff accessed the online module in group sessions.<sup>33</sup> No demographic data was available for these attendees, and the pre- and post-training questionnaire reported in Section 6.3 was not administered to individual attendees in online group training sessions. These attendees have been excluded from the data reported above and in Section 6.3.

#### Costs of providing implementation support and training

The direct costs of delivering implementation support and training for all health centres during the 12month Pilot period included salaries, travel and catering costs, operational costs such as phone calls, administrative and technical assistance and the costs of hosting the online module and website, as shown in Table 6.2.

Items	Costs
Salaries	\$132,365
Travel and catering (site visits to 19 health centres)	\$32,600
Learning management system costs	\$2345
Website hosting	\$240
Basic operational costs	\$3500
Total	\$171,050

<sup>33</sup> Reported by Site Coordinators in responses to the Health Centre Report, mid-2019. Page 47 of 143 Salary costs included a full-time Training and Site Support Officer, two casual facilitators and 0.1 FTE administrative and technical support.

The Training and Site Support Officer role was to

- facilitate the Quality and Safety Checklist process (reminding health centres they needed to complete the QSC; coordinating Menzies' QSC assessment panel; providing feedback to health centres)
- respond to inquiries to the Menzies Helpline
- negotiate and schedule site visits, including the availability of co-facilitators and attendance of Supporting Agency staff if appropriate
- deliver training
- liaise with the Department of Health, DHS and Sonic Healthcare
- maintain records of training participation.

Prior to the commencement of the 12-month Pilot period, the Training and Site Support Officer was closely involved in the development of educational and implementation materials for the Pilot, including the development and testing of the online Participation Details form. This equipped the officer with a detailed knowledge of the NBCSP's operational features, particularly those relevant to the Alternative Pathway, essential knowledge for the role. Other skills the Training and Support Officer brought to the role included training delivery and presentation skills, a strong orientation to customer service, and experience in coordinating and providing cancer support services at the community level with the Cancer Council.

The casual co-facilitator role was shared between two experienced cancer nurses, with skills in training. These part-time staff delivered training about *Understanding Bowel Cancer and Bowel Screening*. The content of the training did not require a high level of clinical expertise; however, the experience of the cancer nurses strengthened the clinical authority of the training team.

Both models of support incurred the base costs of delivering the low-intensity model, as shown in Table 4.3. The high intensity model of support was comprised of the low intensity model plus face-to-face training delivery. The costs of travel, catering and co-facilitators applied only to face-to-face training delivered as part of the high intensity model of support (Group B). The high intensity model also required more time from the Training and Site Support Officer and administrative assistant than the low intensity model, as shown in Table 6.3.

#### Table 6.3: Breakdown of costs to deliver low and high intensity models of support

	Low intensity support	High inten	High intensity support	
	Base costs (% share of cost per item)	Base costs (% share of cost per item)	+ Face-to-face training (% share of cost per item)	
Training and Site Support Officer	30%	30%	40%	
Co-facilitators	-	-	100%	
Admin/technical support	5%	5%	90%	
Travel and catering	-	-	100%	
Learning management system	100%	0%	-	
Website hosting	50%	50%	-	
Basic operational costs	50%	50%	-	
Sub-total costs (\$)	\$38,796	\$38,796	\$93,457	
Total costs per model of support (\$)	Low intensity = \$38,796	Hi	gh intensity = \$132,253	

Source: Project expenditure reports, 1 November 2018 to 31 October 2019, Menzies School of Health Research

Note<sup>:</sup> For the Pilot, Group A (low intensity support; n=24), and Group B (high intensity support; n=23). Four Group B sites did not receive face-to-face training due to their late enrolment (due to ethics and governance requirements). The additional face-to-face training costs in the high intensity model were incurred for 19 health centres, an average of \$4919 per centre.

#### Uptake of helplines

#### **Menzies Helpline**

Throughout the Pilot Menzies provided a Helpline (a phone number and email address) to assist health centres to implement and deliver the Alternative Pathway. This Helpline was activated during the recruitment phase of the Pilot and, as at June 2020, and continues to receive regular inquiries.

Health centres contacted the Menzies Helpline approximately 156 times with questions about the NBCSP, the Pilot and Alternative Pathway. However, most contact from health centres was initiated by email as opposed to telephone (approximately 125 emails and 31 phone calls). Some contacts were made outside the Helpline via direct emails to individual project team members or calls to personal mobiles or landlines. These calls were not necessarily recorded in the contact log, as the number was minimal.

Some requests recurred over the entire Pilot period while others arose during specific phases. For example, how to order NBCSP kits was a regular inquiry throughout the Pilot whereas questions about completing Pilot requirements occurred mainly at the start of the Pilot.

Health centre-initiated inquiries were categorised under a number of themes:

- Understanding the project requirements, for example:
  - What do I have to do to get the kits?
  - What invention group are we [health centre] in?
  - What training will our health centre receive?
  - Who do I contact for support?
  - When is the QSC due?

- Questions about the NBCSP, the Pilot and Alternative Pathway, for example:
  - Eligibility criteria for screening under the Alternative Pathway.
  - Permission to use music videos as promotional resources.
  - Explanation of the Pilot and Alternative Pathway.
  - How to upskill and educate staff.
  - Can IHWs give out kits and complete/submit the online form?
  - Who can doctors contact for test results?
  - How to set up to receive patient results electronically.
  - What are the revenue opportunities related to bowel screening promotion and follow up (i.e. what is the NBCSP payment and how to receive it)?
  - Hot zone dates inquiry and 'work around' requirements.
  - QSC was submitted but no kits received yet?
  - Completing the online module pre-survey.
- Information about NBCSP kits, for example:
  - Confirming the expiry kit date (i.e. start of month or end of month)
  - How to order more NBCSP kits?
  - NBCSP kit order not received.
- Accessing resources, for example:
  - How to access resources and the online module.
  - How to get a copy of the Alternative Pathway manual.
  - What is the username / password for the website?
  - Where to get Indigenous bowel screening resources from?
- The Participant Details Form, for example:
  - How to access and use the online form.
  - How to download the online form.
  - How to integrate online form into health centre information systems.
  - Requests for hard copies of the Online Participant Details Form.
  - What happens to patients results if the 'online form' isn't done?
  - Does the patient need to sign the form?
  - Does changing address trigger an update of their address and that of family members on the same card at Medicare?
  - What to do if the online form hasn't been submitted?
  - Online form didn't email a copy, how can I receive a copy for patient tracking?
- Questions about what happens after the Pilot:
  - For patients who complete screening after the end of October will their results go back to us and to the NBCSP?
  - For patients we give kits to after 31 October: Do we give them the Pilot form (Participant Details Form, Part A and B) to complete or will there be an alternative form to use?

Some health centres also requested their results from the Pilot i.e. number of kits given out, number of patients who returned samples for testing etc. While others provided feedback about the online Participant Details Form, saying transition to the NCSR provided an ideal opportunity to integrate the form with the clinical information system Communicare (owned by the same company developing the NCSR, Telstra Health).

One health centre requested a copy of the Pilot training presentation to deliver to a local community group.

Menzies has continued to provide an informal helpline to health centres still delivering the Alternative Pathway. Over this time approximately 25 contacts have happened, focusing on:

- How to order NBCSP kits (including following up with Sonic Healthcare regarding orders)
- Who to contact about patient results?
- Receiving an updated hard copy version of the Participant Details form
- The process of providing kits to clients after the 15 November transition to the NCSR
- Is the patient's signature needed on the Participant Details Form?
- Do GPs have to complete and submit the online form?
- Request to update health centre contact information (auto filling in online Participant Details Form)
- Inquiry about hot zone restrictions (for continuing the Alternative Pathway)
- Not receiving results
- Password to access the online Participant Details Form

In one instance, an inquiry was received from a nurse (unknown) to contact patient directly regarding their inquiry about the expiration of the kit and when it had to be done.

#### 6.3 Pre- and post-training survey

A pre- and post-training survey was developed to assess the influence of training on staff views regarding offering bowel screening to their Indigenous patients. The survey was a Likert Scale questionnaire designed to measure the attitudes of participating health centre staff around three constructs:

- 1. Perceptions that staff had about their role in promoting bowel screening to their patients (perceived role), for example: 'Providing patients with information about bowel screening is part of my role.'
- 2. Staff motivation to invite patients to screen (motivation): 'There is little I can do to change a patient's attitude towards bowel screening.'
- 3. Staff confidence to engage Indigenous patients in conversations about bowel screening (confidence): 'I am confident I can encourage Indigenous patients to do a bowel screening test.'

For details about the development of the questionnaire and methods of the survey, see Appendix E. Each construct was explored through multiple positive and negative statements that were presented randomly throughout the questionnaire. Staff were asked to rate each statement as it applied to their own perception.

Health centre staff were not required to complete the survey to take part in either mode of training. Completing the questionnaire was voluntary and presented only to staff who accepted the invitation to participate in the research.

Figure 6.2 shows the numbers of those who undertook training, consented to take part in research, and completed both questionnaires.



Figure 6.2: Health centre staff who participated in training and completed questionnaires

Implementation materials provided to health centres encouraged use of the online training module with small groups, and some health centres took up this mode of delivery, including some centres who were flagged as receiving face-to-face training.

	Online training (n = 57)		Face-to-face training (n = 139)	
	n	<b>%</b> <sup>c</sup>	n	<b>%</b> <sup>c</sup>
Gender				
Male	9	16	30	22
Female	48	84	108	78
Other	0	0	1	1
Professional role <sup>a</sup>				
Nurse	24	42	39	28
Indigenous Health	11	19	25	18
Worker/practitioner				
General practitioners	10	18	34	24
Management and admin staff	5	9	13	9
Health promotion and education staff	2	4	4	3
Other	5	9	24	17
Geographic Location <sup>b</sup>				
Urban	12	21	45	32
Regional	21	37	67	48
Remote	24	42	26	19

Table 6.3: Participants who completed the pre- and post-training questionnaires

<sup>a</sup> Participants described their roles in various ways. These were sorted into six professional roles as shown above. <sup>b</sup> Geographic location was determined for each health professional using the post code of the health centre they were employed and the ASGC-RA Framework. The five relevant remoteness areas were reduced to three: Urban (major cities), Regional (inner and outer regional), and Remote (remote and very remote).

<sup>c</sup> Percentages have been rounded to the nearest whole number and when totalled may be greater than 100%.

#### Changes in staff perception following training

The pre- and post-survey questionnaires were analysed to identify whether training made a difference to staff perceptions when delivered face-to-face or online, and for different professional groups or settings. These analyses were conducted to provide evidence about the level of support that might be required to enable health centre staff in general to deliver the Alternative Pathway, and, whether either mode of training was more effective across different professional roles and different geographic locations.

For each analysis, the mean scores were calculated for each grouping of participants, using responses to statements in the pre-training questionnaire that related to each of the three constructs. This process was repeated for the post-training questionnaire. Differences between mean scores were analysed using statistical methods.

#### Online training vs face-to-face training

Participants showed a significant increase in confidence in talking with Indigenous patients about bowel screening from both online and face-to-face training, as shown in Figure 6.3.

Staff perceptions of their role in promoting bowel screening slightly increased among participants receiving face-to-face training, but not by those who accessed training online.



Motivation to promote bowel screening showed little change in either training mode.

#### Figure 6.3: Changes in perception of all training participants who completed pre-and-post training questionnaire

#### Variation in response to training, by professional role

Results from the pre- and post-training questionnaires were compared for online and face-to-face training participants from each of the six categories of professional roles (nurses, IHWs/practitioners, general practitioners, management and administrative staff, health promotion and education staff and other).

All professional groups registered a significant increase in confidence talking with patients about bowel screening after face-to-face training, and for IHWs/practitioners, nurses and GPs, the increase in confidence occurred after both face-to-face and online training.

Nurses, Indigenous Health Workers/practitioners and management and admin staff also recorded higher scores after face-to-face training in relation to how they perceived their role in promoting bowel screening. In contrast, none of the groups showed any change in motivation to promote bowel screening.

The professional categories of health promotion and education; management and admin; and other, had very small numbers recorded for online training, and the small sample size may have affected the results of the analysis.

#### Variation in response to training, by region

Participating health centres were classified into three regions: urban, regional, remote. A significant increase in confidence to talk about bowel screening with Indigenous patients was reported for all regions. Face-to-

face training positively increased the perceptions of participants from all three regions about their role in promoting bowel screening; similar shifts were not seen for online training.

Motivation again showed little change, except for participants in regional areas where there was a significant increase from face-to-face training.

#### Summary

The pre- and post-training survey results show that both face-to-face and online training had a significant impact on the confidence of staff to talk about bowel screening with their Indigenous patients. Face-to-face training improved staff perceptions of their roles in relation to bowel screening, and this was particularly true for nurses and IHWs/practitioners.

The exception was for GPs, the only professional group that had an existing defined role in the NBCSP prior to the Alternative Pathway. Motivation appeared to change little in any of the groupings by which results were analysed and variation across regions was minimal.

#### 6.4 Health centre staff perspectives on training

As described elsewhere in this report, the perspectives of health centre staff on a range of issues related to the Pilot were collected through two sets of interviews: Implementation interviews with site coordinators, and post-Pilot interviews conducted with a wider range of health centre staff between December 2019 and May 2020.

Consistent themes in these interviews included: the design, content, accessibility, delivery and challenges.

There were some limitations to the interview data. These included recall bias due to the length of time that had passed since they did the training (up to 15 months); confusion in identifying resources and materials that were supplied for the Pilot; and in some cases, staff who helped deliver the Alternative Pathway had done neither mode of training because they were not at the health centre when the training was introduced, or because the site coordinator or another champion delivered their own version of the training.

#### **Online training**

The online module was predominantly completed by from Group A (Low intensity support) health centres, who sometimes felt they had 'missed out' on receiving face to face training.

'I was a bit annoyed, how come other people got it [face-to-face training] and we didn't, but you know what, we just did it online and it was fine. I think I preferred that you didn't come and train us now looking back because with so many people coming into the AMS and saying, "We want to educate you on this." "We want to talk to you about this". "We want to promote that". When are we supposed to do our work? So that we could just say, "Okay, there's the resources, right, what do we need to do, let's move forward". It was good.'

*Design:* Participants liked the design and format of the online module, and in particular the inclusion of animations and videos as part of the content. One participant commented:

'I suppose visual, everybody likes visual because you know what you're talking about if you see that visual, then it gives you a better understanding then you can explain it to your patients.'

*Content*: The on-line module content was often described as applicable, fit for purpose, easy to understand and helpful in preparing staff to deliver the Alternative Pathway. One participant described the content as relatable and useful for having *'the conversation'* about bowel screening with their patients. Some comments from those who did the training included:

'It was good, I have done a lot of it before, but it made it easier for our whole team. It made it easy to understand what we were doing and why'.

Others commented it was a good 'refresher' and that it was easy to access.

Some staff said they did not complete the online training because it was too long:

'It was hard to do it, because we had to just do it in between patients, so it took a lot of us probably a good couple of days to actually do it, maybe even a week or so because we just didn't have the time to complete it all.'

*Accessibility*: The main topic raised when considering accessibility of the on-line training was one of convenience. Some staff accessed the training multiple times, and also shared their link to the online module with other staff so they could also do the training. It was a common reflection that the online training allowed them time to sit and think, they said they did not feel pressured and that they could complete it at their own pace and in their own time. Staff commented:

'We sent it out because the thing is, the way that the clinic works, we're opportunistic with our time, so when we're not with clients, that's a good time for you to get this stuff done'.

'I hate – or most people hate going to training that is quite boring that's just written off a slide – written off a slide so yeah, I think the [online] training was great'.

Others commented they liked the accessibility of the online module and its capacity for questions and quizzes to be repeated at individual pace: '*That was pretty simple. Yeah. And it didn't let you fail. So, if you got something wrong you could go back.*'

*Delivery*: While many staff undertook the training in their own time some health centres took a group approach to implementing training. This approach was more common in those centres where there was a proactive pilot champion.

'We did group sessions with them and they had the opportunity to do it individually as well... It was good as a team... Doing at as a team really gave them an opportunity to ask questions and talk about what one may not have understood, get that feedback in other words from whichever other health professional it was.' 'You should definitely do it in a group environment, I think. I guess because other people think of questions that you might not necessarily think of... what about if we get this sort of situation.... Then we could kind of brainstorm together on what we would do.'

Where staff supported other staff to train, there was good communication between staff and 'pilot leaders' (i.e. champions) to make sure everyone was on board and training was received; for example,

'I would go around and say have you done your stuff [the online training] yet? Did you have any questions? But generally, once everyone had done that and we'd gone through and done "This is how you talk to someone about it, these are the conversations you can have, this is why it's so important," it's not a hard subject. It's just [that it] can sometimes be a bit uncomfortable.'

'We had new registrars start in February and August. I just said, "Welcome to (health centre), you're a doctor here now and here's the bowel cancer kits. We give them out, there's a link, click it, if not see me or someone else". That was the training that they got. They have so much else to learn.'

'From our organisational perspective, we got an email to say to do it online and I did it, but there were other staff members that maybe didn't do that online completion because of being busy'

*Challenges*: Staff experienced a few challenges with the online module. The online training module was described by some staff as procedural in detail and commented it would have been better if it was delivered face to face. Several participants said a drawback of online learning was the difficulty of not being able to ask questions or find answers (to questions).

'All the staff did the online training. I think that the one barrier that we found was the online form. It just – it took a little bit of working out and I think, yeah, if someone had the – I think maybe faceto-face probably would have been better just because someone could have talked you through the steps to the form ...'

There were some aspects of the online module that frustrated participants. For example, to access the module, participants needed to go through two password protected access points. The reasons for this was to allow those staff who wanted to participate in evaluating the module through the pre- and post- training survey do so by creating a unique identifier. As a result, the password protected access to the module itself was not very stable. If a user left the module and returned to it later, they would need to change their log in details by creating a new username. This led to problems finding the module, logging on or generating certificates of completion through the online module.

'I remember a few times going, "Oh, where is the online module? Here – here's the video of a patient's experience, here's another community member talking about it, where's what I need?'

In two instances the online training wasn't used at all and staff were not supported to receive or complete it, but these staff were able to draw on other Pilot resources (website, demonstration kit and manual) to learn what they needed. A few staff commented as the module was delivered online it was easier to ignore than face-to-face training:

'If I know it's online, I'm like "Oh, yeah, I'll do it later whereas face-to-face like you've got that date and time, it's set. It's, yeah, much better". Whilst the online module was accessible to most staff not all staff in the health centre knew about it. These staff utilised other resources developed for the pilot. One staff member commented:

'I used the website and I used the demonstration kit, yep. Yeah very helpful. I thought they were both really adequate ... I think I would have personally liked the people that had been trained to prompt me to use those, I found that because I wasn't involved in the training for reasons which I don't know about I had to go and seek them out myself.'

In addition to the convenience of the online module, some staff wanted additional clinical supervision or group style element to the online training.

'We had the video training and the manuals but maybe some more – a webinar or an interaction. Would be go to sort of be able to discuss those obstacles straightaway.'

#### Face-to-face training

Health centre staff commented on the content and delivery of face-to-face training, and their preferences for training mode. Most comments reflected positively on the delivery and content received through face-to-face training with comments accepting of the presentation and explanation of information (i.e. the way it was presented), for example:

'Yeah, the training was good. It just let people know what was going on and, yeah, I think it made the whole team just thinking, "Yeah, this is a really good thing to be involved with, we're keen to support this." And it wasn't too complicated, which was good.

'It prepared and helped us because it was explained properly and we know what we had to do and then it's a matter of how you were going to deliver it to the patient, so it's about the individual person, what language they were going to talk to them and how they were going to say it.'

Respondents overall reflected positive changes in staff understanding and levels of confidence regarding the delivery of bowel screening. Understanding was reflected in two ways. First, as refreshing staff members' existing knowledge of bowel screening:

'I learnt a lot of stuff too like basic stuff like – like it was kind of like a refresher as well. So, refresher and then we did the training, how to do it and all that stuff'.

And second, understanding was reflected as an increase in new knowledge about bowel screening process and outcomes:

'I found it very informative. It also gave us a bit of information that we probably didn't have beforehand about the process and the outcomes and things like that'.

In addition, some interviewees described their engagement and how the training was organised, for example:

'We had a one-day in-house training where we had two sessions, one in the morning and one in the afternoon. And we could put as many staff and GPs through as we could on that day.'

'We had certain times throughout one day – like morning, some people went in the morning, others went in the afternoon, and we did the training in one of the doctor's rooms.'

The way that the training was delivered was effective in ensuring that health professionals understood what they needed to do to deliver the Pilot. For example:

'The way you guys put it across made it simple to understand. You made it simple, easy to understand and that was it.'

Comments were also made about the way in which training was delivered, which put bowel screening into a different perspective for them:

'The enthusiasm and, being something that I wasn't even aware of how to do a bowel test, so it was really good to learn how to do that and then be able to pass that on to our patients.'

Respondents reported the site visits as engaging and geared towards a diverse level of clinical expertise: 'You know, [the trainer], very down to earth person you know, spoke and allowed people, you know, questions and responses for answers and ... he just clarified to make sure that, you know, everyone fully understood. If not ... he would deliver it in a different method.'

This diversity of delivery was also reflected in an increased confidence to be able to inform patients about bowel screening: "All the information that we had and having that site visit it sort of promoted confidence in staff to be able to do it." The potential of face to face delivery of training to increase the baseline knowledge and empower a diverse group was reflected in the following comment: "I think we had a broad range of people's level of baseline knowledge about the bowel screening program and they kind of went from potentially quite a low level of knowledge to actually feeling like they were the local experts about this, and I think having that face-to-face if they had been having to just work through a program online or read stuff I don't think that we would have got the same level of engagement.'

A popular element of the face-to-face training was the use of poo emoji suit used to engage attendees and demonstrate bowel screening in a light-hearted way, using humour to break down the stigma attached to talking about bowel screening:

'Yeah, him dressing up as the poo [laughing], yeah ... Yeah. That was a fun part [laughter].

The demonstration of the NBCSP kit was seen as critical in building staff confidence to offer the Alternative Pathway.

'It wasn't as scary as what you would read it is or as big as what you might read it is'.

'I think having the training and showing staff how to demonstrate the kit that was probably the most useful. So just it kind of takes – you know, when you get that kit and it's got lots of different parts to it, people felt confident showing patients how to go about the process.'

However, as with the online module, some interviewees wanted more time on the process of completing the Participant Details form.

'I think, yeah, the barrier probably was the online form, that people couldn't quite get their head around that or just found that time was an issue.'

'I would have liked a bit more hands-on with actually using the form.'

One negative comment about was that the trainer did not understand how the health service operated, highlighting the importance of having senior clinicians engaged in the training sessions and in driving the implementation of the Alternative Pathway in their centre. 'I think, you know, not quite knowing how the AMS works I think was the ... Yeah, it wasn't anything to do with, you know, his knowledge about the program or anything".

Some interviewees felt that receiving such a large amount of information at one time made it difficult to retain and that providing follow up contact would support continued learning and motivation and correct procedural conduct. For example:

'I know from experience that people do get overwhelmed with too much information and, yeah, sometimes just forget important processes particularly with admin...'

'I would just say that if there was any way to improve it, maybe a reminder email or some follow up information'.

In general, interviewees who received face-to-face training showed a preference for face-to-face training:

'Even if you've got it online and you can see it and watch it, whatever, do – but then if you've got questions, it's – yeah, it's better face-to-face definitely.'

However, a number also supported the use of both training modes (face-to-face and online training):

'I think you need to both do them together. I really do, it's just because I think a lot of stuff gets missed in a face to face, wherein an online, you can always go back and review and I'm probably more of a visual person.'

'I reckon hand in hand they're good. I don't mind doing online ones. I quite like it. I've got time to sit and think. I'm not pressured. You do your time. Face-to-face is good too because you can ask direct questions, so I like both methods.'

Two interviewees suggested using the online training as a 'refresher' to the face-to-face training.

'I did the face-to-face training ages ago. Sometimes it's good to have refreshers ... as a nurse we've got to do a refresher all the time ... so it would be good, yeah, I might give the online training a go, if I can find spare time.'

In one instance the face-to-face training was attended by staff, later done as a 'refresher', then presented to other staff (similar to the online training):

'I did the face to face training with them [Menzies] first ages ago and then I did the online training in September, and then I did the training with the two Aboriginal health workers her.'

Key contacts also commented that availability and ease of access to the range of support and resources provided through the Pilot made things easier for them:

'We had lots of support throughout the program when we needed it. It was like we call; you answer. That was good.' 'There were plenty of resources made available and it was really easily accessible.'

'I made a few phones calls to the hotline and that was easy to get to.'

Overall, the face-to-face training proved to be sufficient and fit for purpose in educating users about the Alternative Pathway; however, the time to consider, discuss and revisit topics was inhibited due to the time granted to deliver the training.

Offering face to face training with other modes or providing follow up would prove beneficial in maintaining compliance and motivation in delivering the Alternative Pathway. In addition, adapting the training to focus more on specific aspects would further support staff to better understand the tasks required, and their compliance.

#### How health centres organised themselves around training

From the staff perspectives described above, it is apparent that the ways in which health centres organised the preparation of their staff to deliver the Alternative Pathway contributed significantly to the impact of the training, regardless of the training mode. Health centres enlisted several differing approaches to train and 'make staff aware' of the requirements of the Alternative Pathway.

Ultimately each health centre was responsible for ensuring their staff took part in training, and were encouraged to develop a clearly articulated plan for how the health centre intended to offer the Alternative Pathway.

Approaches used to inform staff of the Pilot and what was required included: holding staff meetings (n = 12 health centres), hosting training sessions (n = 8), for example, in-services, group viewings of the online module, one-on-one or staff supporting staff educations); sending emails and/or reminding staff (n = 6) to complete online training module. Sixteen health centres used multiple approaches to ensure staff adherence to training (for instance, holding staff meetings and sending email reminders).

All these approaches were instigated by a health centre champion for the Pilot, or the site coordinator.

Champions were sometimes seen as 'gatekeepers' in directing and telling staff what to do, responding to questions or troubleshooting problems for the Pilot. For example:

'L and J were the main people who were responsible for it [the Pilot] so if I had any questions, I would just ask either of those two.'

Fourteen health centres mentioned 'a role of a champion' for supporting health centre staff to deliver the Pilot. Some health centres (n = 5) relied on the face-to-face training to ensure awareness of the Pilot.

While managers or site coordinators could encourage training, at some health centres it was up to staff whether they did the training or not. For example:

'There's an online training module that is part of the Pilot. I've sent that out to the health workers to complete. I've done the training, but no other staff have responded to my email to say that they've done the training.'

Note: The approaches to staff training of three health centres were not specified.

# 7. RESULTS: HOW HEALTH CENTRES OFFERED THE ALTERNATIVE PATHWAY

Health centres had considerable flexibility in how they chose to offer the Alternative Pathway. One of the strongest messages from stakeholders during the development of the Alternative Pathway model was that 'one size couldn't fit all', referring to the diversity of Indigenous communities, health services and even jurisdictional systems in which it would be implemented.

Data gathered over the course of the Pilot were analysed in an iterative process to identify a typology of approaches to delivering the Alternative Pathway. A description of the methods is provided in Appendix F.

This section describes how the Alternative Pathway was offered to Indigenous patients and explores whether different approaches may be associated with differing levels of screening activity or compliance with NBCSP requirements.

#### 7.1 Differences between health centres that gave out kits and those that did not

Forty-seven health centres were enrolled to take part in the Alternative Pathway, however, not all distributed NBCSP kits to their patients. The following section describes how the Alternative Pathway was offered by those health centres that did distribute kits (n=36), in comparison with the approach of those that did not distribute any kits.

Three of the forty-seven health centres were excluded from this analysis as they did not complete the Quality and Safety Checklist process, and therefore were not approved to give out kits.

Of the remaining 44 health centres, more than 80% (n = 36) gave out NBCSP kits. Twenty of the 36 were from Group A (low intensity support) and 16 from Group B (high intensity support).



#### Figure 7.1: Breakdown of health centres enrolled in Pilot

#### Health centres that distributed kits

Health centres used a range of methods to identify patients who were eligible to screen through the Alternative Pathway, including an audit of client records; recalls and flagging; identification through the patient's involvement in an existing regular program (such as an annual health check).

Almost half of the health centres that gave out kits conducted an audit using the centre's clinical information system (CIS). Some (n=10) used the audit to determine a list of eligible patients; while others (n=7) used the CIS to 'flag' or register a 'recall' (e.g. eligible patients had a recall placed on their profile with instructions to 'go through the Alternative Pathway') or to perform a 'recall search', where a staff member might, for example, check the CIS for bowel screening recalls or whether the patient had screened recently.

A small number of health centres (n=3) used other means to identify eligible patients. Two health centres identified eligible patients from the daily appointment book and made notes for those patients to be offered screening through the Alternative Pathway. One centre set up a checklist that was used as a prompt when patients first came into the waiting room, to ask and remind staff about the Alternative Pathway.

Most health centres (n=19) used an existing routine health assessment as a point at which an IHW, nurse or GP could identify eligible and suitable patients for screening through the Alternative Pathway. Some health centres had included a bowel screening question within the annual adult health check prior to the Pilot; others did so during the Pilot.

Health centres engaged with eligible patients about bowel screening either opportunistically – when the patient attended the clinic for another purpose (n=31) – or as a targeted invitation (n=6).

Invitation methods included letters, phone calls, house visits and text messages. Recalls (n=7), which could be used for targeted invitation, were mainly used opportunistically. Targeted invites and recalls were only performed by health centres who conducted an audit or used their CIS to flag or recall patients. One health centre took quite a different approach: the primary method of invitation was that an IHW sought out and invited community members they knew were eligible.

Most health centres used more than one approach to engage with their patients about screening through the Alternative Pathway. Every health centre, for instance, had a process for offering the Alternative Pathway within or around a health assessment or via another routine activity (e.g. chronic disease care plans, GP management plans).

Patients might be assessed as suitable and offered an NBCSP kit during their consultation with whichever health professional they were booked to see. Alternatively, the bowel screening conversation might occur before or after the main consult, usually with a nurse or IHW. For example:

'Patients were invited in two different ways, either the nurse or IHW would opportunistically see a patient [before their appointment] and be aware of the criteria and offer bowel screening; or [it might occur] during either a screening process, a 715 [adult health check] or a care plan.'

Only two health centres offered the Alternative Pathway as a specified appointment and/or a standalone education session.

In some instances, health centres (n=3) introduced patients to the Alternative Pathway before their appointment by giving them information on a journey board, a checklist or a letter while they were in the waiting room. For example:

'The health centre at one stage tried giving out letters of eligibility from the front desk – a laminated page that read, you're eligible to have the conversation with the GP.'

'I did initially get all the girls at reception, for the patients in the age group that might be eligible for the bowel screening, to put a little one of the flyers on their board so the patients could sit and read it and that would also prompt the health workers and the GPs to talk about it when they got in there.'

'The health centre implemented a checklist for when patients first came in the waiting room, to start patients thinking about bowel screening and if they were due. The checklist gave patients a bit of information about screening, when they're due, if they're eligible/suitable, and how to access it and was used as a prompt for patients to ask or remind staff of the Alternative Pathway.'

Four of the health centres that gave out kits used special events and promotions to promote bowel screening and engage patients. These activities included a bowel screening promotional day or week, social media advertisement campaigns, and presentations at elders' or men's and women's groups.

#### The online Participant Details Form

A crucial part of the process of offering screening through the Alternative Pathway was completion of the Participant Details Health Centre Initiated Form. This Form was used to notify the National Bowel Cancer Screening Register (the Register) that a patient had been offered (invited) to screen; accepted a kit; been assessed as unsuitable for screening; or declined a kit.

In the usual pathway for the NBCSP, individuals receive a personalised letter of invitation by mail, generated by the Register using the individual's Medicare details. For the Alternative Pathway, invitation letters could not be initiated from the Register; instead, health centre staff were a conduit for providing information to both the patient and the Register.

The notification to the Register was sent through a secure online Form to the Department of Human Services (DHS), set up by the Department of Health specifically for the Pilot.

The Form had two parts:

- Part A notified that a patient had been assessed for screening; the outcome of that assessment; and whether the patient had accepted a kit.
- Part B of the Form was completed by the patient and contained the same questions as the usual pathway Participant Details Form.

The Form also included privacy and consent questions for the transmission and use of the client's information as per the usual pathway. Health centre staff were to complete Part A of the Form for all patients assessed for screening. If a patient accepted a kit, both Part A and Part B of the Form were to be printed and given to the patient so they could complete Part B, and both parts were to be included with the completed samples when returned for testing.

The two parts of the Form – along with the identifying information written on the sample tubes – provided a safety net to ensure that the samples could be linked to the correct individual, and the test results returned to that individual.

The Participant Details Form was intended to be completed online, however; a hard copy was available to health centres with an unreliable internet connection. Some health centre staff preferred to use a hardcopy form and fax it to the DHS and eight health centres requested to use or submitted a Form in this way.

The Form was a temporary workaround designed to bridge the limited flexibility of the NBCSP Register and the need for secure transmission of the personal health information of individuals, and to ensure the integrity of data going to the Register, while allowing health centre staff to provide kits to their patients at the time of the consultation.

However, there were many aspects of the Form that were not conducive to use in a busy health centre. It could not be fully integrated with a health centre's CIS: the online Form could only be completed by leaving the CIS. Patient details needed to be entered manually, along with most of the other information. The Form could be prefilled and retrieved but the time allowed to do this was limited. The printed Form given to the patient was difficult to fit into the Reply Post envelope with the samples.

The requirement for health centre staff to complete Part A of the Form for all clients assessed for screening, even if the patient was not given a kit, served several purposes. It provided a way to count how many people had been invited to screen. It alerted DHS that an individual had been invited to screen and it was an opportunity to correct inaccuracies in the Register. There were no implications for patients if health centre staff failed to submit Part A of the Form for those who were not given a kit. Only 15 health centres submitted Part A for patients who declined to take a kit or were assessed as unsuitable.

Most of the health centres (n=33) that gave out kits completed the Participant Details Form either during or around the conversation about screening. In most cases (n=15), the Form was completed by a nurse or IHW after seeing a GP. Seven health centres reported filling out the Form during a session with a nurse or IHW before seeing a GP. Only five reported that the Form was completed during a GP appointment.

One health centre used a different approach, completing the Form after the patient had left the clinic. Patients were asked to return the samples to the health centre, where the completed Form would be ready for their signature. Health centre staff would then post the samples and Form to Sonic Healthcare.

'To complete the online Participant Details Form – our practice manager [notified] staff which patients we've given kits to and then we have been completing the Form on their behalf and leaving it to be signed when they come back and deliver their samples.'

The Form was much more likely to be completed by nurses (n=23) or IHWs (n=11) than GPs (n=5). At some health centres (n=13), the job of completing the Form was shared amongst clinical staff; for example, by nurse and IHW (n=5), by nurse and GP (n=2), by IHW and GP (n=1) or by any clinical staff member (n=5). None of the health centres involved a person from outside the clinical team (e.g. reception staff) to complete the Form.

Some health centres tried to reduce the barriers to completing the Participant Details Form. Ten reported setting up a direct link to the Form within a recall or health assessment, or simply by encouraging staff to set up a bookmark or add as a favourite in their web browser.

One health centre had a designated staff member who completed the Form:

'If the patient accepts the kit, they'll let me know [senior RN]. I'm [...] the one who fills out all the Forms and gives it to them and explains to them how to use it.'

One of the anticipated advantages of the Alternative Pathway was that as well as receiving the kit from a trusted health professional, patient follow up would be more effective through the local health centre. The NBCSP provides automatic follow up systems that are activated once a person has been given a kit and a result has not been returned, or if a positive screening result is received. These follow up systems remained in place for the Pilot, recognising that not all health centres may have the capacity to follow up every patient who was given a kit.

Sixteen health centres reported making follow up contact (usually phone calls) to check whether the test had been done, although more often this process was reported as ad hoc. For example:

'Nurses and GPs would sometimes follow up patients when they came back into the clinic however, there was no formal process.'

'Occasionally if patients were coming back and the doctor still hadn't gotten their results, the GP would check with them that they still had the kit or if they had any questions about it. I wouldn't – unless they were in here, I wasn't following them up. It was not uncommon that a GP would receive a letter [from the NBCSP] saying: we haven't received the sample; can you chase your patient up. The doctor who had done the initial sign-off I think would usually make a note in the file of that to discuss at a further appointment.'

Some health centre staff reported their efforts to check whether clients had completed the test were hampered by not receiving their patient's results.<sup>34</sup>

'I think a couple of times it had been sent but we hadn't received the results, so it wasn't until we'd go, "Have they done it?" and you'd call the client going, "Have you done it?" and they said, "Yes", then we've had to call and try and chase those results, for whatever reason haven't come through.'

A small number of health centres (n=4) followed up on all their patient test results (whether positive, negative, inconclusive or no result). Most however only followed up on positive results.

Many of the health centres (n=19) provided patients with the option of returning their completed NBCSP kit to the health centre. Some also offered to pick up samples from the patient homes (n=7).

The health centre would post the kit to one of the Sonic Healthcare testing centres. At one health centre, patients would return the samples there for posting anyway, even though this was not a service the health centre offered:

'Usually we just say [to the patient] to post it off ... If they need to come back and bring us back the kit because sometimes, they feel more comfortable to do that, otherwise we don't, but we'll post it off straight away.'

<sup>&</sup>lt;sup>34</sup> Results were mailed to health centres in hard copy by Sonic Healthcare for all results from samples completed through the Alternative Pathway (positive, negative, no result or inconclusive). However, in some circumstances health centre staff reported that results were not received. This could be explained in a number of ways: Health centre contact details were included in Part A of the Participant Details Form and if this was not submitted, results would only be sent to the patient. Patients could ask that their results be sent to a different health care provider. With the results arriving as hard copies, they were not easily visible when added to some health centre clinical information systems, in comparison to results received electronically.

#### Health centres that did not distribute kits

Eight of the 44 health centres that were approved to give out kits through the Pilot were not recorded as having distributed any kits. The reasons for this were varied. Two of the eight were only approved to give out kits two weeks before the end of the Pilot in October 2019, received their allocation of kits in the final week, and were unable to schedule training or give out any kits before the Pilot finished.

The umbrella organisation for these two health centres required a research contract (legal agreement) as well as HREC approval, which was only completed in September 2019. These health centres were therefore excluded from this analysis as they did not have the opportunity to start giving out kits.

Of the remaining six health centres, interviews confirmed that three had struggled with staff turnover or competing priorities and did not manage to commence offering NBCSP kits. These centres were all from Group A (low intensity support).

DHS records indicated that the three remaining centres did not report any patients who were offered screening or had accepted a kit. No samples were returned for testing that were identified as having originated from these health centres. However, a site coordinator for one centre explained in an implementation interview that they had given out around 50 kits but did not submit Part A of the Participant Details Form or provide their patients with a copy of the Form.

Of the other two health centres, one site coordinator reported that staff had tried to give out kits, but patients would not accept them, and the other described a process that was vague about the completion of the online Form but detailed in describing interactions with patients about screening. All three of these health centres were in Group B (high intensity support).

There were few marked differences between the planned approaches of the six health centres that were recorded as having given out no kits and the 36 that did give out kits. A higher proportion of those that did not give out any kits carried out or intended to hold community events to promote bowel screening. None of the six referred to having prompts in place in the CIS to remind staff to complete the Participant Details Form.

There were more noticeable differences in other characteristics of those that did not record giving out any kits. Four of the six health centres (60%) that did not give out kits were 'very large' (more than 3000 patients), compared to 45% of those that did give out kits. The proportion of health centres with fewer than 50% Indigenous patients was much higher among those that did not give out kits: 50% compared to 20% amongst all health centres.

There were also differences in the approaches that these six health centres took to preparing their staff to offer the Alternative Pathway. The three health centres in Group B (high intensity support) relied heavily on Menzies to supply information about how to offer the Alternative Pathway. Only one of the three followed up the face-to-face training with internal training or discussion.

Of the three health centres in Group A (low intensity support):

One centre supported staff to receive training but lost momentum when their staff champion went on leave:

'We got to the stage of training the nurse and myself and one of the receptionists on the system and we did the video and everything but then it all sort of ground to a halt with that person going on leave...'

One did not support or mandate training – leaving it up to their staff to complete. However, it was expressed:

'We were really disappointed we didn't get the (face-to-face training] because we felt that it would have been a much easier. Everything was sort of done for us, so we have to try and deal with some of this stuff and get it going. If we got face-to-face training our line managers say it would have made it a lot more sense yep.'

The third health centre provided no details of training for their staff.

### 7.2 Differences in health centre screening activity (kits given out by time available)

The 36 health centres that gave out kits were ranked according to the number of kits given out over time eligible to give out kits (as described in Appendix F). The approaches used by the 12 health centres that ranked highest were compared to the 12 that gave out fewest kits in the time they had available.

The two groups used similar methods to offer screening. However, in the higher performing group the approaches were applied in a more systematic and systems-oriented way. For example, the top 12 were much more likely (10/12 compared to 3/12) to use targeted approaches to engage with patients about screening, whereas the bottom 12 were much more likely to be exclusively opportunistic.

The top 12 performing health centres also provided more support to patients, by way of storage of samples, transport and postage, to overcome the barriers to bowel screening their patients experienced. Most (9/12) of the top performers allowed patients to deliver completed kits back to the health centre, which would post the kits to Sonic Healthcare.

In comparison, only 5 out of the 12 lowest performing health centres offered a similar service. Three of the low performers did not offer any support to patients with storage, transport or postage.

The top 12 health centres were also more likely to make sure that staff were trained to offer the Alternative Pathway. A majority of these 12 health centres encouraged training, setup staff meetings about the pilot and/or reminded staff to complete the training. For example:

'At each clinic the Pilot was rolled out along the lines of: the clinic managers being involved in discussing what it is [the Pilot] and then at our larger health professional meetings having a presentation about that, and then encouraging all staff to undertake the training module and then the main clinic supplied the test kits and the education materials.'

These health centres were also more likely to have a champion/key person responsible for the Pilot, supporting other clinical staff to undertake and understand the requirements and engage patients.

#### 7.3 Differences in health centre compliance with NBCSP requirements

NBCSP requirements around the Participant Details form were the components of the Alternative Pathway that were least likely to be complied with by health centre staff.

#### Completion of Part A for patients assessed but not given a kit

Of the 36 health centres that gave out NBCSP kits, only 15 followed instructions to complete Part A of the Participant Details Form for <u>all patients</u> assessed for bowel screening, regardless of whether the patient was given a kit.

Of this grouping:

- Nine health centres were Group B (high intensity support) sites, compared to six Group A (low intensity support) sites.
- Eight of the 15 were ranked in the top 12 for number of NBCSP kits given out by time available. Three ranked in the middle third; four amongst the bottom 12.

With such a substantial overlap between the highest performing 12 health centres and the 15 that gave out kits to all clients assessed for screening, it is unsurprising that the group of 15 was similarly systems-oriented in how they implemented and delivered the Alternative Pathway.

For example, the 15 health centres that followed the instructions for reporting all patients assessed were more likely to perform an audit or use flags or recalls to identify eligible patients; to use targeted strategies for invitation; to provide storage and mailing of kits; to ensure staff were trained; and to have an organisational champion for the Pilot; than those (n=21) that were less compliant in reporting patients who were assessed but not given a kit

This most compliant group of the participating health centres also tended to have a more a collective approach to who was involved in delivering the Alternative Pathway. This was particularly true for the completion of the online Form, where nurses, AHWs and GPs were likely to share this responsibility. At other health centres it was more likely that role would be carried out by one or two specific groups.

#### Completion and provision of Participant Details form for patients given a kit

If a health professional gave a patient a kit, they were required to provide the patient with a copy of the Participant Details form. The health professional was to complete Part A of the form and submit it electronically to the DHS, then print both Part A and Part B of the form for the patient to include when they returned the completed samples to Sonic Healthcare for testing.

Most health centres complied with the requirement to complete the Participant Details Form for patients who were given a kit. Some reported that an occasional kit was given out without the Form.

One health centre, for example, gave out a few kits before realising and rectifying the problem; while a site coordinator from another centre rang the Menzies Helpline seeking help after a doctor inadvertently gave out a kit without a Form.

However, three health centres were confirmed to have given out substantial numbers of kits (ranging from 20 to 50) without completing the Form. In one case, DHS received no report of any kits being given out. At the other two centres, correct procedures were followed for some of the period of the Pilot, but staff changes led to a breakdown in the system: the correct procedure was followed for some of the time or by some staff, but nonetheless a substantial number of kits were given out without complying with the NBCSP requirements.

All three health centres were in Group B (high intensity support).

There were some distinctive similarities in how these three health centres implemented and delivered the Alternative Pathway. For example, eligible patients were engaged opportunistically to talk about bowel screening, rather than in a targeted fashion. None of the health centres reported any prompts or reminders in their CIS to go outside of the system to access the Form, although one had their CIS team develop an internal Form to use instead of the Department of Health version.

'...all GPs basically said "No, we are not doing the online Form, bugger you, you know, we want something pre-filled." So, our [CIS] template manager spent quite a bit of time devolving and putting it [the Participant Details Form] into a [CIS] Form so most of it would pre-fill. I had a look to see how many times that Form's been used, which it was only accessed twice.'

These health centres also relied heavily on Menzies to supply information about the Pilot; for example, two of the three had no internal meetings to discuss how to offer the Alternative Pathway.

They all received face-to-face training, but two of the three requested a very brief timeslot for training to occur. These three health centres also all had at least one senior member of staff who was either strongly opposed to or disinterested in offering the Alternative Pathway.

There may have been two other health centres that gave out kits without submitting or providing the Forms. Interviews with staff at these health centres described a clearly defined process that appeared to include giving out kits – and in some cases filling out the Form – but they had few or no kits recorded by DHS. This suggests some breakdown in the process, quite likely that the requirement to submit Part A of the Form was not followed correctly.

However, due to the Covid-19 pandemic closures of Indigenous communities, this remains unverified. If these two health centres were included in the group that gave out substantial numbers of kits without the Form, the group would have another distinctive characteristic: a much higher proportion of health centres where GPs were designated to complete the Participant Details Form than the other 44 health centres that gave out kits (2/5 compared to 5/42).
# 8. RESULTS: SCREENING ACTIVITY AND OUTCOMES

#### 8.1 Key results

- Screening participation through the Alternative Pathway (39.8%) was significantly higher than that of Indigenous people in the usual pathway (23.3%), and at a similar rate to that of non-Indigenous Australians (40.6%).<sup>35</sup> This was true even in remote areas, where some of the barriers to offering the Alternative Pathway were substantially more challenging than in urban and regional areas.
- Comparison of usual pathway participation over two time periods showed no general increase in screening by Indigenous participants, indicating that the higher participation rates recorded through the Alternative Pathway are not part of a general increase in screening by Indigenous people.
- The Alternative Pathway had greater reach into under-screened sections of the population (those who had been invited previously but not screened; those who live in areas of low socio-economic status or remote areas) than through the usual pathway.
  - Of those who screened through the Alternative Pathway, 70% of those who screened had been invited at least once before through the usual pathway but had never screened. The rate of return of kits for this group (previously invited but never screened) was 42% for Alternative Pathway participants, compared to 18% for all Australians through the usual pathway.
  - Participation by those in the lowest socio-economic group (SEG) was 47% for the Alternative Pathway compared to 37% for all Australians for the usual pathway. Amongst those from the lowest socio-economic group (SEG), those who received their kits through the Alternative Pathway screened at a significantly higher rate than those who received kits through the usual pathway.
- Positivity rates were much higher for Indigenous men who screened through the Alternative Pathway (19.6%), compared to 10.6% for Indigenous men who screened through the usual pathway, and eight per cent of all men who screened. Indigenous women had similar positivity rates across both pathways (10.1% for the Alternative Pathway and 9.1% in the usual pathway), but Australian women overall recorded a significantly lower rate of positivity, 5.6%. Positivity is the proportion of iFOBT test results that are positive.
- Those who screened through the Alternative Pathway did so more promptly than usual pathway participants. The median number of days in which Alternative Pathway kits were returned was 13 days, compared to 34 days for the usual pathway.

<sup>&</sup>lt;sup>35</sup> There are limitations in the calculation of Indigenous participation in the usual pathway, and the invitation rate for the Alternative Pathway, and as a result the participation rates for neither groups is precise. See below in this section for discussion of these limitations and how the Alternative Pathway participation rate has been calculated.

#### 8.2 Calculating screening participation

Limitations in comparing the participation rates of those who screened through the usual and Alternative pathways include:

- different definitions of who is 'invited to screen';
- how Indigenous invitees are calculated for the usual pathway;
- limited data available to assess how many were invited to screen through the Alternative Pathway

#### Definitions of who is 'invited to screen'

For the NBCSP, participation is defined as the number of those who screened as a proportion of those invited to screen. But what does it mean to be 'invited to screen'?

Under the usual pathway, for the Australian population as a whole, 'invited to screen' is defined as those who were sent NBCSP kits, minus those who chose to opt off or suspended their involvement in the NBCSP.

Kits are sent to the most recent address recorded with Medicare for each invitee. If an invitee's Medicare address is not up to date, they are unlikely to receive the kit. The number of people counted as '*invited to screen*' through the usual pathway is likely to be much larger than the number who *receive* the invitation to screen. (Kits not getting to their intended recipient is an issue more likely to affect Indigenous invitees than, for example, middle class white Australians. Indigenous households are likely to be more mobile, less likely to receive mail deliveries to their residence, and less likely to be registered with Medicare.

Under the Alternative Pathway, those who are invited to screen are a different section of the population to those invited to screen through the usual pathway. Alternative Pathway invitees were, by necessity, patients attached to a primary health care service. This is a subset of the group that is eligible, as shown in Figure 8.1, and may include those who did not receive a kit in the mail as well as those who did.



Not to scale

#### Figure 8.1: Different parameters of 'invitees' for the usual and Alternative pathways for the NBCSP.

Source: Menzies School of Health Research

#### Calculating the number of Indigenous people invited to screen through the usual pathway

The method used to calculate the number of Indigenous people invited to screen through the usual pathway is complicated and imprecise. Prior to the transition of the NBCSP Register (the NBCSR) into the National Cancer Screening Register (NCSR) <sup>36</sup>, Indigenous status was only recorded in the Register if self-reported on the Participant Details Form – when samples were returned.

NBCSR data reflects a lower percentage of Indigenous invitees, and a higher percentage of invitees whose Indigenous status is 'not stated', than in the four-yearly Australian Census. The AIHW has therefore

<sup>&</sup>lt;sup>36</sup> The NCSR included plans to broaden the ways in which Indigenous invitees could be identified but we have been unable to ascertain whether these plans have been implemented or the extent to which their implementation might be feasible.

estimated used the population proportions reported through the Census to estimate that a similar proportion of invitees through the NBCSP will be Indigenous.<sup>37</sup>

As a result, the screening participation rate for Indigenous Australians fluctuates with each Census as the number and proportion of Indigenous Australians within the Australian population varies – without necessarily reflecting a change in screening rate.

#### Data available for those invited to screen through the Alternative Pathway

In the Pilot, health centres were asked to report every patient assessed for bowel screening regardless of whether the patient accepted a kit or not. This group is identified in Figure 8.1 as 'Health centre patients assessed for screening'. Patients with a close family history of bowel cancer or existing symptoms of bowel disease could be considered unsuitable for screening and might be recommended a different program of monitoring. If suitable for screening, they would be offered a kit. In either case, health centre staff were asked to submit a brief online form to the DHS to record that a patient had been invited to screen.

Unfortunately, of the 44 health centres approved to give out kits, only 15 sites reported patients who were assessed *but not given a kit*. Post Pilot interviews with health centre staff and managers from other sites confirmed that most reported only those patients *who accepted a kit*. (See Section 7 re non-compliance with NBCSP requirements.)

Consequently, and following discussion with the AIHW, the number of kits given out (reported through the online form) was considered as the denominator for calculating participation in the Pilot.

#### Comparing participation for usual and Alternative pathways: Kits given out as denominator

When screening participation was calculated using *kits given out* as the denominator, 45.1% of those given a kit through the Alternative Pathway returned the test. This compared to 23.3% of Indigenous Australians estimated to have been sent a kit through the usual pathway (the mail out model).

<sup>&</sup>lt;sup>37</sup> This method of estimation does not account for the numerous barriers to Indigenous people receiving the invitation to screen, or the limitations identified in Census counts of Indigenous populations, particularly in southern Australia. See for example: Australian Bureau of Statistics, 2018, Estimates of Aboriginal and Torres Strait Islander Australians June 2016, cat. no. 3238.0.55.001, accessed online <a href="http://www.abs.gov.au">www.abs.gov.au</a> 28 August 2020; Taylor, J, Data for better Indigenous policy evaluation: achievements, constraints and opportunities, in Productivity Commission, 2013, *Better Indigenous Policies: The Role of Evaluation*, Roundtable Proceedings, Productivity Commission, Canberra, pp.119-130.)

### Table 8.1. Participation of Indigenous Australians in the NBCSP, usual pathway compared to Alternative Pathway, 1Nov 2019 to 31 Oct 2019.

Group	Kits given out (N)	Kits returned (N)	Participation rate (%)
Usual pathway <sup>a</sup>			
Male	22317	5262	23.6
Female	24448	5656	23.1
Total persons	46765	10918	23.3
Alternative Pathway <sup>b</sup>			
Male	352	155	44.0
Female	513	235	45.8
Total persons	865	390	45.1

#### Notes

a. Participation is reported for usual pathway invitees for the period 1 November 2018 to 31 October 2019 (kits returned to 31 October 2019). Usual pathway invitees (all Australians who are eligible and have not suspended or opted off) are sent a kit with an invitation to screen. Participation rates for Non-Indigenous, Not Stated and Total categories were calculated using NBCSP register data. Indigenous invitees were estimated by applying 2016 Indigenous status Census proportions to total invitations. Participants who screened through the Alternative Pathway were not included in the count for the usual pathway.

b. Alternative Pathway invitees given a kit were Indigenous people in the eligible age range (50-74), who attended a participating Pilot health centre, were assessed and found suitable to screen and accepted a kit, during the period 1 November 2018 to 31 October 2019 (kits returned to 31 October 2019).

Source: Number of kits given out and kits returned were provided by the AIIHW, after cleaning and cross-checking NBCSR data with that provided to the DHS by Pilot health centres during the Pilot.

Table 8.1 reports the rate of return of kits given out through each pathway, and it is an accurate reflection of this measure. However, as *Figure 8.1* illustrates, this comparison is a less accurate reflection of participation by Indigenous people (kits returned as a proportion of those *invited* to screen) in either the usual or Alternative pathways.

#### Contextualising participation using other analyses

Other analyses (each with their own limitations) were conducted to gain a more multi-dimensional picture of screening participation. These analyses were:

- Change over time in the usual pathway, in geographic areas around Pilot health centres, for a twoyear period before the Pilot and for the duration of the Pilot.
- Comparison of participation rates from the 15 health centres that reported patients assessed for screening but not given a kit. Participation was calculated using two different denominators: *patients assessed,* and *kits given out*.

## Change over time in participation through the usual pathway, in geographic areas around Pilot health centres

NBCSP data are not reported by health centre. Individuals who return samples for testing may include details of their health care provider (often an individual GP rather than a health centre) on their Participant Details Form, but many do not. Primary health care centres are also unlikely to hold records of their patients' involvement in the NBCSP, other than receiving copies of test results.

In order to calculate a background screening rate prior to the Pilot, postcodes were assigned to each Pilot health centre to approximate their catchment areas. Postcodes were matched to Pilot sites based on information provided by health centres and consideration of the demographics of some locations. The AIHW used NBCSR data to estimate screening participation for a two-year period prior to the Pilot (kits given out during the calendar years 2016-2017, with kits returned up to 30 June 2018).<sup>38</sup> Participation estimates for Indigenous people were obtained by applying 2016 Indigenous status Census proportions to the number of total invitations within the designated area around each centre. For 13 of the Pilot centres (11 in the 36 that gave out kits)<sup>39</sup>, the AIHW found that the NBCSR showed more Indigenous people invited than the number estimated using the Census proportions. For those areas, Register data were used instead of the Census proportions.

The AIHW carried out a similar analysis for the same postcode sets for the time period of the Pilot, 31 October 2018 to 1 November 2019. People who screened through the Alternative Pathway were removed and counted separately, and participants through the usual pathway were reported by Indigenous Status (Indigenous, Non-Indigenous and Not Stated) for the postcodes assigned to each Pilot site.

Comparison of the participation rates for Indigenous, non-Indigenous and not stated groups for the areas around Pilot sites shows no pattern of increase among Indigenous participants over the two time periods, although there is a significant increase for non-Indigenous participants. This indicates that the higher level of participation for Pilot participants is a genuine increase and does not reflect a broader trend among Indigenous people.

<sup>&</sup>lt;sup>38</sup> This is the same period the AIHW uses for routine reporting of NBCSP participation: two calendar years, plus kits returned up to six months later to allow for those sent out late in the second calendar year. This extra six months of kit returns was able to be reported for the background screening rates, but the full six months was not available at the time the AIHW reported participation for the Pilot period.

<sup>&</sup>lt;sup>39</sup> For the Pilot period, 12 of the areas around Pilot sites that had given out kits had more people invited than the ABS estimate.

### Table 8.2. Changes over time in NBCSP participation (usual pathway), by geographic area and Indigenous status.

		2016-2017ª			Pilot period <sup>n</sup>		
Indigenous status	Number invited (N)	Kits returned (N)	Participation rate (%)	Number invited (N)	Kits returned (N)	Participation rate (%)	
Geographic areas	around Pilot sit	tes <sup>c</sup>					
Usual pathway Indigenous <sup>d</sup>	7,561	2256	29.8	6,358	2006	31.6	
Usual pathway non-Indigenous	550,043	231,319	42.1	436,968	173,389	39.7	
Usual pathway not stated	36,814	6,004	16.3	28,844	4,751	16.5	
Usual pathway total	594,215	239,579	40.3	472,169	180,146	38.2	
All Australia							
Indigenous	63,539	13,224	20.8	46792	10918	23.3	
Non-Indigenous	3,782,367	1,636,433	43.3	2761617	1122379	40.6	
Not stated	254,440	43,149	17.0	185910	31019	16.7	
All Australia total	4,100,347	1,692,806	41.3	2994319	1164316	38.9	

Notes

a. Participation is reported for 2016–2017 invitees through the usual pathway, with kits returned until 30 June 2018. Participation rates for non-Indigenous, Indigenous status not stated and total were calculated using NBCSP Register data.

b. Participation for the Pilot period includes those invited through the usual pathway between 1 November 2018 to 31 October 2019, including kits returned until 31 October 2019. Those given kits through the Alternative Pathway were not included.

c. Geographic areas around Pilot sites were identified by postcodes approximating health centre catchment areas, or, in the case of metropolitan areas, to an area large enough to avoid postcode-specific outliers. Areas around Pilot health centres were not exclusive; some postcodes were linked with more than one Pilot health centre. (There is no direct link in NBCSP data between health centres and invitees.)

d. Indigenous invitees in areas around Pilot sites were estimated by applying 2016 Indigenous status Census proportions to total invitations, for postcodes defined for each health centre area, except where a higher number of invitations than the Census estimate were recorded in the Register for that postcode. In these cases, the higher number of invitations was counted.

Biennial screening for those aged 50–74 was not fully rolled out during 2016-2017; the specific ages invited within the 50–74 age range included 50, 54, 55, 58, 60, 64, 65, 68, 70, 72 and 74.

Source: 2016-2017 data from AIHW analysis of the NBCSP Register as at 30 June 2018; Pilot period data from AIHW analysis of the NBCSP Register as at 31 October 2019; AIHW data collated and participation rates compared by Menzies.

#### Calculating Alternative Pathway participation using different denominators

Table 8.3 presents a comparison of three different denominators that can be used to calculate screening participation using the available data, to try to gain a broader perspective on the suitability of using 'kits given out' as a denominator for participation through the Alternative Pathway.

*Example 1: Persons assessed for screening*. Participation was calculated for the 15 Pilot sites that reported patients who were assessed for screening but not given kits, in addition to those who were given kits, and compared with usual pathway participation by Indigenous people in the geographic areas around those 15 sites.

Of the 670 individuals assessed by these 15 health centres, 558 were given kits and 112 were assessed as unsuitable for screening or declined to take a kit. Participation using these figures was 37.2%, compared with the usual pathway rate for participation for Indigenous people for the same area and time: 31.6%.

#### *Example 2. Kits given out, cleaned and corrected data*, as reported in Table 8.1 above.

*Example 3. Kits given out plus persons assessed but not given a kit.* When the AIHW cleaned and corrected the data from Pilot sites from the Register data, the number of kits given out by these 15 Pilot sites dropped by 20 to 538, and the number of kits returned increased by 10 to 259. The AIHW only looked at the data recorded in the Register, so these adjustments did not affect the numbers of patients who were assessed but not given a kit. If the number of people assessed but not given a kit is added to the corrected figures of who were given a kit, the participation rate for this sample is 39.8%.

Examples 1 and 3 uses a denominator to calculate Pilot participation that is the closest available to the concept of 'those invited' in routine reporting of the usual pathway for all Australians. It may therefore be a more reliable measure of participation than using the denominator of kits given out. A limitation of using this denominator is that these 15 sites were predominantly health centres that achieved high levels of participation, suggesting the participation rate of 39.8% may still be an overestimate. Unfortunately, this denominator of 'persons assessed' for screening (whether given a kit or not) cannot be applied when comparing other variables or for totals including other Pilot sites. Therefore 'kits given out' is used as the denominator for the reporting of all other screening participation results in this report.

## Table 8.3. Participation in NBCSP through Alternative Pathway (various denominators applied) and usualpathway, for geographic areas around 15 Pilot sites, 1 Nov 2019 to 31 Oct 2019.

Group	Denominator applied	Number invited (N)	Kits returned (N)	Participation rate (%)
Alternative Pathway (AP)				
AP data from DHS (includes those reported a assessed as well as those given kits, uncorrected) <sup>a</sup>	s Persons assessed (inc given kits)	670	249	37.2
AP data ex AIHW (cleaned and corrected, doe not include those assessed but not given kits	es Kits given out	538	259	48.1
AP data ex AIHW (+ those reported as assessed but not given a kit, ex DHS) <sup>c</sup>	Persons assessed (inc given kits)	650	259	39.8
Usual pathway (UP) <sup>d</sup>				
UP Indigenous	Persons invited	3717	1173	31.6
UP Non-Indigenous	Persons invited	269190	105043	39.0
UP Not stated	Persons invited	16032	2894	18.1
UP All persons	Persons invited	288941	109110	37.8

Notes

a. Denominator for participation is calculated using numbers reported to DHS during the Pilot by 15 Pilot sites, for those who were given kits *and* those assessed for screening but found unsuitable or who declined to take a kit, between 1 November 2018 and 31 October 2019. Only these 15 Pilot sites reported patients who were assessed for screening but not given a kit.

b. Participation reported from analysis by AIHW, using same data as a., cleaned and corrected, and data in NBCSP register as at 31 October.

c. The denominator for participation includes the cleaned and corrected AIHW data reported in note b., plus the number of people assessed but not given a kit (N = 112) described in note a.

d. Usual pathway participation reported here for comparison only. Participation is from analysis of NBCSP register data for non-Indigenous, not stated and all persons for those invited through the usual pathway between 1 November 2018 to 31 October 2019, with follow up until 31 October 2019. Indigenous participation is from analysis by AIHW using estimates based on Indigenous status Census proportions.

Source: Analysis by Menzies of raw Pilot data reported by health centres to DHS, uncorrected; AIHW analysis of Pilot data reported to DHS and recorded in NBCSP register, cleaned and corrected; usual pathway participation reported by AIHW from analysis of NBCSP register data for non-Indigenous, not stated and all persons; usual pathway Indigenous participation from analysis by AIHW using estimates based on Indigenous status Census proportions.

#### **8.3 Other screening results**

#### Time between invitation and return of completed screening test, usual and Alternative pathways

An unexpected outcome of the Pilot was that those who screened through the Alternative Pathway did so much more promptly than usual pathway participants, as shown in Table 8.4. The median number of days taken to return Alternative Pathway kits was 13 days, compared to 34 days for the usual pathway.

Factors that contributed to this difference could include the time taken for kits to get to and from usual pathway invitees through the mail, that the health centre staff involved in the Alternative Pathway gave clear directions about getting samples back for testing in a timely way, or, as reported in Section 9, that invitees wanted to complete the test before they went back to see the health worker, nurse or GP who gave them the kit. This marked difference in times to return tests could also be an indicator of what so many primary health care staff said when interviewed: for many patients, receiving an NBCSP kit (with its colourful Pilot sticker on the front) from a trusted health professional created a completely different experience to receiving the kit through the mail.

Indigenous status	Sex	Median days	90th percentile	Returned completed screening test (N)
Usual pathway	Males	37	103	5,262
Indigenous	Females	37	104	5,656
	Persons	37	103	10,918
Usual pathway non-	Males	34	100	528,023
Indigenous	Females	34	97	594,356
	Persons	34	100	1,122,379
Usual pathway not	Males	52	137	16,423
stated	Females	50	136	14,596
	Persons	51	137	31,019
Usual pathway total	Males	36	101	549,708
	Females	34	100	614,608
	Persons	34	101	1,164,316
Alternative Pathway	Males	12	54	155
	Females	14	76	235
	Persons	13	71	390

## Table 8.4. Time between invitation and return of completed screening test, usual and Alternativepathways, 1 November 2018 to 31 October 2019.

Source: AIHW analysis of NBCSP register data as at 31 October 2019 and National Indigenous Bowel Screening Pilot data recorded by DHS.

#### Previous screening status, usual and Alternative Pathway

Previous screening status is routinely reported for the NBCSP, indicating whether a participant who screened within a designated time period was a first-time screener, had screened before, or had been previously invited before and not screened.

The AIHW reported prior screening for the Pilot period for usual pathway (all Australians) and Alternative Pathway participants, for the period 1 November 2018 to 31 October 2019. As shown in Table 8.4, the Alternative Pathway was highly effective in reaching and getting people to screen who had not screened previously. Almost 90% (n = 774) of those given kits through the Alternative Pathway had never screened before. Seventy percent (n = 273) of those who screened through the Alternative Pathway had previously been invited to screen through the usual pathway but had not done so. The rate of return of kits for this group (previously invited but never screened) was 42% for Alternative Pathway participants, compared to 18% for the usual pathway.

	Usual pathway				Alterna	tive Pathway	
Round	Prev screen	Kits given out	Kits returned	Participation (%)	Kits given out	Kits returned	Participation (%)
First	No	337,491	95,788	28.4	143	45	31.5
	All	337,491	95,788	28.4	143	45	31.5
Sub-	No	1,606,946	297,256	18.5	631	273	43.3
sequent	Yes	1,049,882	771,272	73.5	91	72	79.1
	All	2,656,828	1,068,528	40.2	722	345	47.8
All	No	1,944,437	393,044	20.2	774	318	41.1
rounds	Yes	1,049,882	771,272	73.5	91	72	79.1
	All	2,994,319	1,164,316	38.9	865	390	45.1

#### Table 8.5. Previous screening status, by pathway, 1 November 2018 to 31 October 2019.

Source: AIHW analysis of NBCSP register data as at 31 October 2019 and National Indigenous Bowel Screening Pilot data recorded by DHS.

#### Participation by socioeconomic group

A greater proportion (65%) of those who screened through the Alternative Pathway came from areas classified as low socioeconomic status, compared to 40% of those who screened through the usual pathway. Those from the lowest socioeconomic group (SEG) who received their kits through the Alternative Pathway screened at a significantly higher rate than those who received kits through the usual pathway (46.6% compared to 36.6%), as shown in Table 8.6.

	Usual pathway			Alte			
SEG quintile	Kits returned	Kits given out	Participation (%)	Kits returned	Kits given out	Participation (%)	p value
1 (lowest)	220,792	602,536	36.6	162	348	46.6	<0.001
2	238,721	614,040	38.9	90	203	44.3	0.11
3	219,960	569,889	38.6	75	164	45.7	0.062
4	230,649	575,157	40.1	45	105	42.9	0.54
5 (highest)	240,036	593,288	40.5	14	31	45.2	0.59
Unknown	14,158	39,409	35.9	4	14	28.6	0.57
Total	1,164,316	2,994,319	38.9	390	865	45.1	<0.001

Table 8.6. Participation by socioeconomic status group (SEG) quintile, usual and Alternative pathways, 1 November2018 to 31 October 2019.

Notes

1. Socioeconomic status group (SEG) quintiles determined by allocating invitee postcodes to national Index of relative socioeconomic disadvantage scores for 2016.

2. Kits given out and returned are reported for the period of the National Indigenous Bowel Screening Pilot, 1 November 2018 to 31 October 2019.

Source: AIHW analysis of NBCSP register data as at 31 October 2019 and National Indigenous Bowel Screening Pilot data recorded by DHS.

#### Participation rates by remoteness

The Australian Standard Geographical Classification System (ASGCS) was used to classify Pilot health centres by Remoteness Area (RA). The original five ASGCS classifications (Major City, Inner and Outer Regional, Remote and Very Remote) were simplified into three categories for the Pilot: Urban (Major cities), Regional (Inner and Outer Remote), Remote (Remote and Very Remote). Table 8.7 shows that even in remote areas, the rate of kits returned as a proportion of those given out was much higher than the participation estimate for Indigenous Australians through the usual pathway for the same period (23.3%). Rates for all participants through the usual pathway for the same period are Urban = 38.3%; Regional = 40.7%; Remote = 32.5%; with nearly 40,000 invitees for whom a remoteness categorisation could not be assigned.

### Table 8.7. Rate of return of kits given out, Alternative Pathway, by remoteness(simplified ASGCS categorisation)

Remoteness	No. of health centres	Kits given out	Kits returned	Participation rate (%)
category				
Urban	12	438	206	47
Regional	27	286	131	45
Remote	8	141	53	38
Overall	47	865	390	45

Notes

Percentages have been rounded to the nearest whole number. ASGCS-RA have been simplified.

Source: Number of kits given out and kits returned were provided by the AIHW, after cleaning and cross-checking data reported by Pilot health centres to the DHS with NBCSP register data.

#### Participation rates, by state and territory

Figure 8.2 shows the variation across states and territories in the rate of return of kits given out through the Alternative Pathway and usual pathway (Indigenous participants and all participants).



### Figure 8.2 Rate of return of kits given out, by jurisdiction, pathway, and Indigenous status, 1 November 2018 to 31 October 2019.

Notes

Kits given out and returned are reported for the period of the National Indigenous Bowel Screening Pilot, 1 November 2018 to 31 October 2019.

Source: AIHW analysis of NBCSP register data as at 31 October 2019 and National Indigenous Bowel Screening Pilot data recorded by DHS.

# Comparison of participation rates, low intensity support (Group A) vs high intensity support (Group B)

To measure whether low intensity support (Group A), versus high intensity support (Group B), results in higher participation in the NBCSP.

Data on kits given out and kits returned by each participating Pilot health centre was cleaned and checked by the AIHW. Menzies used the statistical software STATA to carry out a comparison of kits returned as a proportion of those given out by health centres in each of the two randomised groups (Group A and Group B). Health centres were weighted for sample size (kits given out).

No statistical difference was found between the screening participation rates of Group A (41.3%, [95% CI 37.1, 45.6] and Group B (44.2% [95% CI 39.7, 48.8], p = 0.78)

#### What does this mean?

When comparing screening participation rates, no significant difference was recorded between those health centres that received low intensity support (Group A) or high intensity support (Group B).

For a more detailed examination of the impact of the two modes of support, see Section 7, where it is apparent that the high and low intensity modes of support each provided different benefits, and each worked better for some individual staff members than others.

#### 8.3 Invitation rate, Alternative Pathway

Invitation rate is the number of people invited to screen as a percentage of the number of people that were eligible to screen. For the Pilot, this is the number of patients invited to screen, as a percentage of the health centre's eligible Indigenous patients aged 50 to 74.

There were, however, limitations in measuring the invitation rate for the Pilot: Health centres were asked to submit Part A of the Participant Details form for <u>all</u> patients assessed for screening regardless of whether they accepted a screening kit or not.

Of the 44 health centres approved to give out kits, only 15 followed this guideline and completed Part A for patients that both accepted a kit and those that declined. The invitation rate was, therefore, calculated using only the 15 health centres that followed the guidelines. The invitation rate was 13% (total number invited = 670; total eligible Indigenous patients = 5097).

Individually these health centres reported invitation rates ranging from 2% to 43%, with a mean screening invitation rate of 15%. This does not, however, take into consideration the length of time health centres had in which to distribute kits.

While invitation rate is not routinely reported for the NBCSP, participation rates are, and this is done for periods of two years. For these 15 health centres, the time available to give out kits ranged from 40 days to 336 days, with an average of 235 days. The total number of people invited to screen by this group was 670, an average of 2.85 people per day. If the same rate of invitation was applied over a two-year period (730 days), the number invited would be 2080, or 41% of the eligible (aged 50 to 74 years) Indigenous patients of this group of health centres.

#### 8.4 Screening outcomes

#### Positivity

Indigenous men who screened through the Alternative Pathway recorded a much higher rate of positive tests than Indigenous or non-Indigenous men who screened through the usual pathway. Table 8.8 shows that the positivity rate for men who screened through the Alternative Pathway was roughly double that of the positivity rate for the Australian population overall. Of the Indigenous men who screened through the Alternative Pathway, 19.6% received a positive iFOBT result, compared to 10.6% for Indigenous men who screened through the usual pathway, and eight per cent of all men who screened. Indigenous women had similar positivity rates across both pathways (10.1% for the Alternative Pathway and 9.1% in the usual pathway), whereas for Australian women overall, the positivity rate was 5.6%.

Usual pathway – Indigenous only			Alternative Pathway			
Sex	Positive result (N)	Valid screening test (N)	Screening positivity (%)	Positive result (N)	Valid screening test (N)	Screening positivity (%)
Males	546	5,159	10.6	29	148	19.6
Females	505	5,535	9.1	24	227	10.6
Persons	1,051	10,694	9.8	53	375	14.1
	Usual pathway – all participants Alternative Pathway				1	
Sex	Positive result (N)	Valid screening test (N)	Screening positivity (%)	Positive result (N)	Valid screening test (N)	Screening positivity (%)
Males	43,454	544,396	8.0	29	148	19.6
Females	34,267	609,840	5.6	24	227	10.6
Porconc	77 704	4 4 5 4 9 9 6		50	275	

#### Table 8.8. Positivity rates, usual and Alternative Pathways, by Indigenous status and sex.

The high positivity rate for Indigenous men may be a result of the small numbers involved, where a few positive cases can make a big difference in the rate, and/or the pattern of slightly higher rates of positivity among first-time screeners, low socioeconomic groups and Indigenous Australians. The AIHW reports that people from low socioeconomic groups and Indigenous Australians tend to record higher proportions of positive results.<sup>40</sup> Cohorts of first-time screeners also tend to register slightly higher positivity levels than those who have previously screened. However, these results warrant further investigation and reinforce the importance of increasing the participation of Indigenous people in the NBCSP.

<sup>&</sup>lt;sup>40</sup> Australian Institute of Health and Welfare 2020, *National Bowel Cancer Screening Program: monitoring report 2020*, AIHW, Canberra.

Alternative Pathway screening participants from WA recorded the highest reported positivity rate, with 20% (all persons), followed by the NT with 15.4%. At jurisdiction level, the number of positive results for the Alternative Pathway are very small, which may affect the reliability of these rates. Figure 8.4 shows that positivity rates for the usual and Alternative pathways were higher in Remote and Very Remote areas. WA and the NT had a higher proportion of Pilot sites located in Remote or Very Remote areas than other states.



Figure 8.3. Positivity rates by remoteness, pathway and Indigenous status.

#### Notes

Only valid screening tests (those which returned a positive or negative result) are used in the calculation of positivity rates. Postcodes of invitees were mapped to 2016 Australian Statistical Geography Standard Remoteness Areas. Residential postcodes were used where available but non-residential identifiers (such as post office boxes, or, for the Alternative Pathway, health centre postcode) were used otherwise.

Usual pathway participation was calculated for invitees during the period 1 November 2018 to 13 May 2019, with kits returned until 31 October 2019. The six-month timeframe for return of kits is as used for routine reporting of the usual pathway, but at the time of reporting kit returns were only available up to 13 November 2019 (six months from 13 May.).

Alternative Pathway figures are for those who were given and returned kits between 1 November 2018 to 31 October 2019. Data on the six-month allowance for kit returns beyond the end of the Pilot was not available at the time of reporting.

Pilot participants were removed from the usual pathway data. Indigenous status was derived from the Participant Details form.

Remoteness status was unable to be reported for a small number of participants in both pathways and these participants have been removed from this analysis

Source: Alternative Pathway data from AIHW analysis of National Indigenous Bowel Screening pilot and NBCSP register data from DHS; usual pathway data from AIHW analysis of the NBCSP Register as at 31 October 2019 (kit returns were available up to 13 November 2019).

#### Other screening outcome data

No data is available on diagnostic testing rates (GP assessment of positive results; colonoscopy) or outcomes; numbers may be too small to report.

# 9. RESULTS: PERSPECTIVES OF INDIGENOUS PATIENTS

#### Perspectives of Indigenous patients who screened through the Alternative Pathway

This component of the report summarises the perspectives of a small number of Indigenous adults who completed bowel screening through the Alternative Pathway at a participating health centre.

It was originally planned to gather information by conducting Yarning Circles or individual interviews with patients who were offered screening through the Alternative Pathway. The '*Yarning*' methodology is a recognised culturally appropriate style of communication and is used to gain information from participants through story telling. This method of gathering information respects the oral traditions of Indigenous Australians and privileges Indigenous Australian knowledge.<sup>41</sup>

A discussion guide was developed for use in the Yarning Circles and individual interviews. The specific content of these discussions focussed on the following topics: their invitation to screen; their awareness of and interest in screening; the acceptability of screening through the Alternative Pathway; and any barriers or enablers to participating in bowel screening.

Separate Yarning Circles were planned for participants who had completed bowel screening and those who had not, to avoid any sense of shame among those who had not screened. Individual interviews could be conducted if participants did not want to discuss bowel screening in a group session.

Participants (health centre patients) were to be identified and recruited through the health centre at which they were invited to screen. If they agreed to participate in the Yarning Circle their details were to be passed onto the Menzies project team. Expected recruitment was for a total of 28 patients from three – four health centres from across the three geographical classifications (remote, regional and urban).

The Menzies project team planned to conduct Yarning Circles from early November 2019, in conjunction with visits to each site to conduct post-pilot data collection, feedback and, if requested, training, with health centre staff. Initial discussions with health centre staff indicated that it would be possible to engage the assistance of at least one health centre from each of the geographical regions (remote, regional, urban) to identify and contact potential Yarning Circle participants.

Ethics approval was obtained from the Northern Territory Health Department and Menzies School of Health Research Human Research Ethics Committee and by the respective jurisdictional and organisation ethics committees where research would occur.

<sup>&</sup>lt;sup>41</sup> Bessarab D, Ng'andu B. Yarning about yarning as a legitimate method in Indigenous research. International Journal of Critical Indigenous Studies 2010; 3 (1),37-50.

Unfortunately, several barriers disrupted the planned approach to data collection. These barriers included: health centres being unable to recruit potential participants due to the challenges in identifying eligible clients, senior staff required to sign off on recruitment being on leave and the logistics of coordinating patients to attend Yarning Circles.

Some health centres were unable to assist with recruitment because of the bushfires of 2019-2020 that particularly affected NSW, Victoria and SA. In March 2020 the COVID-19 pandemic halted all research activity involving site visits to Indigenous communities, and health centres were unable to continue to recruit participants because of increased workload due to the pandemic

As a result, only individual interviews were conducted, and participant numbers were significantly reduced. Interviews were conducted with five participants: four in person and one over the phone.

These participants were recruited from two health centres: one regional Aboriginal Community Controlled Health Organisation, and one urban private practice. The participants were between 52 to 68 years of age; two were females and three were males. All had completed the bowel screening test through their local primary health care centre.

No patients were able to be recruited from remote areas, or from those who had been offered screening but not completed the test.

The qualitative interview data were thematically analysed, and a summary of findings is outlined below. Five themes were identified these were:

- 1. awareness and understanding
- 2. a safe and culturally appropriate health care environment
- 3. personal health concerns
- 4. health promotion
- 5. advocacy

#### 1. Awareness and understanding

Most participants had some awareness of bowel screening prior to participating in the Alternative Pathway and identified several sources by which they accessed this information (e.g. receiving the kit in the mail, from family or friends affected by bowel cancer, advertisements on TV).

One participant commented:

'I haven't heard about it, but at one stage, we got [it] through the mail. But that one I just pushed it aside, I wasn't keen to do it. I just put it aside and [I had] forgotten about it.'

Participants indicated their knowledge and understanding about bowel screening improved as a result of primary health centre staff explaining the test and demonstrating what to do with the kit. Health centre staff also explained the importance of the bowel screening test and as a result participants said they understood the relevance of bowel screening more personally.

Participants indicated one of the main differences between receiving the kit in the mail and being offered it at the health centre was increased understanding about what the kit was for and why it was important.

'I been receiving them and [the health centre staff asked me] if I did understand why I was getting them and I said, 'No not really'. I think sometimes when they come out of the blue and it's the government envelope, kind of another imposition too [and more Government data collection or] survey study ... when it just comes out of the blue.'

'He [Aboriginal Health Worker] explained it all to me ... rather than just having the package arrive ...'

Having the kit distributed, demonstrated and explained at the local health centre removed many of the barriers to screening. However, for some participants there were other challenges in completing the test.

'I remember thinking that, "Gee, thank goodness I've got this new fridge," ...I had an old second-hand one which had been on its last legs... I didn't worry about the previous three years of bowel screening because I didn't have a [good] fridge. I just thought [of the dislike] of storing goona [faecal sample] in your fridge too.'

#### 2. A safe and culturally appropriate health care environment

Most participants saw their health centres as trusted, credible and culturally safe places, and this improved their receptiveness to and completion of screening. The persistence of staff in asking participants whether they had done the test yet also encouraged completion.

The local health centre's supportive approach to primary health care, and the trust relationship between staff and their Indigenous patients, provided important encouragement and support that was missing when the kit was received in the mail.

'Yeah well I like it better through our health workers to be honest because they do talk you through the process, they just check up on you, it's more personal, it's more culturally, it's our culture, it's more culturally our way.'

'... I think it would be easier for them to initiate it from here. Because I do all my health things here, it's like a great big family here, so [I] come in and feel comfortable with them to do things like that.'

The importance of cultural safety and cultural appropriateness was highlighted by one female participant who described how an Indigenous male health professional respectfully talked with her about doing the bowel screening test.

*'*[The Aboriginal Health Worker] contacted me and we had that little yarn and then in the way ... he's very respectful and diligent and thorough and a good bit of sense of humour you know. He wasn't – he didn't cross the line sort of thing, he was respectful.'

Being encouraged to do the test, and the matter-of-fact way in which some health centre staff presented the kit also prompted participants into action.

'Yeah, when I went to my regular check-up, they asked me at the time, "Uncle, have you had your bowel test done recently?" and I said, "No, I haven't." Then they said, "Well, we'll – we might give you a kit, hey, and have a go" and I did that, yeah...that's why I decided to do it ...'

'[The health worker] initiated it. He actually handed it to me. I was [at the] clinic for some reason and he called me in and said "Aunty, you could do this. Do this and then give it back to us".' 'During an annual check-up [the nurse] seen my age and ... so she gave me the kit and she explained things to me and off we went from there.'

The ongoing relationship between clients and health centre staff also prompted some participants to complete the test, with some describing it as a sense of obligation to the local health centre.

'Initially though I think people don't want to know about it and will probably park it somewhere and forget about it but if you come in here and you've got [health professionals] on your case, well you get it done.'

'[An Aboriginal Health Worker] and the other health worker they both come and dropped it off [at home] yeah and they explained it – he just went through a bit of an explanation and so I found it quite simple ... but I think, to me, I probably wouldn't have bothered for a few more years unless they came and chased me...'

'I think I like coming here to [the primary health care centre]. I've got to return it, that's one of the commitments I have to do it.'

#### 3. Personal health concerns

Other factors influencing a participant's decision to screen included a desire to stay healthy (particularly when reaching older age), family history, support and encouragement from PHCC and having a working fridge to store samples.

'Because of my other co-morbidities, my diabetes, and I thought well, you know, this is the age now for me to go through everything to make sure that I'm well.'

'Well, I didn't ... I didn't want to end up being one of them people dying of bowel cancer.'

One participant commented that having an immediate family member who had to have polyps removed during a colonoscopy was an important influence, as it meant he was already aware of the importance of the test.

'My dad has had to go a couple of times and had the procedure [colonoscopy], and they were cutting polyps off and stuff like that [with him], so that sort of made me aware a little bit of it and then of course [the nurse] here just says, 'Here, do it' and I do it, so that was that.'

'... If it comes to your health do it.'

'Well it's for my own benefit to do it, yeah, because now I've tested positive there's obviously something not going right so I'll get it checked out and fixed. Like it's only a couple of minutes out of your day.' I can't see why I wouldn't. Get in and do it. Simple as that, get in and do it. You get old like things don't work like they used to, your body can't do what it's supposed to be doing all the time.'

#### 4. Health promotion

Most of the participants had seen television advertising about bowel screening prior to being invited to screen through the Alternative Pathway but had not necessarily seen the advertising as directed at them.

'I probably saw it on TV, but it didn't click to me that I was part of that group...'

Some participants commented that the medical information TV channel or other media in their health centre helped them relate to the messaging.

'[They] ... showed me a film ... that they had and showed me how to do it and also they had some stuff on – pictures on the wall explaining what is was and what it does and stuff like that, yeah.'

'Yeah, they have a TV [medical information channel] thing going out the front so I saw one lady talking about her dad and she wished that he had done it, that he'd sought out help a lot earlier and he wouldn't have died on her ... because of the similarities in his life and my life, because she talked about what he'd get up to in his life and it was sort of down my wat too so I was thinking, "oh well, that might happen to me (so I) better have a check-up first.'

The participants suggested a variety of ways that could improve the way bowel screening is promoted in their communities.

Humour was suggested as a good way of getting the message about bowel screening as 'it's a lighter approach...because there is that stigma about doing it'.

'I just hope that a lot of our people could see the importance of it. I think that's through advertising, education is the most important. Maybe letterbox dropping, and in the mail and a lot of people like looking at the phones these days and even – even when we go to the medical centre and [Aboriginal and] Torres Strait Islander medical centre we should be asked if it would be all right if they sent us little notifications about it, 'Have you had your bowel test?' and all that, you know.'

'I know in the [health centre] they have a women's group, so they are gathering under the umbrella of the health centre, it'll be a really appropriate place to do it, you know?'

'Look, you've got to have some posters that catches our eye, so if it's got some of our art on it or a really good message... using a really strong head [headline] message, you know, something [like] testing heals. That grabs them to say, 'Oh' rather than 'Not testing kills', you know what I mean?'

'Yeah, that was the major – and a lot of people – like they showed us about a lot of people in our culture that a lot of us don't really care about what – until you're [sick] – unless you really sit down and watch those [cancer screening awareness] films and someone explains it to you properly about what can happen to you in your life, yeah, it's a bit scary. So that made me – made me want to go and do it.'

#### 5. Advocacy

Having completed the bowel test themselves through the Alternative Pathway, three of the five participants felt strongly about promoting bowel screening to other community members.

'I would tell them that I've done it and talk to them about my experience. It's no problem at all. You're going to the toilet anyway.'

'After – after that first time... I was actually telling my mates down the pub and everywhere, you know, about doing the test and, you know, because you never know it can grab you any time bowel cancer...'

#### Limitations

The generalisability of these findings is limited due to the small number of participants, and the fact none were from remote regions. In addition, the views and experiences of eligible Indigenous adults who did not complete the bowel screening test are not captured in this report.

#### Conclusion

These findings suggest that offering kits from primary health care centres can overcome many of the barriers to bowel screening. Positive encouragement from the local health centre replaces a negative response to receiving the kit in the mail. This cohort of patients had close relationships with their primary health care centre and staff; not all patients are so engaged with their health care.

The findings here are highly consistent with what health centre staff across all regions observed as the response of many of their patients to being invited to screen through the Alternative Pathway.

## **10. FINDINGS**

This section of the report brings together the results from earlier sections to respond to the evaluation questions. Where questions have been answered in earlier sections (for example, in describing training provided) this is referenced rather than repeated, as shown in Table 10.1 below.

#### 10.1 What support did health centres require to offer the Alternative Pathway?

#### Table 10.1: Evaluation questions about training and implementation support provided to Pilot health centres.

Eva	luation question	Report sections
Ho Pat	w well were [health centres] supported to implement the Alternative hway?	
g.	What implementation support (including training opportunities) was made available to [health centres] taking part in the Pilot? Was the implementation support provided as planned? If not, why, and how did it differ?	Sections 4.3 and 6.2
h.	What were the key barriers and enablers to providing implementation support for the Alternative Pathway?	Sections 2.3, 6.2, 10.1
i.	How effective and fit-for-purpose <sup>42</sup> were the training opportunities, resources and supporting materials?	Sections 6 and 10.1
j.	What activities or programs related to the Pilot aims were carried out by Supporting Agencies during the Pilot? Were any of these activities or programs provided directly to Pilot health centres?	Section 5 and Appendix G
k.	What support was provided to [health centres] taking part in the Alternative Pathway by the NBCSP pathology provider (Sonic Healthcare) and the Department of Human Services (during implementation and/or	Section 4.3
	feasible or sustainable if an Alternative Pathway was rolled out more widely (with the new National Cancer Screening Register operational)?	Section 10
I.	Did [health centre] staff report increased knowledge and skills about bowel screening, and increased confidence and capability to deliver the Alternative Pathway, as a result of the training and implementation support activities? Did health centre staff view the support provided as sufficient to prepare them to offer the Alternative Pathway?	Section 6

<sup>&</sup>lt;sup>42</sup> 'Fit for purpose' was defined as whether the support provided through the Pilot addressed key knowledge and skill requirements to deliver the Alternative Pathway; barriers identified through earlier phases of the project such as lack of motivation or confidence or a shortage of suitable resources for use with Indigenous patients; and was delivered in modes that were suitable for the target audience (primary health care centre staff including Indigenous Health Workers and Practitioners, nurses and GPs).

The training and implementation support, resources and other materials made available to health centres for the Pilot were of high quality, appropriate for their intended users, well regarded by and accepted by staff and managers.

The support and resources were fit for purpose to address the barriers that could discourage primary health care professionals from promoting bowel screening to their patients, as is evident from the views of health centre staff reported in Section 6.

One element of the Alternative Pathway that fitted less easily into the primary health care setting was the online Participant Details form. Numerous interviewees said they wanted more information or training on using the form. Training and implementation material around this and other procedural information, while available, was not provided in formats for handy use in a clinical setting. However, with the exception of the online form, health centre staff felt well equipped to promote bowel screening with their Indigenous patients.

There were some differences between the implementation support as planned and what was delivered. The major triggers of these changes were (a) health centre uptake of the support offered; and (b) the Pilot proceeding without the NCSR and the consequent level of activity that had to be carried out simultaneously.

The decision to conduct the Pilot before the introduction of the NCSR meant that procedures and materials to engage with the NBCSR needed to be developed quickly and without time for extensive testing and review as other Pilot materials. At the same time, Menzies needed to revise clinical trial and ethics documents to reflect the change of plan; recruit participant health centres; and prepare to rollout the Pilot. In the process, the production of a small but important resource was overlooked: A sticker or flipcard containing the most critical information for clinicians about for instance, eligibility and suitability for screening, and the online Participant Details form.

The Quality and Safety Checklist was adapted several times during the first few months of the Pilot to make it clearer to health centre staff what was required. Active contact with Site Coordinators was increased to ensure health centres progressed in a timely way to give out kits.

Training and implementation support during site visits (Group B sites only) was constrained by the amount of time health centres were prepared to make staff available – even though they were offered flexible and tailored sessions to suit the needs of different groups of health professionals and to allow attendance at sessions at different times.

In addition to receiving face-to-face training, Group B sites were originally planned to have two points of follow up from Menzies after starting to give out kits and offered the opportunity to send staff to a regional workshop. These elements of implementation support did not proceed because of the amount of contact with health centres around the QSC and the constraints on staff time available for training.

#### Training

Results from the pre- and post-training survey and interviews confirmed that both face-to-face and online training were effective in increasing confidence to promote bowel screening among nurses, IHWs and GPs. Face-to-face training provided some professional groups with an increased understanding of the role they could play in promoting bowel screening, and the motivation to do it.

Both modes of training were seen by health centre staff as containing strong elements that helped staff see themselves having the conversation with their patients about bowel screening.

The style and format of face-to-face training received overwhelmingly positive feedback. Some health centre staff would have preferred face-to-face training than online, but the content and style of the online module was very positively received. A benefit of the online module was that staff could 'go back to it', and it was available to orientate new staff to the process.

However, once the basic procedures for offering screening had been absorbed into the health centre's routines, the amount of training required or offered was minimal. This was both a mark of success (the process had been normalised) and a risk: breaches of NBCSP requirements were often associated with new staff offering screening without understanding the requirements.

While the feedback on face-to-face training was very positive, there was often a reluctance to allocate time for training, even though the training was offered at the health centre and with flexible delivery options to minimise the time that staff were away from their clinical roles. Few health centres took advantage of this flexibility. There were staff who felt some of the content of face-to-face training was 'beneath them'; however the level at which training sessions were pitched was set out in information provided to health centres in advance and Menzies strongly advised against the attendance of GPs at a session on bowel cancer and bowel screening that was designed specifically for IHWs.

The interviews reinforced the survey evidence that face-to-face training could increase motivation. However face-to-face training also seemed to evoke a dependency response at some health centres, an expectation that the visiting trainers would 'provide all the answers'. Meanwhile health centres in Group A, which did not receive face-to-face training, were unlikely to make this assumption and tended to draw more on the broader Pilot resources such as the implementation manual and Helplines.

On the other hand, all three of the health centres that completed the QSC but did not manage to implement the Alternative Pathway were Group A sites and received only online training. These sites reported that while they were keen to take part, they had too many competing priorities and often significant staff shortages. It may be that when things were tough, implementing a new program needed the extra motivational push that face-to-face training provided.

A smaller number of IHWs completed the online module than took part in face-to-face training, but not greatly smaller. And responses from Indigenous staff who did the online module were very positive\ IHWs showed significant shifts in confidence to offer screening, and recognition of their role in promoting bowel screening, from both modes of training.

Some staff commented that online training did not provide the same benefits of group discussion, shared experience and opportunities to ask questions as they arose. For some people, the online module was not an appealing learning model, whereas for others it worked well. Some health centres in Group A (which did not receive face-to-face training) organised group training sessions using the online module and staff saw these as very positive experiences.

Another key difference between the two training modes was that face-to-face training included practical demonstration and interaction with the kit. This was a powerful element of the training, often prompting staff to exclaim: 'Is that all it takes?' The realisation that doing the test was not so bad, and that they would

be ok explaining it to patients, had a powerful effect on staff, and may explain the increased motivation associated with face-to-face training. Staff who completed online training only were less likely to comment in interviews on the kit demonstration and it may be the case that watching the kit demonstration in an online animation had less of an impact.

#### **Resources for staff**

The resources available for staff to support implementation of the Alternative Pathway included an implementation manual<sup>43</sup>, the online module, face-to-face training presentations, the websites <u>www.Indigenousbowelscreen.org.au</u> and <u>www.cancerscreening.gov.au</u>; two fact sheets; and the helplines offered by Menzies, DHS, the Department of Health and Sonic Healthcare.

The implementation manual provided comprehensive details about the NBCSP and the Alternative Pathway and was designed for use by site coordinators. However, as one site coordinator commented: 'It was a bit of a dry read.' The manual needed to include detail, and the detail was appreciated by those who used it, but the manual could have been reduced to half its 58 pages and made more user-friendly. As mentioned above, there was also an unmet need for easily accessible, user-friendly information about procedures and guidelines that could be used as a day-to-day reference in the clinical setting.

One of the challenges for the Menzies project team was how best to explain the procedural requirements for the Alternative Pathway, when the audience was largely unfamiliar with the usual pathway of the NBCSP. Instead of trying to explain the NBCSP and how the Alternative Pathway differed, which was the approach taken, a better option may have been to compare the Alternative Pathway procedures to those of a program more familiar to the primary sector, such as cervical screening.

Difficulties finding materials online were frequently raised by interviewees. Sometimes these difficulties were as simple as not knowing where to find the online form. Many health centres resolved this problem by placing a link to the online form into their CIS. Access to materials in some cases could have been improved. For example, some staff mentioned using www.Indigenousbowelscreen.com.au but that it was 'difficult to find what I need'.

This was partly a consequence of the website's dual function serving Pilot sites and as a public site providing information for community members and health professionals who were not part of the Pilot. Access to resources for the Pilot sites required a password. Access to the online module was also made more difficult by username and password issues. Users needed to set up their own password protected account, and because of the way that data were collected to evaluate this component of the Pilot, access could be frustratingly difficult. These seemingly small glitches could be barriers that prevented staff from accessing training or resources.

 <sup>&</sup>lt;sup>43</sup> Menzies School of Health Research, *The Alternative Pathway in your Health Centre: A guide to getting started*.
 Manual for National Indigenous Bowel Screening Pilot, Australian Government Department of Health, Canberra, 2018-19.

Other resources for staff, such as posters prompting clinicians to offer screening, the two fact sheets (*Information for Health Workers: Bowel screening and Aboriginal and Torres Strait Islander people* and *Information for GPs: Bowel screening and Aboriginal and Torres Strait Islander people*), and other resources available for download from www.indigenousbowelscreen.com.au, did not appear to have been used widely, if at all.

#### **Resources for use with patients**

Resources produced for use with Indigenous patients received a more varied response: for those staff who were aware of them, the resources were rated highly; but some staff were unaware of them, used them only occasionally, or suffered from 'resource burnout' from the continual flow of new materials, training and resources coming into the health centre from external organisations.

Patient resources provided through the Pilot included a flipchart, posters, postcard and NBCSP brochures and leaflets. The resource that health centre staff used most was the NBCSP kit with its colourful Indigenous-design sticker added to the front of the kit envelope.

As mentioned above, once staff realised the effectiveness of opening up the kit, explaining how the test was done, and why it was important, they saw little need to use other resources. Some staff used the flipchart when talking with patients, and a few health centres placed the flipchart in their waiting room for patients to examine. Posters, postcards and brochures for patients were used when the Pilot began, but their use tapered off over time.

Patients reported noticing posters and seeing NBCSP resources on the health centre television service (provided by Sonic Healthcare). Some had seen television advertisements run during 2019, but as one patient commented, 'It didn't click that they were relevant to me'.

#### The online Participant Details form

Prior to the Pilot a member of the Evaluation Committee warned that that GPs would not fill out the form unless it was integrated and able to load patient details from the CIS, and this proved to be correct. Some GPs filled out the form, but it was more likely to be done by a nurse or IHW. At one health centre, GPs flatly refused to use the form.

The original plan was to run the Pilot on the newly built NCSR, which was expected to include a portal for primary health care professionals to interact with the Register. The preparation of training materials for health centres on how to use the NCSR for the Pilot was a responsibility designated to Telstra Health, the company building the new Register. When work on the NBCSP component of the NCSR was put on hold in early 2017, there were still no details available on how Pilot health centres would engage with the Register.

When the decision was made in mid-2018 that the Pilot should proceed without waiting for the NCSR's completion, a temporary workaround had to be developed to use the NBCSR to support the Pilot and ensure that patient safety and the integrity of Register data were maintained. There were constraints on what was possible within the capacity of the NBCSR, privacy legislation, technical and data integrity requirements, and the recognition that for a Pilot project, investing in an expensive but temporary technical solution would not be feasible, particularly in the timeframe available. The Department of Health, DHS and Menzies worked

together to develop and test the online Participants Detail form; and DHS developed a process around it to keep track of screening information and manually enter it into the NBCSR.

The development of such critical procedures so soon before the Pilot was rolled out meant the development of materials to support their use was rushed. Other materials developed for the Pilot were extensively tested and refined, but the procedural details of the workaround were sometimes being refined as they were being written into the implementation manual.

Participants in both training modes said they needed more explanation about the form and what was required.

Nonetheless, the form enabled the Pilot to proceed, and observation of the ways that health centres engaged with the form provided valuable information to inform any broader rollout of an Alternative Pathway.

#### Helplines

Health centres were provided with details of three different helplines they could contact for information or troubleshooting around the NBCSP and the Pilot – one for each of the different organisations involved in supporting the NBCSP, plus Menzies. Most contact was made with Menzies Site Support, often to find out who to call to order more kits or follow up on patient results. Fewer helplines, or more consistent procedures for handling calls, may have made it less confusing for Pilot health centres to interact with the NBCSP.

#### Summary of findings on training, resources, other support materials

The training, resources and other support materials provided to Pilot health centres were high-quality, appropriate for their intended audiences, and achieved the intended outcomes of increasing motivation, confidence and capacity to promote bowel screening to Indigenous patients.

The online Participant Details form was not an ideal solution. However, nurses and IHWs had fewer complaints than GPs about the form, and in most cases were responsible for its completion. The online form made it possible for the Pilot to occur during 2018-2019 and provided valuable lessons about what will and won't for primary health care professionals to interact with the NBCSP and the NCSR.

Many of those who took part in either of the two training modes said they needed more explanation about the form and what was required. Some attendees at face-to-face training commented that the training couldn't explain how the process was going to be carried out at the health centre (because those details were to be determined at the health centre level. With these exceptions, staff felt the training was more than sufficient to equip them to offer the Alternative Pathway.

The Pilot demonstrated the vital importance of well prepared, minimal and tested materials to support not only implementation but ongoing delivery of critical procedures, such as completing the online form. Testing these materials in situ and as part of a system would also help iron out potential barriers to their use.

For example, the online form was tested as a standalone item with a small number of health centre staff. Feedback was positive – it was easy to use. Filling out the form during a clinical consultation was not so easy, as it took time to find the URL and type in the patient details. When the Participant Details form was printed to give to the patient, from a printer that could only print single-sided (the type of printer many GP offices contain), it was almost impossible to fit into the Reply-Paid envelope to be returned with the completed samples.

While the use of resources that connect with their intended audiences is critical, the capacity of health centres to absorb these resources is limited, in part because health centres are inundated with health promotion resources and training to such an extent that they became overwhelmed.

The Pilot showed that a process that embedded the promotion of bowel screening into routine practice did not necessarily require fancy resources to be effective. For many health professionals the colourful kit, along with a demonstration of how to use it and an explanation as to why it is important, was all that was necessary.

However, the broader range of resources gave health professionals the option to choose tools that they felt comfortable using and that suited their patient's needs. The resources also served other functions: they provided a range of messages that health centre staff could make their own and played a role in building confidence about the project among health professionals and other stakeholders.

#### Supporting agencies

As reported in Section 5 and Appendix G, there was considerable activity occurring around bowel screening during the Pilot period, including activity to strengthen the capacity of Indigenous primary health care centres and promote bowel screening to Indigenous people in the eligible age range. Some of this activity directly involved Pilot sites; for example, three sites in Victoria were able to host a Bowel Comedy Show; an ACCHO peak body visited sites prior to and during the Pilot building capacity to use the CIS, and several supporting agency staff attended Pilot training sessions. However, these instances were quite rare.

While supporting agencies did not deliver specific elements of Pilot training or implementation support, the level of activity in the public arena to promote bowel screening may well have influenced public perceptions about bowel screening, including that of Indigenous Australians. The second phase of background screening data – still to be released by the AIHW – should allow some scrutiny of the extent to which this may have influenced Indigenous people in the areas around Pilot sites.

The reports from supporting agencies are described in more detail in Appendix G and are helpful in considering options around further rollout.

#### 10.2 Did the Alternative Pathway increase screening participation?

#### Table 10.2: Evaluation questions about screening participation

Eva	luation question	Report section
Did scre whe	the Alternative Pathway achieve its objective of increasing bowel eening participation by eligible Indigenous Australians (aged 50-74 years, o may or may not have done a previous bowel cancer screening test)?	
f.	To what extent did the Alternative Pathway increase screening participation rates of eligible Indigenous Australians, compared to the usual direct mail approach?	Section 8
g.	Did the diagnostic assessment rate and median time between a positive screen and diagnostic assessment (colonoscopy) for Indigenous Australians differ between the Alternative Pathway and usual direct mail approach?	Section 8 (awaiting release of AIHW data)
h.	What factors contributed to eligible Indigenous Australians participating in screening through the Alternative Pathway?	Section 9
i.	Did the proportion of Indigenous participants with inconclusive screening results differ between the Alternative Pathway and usual direct mail approach?	Section 8 (awaiting release of AIHW data)
j.	Were there any unintended consequences (positive or negative)?	Section 10

The Alternative Pathway increased screening participation rates for Indigenous Australians, as explained in Section 8. While there are limitations to all of the methods of calculating participation using the available data, the most reliable estimate is that just under 40% of those invited (assessed) to screen returned a completed test, compared to 23% of Indigenous participants through the usual pathway.

#### Factors contributing to eligible Indigenous Australians screening through the Alternative Pathway

Across Australia, health centre staff reported that giving out the kit to their Indigenous patients face-to-face removed many of the barriers to screening. Seeing the kit demonstrated took away the fear of how distasteful it was, and patients were glad to see it was so straightforward. Having a trusted health professional explain what the test was for, and why it was important was also a motivation. One GP said patients seemed to feel 'cared for' after receiving the brightly coloured kit and having the talk about screening – 'It was a special thing – for them.'

One of the reasons patients gave for completing the test was that they knew the health centre staff would ask whether they had done it next time they were in the clinic. Their most common reference however was how different it was to receive the kit at the health centre than having it turn up in the mail.

Promoting bowel screening through the primary health care centre had other benefits too: Health professionals were more engaged in the patient's whole screening journey. General practitioners (GPs) tend to be involved in the usual pathway of the NBCSP only if a patient receives a positive test and needs Page 102 of 143 assessment for referral for a colonoscopy. However, 41% of Indigenous Australians who receive a positive test result through the usual pathway of the NBCSP do not receive a GP Assessment, so do not proceed to further diagnostic testing (colonoscopy),<sup>44</sup> which effectively makes the screening process redundant for those individuals.

#### Benefits of the Alternative Pathway

The Alternative Pathway brought many benefits in addition to increased screening participation.

- <u>Many barriers to screening were removed</u>. Health centre staff reported that giving out the kit directly to their Indigenous patients removed many of the barriers to screening. Having a trusted health professional explain what the test was for, demonstrate what they needed to do and say why it was important, gave patients the confidence and motivation to complete the test. One of the many reasons patients gave for their motivation to complete the test was they knew health centre staff would ask them about it the next time they were in the clinic. Health centres also offered to store or post completed samples for patients, overcoming patient concerns about keeping the samples in the refrigerator. Some even offered to have the samples picked up from patient homes.
- Invitation to screen became a culturally safe and more positive experience. Patients described the interaction that they had with a nurse or an Indigenous Health Worker (IHW) who gave them the kit as a positive one. They may have felt initial embarrassment, but they said the health professional 'did it well' and 'did it properly, culturally' explaining things clearly, removing any stigma with touches of humour, and making it just another routine thing to do.
- <u>Greater engagement of primary care health professionals across the bowel screening journey.</u> General practitioners (GPs) tend to be involved in the usual pathway of the NBCSP only if a patient receives a positive test and needs a GP assessment for referral to a colonoscopy. However, 41% of Indigenous Australians who receive a positive test result through the NBCSP usual pathway did not receive a GP assessment, or proceed to further diagnostic testing (colonoscopy),<sup>45</sup> which effectively makes the screening process redundant for those individuals. Where the Alternative Pathway was implemented systematically, health centres put in place systems to support their patients if they received a positive test.
- <u>Opportunities to increase participation over time, through improved approaches to invitation</u>. During the Pilot, health centres were trying different quality improvement approaches (formal or informal) to encourage patients to screen. Working so closely with those being invited to screen,

<sup>&</sup>lt;sup>44</sup> Australian Institute of Health and Welfare, *Cancer in Aboriginal and Torres Strait Islander people of Australia*, Cat. no. CAN 109. Canberra: AIHW. 2018.

<sup>&</sup>lt;sup>45</sup> Australian Institute of Health and Welfare, *Cancer in Aboriginal and Torres Strait Islander people of Australia*, Cat. no. CAN 109. Canberra: AIHW. 2018.

primary health care staff were able to quickly see if their strategies were working or needed to be improved. They were also able to re-invite patients who did not accept a kit.

- More targeted distribution of kits. Under the usual pathway's systematic invitation process, kits are sent to everyone who is eligible: they must be on the Register, aged 50 to 74, and not screened in previous two years. To receive a kit, their Medicare address must be up to date. Under the Alternative Pathway, each kit was handed to the person it was intended to reach. Patients could be assessed for their suitability to screen and kits were only given to those who agreed to accept them.
- <u>More accurate recording of Indigenous status and personal details for the NBCSP.</u> Many of the participating health centres helped their patients to correct or update their details with Medicare (the major source of names and contact details for invitation through the NBCSP).

#### **Remaining challenges**

- Not all barriers to screening were removed. Over fifty percent (55%) of those who received a kit did not complete the test. There is little data available to understand the reasons for this as no interviews were held with those patients who declined the offer to screen through the Pilot, or who had accepted a kit but did not complete it. Health centre staff spoke of patients for whom, at that time, 'you know there's just no way they're going to do it'.
- Not all health centres offered the Alternative Pathway. Eight health centres were recorded to have given out no kits. The reasons for this included: lengthy processes to negotiate a legal agreement to cover their participation in a clinical trial (n=2); they were overwhelmed with staff turnover, management changes and other competing priorities (n=3); and three health centres gave out kits but did not complete the necessary procedures to report the kits as given out.
- Not all health centres complied with the requirements of the NBCSP. Five health centres gave out substantial numbers of kits without completing the necessary paperwork, which included providing the patient with a Participant Details form as well as a kit. Two of these did report some screening invitees using the online form. Only 15 of the 36 health centres complied with the requirement to record all patients assessed for screening as well as those who accepted a kit. At least two health centres gave out some kits during hot zone restrictions (when kits should not have been given out), although one promptly rectified the error. The lack of compliance might be partly explained as an assumption that the requirements were those of a research project, and not a live part of the NBCSP.
- <u>Follow up to see if patients had completed the test was often ad hoc.</u> Health centres varied greatly in the records they kept in their Clinical Information System (CIS) for patients invited to screen. This was partly a result of the inconvenient way in which they had to interact with the Register (through the online form), but also because it was difficult to find out if a patient had completed the test or not. Several health centre staff commented that they thought they could increase the participation rate significantly if they followed up patients who had not completed the kit.

#### Expectations

Some of those involved in supporting the Pilot and some health centre staff expected a higher rate of return from the Alternative Pathway.

'Yeah, I almost took it as a bit of a given that anybody who was given a kit would virtually do that kit.'

One site coordinator commented after being told the health centre's (quite high) participation rate: 'What happened to the other \*\* per cent of them?'

In comparison, a site coordinator from a different health centre explained they had been trying to encourage their patients to complete bowel screening using standard pathology FOBT kits for many years and expected the centre would need to provide sample pick-up, storage and postage for their patients under the Alternative Pathway. However, she said they had no requests for this under the Alternative Pathway and the rate of return of samples was much higher than with the standard pathology kits.

#### **10.3 Delivery of the Alternative Pathway by Pilot health centres**

Evaluation question	Report section
How effectively was the Alternative Pathway delivered by health services?	
How did IPHCCs incorporate bowel screening into their practice systems and processes? (i.e. how were eligible clients identified and offered screening, and how was follow-up provided?) This includes: (1) how the Alternative Pathway was implemented at the health centre (the service model used); (2) health promotion or other activities carried out by health centre staff or others, with local community members, that occur outside the health centre itself.	Section 7
What proportion of the eligible active client group of participating health centres were invited to screen?	Section 8
To what extent was the NBCSP as delivered through the Alternative Pathway manageable for IPHCC staff and managers? Were some elements of the NBCSP more/less manageable than others?	Section 7
What were the barriers and enablers for health centres in delivering the Alternative Pathway?	Section 7

#### Table 10.3: Evaluation questions about how health centres offered the Alternative Pathway

Health centres that gave out kits showed considerable consistency in the approaches used to organise and offer the Alternative Pathway. Eligible patients were identified through an audit or within routine health assessments and flagged in the CIS for bowel screening. The online Form was completed mainly by nurses (n=23) followed by AHWs (n=11) and GPs (n=5). Most health centres used a variety of approaches to engage with their patients about bowel screening within the health centre.

Those health centres (n=6) reported by DHS to have given out no kits tended to have larger patient numbers, a smaller proportion of Indigenous clients, and were more likely to have planned to rely on community events for engagement and to have GPs designated to complete the Participant Details Form.

Within these six health centres, there were two sub-groups: health centres that had struggled with staff turnover and competing priorities and did not manage to start giving out kits; and a group that gave or may have given out kits without using the Participant Details Form, which meant the kits were invisible to DHS as being part of the Alternative Pathway.

Health centres demonstrated varying levels of compliance with the requirements of the NBCSP. Only 15 out of 36 health centres followed the request to report on all patients assessed for screening, whether the patient accepted a kit or not. This was an administrative requirement that did not have any real effect on patient care but was important to maintaining data integrity in the Register.

However, at least three health centres gave out substantial numbers of kits without a Participant Details Form being submitted or provided to the patient, a more serious lack of compliance which could have consequences for patient care

The health centres that distributed the greatest number of kits in the time available to them applied a more systematic and systems-oriented approach than those that gave out the lowest number of kits. The higher performing centres were more likely to use targeted invitations or recalls to identify and engage eligible clients for bowel screening, and to offer to store or post completed kits at the health centre.

These centres used systematic approaches to ensure that staff completed training and held meetings or delivered their own group sessions to plan, train and sometimes review the implementation of the Alternative Pathway at their service. They were also more likely to have an identified organisational champion for the Pilot.

#### **10.4 Cost-effectiveness of support**

#### Table 10.4: Evaluation questions about Group A vs Group B

Evaluat	ion question	Report section
How co	st-effective are the two variants of the Alternative Pathway?	
Was the support followin	ere a difference in the performance of IPHCCs in Group A (low intensity c) compared to Group B (high intensity support) in terms of the ng outcomes:	Section 8
-	Screening participation rates	Section 8
-	Invitation rates	Section 8
-	Measures of quality (adherence to Hot Zone restrictions by IPHCCs; sample viability; proportion of invitees with a positive result who progressed to diagnostic assessment (colonoscopy)/timely diagnostic assessment.)	Sections 7 and 8

Evaluation question	Report section
How cost-effective are the two variants of the Alternative Pathway?	
What was the extent of variation in performance between IPHCCs within either Group A or Group B? Were there common characteristics shared by IPHCCs that attained particularly high or low participation or quality outcomes, and if so, to what extent might these factors have implications for the feasibility of wider rollout of an Alternative Pathway model?	Section 8
What was the difference in the cost of providing the low intensity compared to the high intensity level of support for IPHCCs to implement the Alternative Pathway? (These costs will not include those of setting up or evaluating the Pilot but will include the cost of ongoing support for each option, including the Quality and Safety Checklist process and any difference in use of Helplines or email contact to Menzies.)	Section 10

#### Difference in performance of low/high intensity support groups

The Pilot provided training and implementation support to help participating health centres get started with offering the Alternative Pathway. Health centres were randomised into two groups, and each was offered a different level of training and support: high or low intensity support. Both groups received access to an online training module and a range of other resources. The high intensity model also provided face-to-face training at the health centre; the low intensity support group did not receive face-to-face training. When participation rates were compared between the two groups, there was no significant difference. Whereas the results from pre- and post-training questionnaires and thematic analysis of interviews showed the two levels of support did produce different outcomes in terms of staff attitudes and behaviour, which could be relevant to planning broader rollout of an Alternative Pathway (see Section 6).

The training and implementation model used for the Pilot encouraged the embedding of bowel screening into routine practice. Beyond the NBCSP requirements to provide information about screening activity to the DHS (for the Register), it was up to each health centre to determine how the Alternative Pathway would be offered to patients and embedded in routine practice. For health centres with an organisational champion to set up the systems to support routine delivery, the low intensity version of Pilot support was sufficient. Health centres undergoing significant staff turnover or disruption found it more difficult to get started under the low intensity mode. The opportunity for face-to-face training on-site helped increase motivation and broad staff engagement, but for some health centres provoked an expectation that the visiting trainers would provide all the answers about how the Alternative Pathway was delivered. Health centres in the high intensity support group were also more likely to systemically fail to follow the correct procedures for reporting screening activity to DHS. Health centres that achieved high rates of invitation to screen within the time available were characterised by a systematic and team approach to offering the Alternative Pathway; had a motivated organisational champion to oversee the implementation of the Alternative Pathway; took a targeted rather than opportunistic approach to inviting patients to screen; had a higher percentage of Indigenous patients; and offered a greater level of support to help their clients overcome barriers to screening. Community concerns about bowel cancer deaths was a strong motivating factor for some of these health centres too.

#### Difference in costs of low / high intensity support

The cost to deliver the low intensity and high intensity models of support during the Pilot are reported in Section 6.2. The low intensity model was delivered for all 47 health centres at a cost of \$77,500 – an average cost per health centre of \$1650. The additional component of face-to-face training provided to make up the high intensity model of support cost just under \$5000 per health centre. The number of eligible Indigenous patients aged 50 to 74 who attended the 47 health centres enrolled in the study was approximately 18,000.

Both models were therefore relatively inexpensive. The NBCSP is considered a highly cost-effective programme, and increased participation makes it even more so<sup>46</sup>. Based on the findings of this evaluation, the Alternative Pathway would be an inexpensive way to increase the participation of Indigenous people in the NBCSP, and a mix-and-match option that allowed the provision of more support to health centres with less capacity would be a valuable way to improve equity of access for Indigenous peoples.

#### **10.5 Considerations for further rollout**

Evaluation question	Report section
Based on the findings from questions 1-4, is the Alternative Pathway feasible to be rolled out further?	
What level of implementation support for [health centres] is required for the Alternative Pathway to maximize screening participation rates (initial setup and ongoing delivery)? Does the level of implementation support required vary according to health centre or environmental characteristics?	Section 1
Do [health centres] participating in the Alternative Pilot differ from other IPHCCs?	Section 5
What other considerations (including opportunities and risks) are there for a potential further roll-out?	Section 10

#### Table 10.5: Evaluation questions about further rollout

Overall, the Pilot demonstrated that an Alternative Pathway offering NBCSP kits to eligible Indigenous adults via primary health care centres is feasible to be rolled out more broadly, under certain conditions. The way primary health care practitioners access and provide information to the program's Register (now the NCSR) would need improvement. Nurses and AIHWs and some GPs showed a commitment to offer screening to their Indigenous patients despite the inconvenient online form that needed to be completed for each patient, and these were the people who drove the systematic implementation of the Alternative Pathway.

However, it would be difficult to sustain a broader Alternative Pathway without more workable IT arrangements for primary health care staff to communicate with the National Cancer Screening Register

<sup>&</sup>lt;sup>46</sup> J Lew et al. 'Long-term evaluation of benefits, harms, and cost-effectiveness of the National Bowel Cancer Screening Program in Australia: a modelling study,' *The Lancet Public Health*, Volume 2, Issue 7, e331 - e340. 2017.
about the distribution of kits, patient screening histories and results. There are also risks related to the use of the online form: for the integrity of the program's data and for patients.

Other necessary conditions for a broader rollout of the Alternative Pathway are that health centres would need to self-nominate and would need to commit to following the NBCSP's procedures. Having at least one staff member who was motivated to lead and oversee the introduction of the Alternative Pathway was a key success factor for Pilot sites. Health centres would need to commit to follow the NBCSP procedures. Barriers that discourage health centre staff from following those procedures, such as the online form, would need to be addressed.

Around the world there has been growing interest in offering screening outside of a standard systematic invitation program, as a means of creating more equitable access to screening. But there are challenges in integrating program data across these two different approaches to invitation and this is true for the NBCSP. Broader rollout would require easier ways to fit Alternative Pathway invitees into the Register. The National Bowel Cancer Screening Register (NBCSR) treated invitees as 'cohorts' – large groups of people invited to screen in the same 'round'. For the Alternative Pathway, individual participants screening outside of their 'round' were fitted into the NBCSR manually. That level of support is manageable for a Pilot project, but not as part of an ongoing program.

The Pilot was carried out before the NBCSP transitioned to the NCSR (in November 2019). The NCSR will reportedly provide easier access through a 'portal' for primary health care professionals at a future date. The lesson from the Pilot is that the design of these administrative procedures must be informed by those who will use them *and tested in situ and as part of broader organisational systems*.

A key part of the implementation support provided through the Pilot was a quality and safety process. Health centres were required to complete a Quality and Safety Checklist to a satisfactory standard before giving out kits. Because the Pilot was conducted as a research project, most effort went into ensuring health centres moved through the quality and safety process and were approved to give out kits in a timely way. Feedback from those involved with supporting the Pilot from within the NBCSP suggested that checking in with health centres on a regular basis *after* they started giving out kits may have helped identify and correct procedural errors more quickly.

The Pilot provided tools that could be used at multiple levels to support the implementation and ongoing delivery of the Alternative Pathway: training, implementation planning and materials, resources for use with patients, and external sources of help when needed. These same levels of support should be provided if broader rollout were to proceed. Support would be required, until promoting the NBCSP through primary health care became widespread and more staff understood the program.

The Pilot findings suggest that a simpler version of the quality and safety process, combined with a variation of the site support function provided through the Pilot by Menzies, could be a more effective way to ensure that the procedural requirements of the NBCSP are followed. The online and face-to-face training used in the Pilot worked well to engage teams and to build their confidence to offer screening to patients. The same or similar online module and/or face to face training should also be available and could be supported through regional organisations like PHNs, ACCHO peak bodies, Cancer Councils or state and territory health services, or a collaboration between two or more of these organisations.

However, not all Indigenous primary health care centres will have the capacity to offer the Alternative Pathway without a higher level of support. To avoid creating further inequity, with some health centres offering their Indigenous patients the Alternative Pathway and some not, more intensive support strategies are likely to be needed.

For example, establishing systems and ensuring staff were skilled to offer bowel screening during the implementation was described as the most time-consuming part of the process. However, once the system was up and running, it took little maintenance so financial and or technical assistance to establish the process, combined with face-to-face training to motivate health centre participation, might be needed to extend the Alternative Pathway to a greater number of health centres.

The Pilot focussed on getting health centres to embed bowel screening into routine practice. Achieving higher screening rates, as for the broader community, will need to build on that foundation with approaches that evolve over time. Quality improvement initiatives and/or learning networks, at the health centre, regional or even national levels, could build a greater body of knowledge amongst health professionals about what works to increase bowel screening participation across the entire eligible population.

#### Other opportunities

There is an increasing awareness and desire to reduce deaths from cancer in Indigenous communities. In interviews with health centre staff, it was suggested that a dedicated cancer workforce is needed in Indigenous primary health care centres to encourage screening, prevention and early detection, in the same way that chronic disease management has been targeted with specific workforce roles and funding. A broader agenda of increasing awareness and building primary health care capability to promote and manage cancer screening across the three current screening programs could be built around such a workforce, and the implementation support recommended above could be adapted to support this workforce.

A number of supporting agencies that provided reports to the Pilot (see Appendix G) have developed or are in the process of developing or running programs to build and strengthen capacity to support bowel screening promotion at a range of levels, including in the Indigenous primary health care sector. These provide many opportunities, not only for action but for new ways of thinking about things.

When the National Indigenous Bowel Screening Project began, a GP made the comment that it was a 'no brainer' to give out kits to Indigenous Australians from their primary health care centre. Similar comments have been made many times since then, and in relation to the whole Australian population, not only for Indigenous Australians. There is a risk though in thinking that the model of Alternative Pathway used in the Pilot could simply be picked up and dropped into Australia's general practice sector, without careful consideration of the setting, the barriers and enablers to uptake, and the strategies to address those.

## Appendix A

#### Stakeholder engagement

#### Original project consortium members

Tamara Cunnett	Northern Territory Primary Health Network
Emily Raso	Northern Territory Primary Health Network
Professor Jeff Dunn	Cancer Council Queensland
Melissa Ledger	Cancer Council WA
Dr Sanchia Shibasaki (no longer on project)	University of Western Australia
Professor Sandra Thompson	University of Western Australia
Professor Neil Drew	Australian Indigenous HealthInfoNet
Dr Mick Adams	Australian Indigenous HealthInfoNet
Professor John Zalcberg	Monash University
Professor Richard Reed	Flinders University
A/Professor John Condon	Menzies School of Health Research
Professor John Cass	Menzies School of Health Research
Professor Joan Cunningham	Menzies School of Health Research
Professor Ross Bailie	Menzies School of Health Research

## Project Advisory Committee

Professor Jacinta Elston (Chair)	James Cook University
Cassandra Clayforth	Cancer Council WA
Chamandeep Chehl	Cancer Council Western Australia
Craig Dukes	National Aboriginal and Torres Strait Islander Health Worker Assn.
Karl Briscoe	National Aboriginal and Torres Strait Islander Health Worker Assn.
David Copley	Pangula Mannamurna Inc / Menzies School of Health Research
Dr Jason Agostino	Gurriny Yealamucka Health Service, Cairns
Kathleen O'Connor	WA Cancer and Palliative Care Network
Kim Coulter	Department of Health, NT
Professor John Zalcberg	Monash University
Rebecca Lowe	Cancer Council Queensland
Rose Durey	Victorian Department of Health
Sally Doncovio	Victorian Department of Health
Sharon Wallace	AMSANT
Sandra Bailey	Aboriginal Health and Medical Research Council NSW
Anna Feiss	Murray Primary Health Network
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Janine Jackman	Department of Human Services
Kath Duggan	Primary Health Network
Peter O'Mara	RACGP representative
Dr Tim Senior	Tharawal Health Service

#### **Education and Training Reference Group**

Carmel McNamara	Cancer Council South Australia
Anne-Marie Dewar	Cancer Council Queensland
Melissa Ledger	Cancer Council Western Australia
Christopher Horn	Cancer Institute NSW
Blanche Marchant	Cancer Institute NSW
Justine Holmes	Cancer Council Victoria
Brad Brown	Cancer Council Victoria
Dr Laurie Barrand	Department of Health, NT
lan Watson	26 Letters/Giliimba
Louise de Busch	Cancer Council Western Australia

## Appendix B

### **Evaluation questions**<sup>47</sup>

#### How well were IPHCCs supported to implement the Alternative Pathway?

- a) What implementation support (including training opportunities) was made available to IPHCCs taking part in the Pilot? Was the implementation support provided as planned? If not, why, and how did it differ?
- b) What were the key barriers and enablers to providing implementation support for the Alternative Pathway?
- c) How effective and fit-for-purpose were the training opportunities, resources and supporting materials?
- d) What activities or programs related to the Pilot aims were carried out by Supporting Agencies during the 12-month Pilot period? Were any of these activities or programs provided directly to Pilot health centres?
- e) What support was provided to IPHCCs taking part in the Alternative Pathway by the NBCSP pathology provider (Sonic Healthcare) and the Department of Human Services (during implementation and/or ongoing through the Pilot)? To what extent would this support be required, feasible or sustainable if an Alternative Pathway was rolled out more widely (with the new National Cancer Screening Register operational)?
- f) Did IPHCC staff report increased knowledge and skills about bowel screening, and increased confidence and capability to deliver the Alternative Pathway, as a result of the training and implementation support activities? Did IPHCC staff view the support provided as sufficient to prepare them to offer the Alternative Pathway?

#### How effectively was the Alternative Pathway delivered by IPHCCs?

- a) How did IPHCCs incorporate bowel screening into their practice systems and processes? (i.e. how were eligible clients identified and offered screening, and how was follow-up provided?) This includes: (1) how the Alternative Pathway was implemented at the health centre (the service model used); (2) health promotion or other activities carried out by health centre staff or others, with local community members, that occur outside the health centre itself.
- b) What proportion of the eligible active client group of participating IPHCCs were invited to screen?

<sup>&</sup>lt;sup>47</sup> Australian Government Department of Health, *Evaluation of the National Pilot of an Alternative Pathway for the National Bowel Cancer Screening Program (NBCSP) for Indigenous Australians: Evaluation Plan.* Australian Government, Canberra, 2019.

- c) To what extent was the NBCSP as delivered through the Alternative Pathway manageable for IPHCC staff and managers? Were some elements of the NBCSP more/less manageable than others?
- d) What were the barriers and enablers for IPHCCs in delivering the Alternative Pathway?

### How cost-effective are the two variants of the Alternative Pathway?

- a) Was there a difference in the performance of IPHCCs in Group A (low intensity support) compared to Group B (high intensity support) in terms of the following outcomes:
- Screening participation rates
- Invitation rates
- Measures of quality (adherence to Hot Zone restrictions by IPHCCs; sample viability; proportion of invitees with a positive result who progressed to diagnostic assessment (colonoscopy)/timely diagnostic assessment.)
- b) What was the extent of variation in performance between IPHCCs within either Group A or Group B? Were there common characteristics shared by IPHCCs that attained particularly high or low participation or quality outcomes, and if so, to what extent might these factors have implications for the feasibility of wider rollout of an Alternative Pathway model?
- c) What was the difference in the cost of providing the low intensity compared to the high intensity level of support for IPHCCs to implement the Alternative Pathway? (These costs will not include those of setting up or evaluating the Pilot but will include the cost of establishment and ongoing support for each option, including the Quality and Safety Checklist process and any difference in use of Helplines or email contact to Menzies.)

## Based on the findings from questions 1-4, is the Alternative Pathway feasible to be rolled out further?

- a) What level of implementation support for IPHCCS is required for the Alternative Pathway to maximize screening participation rates (initial setup and ongoing delivery)? Does the level of implementation support required vary according to health centre or environmental characteristics?
- b) Do IPHCCs participating in the Alternative Pilot differ from other IPHCCs?
- c) What other considerations (including opportunities and risks) are there for a potential further rollout?

# Appendix C

#### Training needs analysis: Indigenous Health Workers

The consultations in Phase One identified the skills and knowledge that Indigenous Health Workers (IHW) feel they require to confidently encourage patient participation in bowel screening. IHWs also indicated the need for ongoing professional development as necessary and empowering.

The priority skill or knowledge needs identified by IHWs were:

- Knowledge about bowel cancer screening and early detection risks and benefits and the signs and symptoms of bowel cancer.
- Techniques for talking about bowel screening take the shame out!
- Knowledge of the technical aspects of performing the test and of the NBCSP.
- Knowledge about what happens after a positive test is returned the pathways to colonoscopy.
- Managing cultural issues and protocols that might affect IHWs engaging with patients about bowel screening, e.g. keeping men's and women's business separate.

#### Each of these training needs are described and discussed in more detail below.

#### Knowledge about bowel cancer screening and early detection

This was the knowledge requirement most often highlighted by participants in the survey and face-to-face workshops. IHWs commented that they lacked confidence in their knowledge about bowel screening and bowel cancer in general and were less likely to raise the subject of bowel screening with patients because they were not sure what questions may be asked and doubted their ability to be able to provide accurate information. For example:

*'(We need) a greater awareness and understanding of the importance of bowel cancer screening, about cancer in general and the importance of early detection.'* 

#### Techniques for talking about bowel screening

The concept of 'shame job' was mentioned often in relation to bowel screening, both in terms of collecting a sample from the patient or having to discuss it with the patient as the health care worker. Many Indigenous people involved in the consultations said they would prefer to talk with a non-Indigenous health professional about bowel screening, as it would take some of the shame away.

For IHWs, this sense of shame can be a major barrier to promoting bowel screening.

'I don't want to be identified as the person who talks about bowel cancer - too shaming'

'... (We need) strategies for approaching the subject.'

Many IHWs and other clinical staff indicated they would like learn more about how to discuss bowel screening with patients, including 'scripts' that they could use. There was also interest in learning more about the specific barriers Indigenous people experience in relation to bowel screening and having the skills and knowledge to address these when talking with patients (motivational interviewing).

Cancer remains a subject that has been largely unspoken of in many Aboriginal and Torres Strait Islander communities (Treloar 2013). This is changing to some degree, but in many areas and among many groups it continues to be off-limits. The consultations heard frequently, for example, that it would be better not to use the word cancer on the bowel screening test kit box.

## Knowledge of the technical aspects of performing the test and of the NBCSP

Many IHWs said they were not familiar with the kits (in common with other PHC professionals) or the technical aspects of doing the test themselves, making it difficult to confidently provide instruction to a patient. It was suggested that health workers use the kit to make it easier to explain to patients and encourage them to do the test.

'A thorough knowledge about technical aspects of screening e.g. collection of samples, safe return of samples for analysis as well as a clear understanding of the principles of screening.'

## Knowledge around what happens after a positive test is returned – the pathways to colonoscopy

IHWs were also concerned about being able to provide accurate information about what would happen following a positive test result. While the focus of this project is to increase screening participation, the pathways to colonoscopy were frequently raised in the consultations, particularly around the ethics of screening if follow was difficult to access.

In rural and remote areas, it may be costly and complicated to travel to a location where a colonoscopy can be performed, and Indigenous patients may be fearful of going to a far-off hospital, particularly for a treatment related to cancer.

'IHWs need to understand the procedures and how a (colonoscopy) is performed at the hospital if there is a positive finding.'

'Health services need training and support around follow-up – what happens if further investigation is needed, what happens if someone is diagnosed, what systems – and support are in place?'

Some of these procedural issues are likely to be specific to a region or individual service and may depend on pathways identified and agreed by a range of organisations. Training in relation to those aspects of a national Pilot may be better delivered at the organisational level than through training of individual health professionals.

# Managing cultural issues and protocols that might affect the engagement of IHWs or other clinical staff with clients, e.g. keeping men's and women's business separate

The sensitivities around discussing bowel screening are heightened when cultural protocols apply, for example in relation to men's and women's business, or in particular regions where faeces are associated with black magic.

## 'Ensure total privacy when speaking about topic, to decrease 'shame' in our community, females teaching females /males teaching males decreases 'shame' factor'

These too are issues that may be best addressed at the operational level, as it is at the health service level that such barriers will need to be managed. For example, in the Top End of the Northern Territory, the issue around black magic – which might otherwise seem insurmountable – could be addressed if a non-Indigenous man was given the sample and could assure its safe delivery to the pathology service.

'I as a white man could take the sample of poo and store it because I'm not a member of a clan. I'm not going to use it in black magic. So I got a lot of samples that way and they knew that I would protect them and not pass them around'

Nonetheless, managing cultural sensitivities is an issue that confronts individual IHWs, particularly given that many smaller clinics may have only female IHWs. Many younger female IHWs expressed discomfort at the prospect of talking to older men about a subject like bowel screening.

In one workshop this prompted a discussion with an older woman responding that 'as an IHW your role is to do what is necessary to make sure your clients receive good care'. These complex issues are not going to be resolved through training – but they are issues that deserve space in the preparation of IHWs to take a greater role in promoting bowel screening.

'... I know that it is the third most common cancer in Australia but it is not culturally appropriate for me to talk to men about this, in particular traditional men who have been through ceremony.'

#### Training modes

Survey respondents were asked about training modes they had experienced as effective. A number of modes and types of training had been suggested throughout the consultations as potentially useful, and survey respondents were asked to rate these in terms of their usefulness in helping PHC staff take on a greater role in promoting the participation of Aboriginal and Torres Strait Islander people in bowel screening.

Table C-1 shows there was a strong preference for 'training' embedded into workplace practice, i.e. so workplace systems and information resources provided ready access to reinforce both knowledge and behaviours.

Table C-1: l	Usefulness o	f types and	modes o	of training
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Training	Very useful	Useful
	%	%
Changes to the information system your organisation uses for patient records so that it provides prompts and reminders about bowel screening	67	23
Training in community engagement / health promotion skills	62	35
Content about bowel screening included in formal clinical training	57	41

User friendly guidelines and referral pathways for bowel screening (can be stuck on the wall in consulting room)	54	40
On the job training specific to organisational needs	52	42
A 'script' that gives examples of how to talk about bowel screening with Aboriginal and Torres Strait Islander people	46	36
Training in use of the health centre's patient information system	44	43
Short course (1-2 days) at centralised location	44	44
Training in how to use social media to promote health messages for Aboriginal and Torres Strait Islander people	39	46
Online module/s	28	46

Source: National survey conducted as part of the National Indigenous Bowel Screening Project

There were some differences of opinion on the usefulness of distance learning (such as online modules) or social media. Survey respondents ranked these as among the least useful of the range of types or modes of training that had been proposed. However, others emphasised the importance of a range of flexible options for training, to suit the diverse needs and capacity of different regions, communities and learners.

## Appendix D

#### **Quality and Safety Checklist process**

All health centres approved to participate in the Pilot were required to complete a Quality and Safety Checklist (QSC) to a satisfactory standard before being able to distribute National Bowel Cancer Screening Program (NBCSP) kits through the Alternative Pathway.

The QSC was designed to assist site coordinators understand the requirements of the NBCSP and to encourage planning to introduce, deliver and manage risks around the Alternative Pathway at their health centre.

The QSC covered six critical quality and safety issues that might represent risks for primary health care centres, their staff and/or patients arising from the delivery of the NBCSP through the Alternative Pathway.

The issues were identified from consultations prior to the Pilot (Stage One, 2015-16), informed by implementation science and health services research literature<sup>48</sup>, and refined as the revised model of the Alternative Pathway was developed during 2018.

Major contributors to risk were the widespread lack of knowledge or misunderstanding about the NBCSP amongst primary health care staff identified during Stage One of the project, and an inconvenient workaround put in place to ensure health centre staff provided essential information about clients invited to screen and/or given kits to the National Bowel Cancer Screening Register (NBCSR). The QSC was seen as a check that at least one person at each health centre understood what was required before the health centre was approved to give out kits.

Topics in the QSC included the management of kits and samples; staff skills and managing capability in the face of staff turnover; barriers that clients may face in doing the test; recording patient invitations and participation; managing patient follow-up (i.e. timely access to colonoscopy), and privacy and confidentiality issues.

The QSC went through several iterations during the first five months of the Pilot, increasingly directing health centre staff to where they could find the answers. The original version outlined potential risks, barriers and 'things to consider' that had been identified through the earlier stages of the project, and asked respondents to explain how they would address those risks that pertained to their health centre.

A second version (8 November 2018) involved substantial changes, replacing 'things to consider' with specific questions about each topic. Respondents were required to answer every question or explain why the question was not applicable to their situation. Minor changes were made in two further versions of the

<sup>&</sup>lt;sup>48</sup> Implementation references

QSC (26 November 2018 and 10 March 2019), in both cases to reinforce critical pieces of information and where these could be found in the Pilot implementation manual.<sup>49</sup>

Health centres were provided with the QSC to complete once they were formally enrolled in the Pilot (i.e. all ethics and governance approvals were in place).

The QSC was both a part of the project administration (a hurdle to be completed before kits could be given out), but also a part of the training and implementation processes. Site coordinators were encouraged to contact Menzies Site Support for help in completing the QSC at any time.

Once health centres completed their QSC they could email or fax it back to Menzies Site Support where it was de-identified and assessed by at least three members of the Menzies project team. If the QSC was found to be of a satisfactory standard – indicating that it's author had understood and addressed the key risks and critical procedures for offering the Alternative Pathway – the health centre was notified and an email sent to the Department of Health, DHS and Sonic Healthcare to let them know that the health centre could be sent a bundle of kits. If the QSC was not assessed as of a satisfactory standard, feedback would be provided to the health centre and they were encouraged to re-submit.

<sup>49</sup> Australian Government Department of Health, *The Alternative Pathway in your health centre*. Menzies School of Health Research. Report to the Department of Health. 2018

# Appendix E

#### Methods for pre- and post-training survey development and analysis

A repeated measures research design was used to analyse pre-and post-training where an Attitudes Towards Indigenous Bowel Screening Questionnaire (ATIBSQ) was developed and administered to staff who would offer screening to Indigenous patients under the Alternative Pathway.

#### Developing the questionnaire

The ATIBSQ was developed to measure staff attitudes towards bowel screening as part of the pilot assessment. Three constructs were used to inform the items of the questionnaire:

1. Perceptions that staff had about their role in the Alternative Pathway, an example of an item in the questionnaire related to this component is 'Providing patients with information about bowel screening is part of my role.'

2. Staff motivation to invite patients to screen for bowel cancer, e.g. 'There is little I can do to change a patient's attitude towards bowel screening.'

3. Staff confidence to engage Indigenous patients in conversations about bowel screening, e.g. 'I am confident I can encourage Aboriginal and Torres Strait Islander patients to do a bowel screening test.

Sixteen items were developed. Ten items were attached to a 5-point Likert-scale where 1 = Strongly disagree, 2 = Disagree, 3 Neither agree nor disagree, 4 = Agree, and 5 = Strongly agree. Six items were attached to a 5-point Likert-scale where 1 = Not Confident, 2 = Somewhat Confident, 3 = Moderately Confident, 4 = Confident, and 5 = Highly Confident. Demographic questions were added in order to describe the sample of participants.

## Recruitment

The following describes the method used to recruit training participants to the survey during administration of the Alternative Pathway training to health centre staff.

## **Online training**

Health centre staff assigned to the online training group were invited to complete the ATIBSQ via the internet using the following method: The National Bowel Screening Pilot webpage contains information and a number of resources designed to assist staff at participating health centres implement the Alternative Pathway.

A training resource link and access description (e.g. username and password) were distributed to participating health centres through email. This email contained the 'next steps letter' and an Implementation Manual, which contained information on how to access the online training module link.

Selecting this link directed health centre staff to a log in page where they were required to register before they could use the resource.

Once logged in health centre staff were directed to a detailed information page containing research and participation information. The information page included two active nomination buttons where staff were asked to either accept or decline participation. The 'I decline participation' button routed staff to the online training module where they could complete training without participating in the research.

The 'I accept participation' button routed participants to the ATIBSQ hosted at Menzies School of Health Research. Submitting the questionnaire after completion automatically routed participants to the online training. After completion of the training module, participants were automatically rerouted back to the ATIBSQ for a second time.

## Face-to-face training

Health centre staff attending face-to-face training were presented with an information page containing detailed information about the training research, participation and informed consent. Staff were then invited to participate in the research. Consenting participants completed a paper version of the ATIBSQ before commencing training. A second ATIBSQ was administered to participants on completion of face-to-face training.

## Participants

A total of 316 health centre staff from both groups completed training. One hundred and fifteen registered for online training. Eighty-six health centre staff consented to participate in the online research, fifty-seven consenters completed both pre- and post-questionnaires. Subsequently, fifty-seven participants were included in the online final analysis.

Two hundred and one health centre staff attended face-to-face training: One hundred and fifty-four consented to participate in this research component. Thirteen consenters did not complete the questionnaire. One participant requested to withdraw after completing the first questionnaire. One participant was later discovered to have completed the online training method before the face-to-face presentation and was removed from the face-to-face data set. Subsequently, a total of one hundred and thirty-nine participants were included in the face-to-face data set.

Staff training attendance and participant recruitment are presented in Table E-1.

## Data cleaning and validating the questionnaire

Raw data was cleaned, de-identified and entered into SPSS for analysis. Ten items of the ATIBSQ administered using a neutral reference point (neither agree nor disagree) on the Likert scale were subjected to Principal Axis Factoring (PAF) to statistically identify factors that grouped together and to provide evidence of construct validity (construct validity provides evidence to support that all items within a factor are measuring the same thing).

Table E-1: Training attendees and recruitment of research participants

Training method	Training attendees	Staff consent to participate	Participants completing	Participants perParticipants perParticipantsgeographic locationprofessional roleprofessional		Participants per
<u> </u>		0.0 (750()			(20)	professional group
Online	115	86 (75%)	57 (66%)	Urban: 13	Nurse: (20)	Nurse n=24
				Regional: 20	Nurse Support/Community Care (4)	
				Remote: 24	Indigenous Health Worker (11)	Indigenous Health Worker n=11
					Indigenous Health Practitioner (0) Indigenous Liaison Officer (0)	
					General Practitioner (10)	GP n=10
					Health Promotion/Project Officer (2)	Health & Education n=2
					Health Service Manager (3) Administration/Coordinator (2)	Management & Admin n=5
					Social & Emotional Well-being Officer (0) Other (5)	Other n=5
Face-to-	201	154 (77%)	139 (90%)	Urban: 50	Nurse (38)	Nurse n=39
face				Regional: 62	Nurse Support/Community Care (1)	
				Remote: 27	Indigenous Health Worker (7) Indigenous Health Practitioner (17) Indigenous Liaison Officer (1)	Indigenous Health n=25
					General Practitioner (34)	GP n=34
					Health Promotion/Project Officer (4)	Health & Education n= 4
					Health Service Manager (5) Administration/Coordinator (8)	Management & Admin n=13
					Social & Emotional Well-being Officer (2) Other (22)	Other n = 24

Two factors were validated in the PAF: Role perception and motivation. Similarly, the remaining six items of the ATIBSQ without a neutral reference point were also subjected to PAF where one item was discarded in the process leaving five remaining items, forming a unilateral scale that was validated as the confidence factor. Total participant mean scores were calculated for the three factors in SPSS and included in further analysis.

#### Analysis

A between subjects repeated measures ANOVA, was conducted on two training groups, using before and after training mean scores from three constructs. The three constructs were: 1) Perceived Role; 2) Motivation; and 3) Confidence. The two training groups were online training and face-to-face training, findings are presented in Table E-2.

#### Results

Training Method	1	n	Mean	Standard deviation
	Role Perception			
Online	Pre	53	4.19	.61
	Post	53	4.16	.59
Face-to-face	Pre	132	3.90	.68
	Post	132	*4.15	.69
	Motivation			
Online	Pre	56	3.79	.62
	Post	56	3.79	.59
Face-to-face	Pre	131	3.75	.64
	Post	131	3.82	.70
	Confidence			
Online	Pre	57	2.74	.99
	Post	57	**3.54	.83
Face-to-face	Pre	135	3.05	1.05
	Post	135	**3.87	.75

#### Table E-2: Means and standard deviations for Role Perception, Motivation and Confidence.

Note\* <.05, \*\* <.001

#### Online vs face-to-face training

Both online and face-to-face participants recorded significant increases in confidence to engage Indigenous patients regarding bowel cancer screening after the training intervention. No change in motivation post training was reported for either training method.

## Differences between groups

The face-to-face group reported a significant increase in perceived role suggesting, that face-to-face training positively influenced participant perception of their role in the Alternative Pathway. In contrast, change was not evident for participants receiving online training. One explanation for this may be that participants were encouraged to interact with team members and presenters during face-to-face sessions. Interaction with others and questioning and camaraderie during face-to-face training sessions could have influenced the clarity of the role individuals would play in delivering the Alternative Pathway.

The online environment did not provide the same opportunities for team discussion and personal role enquiry with the facilitator, and as such personal interaction and camaraderie was unavailable in this method of training delivery.

## Training influence on professional group attitudes towards promoting bowel screening

Further analysis was conducted to see how each training method influenced professional groups. Six groups were investigated: Nurse; IHW; GP; health and education worker; management and admin; and other. The amalgamation of roles represented in the six professional groups are reported in Table E-1. Membership in some categories was very small; as a result, sample size should be taken into consideration for the results of the following analysis.

## Method

A between subjects repeated measures ANOVA was conducted to investigate staff changes in Role perception, motivation, and confidence after online and face-to-face training.

## Results

## **Role perception**

The analysis found differences between how professions collectively responded to the two modes of training. A significant increase in role perception occurred for nurses, IHWs and management/admin staff after completing face-to-face training, but not after online training.

On the flipside, some professions, such as GPs, health education officers, and other professionals within the health centre, experienced no change in perception, regardless of the training mode.

A number of explanations may be drawn from this collective response to the way training was received. One explanation that may account for the different response between professions may be the specific role that professions play within the health centre. For example, IHWs, managers and nurses often have a complex and diverse role when delivering services to Indigenous patients and may have a holistic approach to patient care and wellbeing.

On the other hand, GPs, health education officers and other professions in the centre may have more defined roles with a specific physical health focus. Given these extended parameters, benefit may have been extended through an exploration of role in the Alternative Pathway and through open discussion and camaraderie during the face-to-face training, whereas the opportunity for camaraderie and networking was not available during online training.

In addition, more defined professional roles such as GPs and health education officers may already have a remit that encompasses cancer screening, subsequently, training, regardless of how it was delivered may not have been significantly influential.

## Confidence

Little discrimination between professional groups was observed in the confidence analysis. Both modes of training revealed significant increases in most professional categories. The exception was for health education and management/admin professions accessing online delivery. However, this may be attributed to small sample sizes in these professional groups. Further analysis would require larger sample sizes in these groups to substantiate the findings.

	Role Perception			Moti	Motivation		Confid	ence	
	n	Pre	Post	n	Pre	Post	n	Pre	Post
Nurse									
Online	22	4.27	4.16	23	3.91	3.90	24	2.73	**3.52
Face-to-face	42	2.96	**4.10	42	3.83	3.95	42	2.96	**3.84
Indigenous									
Health									
Online	10	4.00	4.15	11	3.45	3.82	11	2.27	**3.69
Face-to-face	25	3.83	**4.35	24	3.85	3.93	26	2.63	**3.80
GP									
Online	10	4.63	4.45	10	3.70	3.63	10	3.70	*4.10
Face-to-face	34	4.45	4.46	34	3.67	3.74	34	4.07	**4.46
Health and									
Education									
Online	2	4.00	3.38	2	3.83	3.80	2	2.30	3.10
Face-to-face	4	4.38	4.50	3	3.67	3.78	4	3.15	*4.15
Management									
and Admin									
Online	5	3.60	4.24	5	4.13	3.93	5	2.36	2.92
Face-to-face	10	3.10	*3.43	10	3.73	3.73	11	2.44	*3.11
Other									
Online	3	4.08	3.38	3	3.70	3.17	3	2.80	3.10
Face-to-face	17	3.49	3.74	18	3.57	3.59	18	2.31	**3.36

Table E-3: Role Perception, Motivation and Confidence mean scores for six professional groups

Note: \*Post intervention change <.05, \*\*Post intervention change <.001.

#### Training influence in different geographic regions

The data were also investigated to explore training influence across health services located in three geographical locations.

#### Method

Data were grouped together using demographic information to form participant groups from three geographic locations: Urban; Regional; and Remote.

A between subjects repeated measures ANOVA, was conducted to compare online and face-to-face training between the three geographic location groups. The results of the analysis are presented in Table E-4.

#### Results

_	Role Perception			Moti	Motivation			Confidence		
	n	Pre	Post	n	Pre	Post	n	Pre	Post	
Urban										
Online	12	4.00	3.96	13	3.64	3.79	13	2.89	**3.65	
Face-to-face	47	3.98	*4.24	46	3.82	3.78	48	3.03	**3.84	
Regional										
Online	19	4.04	4.13	20	3.88	3.87	20	2.67	**3.57	
Face-to-face	59	3.89	*4.10	58	3.74	*3.95	60	3.09	**3.94	
Remote										
Online	22	4.42	4.30	23	3.80	3.72	24	2.72	**3.45	
Face-to-face	25	3.80	*4.09	26	3.63	3.55	26	2.97	**3.78	

#### Table E-4: Mean training intervention scores related to each geographic location

Note \*Post intervention change <.05; \*\*Post intervention change <.001

## Urban

The analysis revealed both differences and similarities between staff providing services in different geographical locations. The findings from the three component measures are presented below under the headings Urban; Regional; and Remote, and reflect staff working with Indigenous patients at health centres situated in the three different geographic locations.

The majority of the Urban health centre sample had the following characteristics: A full complement of staff with access to a greater pool of professionals; most Indigenous patients attended the centre with little or no outreach; they were very well resourced; good capacity; GP-centric with good community relationships and an individual patient health needs focus and good allied health representation.

## **Role Perception**

While participants in the urban environment reported no great change in perception of their role in offering bowel screening to Indigenous patients, face-to-face participants revealed a significant increase. This suggests face-to-face delivery described what was required more effectively than the online module training for urban health services staff.

As explained earlier, the significant increase in perception of role for face-to-face delivery across all three geographic locations may be attributed to interactivity. Human interaction with the training facilitator, and other health centre staff, during face-to-face delivery offered reassurance and guidance and opportunities for participants to ask questions and seek clarification.

## Confidence

The confidence analysis revealed a significant increase post training for both online and face-to-face delivery.

## Regional

The sample of health centres in regional locations generally presented with the following characteristics: Most had a full complement of staff; a majority of patients attended the health centre for health care; good cultural connections demonstrated by artefact displays; elder story representation on the walls; they were well resourced; capacity was not under stress due to lack of staffing; Indigenous mentoring; a very good individualised and collective support relationship with patients; a staff interactive support structure with their local Indigenous communities (sport, other artistic activities).

## **Role Perception**

Regional health service staff experiencing face-to-face training reported significant increases in role perception after training, while participants who completed online training did not. The more interactive style, which encouraged interaction and camaraderie between staff, generally led to a better understanding of what staff had to do to implement the Alternative Pathway at their service.

## Motivation

Similarly, regional participants experiencing face-to-face training, reported significant increases in motivation after training, while participants experiencing online training did not. Regional health services were the only type to record a significant increase in staff motivation to invite patients to screen.

This reveals that motivation may be influenced by characteristics that are unique to regional locations. When training is delivered face-to-face it opens the potential for human motivation to assist, question, explore and to receive encouragement. The theme of cultural knowledge and cultural support was evident in the unique characteristics of regional health centres whether this was through artefact displays or health promotion through community sports. Pride in health delivery connected to cultural knowledge was unique in regional centres and not as evident in other locations.

## Confidence

The regional confidence analysis revealed significant increases in confidence for both online and face-to-face training. This suggests both methods of training positively influenced staff confidence in regional environments regardless of how training was delivered. This was a common response across the sample.

## Remote

Remote health centres included in this sample reported the following characteristics: A small number of staff servicing many communities; they were often poorly resourced and understaffed and under pressure to manage a greater workload than professionals in regional or urban locations; there was minimum allied health representation; there was very good understanding and involvement with the communities they served and there was often personalised door knocking to maintain health service and for community outreach.

## Role perception and confidence

Health centre staff from remote locations reported a similar outcome to that of their urban and regional counterparts in that the face-to-face training group reported a significant increase in perceived role while the online group did not. Both training methods increased confidence to implement the Alternative Pathway for remote staff.

# Appendix F

## Methods used to describe and classify how health centres delivered the Alternative Pathway

Three sets of qualitative data were gathered over the course of the Pilot that included information about how health centres intended to, or had, offered the Alternative Pathway to clients. These data were collected through:

- 1. The Quality and Safety Checklist (QSC), described earlier, conducted before sites were approved to distribute kits);
- 2. *Implementation phase* interviews with site coordinators (conducted at least nine weeks after health centres were approved to give out kits to patients);
- 3. *Post-Pilot* interviews with staff and managers, including site coordinators (November 2019 to March 2020).

Health centre participation in each round of data collection was less than 100%. In particular the number of health centres covered by post-Pilot interviews was dramatically limited by the closure of Indigenous communities due to the Covid-19 pandemic. As a result, interviews were collected from only 18 health centres (50 staff interviewed). Where post-Pilot interviews were unavailable, the analysis below drew on the implementation interviews or QSC. Table F-1 shows the number of health centres represented in each data set, by group.

Key steps in the process of offering the Alternative Pathway to patients were identified from the QSC and implementation phase interviews. Two coders reviewed the data for each health centre, categorising the approach at each step. The resulting typology of approaches was then fed back to health centre staff and managers as part of a post-Pilot feedback session (held *after* post-Pilot interviews were conducted).

Unlike the QSC and implementation interviews, the post-Pilot interviews offered multiple perspectives on a health centre's approach. The interviews from staff and managers at each health centre were read and analysed, with key information extracted and combined to develop a brief description (reflecting the collective views) of how each health centre offered the Alternative Pathway.

Table F-1: Health centre coverage in qualitative data se	ts
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Health centre grouping	Number of health centres in each data set					
	Post-Pilot interviews		Implementation interview		Quality and Safety Checklist	
	n	%	n	%	n	%
All health centres	18/47	38.29	41/47	87.23	44/47	93.61
Screening activity						
Gave out kits	17/18	94.44	35/41	85.37	36/44	81.82
Did not give out kits	1/18	5.56	6/41	14.63	8/44	18.18
Adherence to NBCSP requirements						
Reported all patients assessed	11/17	64.71	15/35	42.86	15/44	34.09
Reported only patients given a kit	6/17	35.29	20/35	57.14	29/44	65.91
Gave out significant number of kits without reporting / providing patient with form	0/17	_	3/35	8.57	3/44	6.81
Health service type						
АССНО	14/18	77.78	35/41	85.37	36/44	81.82
Private practice	2/18	11.11	3/41	7.32	3/44	6.82
State or territory health centre	1/18	5.55	2/41	4.88	4/44	9.09
Indigenous Community Co-Op	1/18	5.55	1/41	2.44	1/44	2.27
Months restricted by Hot Zone						
None	14/18	77.78	26/41	63.41	28/44	63.64
1-3 months	2/18	11.11	6/41	14.63	6/44	13.64
4-6 months	1/18	5.55	7/41	17.07	8/44	18.18
6-12 months	1/18	5.55	2/41	4.88	2/44	4.55

From these descriptions, a coder compared and categorised the health centre approaches against the typology developed from the QSC and implementation interviews, reviewing and noting changes in approach or events that affected how the health centre offered the Alternative Pathway. The results were checked again against the typology developed from the QSC and implementation interviews. No new categories were identified but refinements were made within categories. The final typology is shown in Table F-2.

Stage of process	Approaches used within stage	Variations within approach
How were eligible patients identified?	Audit using clinical information system	Described as audit or described in other terms but included an audit
	From within membership of another group/program (e.g. health assessment)	Health assessment or other recurring consultations such as care plan
	Not reported	
	Other	
When did bowel screening conversation occur?	Opportunistic (at attendance at clinic)	Opportunistic
	Active/targeted (recall, invite etc)	Actively recruited patients/targeted eligible patients
	As part of health assessment or other routine activity	Health assessment only
		Health assessment at outreach clinic
		Health assessment or other routine assessment such as GP care plans/management plans, immunisations, or at-home care visits
	Individual education session, before or after consultation	Individual appointments/education session
	Special event (promotion day, NAIDOC, information session)	Special event
	Not reported	
	Other	
How was the Participant Details	Format	Online, hardcopy, not at all
	During a consultation or assessment	Before seeing GP, with GP, after GP

 Table F-2: Approaches used by health centre staff to offer the Alternative Pathway

Stage of process	Approaches used within stage	Variations within approach
form completed and provided to clients?	Outside of consultation	For example, providing the form to the patient to complete and sign when the patient returned samples to the clinic
	Not specified	Not specified
	Who completed the form?	Nurse, IHW/IHP, GP, all/any clinical staff (including receptionist), not specified, other (including non-clinical staff).
	Prompts used to encourage completion of online form	Pop up, link to form, other, none specified
What client follow up was provided?	Type of follow up	To check whether the test was completed
		To discuss results (if a positive result was received; if other result received)
		Not reported
	How follow up occurred	Opportunistic when patient revisited clinic, follow up from list of kits given out, checking clinical information system to see if results had been received, opportunistic external to clinic
Did the health centre	No service provided	
provide clients with storage or transport of samples?	Storage at health centre	
	Pick up from home	
	Client brought samples to health centre	
	Health centre sent samples to Sonic Healthcare	
	Other	

Data collected by DHS during the Pilot, and later checked against the Register by the AIHW, were used to group health centres as described in Table F-3. The approaches used by the health centres in each group were then compared to identify differences or similarities.

Health centre groups compared	Group criteria
Did/did not give out kits	Of the 47 health centres enrolled to take part in the Pilot, three were excluded from this analysis because they did not complete the QSC and were not approved to give out kits. Of the remaining 44 health centres, DHS reported 36 gave out kits and eight (8) did not.
Did/did not comply with NBCSP requirements	Health centre staff were required to complete Part A of the Participant Details form and submit it to DHS to notify that a patient had: been assessed for screening, accepted a kit, declined a kit, or been assessed as unsuitable for screening. Eleven (11) health centres reported having assessed any clients <i>other</i> <i>than those who accepted a kit</i> and were categorised as having complied with requirements.
	If a patient accepted a kit, Part A and Part B of the form were to be printed and given to the patient to include when they returned their completed samples for testing. Some health centres reported occasional incidents where the form was not given to the patient. Three (3) health centres gave out substantial numbers of kits without forms and were categorised as not complying with requirements.
High/low screening activity by time available	Comparing health centre performance by screening activity was complicated by several factors: Variation in health centre size (number of patients); small numbers of kits given out; and time available to distribute kits. Each of these factors had the potential to misrepresent health centre performance.
	Variation in health centre size Health centres ranged in size from 347 Indigenous patients to more than 11,000. Comparisons based solely on the number of kits given out or returned reflected the efforts of larger health centres more favourably than smaller centres.
	Small numbers of kits given out Small numbers of kits given out could result in a high participation rate. A centre that gave out one kit, for example, and had that kit returned for testing, achieved a 100% participation rate; a centre that gave out 91 kits and had 45 returned achieved a participation rate below 50%. Comparisons based on participation rate advantaged centres that gave out few kits.
	The time available to distribute kits The time available to distribute kits was affected by the health centre's location (whether Hot Zone restrictions applied); governance (which affected the level of ethics and governance approval required) and the time a health centre took to complete the Quality and Safety Checklist. Time available to distribute kits

Table F-3: Groupings by which health centre approaches to offering the Alternative Pathway were compared

Health centre groups compared	Group criteria
	during the Pilot ranged from 29 working days to 234 working days, with an average of 153.5 working days.
	Method of calculation
	A calculation of kits given out by time available to distribute kits was used as the prime determinant of health centre performance in this analysis. This measure was considered by the research team to provide the least amount of distortion given the variability of the data.
	The 36 health centres that gave out kits were ranked by number of kits given out by time available, and the approaches of the 12 health centres with the highest scores and the 12 with the lowest scores were compared.

## Appendix G

## **Supporting Agencies Activity Report**

'Supporting Agencies' were a diverse group of organisations identified early in the National Indigenous Bowel Screening Project as important stakeholders and potential contributors to developing or sustaining the Alternative Pathway. They included state and territory health departments, ACCHO peak bodies, Cancer Councils, Primary Health Networks and others. In December 2019 Menzies invited Supporting Agencies located in or active near Pilot health centres to complete an activity report via an online survey. The survey aimed to identify activities that might directly or indirectly have affected the health centres participating in the Pilot or the uptake of the usual pathway.

A total of 34 Supporting Agency Activity reports were received between 16 October 2019 and 7 January 2020. Of the 34 reports received, 5 were duplicates and 9 were incomplete. The duplicate and incomplete reports were not included in the analysis.

Duplication of reporting also occurred when multiple officers in a supporting agency each submitted the same report. Three staff from the same agency submitted a survey. These surveys were combined because they provided similar information, with only minor differences. Where differences occurred, these were retained.

All agencies except one gave their consent for information being used as part of the evaluation of the Pilot.

A total of 16 reports were analysed to see if there were interactions between health centres and supporting agencies that may have directly or indirectly affected centres participating in the Pilot.

Nine of the supporting agencies reported interactions relevant to bowel screening activity with health care centres in their respective areas taking part in the Pilot between the period of 1st November 2018 to 31 October 2019. These interactions involved:

- Promotion of the Pilot which was reported to have happened outside of the Pilot reporting period;
- Attending and supporting face-to-face training;
- Providing support to health centres, that were also Aboriginal Community Controlled Health Organisations who were members organisations) with service improvement activities regarding prevention and management of chronic disease, improving administrative practices and improve data recording;
- Planning and developing external promotion campaigns or services for bowel cancer screening – for example, advertising campaigns or the One Stop Screening Shop to support increased cancer screening; and
- Funding non-Government organisations to improve cancer screening systems.

Seven survey respondents reported their agencies had no bowel screening-related interactions with Pilot health centres in their catchment; however, one respondent stated that 'though interactions hadn't occurred, they would follow up with participating services.'

A majority of supporting agencies, 12 of the 16 organisations, reported providing bowel screening support including:

- Resource dissemination;
- Education and training programs/in-services;
- Funding (e.g. Innovations in Cancer Control Grants 2019 Bowel screening Aboriginal Community Education grant);
- Campaign activities (e.g. tailored Aboriginal print, radio, TV and Facebook advertising: 'Do the test');
- Screening programs; and
- Community awareness events.

A further 9 of the 16 supporting agencies reported delivering programs relating to cancer and Aboriginal and Torres Strait Islander peoples, these included:

- Health promotion and education sessions;
- In-services;
- Funding; and
- Organisational support (e.g. prevention and management of chronic disease, improving health service administrative practices, improving recording).

A total of 10 of the 16 supporting agencies provided preventive health care measures/programs for Aboriginal and Torres Strait Islander people which delivered:

- Conference presentations, community education sessions, health promotion activities at various health centres;
- Support activities (prevention focused Continuous Quality Improvement (CQI) activities); a
- Aboriginal and Torres Strait Islander Health checks, and also delivered programs (e.g. Healthy Black and Deadly Lifestyle Program).

A further 10 of the 16 supporting agencies providing activities to strengthen primary health care services for Aboriginal and Torres Strait Islander people; for example, CQI or Information Technology support systems. These activities included:

- Developing a cancer screening quality improvement [QI] toolkit for primary health networks to use with local health practices to implement tailored QI activities;
- Increasing the uptake of Health Assessments in the Indigenous population to support General Practice services to utilise support from an Indigenous Health Project Officer; and
- Use of PEN, or clinical audit tools, for reports and data systems to identify service areas in need of further support for Aboriginal and Torres Strait Islander people.

Supporting agencies were also asked to describe programs or activities related to bowel cancer screening conducted by other organisations they were aware of. These activities and/or program reported included:

- Hunter New England Local Health District developed the Aboriginal Cancer Awareness Initiative 'I'm going to get checked, Wanna Come?' program;
- North Sydney Local Health District implemented an Aboriginal and Torres Strait Islander Men's Health Plan 2015 – 2020 (which includes men's health check days);
- Cancer Council Victoria promoted a Bowel Comedy which was performed at g three Pilot sites – Wathaurong (Geelong), Ballarat and District Aboriginal Co-operative (Ballarat) and Mallee District Aboriginal Services (Kerang);
- Gold Coast Public Health Unit held general information and awareness workshops for general practice staff focussed on cancer screening;
- There are six Bowel Health Promotion Officers (HPOs) in Queensland who work to increase participation in bowel cancer screening. There are also three other non-HPO positions who work to a lesser extent to increase participation in the NBCSP. These officers work with different organisations in their communities to increase screening participation. HPOs and non-HPOs reported engaging and working with primary health care centres involved in the Pilot; and
- Significant engagement with large GP practices during bowel cancer awareness month to raise awareness and increase participation in the NBCSP.

Survey respondents were also asked to rate the 'usefulness' of the Pilot to improve bowel screening. A total of 15 out of 19 respondents gave a mean score of 4.36 (out of 5) to support the efficacy of the Pilot. A number of interview comments underpinning the effectiveness of the Pilot were given:

- 'NBCSP kits are not always received by the eligible individual reasons identified include lack of up to date address with Medicare, not residing at documented address, transient lifestyle, lack of awareness of bowel cancer and bowel cancer screening so kit is discarded, instructions and steps to screening may be a barrier, not wanting to post in mail as this brings shame (in smaller towns where everyone knows the post office staff), not wanting to store sample in fridge whilst waiting for second sample etc. ACCHOs staff are in the position to really support their practice population with screening participation and reduce or mitigate many of the barriers to bowel screening.'
- 'More Aboriginal people need to be educated in National Indigenous Bowel Screening Pilot, especially Aboriginal health workers.'
- 'An alternative method of providing kits to the Indigenous community is a worthwhile investment and is confirmed by evidence.'
- 'The Pilot is crucial to building the evidence to support a direct distribution model for Aboriginal people in NSW and across Australia. Direct distribution and the involvement of Aboriginal primary care services is key to addressing barriers to bowel screening within these communities. Given the complexities of health and maintaining health, any processes whereby barriers to access, particularly in bowel screening is removed is paramount. Further

consideration needs to occur in regard to further optimal care pathways for bowel screening and bowel cancer treatment, including access to follow up services and addressing associated barriers (financial, distance, travel and cultural safety of organisations).'

- 'A health professional (from AHW to GP) recommending to do a bowel test and being able to follow up by handing out the kit enforces this as important. It enables the client a chance to ask questions and not be intimidated by it. It decreases the chance of the test being avoided as they know the health worker may enquire about it.
- 'Hoping that it will be useful and improve participation rates for Aboriginal people. This is a very important national screening pilot. The more we can encourage Indigenous people to participate in the pilot the better.'
- 'I have access[ed] many times Menzies especially the [Site Support Officer] Boden Tighe, who has always provided[d] me with the information very quickly. The AHW online training [produced for use by health professionals outside of the Pilot] was provided by [Hunter New England Local Health District] to our AHW's as part of the upskilling. We also have hard copies and soft copies uploaded into our training program from Menzies. Thank you for the amazing resources this has given the tools to educate and change stories. We have had people go get a bowel test with positive results early that would normally not do the test.'
- 'It is a more culturally appropriate pathway where people can receive kits from a health care facility in their own community and be supported in doing the kit step by step.'
- 'The pilot will allow valuable evaluation of alternative methods for increasing bowel cancer screening in the Aboriginal and Torres Strait Islander population.'
- 'Positive feedback from services who feel being able to hand out kits is useful for raising participation rates; need to improve systems to record testing if rolled out more widely.'
- However, there were some concerns noted. One respondent who strongly supported the Pilot also commented 'unfortunately, limitations due to research methodology and time frame not imposed by researchers meant the success of this project may have been compromised.'
- Another respondent was keen to hear the results: 'It would be fantastic to see some results to better understand/evaluate the impact – has the pilot demonstrated increased participation in the NBCSP by Aboriginal and Torres Strait Islander people in the target population?'

Lastly, supporting agencies were asked: 'What – if any – role do you think your organisation could have in supporting primary health care centres to offer bowel screening for Aboriginal and Torres Strait Islander people beyond the Pilot?'

A majority of 13 of the 16 respondents stated that beyond the Pilot they would:

- Provide education information and advice relating to the NBCSP for Aboriginal Health Workers and Medical Service staff;
- Continue to liaise with Pilot sites and encourage their involvement in screening. To ensure learning and education gained along the way are not lost, especially if staff move on from their roles;

- Develop a co-design model for effective Aboriginal governance and engagement and a framework to oversee cancer control activities for Aboriginal people in NSW. Funding to PHNs to support cancer screening work as well as communicating with PHNs which ACCHO's are part of this project;
- Advocate for and encourage primary health care centres to promote and encourage patients to screen (and participate in the Pilot);
- Support CQI activities (through Practice Support function) as well as Quality Improvement Activities using practice software including PEN to identify never-screened or under screened clients;
- Promote bowel screening for Aboriginal and Torres Strait Islander people through our regular communication channels (e.g. newsletters, Basecamp) and through our Provider Support Team (who visit practices and disseminate resources);
- Involvement in providing feedback in the development of Health Promotion strategies and resources which may be developed to promote the alternative pathway across Queensland; and
- Support primary health care centres to continue offering bowel screening beyond the pilot developing new programs (e.g. One Stop Screening Shops will be continuing beyond the end date of the Pilot).

Overall, supporting agencies activities were in keeping with the aims of the Pilot, but extended to a broader range of activities. The Pilot period from 31 October 2018 to 1 November 2019 saw growth in:

- Funding (e.g. Innovations in Cancer Control Grants 2019 Bowel screening Aboriginal Community Education grant);
- Advertising campaigns (e.g. tailored Aboriginal print, radio, TV and Facebook advertisements); and
- Screening Programs/Trainings and Community Events (e.g. One Stop Shop).

The contributions from supporting agencies during the Pilot period may have supported increases to participation rates for bowel screening. For example, advertising campaigns were used to target and improve awareness of bowel screening and to increase participation.

The Cancer Institute of NSW continued a major bowel cancer awareness campaign called Do the Test which included tailored Aboriginal print, TV, radio and Facebook advertising. Tailored creative materials were tested with Aboriginal audiences to ensure materials were culturally appropriate. The evaluation of the Do the Test campaign is currently underway and it appears the campaign resulted in an increase in the number of bowel screening kits being returned over the campaign period.

Furthermore, the distribution of funding for and by supporting agencies may also have helped to increase participation (i.e. aimed to build capability within Aboriginal Health Services); for example, the South Eastern Melbourne Primary Health Network (SEMPHN) commissioned Cancer Council Victoria to work towards increasing bowel screening participation rates in the SEMPHN service

catchment. This program began January 2019 and ends June 2021. One key aim of the funding program is facilitating targeted community engagement to increase Aboriginal and Torres Strait Islander people's cancer screening rates.

The delivery of screening programs, training and a community event may have contributed to localised increases in screening participation rates. For example, Hunter New England Health developed and embedded a 'I'm going to get checked, Wanna Come' program, which included a comprehensive on-line training program, as well as a toolbox including printed and digital resources for Aboriginal Medical Services to access and promote cancer screenings within their local service areas. The impact of this program on bowel screening participation was not known at the time of the survey as evaluation of the program was still underway.

## Abbreviations

Acronym	Description
ACCHOs	Aboriginal Community Controlled Health Organisations
ACCHSs	Aboriginal Community Controlled Health Services
AIHW	Australian Institute of Health and Welfare
AMSs	Aboriginal Medical Services
ANOVA	Analysis of Variation
ASGC	Australian Standard Geographical Classification
CINSW	Cancer Institute New South Wales
CIS	Clinical information system
Department of Health	Australian Government Department of Health
DHS	Department of Human Services (now Services Australia)
GP	General Practitioner
HREC	Human Research Ethics Committee
ifobt	Immunochemical faecal occult blood test
IHW	Indigenous Health Worker
IPHCC	Indigenous Primary Health Care Centre
NACCHO	National Aboriginal Community Controlled Health Organisation
NBCSP	National Bowel Cancer Screening Program
NBCSR	National Bowel Cancer Screening Register
NCSR	National Cancer Screening Register
OSR	Online Services Report
PFUF	Participant Follow Up Function
РНС	Primary Health Care
РНСС	Primary Health Care Centre
PHN	Primary Health Network
QSC	Quality and Safety Checklist
RACGP	Royal Australian College of General Practitioners
Sonic Healthcare	Sonic Healthcare Limited