Deloitte.

Review of Phase Four of the National Bowel Cancer Screening Program

Evaluation Report

September 2021

Deloitte Access Economics

Contents

Acronyms

Acronyms referenced throughout the report are outlined below.

Acronym	Full name
ABS	Australian Bureau of Statistics
ACD	Australian Cancer Database
ACSQHC	Australian Commission on Safety and Quality in Health Care
AIHW	Australian Institute of Health and Welfare
C	Celsius
CAG	Clinical Advisory Group
CEA	Cost-effectiveness analysis
DALY	Disability Adjusted Life Years
gFOBT	Guaiac faecal occult blood test
GP	General Practitioner
HPP	Healthcare Provider Portal
HHS	Hospital and health service
ICER	Incremental cost-effectiveness ratio
iFOBT	Immunochemical faecal occult blood test
KPI	Key performance indicator
LHD	Local Health Districts
MBS	Medicare Benefits Schedule
NBCSP	National Bowel Cancer Screening Program
NCSR	National Cancer Screening Register
NGO	Non-government organisation
NHMRC	National Health and Medical Research Council
PDAG	Program Delivery Advisory Group
PICO	Population, intervention, comparator, and outcomes
PFUF	Participant follow up function
QALY	Quality Adjusted Life Year

Glossary

Key words referenced throughout the document are defined below.

Word	Definition
Economic evaluation perspective	The perspective is the point of view adopted when deciding which types of costs and benefits are to be included in an economic evaluation.
Healthcare Provider Portal	A Healthcare Provider Portal is linked to the National Cancer Screening Register. The portal allows healthcare practitioners to access and submit screening data electronically. As part of this, it allows practitioners to update participant details and nominate an alternative postage address (e.g. a GP or community health centre).
iFOBT	The immunochemical faecal occult blood test is a diagnostic test to assess for occult blood in the stool.
Invitee	An individual (from the target cohort) who is invited to participate in the NBCSP.
National Cancer Screening Register	The NCSR is a register containing a single electronic record for each person in Australia who receives an invitation to participate in the NBCSP. The National Cancer Screening Register offers a digital infrastructure for the collection, storage, analysis and reporting of screening data. It facilitates invitations for screening, mailing of test kits, participant support, clinical decision making, and easier reporting for health care providers.
Non-completer	A sub-group of the 'non-participants'. This is an invitee who received a NBCSP kit but did not complete and return it and did not complete another form of bowel cancer screening.
Non-participant	An invitee who did not complete and return a NBCSP kit (for any reason).
Participant	An invitee who completed and returned a NBCSP kit.
PFUF officer	PFUF officers complement the Program reminder letters and usual care provided for participants. Their role is to phone participants with a positive immunochemical faecal occult blood test result who have no record of follow-up with a GP or a colonoscopy in the National Cancer Screening Register and encourage them to schedule appointments, while also answering any questions about the next steps in the screening pathway.

Executive summary

Background

The Department of Health (the Department) established the National Bowel Cancer Screening Program (the NBCSP or the Program) in 2006 to address the rising incidence and mortality of bowel cancer in Australia. This decision made Australia one of the first countries to offer free bowel cancer screening to a national population.

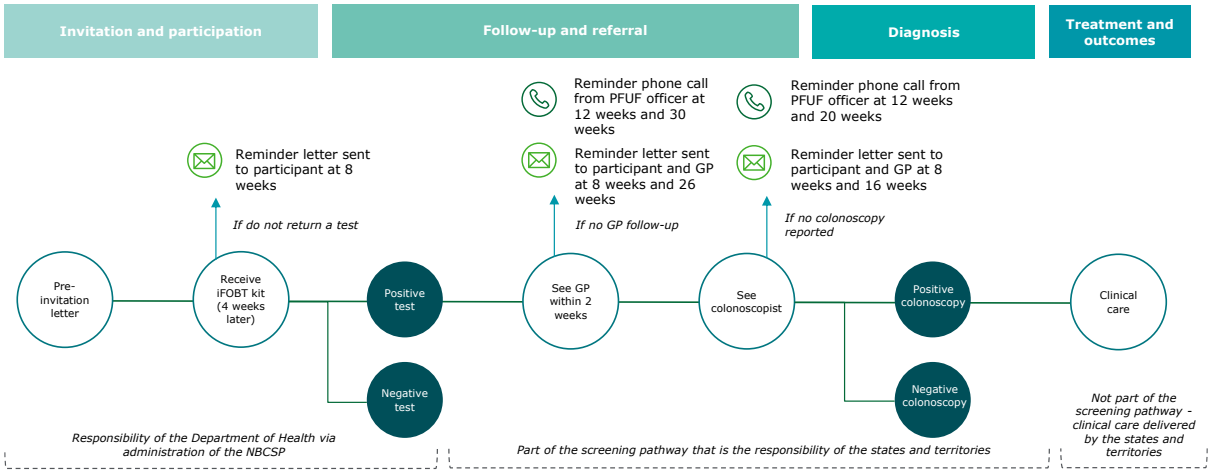
The Program aims to reduce the incidence of bowel cancer through detection of pre-cancerous growths (i.e. adenomas), and improve survival from bowel cancer through detection of cancer at an early stage. Screening was initially offered to Australians aged 55 and 65, and gradually expanded over time. In 2014-15, the Program committed to implementation of biennial screening of people aged 50 to 74 by 1 July 2020. This time period was consequently referred to as Phase Four of the Program.

The Program is now fully biennial for people aged 50 to 74, which aligns with the *Clinical practice guidelines for the prevention, early detection and management of colorectal cancer* (the Clinical Guidelines). The Department commissioned Cancer Council Australia to develop the Guidelines through an independent group of experts. The National Health and Medical Research Council (NHMRC) subsequently approved these Guidelines.

The completion of Phase Four allows the Program to shift from a focus on expansion to optimisation, and thus represents an opportune time to review the Program and consider its strengths and opportunities for improvement.

An overview of the NBCSP participant pathway and how it aligns with the five steps in the Australian Population Based Screening Framework (recruitment, screening, assessment, diagnosis and outcomes) is provided in Figure i.

Figure i: NBCSP participant pathway



Source: Deloitte Access Economics diagram, using Department of Health information.[1]

Scope of the review

The Department engaged Deloitte Access Economics to undertake a comprehensive review of Phase Four of the Program. The purpose of the review was to assess:

- **Appropriateness**: The suitability of the Program design including the clinical pathway, diagnostic elements and the Alternative Pathway pilot.

- **Fidelity:** The extent to which the Program was implemented as intended, including Program delivery, data collection, reporting, as well as the operations of governance structures.
- **Awareness and adoption**: The extent to which consumers and clinicians are aware of, and have adopted, the Program.
- **Effectiveness**: The extent to which the Program is effective in achieving its stated objectives, including maximising benefits and minimising harms to individuals participating in the Program.
- **Efficiency**: The extent to which the Program is cost-effective relative to no screening, across different age brackets and participation rates.

Themes related to Program sustainability (i.e. identified opportunities for improvement as part of the next phase of the Program) and equity of access are discussed where relevant under each of the domains listed above.

Out of scope
The National Cancer Screening Register (NCSR) was implemented in 2019 (during Phase Four). The NCSR offers a digital infrastructure for the collection and reporting of screening data, and facilitates invitations for screening, mailing of test kits, and participant support. An evaluation of the functionality of the NCSR will be conducted separately, and was thus out of scope for the review. The Healthcare Provider Portal (HPP) is a second piece of enabling infrastructure for the Program, which was piloted during Phase Four. An evaluation of the implementation and functionality of the HPP was also out of scope for the review.

Methodology

A mixture of primary and secondary data informed the review.

Secondary data sources included publicly available Program reports from the Australian Institute of Health and Welfare (AIHW), academic literature, pathology data, and an extract of data from the NCSR.

As part of primary data collection, an extensive stakeholder consultation process was conducted (67 consultations with 117 stakeholders) with groups including Program officers, clinicians, peak professional bodies, non-government organisations and consumer representatives. Other primary data sources included a consumer survey, a clinician survey, as well as an online public submission process to ensure that all interested stakeholders could express their views.

Limitations

The review of Phase Four of the Program was limited by the following factors:

Data completeness. A longstanding challenge to the Program is the voluntary provision of data from General Practitioner (GPs), specialists and histopathologists related to follow-up consultations and the outcomes of these consultations. This issue affects the reporting of key Program performance indicators, notably diagnostic assessment rates, adenoma and colorectal cancer detection rates, interval cancer rates, and adverse events. Consequently, this issue limited the ability to reliably report on these indicators.[i]

Inability to compare cancer-related outcomes for Phase Four participants vs. non-participants. To assess whether Program participation impacts bowel cancer morbidity and mortality, data linkage is required between:

- jurisdictional cancer registries (cancer diagnoses and stage at diagnosis)
- the National Death Index (deaths including cause-of-death)
- the NCSR (participation data).

[i] This issue is attributable to the voluntary nature of information provision by healthcare practitioners, it is not a limitation of the functionality of the NCSR.

A data linkage study was not in scope for the review. Analysis of this nature also requires a substantial lag period to observe mortality outcomes over time (e.g. five-year relative survival). The most recent project of this nature was the 2018 AIHW report *Analysis of bowel cancer outcomes for the National Bowel Cancer Screening Program*, using data from Program invitees between 2006 and 2010. Thus, reporting cancer-related outcomes linked to Phase Four was not feasible at the time of the review. In the absence of Phase Four-specific data, the review instead refers to the 2018 AIHW report as an indication of the impact of the Program on earlier detection and better survival.

Opportunities to address these data limitations are discussed in the 'Fidelity' sub-section of the Executive Summary.

Summary of findings

Overall, the Program is a major strength of Australian's public health system. The Program has contributed toward improved population health for Australians through earlier detection of bowel cancer and better survival. Since the Program's inception in 2006, it has played a key role in Australia's eminence in cancer screening and prevention for the following reasons:

- Australia was one of the first countries to offer free screening for bowel cancer to a national population
- Australia was one of the first countries to collect quantitative Immunochemical faecal occult blood test (iFOBT) results, which is now used globally as best-practice
- Australia offers screening to the widest age range of all countries utilising FOBT screening via a mail out method.

Findings and opportunities for Program improvement are presented below by each of the key evaluation domains.

Appropriateness

The review explored the appropriateness of different aspects of the clinical pathway, including invitation and participation, follow-up and referral, as well as diagnostic assessment.

Most facets of the Program broadly align with best practice features of bowel cancer screening programs. More detailed findings related to the appropriateness of various aspects of the Program are described below.

Invitation and participation (including kit instructions and the test)

- The current age bracket (50 to 74) and screening interval reflects best practice at a whole-of-population level, based on the current Clinical Guidelines and results from a cost-effectiveness analysis. *See the 'Efficiency' section below for further detail on the target age bracket, and specific opportunities identified for Aboriginal and Torres Strait Islander people.*
- A trial of a National Alternative Pathway to the NBCSP (Alternative Pathway) to increase participation among Aboriginal and Torres Strait Islander people demonstrated efficacy and appropriateness. The pilot achieved a participation rate of 40 per cent (similar to the overall Program participation rate), compared to 23 per cent in the traditional screening pathway.
- The current mail-out approach with a pre-invitation letter is broadly appropriate, however the consumer survey found that approximately 9 per cent of invitees had not received a kit in the past two years. A HPP linked to the NCSR was implemented in October 2020. The portal allows healthcare practitioners to access and submit screening data electronically. Use of the HPP to ensure participant addresses are correct may help to overcome this issue.
- The Hot Zone policy is appropriately designed to comply with the iFOBT kit storage requirements. However, it will be important for the Program to continue to monitor positivity results from postcodes affected by the policy to determine whether further amendments to the policy are required.
- The revised kit instructions in 2018 were associated with an improved rate of valid kit returns. However, there is scope to consider how kit messaging could be better tailored to overcome common behavioural and attitudinal barriers to participation*. See the 'Awareness and Adoption' section below for further detail opportunities identified to enhance kit messaging.*
- The diagnostic value of Australia's test is considered by stakeholders to be a major strength of the Program. The iFOBT is considered the most accurate and easy-to-use at-home test available, and the diagnostic accuracy of Australia's two-sample test is higher than the tests used in many comparable programs overseas. This results in enhanced detection of lesions (due to higher sensitivity) and reduced colonoscopy workload (due to higher specificity).

- New and emerging research in overseas literature shows that interval cancers (i.e. missed cancers) predominantly occur in people with a high-negative iFOBT result.[2,3] This suggests that iFOBT results, which are habitually reported in a dichotomised manner (i.e. below or above a pre-specified threshold), could be used in a more nuanced way to improve Program outcomes. Pathologists consulted agreed that validation of this research in local settings should be a priority for the Program and would further support Australia's eminence in bowel cancer screening.

Follow-up, referral and diagnostic assessment (part of usual care model)

- The diagnostic assessment rate (66 per cent[ii]) is low relative to international programs which use iFOBT kits via a mail-out method. There are several contributing factors to this reported rate. Firstly, this rate is underreported as there is no reporting obligation for colonoscopy providers to provide information to the NCSR about Program participants. Secondly, it is recognised that participants may not proceed to a colonoscopy for clinical reasons, as determined by a GP or specialist.

- Challenges with timely access to a publicly delivered colonoscopy for Program participants have persisted for several years. The median time to diagnostic assessment in 2018 was higher than the benchmark in the NBCSP Quality Framework (51 days[iii] and 44 days, respectively), and notably worse for participants treated in the public system (77 days[iv]). As of 2016, 58 per cent of gastroenterologists and hepatologists practised in the private sector.[v] Consequently, the availability of publicly delivered colonoscopies may be a downstream consequence of these workforce dynamics.

- A review of publicly available reports indicated that a high-volume of low-value colonoscopies occurring for first-line screening outside the Program may contribute to colonosopcy capacity constraints. This was supported by insights gleaned from consultations.

  It is worth noting that in 2019, the Medicare Benefits Schedule (MBS) Taskforce made multiple changes to the MBS item codes relating to colonoscopy.vi These changes were designed to reflect the latest evidence-base and reduce the number of low-value colonoscopies. The impact of this measure should be evaluated over time.

- Stakeholders observed that the Australian Commission on Safety and Quality in Health Care's (ACSQHC) development and implementation of the Colonoscopy Clinical Care Standard (CCCS) in 2018 was a positive step toward improving the quality of colonoscopies performed in Australia. Another positive change cited that occurred during Phase Four was the establishment of a National Colonoscopy Recertification Program, governed by the Gastroenterological Society of Australia (GESA) and supported by the Program.

Timing for reminders

- Shortening the current reminder intervals related to GP follow-up and increasing the current reminder intervals related to colonoscopy follow-up may be appropriate based on any understanding of the key access barriers along the screening pathway (i.e. relatively short timeframes associated with accessing GP appointments, while colonoscopy waitlists can be several months). However, it is important that the suitability of any change is tested and

[ii] This key performance indicator is defined as the percentage of people who return a positive iFOBT test between 1 January and 31 December, that had a follow-up diagnostic assessment within that period or by 31 December of the following year. In the AIHW National Bowel Cancer Screening Program Monitoring Report 2020, the recorded rate was 66 per cent, noting that the observation window was shortened by two months due to the transition to the National Cancer Screening Register in November 2019.
[iii] AIHW National Bowel Cancer Screening Program Monitoring Report (2020)
[iv] Ibid.
[v] Australian Government Department of Health (2016), *Gastroenterology & Hepatology 2016 Factsheet*.

validated with clinical experts, given their unique understanding of colonoscopy waitlists and other clinical implications associated with a change of this nature.

Participant Follow-Up Function (PFUF)

The Program has a Participant Follow-Up Function (PFUF), with a purpose of encouraging participants with a positive iFOBT to progress through the screening pathway. Participants are followed up if they have a positive iFOBT result and no record of GP and/or colonoscopy activity in the NCSR within set time intervals. The efficacy of this function was assessed.

- NCSR records on timing of GP appointments show that the number of participants with a GP follow-up date recorded that may have been influenced by the second phone call and/or reminder letter was low. Just over one per cent of participants had a GP appointment recorded after 26 weeks – the timing of the second reminder. This supports the idea that timing intervals for reminders should be reviewed.
- Overall, NCSR records show that 73 per cent of PFUF interactions were successful. Successful contacts are broadly defined as the officer successfully reaching the intended recipient. Overall, 44 per cent of interactions were targeted to participants, followed by specialists (19 per cent) and healthcare professionals (18 per cent). Healthcare professionals and specialists were more likely to be successfully contacted. Potential explanations include participants being of working age and/or less likely to answer phone calls from unrecognised numbers, whereas health care professionals and specialists have administrative support in their workplace to facilitate successful contact within the business hours that PFUF officers operate.

  Given that nearly half of all PFUF interactions are aimed at participants, methods of communication which increase the likelihood of successful contact with this recipient type may help to improve the efficiency of the follow-up function. As such, consideration could be given to communication modes that do not require simultaneous availability between the PFUF officer and the participant (e.g. text message or email).
- Data gaps limit the efficiency of the PFUF officer role. Because clinical practitioner data entry in the NCSR is voluntary (beyond the record of a positive iFOBT result), data is incomplete. As a result, officers may follow up participants who are proceeding through the pathway, but their clinician interactions have not been recorded (i.e. making reminder phone calls to participants who have already visited a GP and/or a specialist).

  The extent to which PFUF officers' time is spent performing data entry tasks to update the participant's record is difficult to determine precisely, however NCSR data can be evaluated for a selection of scenarios. For example, from an analysis of the cohort recording a positive iFOBT between 1 September 2019 and 29 February 2020, 27 per cent of total PFUF interactions recorded occurred after the date recorded for the participant's colonoscopy.
- Innovative follow-up models implemented in Australian and international contexts (see Box 2 in the body of the report) have shown that follow-up roles which have an expanded scope of practice (e.g. nurse navigators who schedule colonoscopies and triage patients) have the ability to achieve high diagnostic assessment rates, reduce waiting times and increase patient satisfaction.

  The PFUF officer's scope of practice (which is currently limited to *encouraging* compliance across the entire pathway) may be more effective in improving the rate and timelines of diagnostic assessment if it was expanded to include activities such as scheduling and prioritising colonoscopies; however, this needs to be balanced with the potential additional cost.

Opportunities:

- Review the appropriateness of timing intervals for GP and colonoscopy reminders with input from clinical experts.
- Consider alternate forms of PFUF communication which do not require simultaneous availability of the PFUF officer and recipient (e.g. email/SMS).
- Encourage states and territories to pilot innovative colonoscopy access models. It is envisaged these pilot models would involve reshaping aspects of the PFUF officer role to a scope of practice which directly facilitates the process of colonoscopy follow-up. This opportunity would require consultation with the states and territories to create stakeholder buy-in and facilitate integration with local colorectal departments, as well as engagement with GPs as potential referrers.
- Engage with PHNs and professional bodies (e.g. Royal Australian College of General Practitioners and Royal Australian College of Physicians) to promote a comprehensive set of educational materials which describe the NHMRC-approved clinical practice guidelines, the Program's full alignment with biennial screening recommendations, and recent changes to the MBS item codes for colonoscopy.
- Continue to support the ACSQHC with its implementation of the CCCS and monitor colonoscopy performance against colonoscopy quality standards.

Fidelity

The review explored the extent to which the Program was delivered as intended, including Program delivery, data collection and reporting, as well as the efficacy of governance structures.

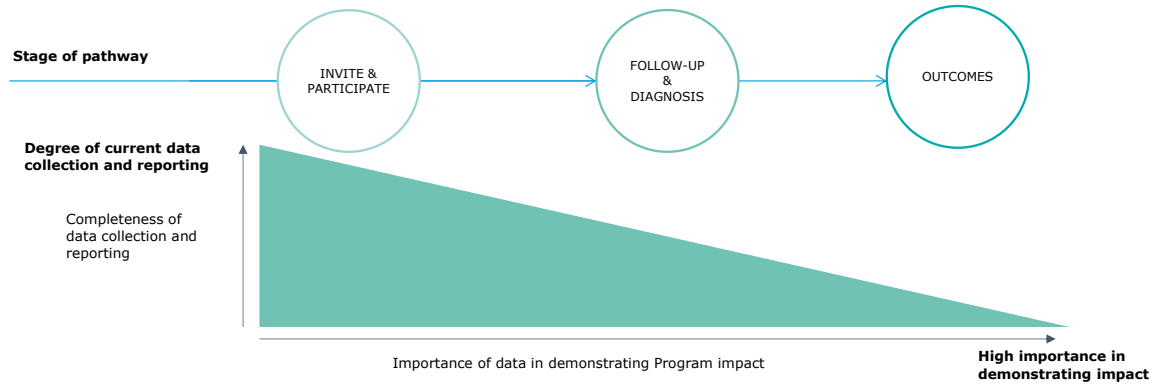
Program delivery

Overall, the Program was broadly delivered as intended in Phase Four. A key highlight was achieving biennial screening for people aged 50 to 74 earlier than expected in 2019. Other key activities included development of the HPP, implementation and evaluation of the Alternative Pathway pilot, and migration to the NCSR.

Data collection and reporting

Regarding data collection and reporting mechanisms, AIHW reporting highlights that data completeness and quality issues limit the feasibility of reporting on key Program indicators. As shown in Figure i, data collection and reporting is relatively complete at the screening pathway entry point (i.e. participation and iFOBT positivity rates), but gradually declines across the continuum. As a result, KPIs which are designed to monitor Program impact are often not able to be reported with an adequate level of certainty (e.g. adenoma and cancer detection rates, interval cancer rates etc.).

Figure i: Completeness of data collection across the participant pathway



Source: Deloitte Access Economics diagram, using Department of Health information.[4]

These challenges lie in the requirement for data provision – the NCSR reliably captures data related to activities where the Department has direct oversight (e.g. invitations and iFOBT results), however information provision from GPs, specialists and pathologists regarding their consultation with patients and the outcomes of diagnostic assessment is voluntary.

Further, the ability to assess cancer-related outcomes between Program participants and non-participants requires data linkage between the NCSR, jurisdictional cancer registries and the National Death Index. This type of data linkage is only performed on an ad hoc basis for bespoke projects. An assessment of cancer-related outcomes also requires time to elapse in order to report on mortality measures such as five-year relative survival. Both factors contribute to challenges in assessing the effectiveness of the Program in a timely manner.

External research

Program, sectorial and academic stakeholders consulted raised the importance of commissioning research targeted at improving the Program. It was noted that to date, there has been a limited number of Randomised Controlled Trials or other observational research studies conducted with the intent of examining changes to Program design and its impact on uptake and outcomes. Research of this nature is important for establishing an evidence-base, before deciding to change a Program feature at scale.

It was noted that now the Program is fully biennial, the next phase of the Program can shift from a focus on Program expansion to a focus on optimising Program design. In addition, transition to the NCSR provides the enabling infrastructure to better support targeted research. A number of opportunities to pursue research grants already exist (e.g. through the NHMRC or elsewhere), and external researchers could use these mechanisms to address the Program's key research objectives.

Governance

Regarding the efficacy of governance structures, the current overall structure, whereby the Department maintains decision-making responsibility but draws on the Clinical Advisory Group (CAG) for clinical advice and the Program Delivery Advisory Group (PDAG) for operational advice is appropriate. However, opportunities were identified to optimise Program governance mechanisms, including considering the inclusion of representatives from colorectal departments on PDAG, and improving communication by resetting expectations on information sharing across and between the various advisory groups.

Opportunities:

- Reconvene a working group with the goal of prioritising initiatives to address data gaps and agree on any required changes to the endorsed set of KPIs. The purpose of this group should be two-fold:
    - confirm an agreed revised set of KPIs and calculation approaches (see examples provided in Table 3.2 in the body of the report)
    - improve the feasibility of reporting against each indicator by prioritising initiatives and/or dedicated resourcing to address data gaps, such as data linkage or clinical interoperability, noting that a number of these initiatives may require detailed workplans and dedicated funding.

  This group should be set-up over a medium to long term period, given the timeframes, effort and stakeholder engagement required to oversee initiatives to improve data quality and completeness.
- Improve visibility of the target population's participation in other forms of bowel cancer screening, including via over-the-counter iFOBT kits or kits provided by clinicians. This would also allow a more accurate measure of the true Program participation rate.
- Promote the Program's research priorities to external researchers. External researchers should be encouraged to pursue research which is a priority of the Program. Current Program-related priority research areas should include the pilot projects suggested in the review to improve participation (see the 'Awareness and adoption' section below) and opportunities to validate emerging overseas innovations related to quantitative iFOBT readings in the Australian context.
- Re-configure PDAG to include jurisdictional representatives that can provide operational advice on contextual issues related to colonoscopy access.
- Reset the working relationship with all governance advisory group stakeholders to ensure needs are being met in regard to the purpose of each governance group and expectations on information sharing.

Awareness and adoption

The review explored awareness and adoption of the Program by clinicians and consumers, with a view to better understanding the key enablers and barriers to Program participation.

Overall, 92 per cent of consumers (in the current target population) surveyed were aware of the Program and 71 per cent of respondents to the clinician survey agreed that they had a very good understanding of the Program. However, consultations indicated understanding of the screening frequency is mixed owing to the recent changes to the screening interval – a policy change that was not announced via a large-scale communications campaign.

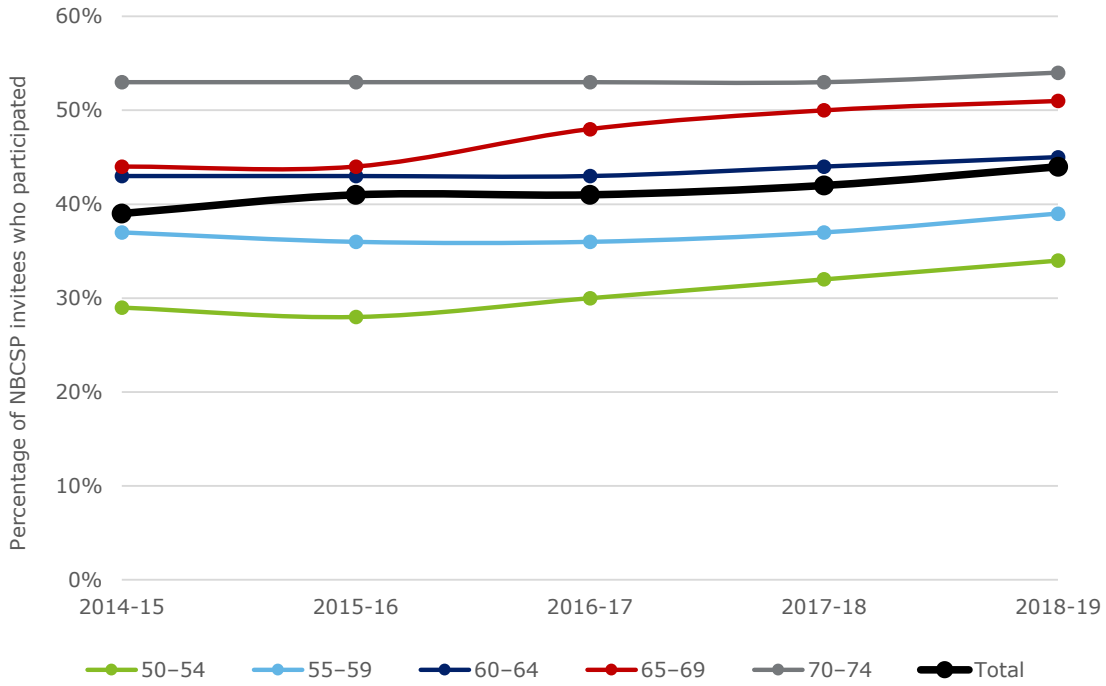
Program participation increased during Phase Four (approximately 41 per cent in 2015-16 rising to 44 per cent in 2018-19, as shown in Chart i), however participation rates remain relatively low compared to other Australian cancer screening programs as well as comparable programs across Europe and New Zealand. Improving the participation rate is therefore a key focus for the Program moving forward.

As shown in Chart i, in 2018-19, the participation rate among people aged 50 to 54 was 34 per cent, a rate that has gradually improved over time. The participation rate was 54 per cent for people aged 70 to 74 in 2018-19.

Several underlying factors may be contributing to older invitees participating at higher rates. Firstly, the re-participation rate for all invitees was recently calculated at 80 per cent. [vii,viii] As such, invitees at the upper end of the age bracket are more likely to have previously participated in the Program. Secondly, public health promotions regarding bowel cancer may implicitly or explicitly target older cohorts, resulting in higher participation. Findings from the consumer survey also suggest an attitudinal barrier among younger cohorts on the perceived 'need' for screening. Sub-groups with lower than average participation rates included Aboriginal and Torres Strait Islander people (23 per cent), residents in very remote areas (27 per cent), those who speak a language other than English at home (estimated at between 24 per cent and 33 per cent) and people with a disability (36 per cent).

[vii] The re-participation rate is defined as an invitee participating in the current screening round who also participated in their previous invitation round.
[viii] AIHW National Bowel Cancer Screening Program Monitoring Report (2020)

Chart i: NBCSP participation rate, by age, over time



Source: AIHW, *Cancer Screening programs: quarterly data* (2020).

The results of the stakeholder interviews and consumer survey identified a number of factors that enabled participation, as well as other factors that acted as a barrier.

Key enablers to Program participation included:

- **Pre-invitation letter.** A pre-invitation letter is considered best-practice in the mail-out cancer screening program literature and was cited by a number of stakeholders as important in increasing the readiness of participants (especially first-time participants).
- **Simplified kit instructions.** The use of plain English and illustrations were seen to be significant improvement to kit instructions by stakeholders consulted, particularly for people with low literacy levels.
- **'Peace of mind'.** The consumer survey found that approximately eight in ten people who participated in the Program did so, in part, for *'peace of mind'.*
- **Culturally tailored pathways for people from Aboriginal and Torres Strait Islander backgrounds.** *See the 'Appropriateness' section above for further detail on the Alternative Pathway Pilot.*

Key barriers to Program participation included:

- **Procrastination.** For the consumer survey respondents who received a kit and did not complete another form of screening, the number one reason for non-completion was *'wanted to do it but did not get around to it'* (61 per cent of non-completers[ix]).

[ix] Note: A non-completer is defined as an invitee who received a NBCSP kit but did not complete and return it, and did not complete another form of bowel cancer screening.

- **Perceived hygiene concerns.** Following procrastination, the number two reason for non-completion was perceived hygiene of the kit and/or personal embarrassment (54 per cent of non-completers).
- **Strict return postage requirements.** This was highlighted as a barrier for people residing in rural and remote locations due to their unique barriers in accessing post offices and post boxes at appropriate times. The consumer survey showed that the number one change to the Program that would encourage people from rural and remote regions to complete a kit next time was, *'I could return the test to a GP, pharmacy or pathology collection centre'*.
- **Underuse of primary care as a resource.** Currently, GPs are not involved in the screening pathway until the participant has completed the kit. There was consensus across stakeholders consulted that GPs, or other practitioners such as practice nurses or pharmacists, could act as a 'trusted advisor' and encourage participation in the Program, through providing education about the benefits of screening and encouraging compliance.

  GPs and practice nurses could also be used a resource to identify and 'opt-out' (via the HPP) patients for whom screening may not be appropriate (e.g. those with overt bleeding or where a colonoscopy is considered too risky) or those who have recently used other forms of screening.
- **Single mode of kit distribution**. Multiple stakeholders consulted held the view that the single mode of kit distribution (via the mail) may have contributed to use of alternative at-home kits. It was noted that GPs and pharmacists often promote screening as part of routine health checks, yet the timing of receipt of the Program kit may not align with the timing of these health checks, resulting in the use of more accessible kits through GPs and pharmacies.
- **The letter content and kit design.** The consumer survey found that 39 per cent of non-completers decide to not complete the kit after reading the kit instructions. This suggests that the kit and instructions are an important hook but can also act as a deterrent to participation.
- **Health literacy.** The consumer survey found that non-participants located in rural and remote areas and low socio-economic status were more likely to cite *'did not see the need'* as a reason for non-completion, as compared with other groups of non-participants.

  The survey also showed that people in these groups were more likely to decide not to complete the kit before reading the instructions, suggesting that mechanisms to overcome this barrier should occur outside of modifications to the kit itself (e.g. via education from a healthcare professional, through media campaigns or through messaging modifications to the pre-invitation letter, the packaging of the kit or the kit).
- **Fragmented and time-limited communications.** Evidence in the literature shows that public health media and communications campaigns are effective in facilitating behaviour change at their peak, but their benefits gradually diminish over time.[5,6] To date, the Program has not invested in long-term media and communications campaigns.
- **Accessibility for Culturally and Linguistically Diverse (CALD) groups.** The consumer survey showed that the number one change to the Program that would encourage non-completers from CALD backgrounds to complete a kit next time was '*the information provided showed someone I trust talking about screening'*, followed by *'I could see a demonstration through a cartoon or video'*

Opportunities:

- Implement sustained and coordinated media and communications campaigns. Campaigns should be national in nature (across jurisdictional and cancer charities, where possible) to promote a coordinated message that minimises fragmentation and duplication of effort.
- Modify kit contents and accessories to mitigate common reasons for non-completion. This may include an action plan for completion contained in the kit instructions (to overcome the procrastination barrier), and/or provision of accessories such as an opaque bag for fridge storage (to overcome perceived hygiene concerns).
- Explore options to better utilise the NCSR to improve participation. This could include electronic reminders, streamlined processes for completion of personal details, access to in-language communications, as well as personalised invitations based on Program screening history and/or demographic factors. However, given phone/email contact information is unavailable in the NCSR for first time screeners, mechanisms to collect this information from other government databases, such as MyGov, may be required.
- Use the primary care sector as a resource to promote participation through education and opportunistic provision of kits. Primary care professionals such as GPs, practice nurses and pharmacists, are important in promoting patient participation in the Program and counselling and advising patients throughout the screening, diagnosis, and treatment process.

  In addition, the HPP and its integration with primary care management software provides important enabling infrastructure to facilitate the role of primary care in promoting participation. The HPP could be used:

  - Within existing Program parameters. For example, by initiating conversations about bowel cancer screening, confirming eligibility to participate and appropriate postage details, and following-up patients who have been sent a kit but not completed it.
  - Beyond current Program parameters. For example, invitees could collect a kit from a registered community pharmacy or a GP, and their participation could be recorded by a practitioner who notifies the NCSR through the HPP. Alternatively, the pre-invitation letter could include a voucher to collect the kit from a pharmacy or a practice.
- Consider piloting sample drop-off points. Trials of this nature should initially be targeted at people in regional areas due to their unique challenges in complying with the strict return postage requirements.
- Scale up the Alternative Pathway pilot, as appropriate in other population groups. This includes other locations targeted at Aboriginal and Torres Strait Islander people, as well as exploration of how the pilot could be tailored to address access barriers faced by invitees from CALD backgrounds.

Effectiveness

The review explored the extent to which the Program is maximising benefits and minimising harm to individuals who participate in the Program.

As discussed earlier under 'data collection and reporting', data linkage is required between the NCSR, jurisdictional cancer registries and the National Death Index to assess the impact of the Program on earlier detection and better survival. A data linkage project of this nature was out of scope for the review, and thus reference is made to AIHW's 2018 project that linked data from Program invitees between 2006 and 2010 to data from jurisdictional cancer registries for people diagnosed with bowel cancer from 2006 to 2015.

The AIHW report observed:

- **Stage at detection.** Among invitees, those with screen-detected bowel cancers were more likely to be diagnosed at an earlier stage (1.71 times as likely), compared with bowel cancers later diagnosed in the invitees who did not participate.
- **Survival.** Among Program invitees diagnosed with bowel cancer, the risk of death from bowel cancer was half that of participants whose cancer was screen-detected, compared to invitees that did not participate.

These findings confirm that Phase One and Two of the Program effectively contributed to reducing morbidity and mortality from bowel cancer in Australia. However, the ability to compare these findings with Program cohorts screened biennially would be valuable.

Alongside the benefits of the Program, there are associated harms that may occur as a result of participation. All colonoscopies have a risk of adverse events and participants that record a false positive iFOBT will have associated anxiety until their colonoscopy results are received. The Program minimises harm in this respect, as it uses a test with a high diagnostic value, relative to overseas bowel cancer screening programs.

However, the availability of complete data sets to inform the positive predictive value of the iFOBT (i.e. the extent to which a positive iFOBT reflects true detection of a lesion) would inform a more robust assessment of Program harms. This assessment would also benefit from more complete data on adverse events post colonoscopy for Program participants (e.g. through a data linkage project with hospital inpatient datasets), as currently the collection of this data is voluntary.

Efficiency

The review undertook a cost-effectiveness analysis to assess the value for money of the current configuration of the Program (biennial screening for those aged 50 to 74) relative to no screening, as well as relative to other target age ranges.

Whole of population

A cost-effectiveness analysis (CEA) assesses the value for money of a particular policy or program. A CEA calculates the incremental net costs and benefits of an intervention relative to a comparator, by providing evidence to answer the question – *do the extra benefits outweigh the extra costs?*

A CEA was performed to assess the value of the current configuration of the Program (i.e. biennial screening for those aged 50 to 74 using observed participation rates from Phase Four[x]) relative to no screening. In addition, scenario analysis was performed on different eligible age ranges and

[x] A participation rate of 44 per cent was based on the Program participation rate reported across January 2018 to December 2019.

participation rates to assess how changes to Program scope and uptake may impact cost-effectiveness.

The analysis showed the Program in its current form is highly cost-effective relative to no screening, at a value of $1,931 per Disability Adjusted Life Year (DALY) avoided, when evaluated from a societal perspective; and $8,992 per DALY avoided, when evaluated from a healthcare system perspective. Both values are below the commonly used willingness-to-pay threshold of $50,000 per DALY averted.

Screening age brackets of 45 to 74 and 40 to 74 were also modelled as alternative scenarios, relative to no screening.

- **45 to 74**: This age bracket was found to be more cost-effective than the current target age range from a societal perspective ($1,381 per DALY avoided), but less cost-effective from a healthcare system perspective ($9,936 per DALY avoided).
- **40 to 74**: This age bracket was found to be both less cost effective than the current target age range from a societal perspective ($2,012 per DALY avoided) and less cost-effective from a healthcare system perspective ($12,021 per DALY avoided).

These results are broadly consistent with Lew et al. (2018), which found that commencing the Program at age 50 is marginally more cost effective than commencing at age 45 or 40, when evaluated from a healthcare system perspective.[7]

Scenario analysis of higher participation rates and diagnostic assessment rates showed that there is benefit in prioritising Program investment efforts to improve Program participation and the rate of diagnostic assessment, as both factors are associated with improved cost-effectiveness ratios.

Aboriginal and Torres Islander people

Aboriginal and Torres Strait Islander people represent a distinct cohort within the broader Australian population in relation to their experience of bowel cancer. Consequently, there is merit to analysing cost-effectiveness considerations for Aboriginal and Torres Strait Islander people separately.

In a pre-published report '*The potential for tailored screening to reduce bowel cancer mortality for Aboriginal and Torres Strait Islander peoples in Australia: modelling study*', Lew et al. analysed the cost-effectiveness of different target age ranges for the Aboriginal and Torres Strait Islander cohort.

Overall, Lew et al. reports that the Program is cost-effective for the Aboriginal and Torres Strait Islander cohort at $11,927 per life-year saved compared to a baseline of no-screening, though this estimate is higher than the cost per life-year saved attributed to the broader Australian Program cohort in previous Lew et al. papers. Contributing factors for this result include lower modelled incidence rates, lower participation and lower diagnostic assessment rates in the Aboriginal and Torres Strait Islander cohort.

Lew also modelled scenarios to assess the cost-effectiveness of increasing the Aboriginal and Torres Strait Islander participation rate, as well as extending the screening age cohort for this population. The following results were reported:

- At the current participation rate, extending the screening age cohort from 50 to 74 (the status quo) to 45 to 74 was cost effective at $28,145 per life year saved.[xi]
- With the current screening age cohort, increasing the participation rate from ~20 per cent to ~40 per cent was also cost-effective at $25,636 per life-year saved.[xii]

[xi] At the current Aboriginal and Torres Strait Islander participation rate, Lew also reports an incremental cost-effectiveness ratio of $30,384 per life-year saved for a 40 to 74 screening age cohort, compared to a 45 to 74 screening age cohort. However, given the current Program policy settings of a 50 to 74 screening age cohort, ICERs using 50 to 74 as the comparator are the most relevant for the Program at this stage.
[xii] A participation rate of ~40 per cent reflects the current overall participation rate in the Program. As well, any costs associated with strategies to improve the participation rate were not included in the modelling process.

Lew concludes, "The evidence … supports cost-effective screening for Aboriginal and Torres Strait Islander people in their forties, but not for the general population in their forties" (p5).[8]

Conclusions:

- Overall, the CEA results show that the Program is highly cost-effective compared to a no screening scenario. The analysis found that the most cost-effective entry age varied slightly depending on the perspective taken, however, overall, there was a marginal difference between starting screening at age 45 or 50. Deciding which entry age is most cost-effective depends on the extent of value placed on a societal perspective versus a healthcare system perspective.
- A positive return on investment could be achieved by prioritising efforts to improve Program participation and the rate of diagnostic assessment, as both factors are associated with improved outcomes and cost-effectiveness ratios.
- Based on Lew et al.'s (pre-published) findings and conclusions, it is worthwhile to consider lowering the starting screening age for Aboriginal and Torres Strait Islander people. When considering a policy change to the Program it is necessary to consider both value for money and equity of access considerations with a view to closing gaps in health disparities for certain population sub-groups. It is on this basis the review supports Lew et al.'s conclusion that there is an opportunity to consider lowering the starting screening age for Aboriginal and Torres Strait Islander people but not the general population.
- Given the important role of the Alternative Pathway Pilot in increasing participation for Aboriginal and Torres Strait Islander people it is prudent to consider coupling any lowering of the screening starting age for Aboriginal and Torres Strait Islander people with a scale up of the Alternative Pathway Pilot for this group. This is particularly important given there is a positive correlation between age and participation.

Opportunities:

- Consider the feasibility of lowering screening entry age to 40 or 45 for Aboriginal and Torres Strait Islander people, coupled with scale up of the Alternative Pathway pilot for this group.

1 Introduction

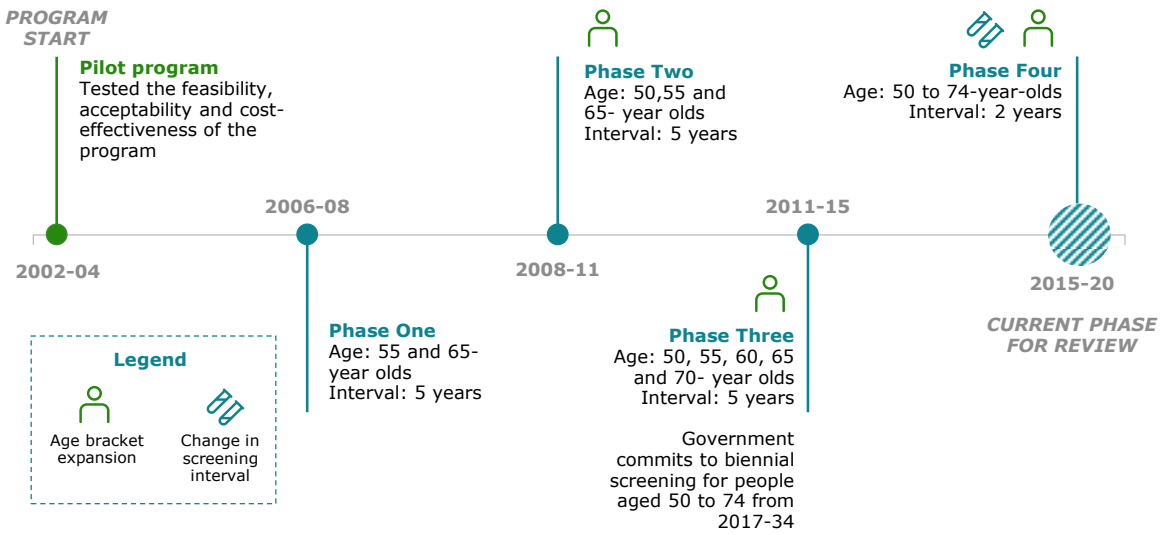
This chapter provides an overview of the Program, the scope of the review, the methodology and the structure of this Report.

1.1 Background

In 2017, there were 15,206 cases of bowel cancer diagnosed in Australia, and 90 per cent of cases were in people aged 50 years or older.[9] Both the crude rate and the age-standardised rate of bowel cancer are projected to decline between 2017 and 2021, while the number of cases diagnosed is still projected to slightly increase. Bowel cancer incidence can be reduced through the early detection of pre-cancerous growths, and the majority of early stage bowel cancers can be successfully treated. As such, this highlights the potential impact of a screening program with high uptake,[10] and the importance of appropriate investment in prevention and early detection.

The National Bowel Cancer Screening Program (the NBCSP or the Program) was implemented in 2006 by the Commonwealth Department of Health (the Department) to address the rising incidence and mortality of bowel cancer. The NBCSP was implemented in a phased approach, starting with limited age brackets in 2002 and extending to full biennial screening for those aged 50 to 74 years as part of Phase Four. A policy timeline is provided in Figure 1.1.

Figure 1.1: NBCSP policy timeline



Source: Deloitte Access Economics.

In addition, Phase Four included a transition from the National Bowel Cancer Screening Register (administered by Services Australia) to the new National Cancer Screening Register (NCSR). Migration to the NCSR occurred in September 2019, following migration for the National Cervical Cancer Screening Program in 2017.

The NCSR provided digital infrastructure for the collection, storage, analysis and reporting of screening data. It facilitates invitations for screening, mailing of test kits, participant support, clinical decision making, and seeks to improve ease of reporting for health care providers. Another key change as part of Phase Four included the pilot of the National Alternative Pathway to the NBCSP (Alternative Pathway) for Aboriginal and Torres Strait Islander people.

1.2 Review of the NBCSP

In September 2020, the Department commissioned Deloitte Access Economics to undertake an independent review of the Program with a focus on the implementation of Phase Four. Researchers from the Centre for Behavioural Economics, Society and Technology at the Queensland University of Technology supported the review. A review of the Program had not been undertaken since 2012 (Phase Two).

The purpose of the Program review was to generate new and novel evidence on the implementation, outcomes, and cost-effectiveness of providing the NBCSP. Understanding the Program's strengths and areas for future improvement or innovation will enable the Department to make informed, evidence-based decisions regarding ongoing Program investment to maximise the benefits and minimise harms for all participants.

The scope of the review included aspects related to the implementation of the Program as well as the outcomes achieved for participants and the broader healthcare system. Key focus areas for assessment included:

- Program adoption, efficacy, efficiency (i.e. value for money assessment), equity of access and appropriateness of the clinical pathway
- attitudes, behaviours and the drivers of participation, with a view to using this information to maximise uptake
- effectiveness of Program delivery, including recruitment and invitation methods, governance, diagnostics, reporting and key performance indicators (KPIs)
- new Program features including enhanced data collections, reporting and pathway pilots
- compliance with the Phase Four Policy Framework.

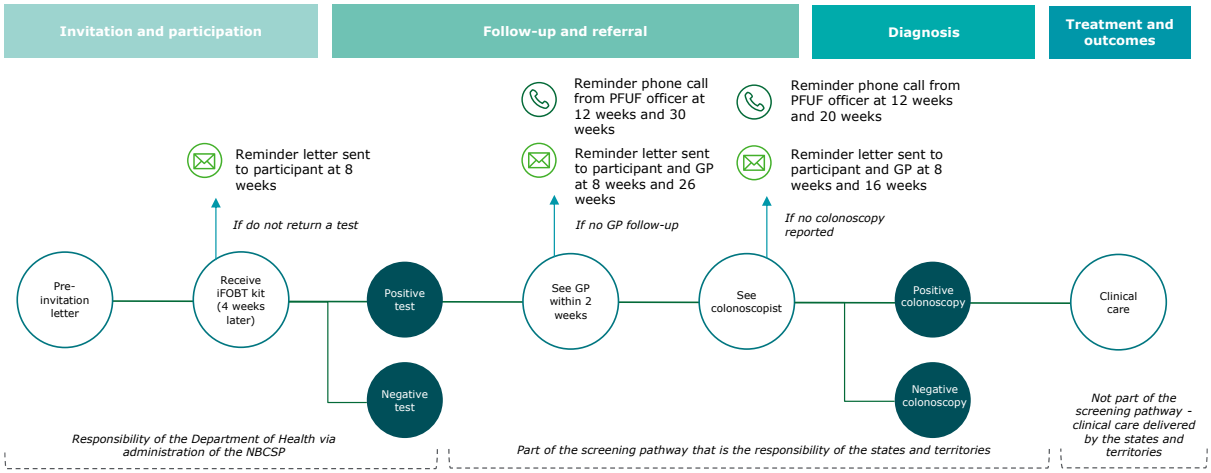
1.2.1 Out of scope

An evaluation of the functionality of the NCSR will be conducted separately, and was thus out of scope for the review. The Healthcare Provider Portal (HPP) is a second piece of enabling infrastructure for the Program, which was piloted during Phase Four. An evaluation of the implementation and functionality of the HPP was also out of scope for the review.

1.3 NBCSP participant clinical pathway

An overview of the NBCSP participant pathway and how it aligns with the five steps in the Australian Population Based Screening Framework (recruitment, screening, assessment, diagnosis and outcomes) is provided in Figure 1.2 and described in further detail below.

Figure 1.2: NBCSP participant pathway



Source: Deloitte Access Economics diagram, using Department of Health information.[11]

Invitation and participation
The invitation part of the pathway starts with a participant (aged 50 to 74 years) receiving a pre-invitation letter, followed by a home test kit four weeks later. The participant then completes the test kit and the Participant Details Forms and sends it directly to the pathology laboratory by returning a pre-paid envelope to a post office or a pillar box (in the afternoon before 6pm). The kit results (both positive and negative results) will be shared with the participant and the nominated general practitioner (GP). If the result is negative, the patient will exit the pathway and be sent another kit in two years.

Follow-up and referral (part of usual care model)
If the immunochemical faecal occult blood test (iFOBT) result is positive, it is recommended that the participant talks to the GP within two weeks. If the NCSR does not receive a record of the participant seeing a GP, a reminder letter will be sent at 8 weeks with a phone call from a Participant Follow Up Function (PFUF) officer at 12 weeks. If the NCSR does not receive a record of the participant seeing a GP, another letter will be sent at 26 weeks, and a reminder phone call from a PFUF officer at 30 weeks.

The Guidelines advise the GP to ask the participant about symptoms and family history, will suggest next steps and may refer the participant to a colonoscopy. If no colonoscopy is reported a reminder letter will be sent at 8 weeks and 16 weeks post GP follow-up and a reminder phone call from a PFUF officer will occur at 12 weeks and 20 weeks post GP follow-up.

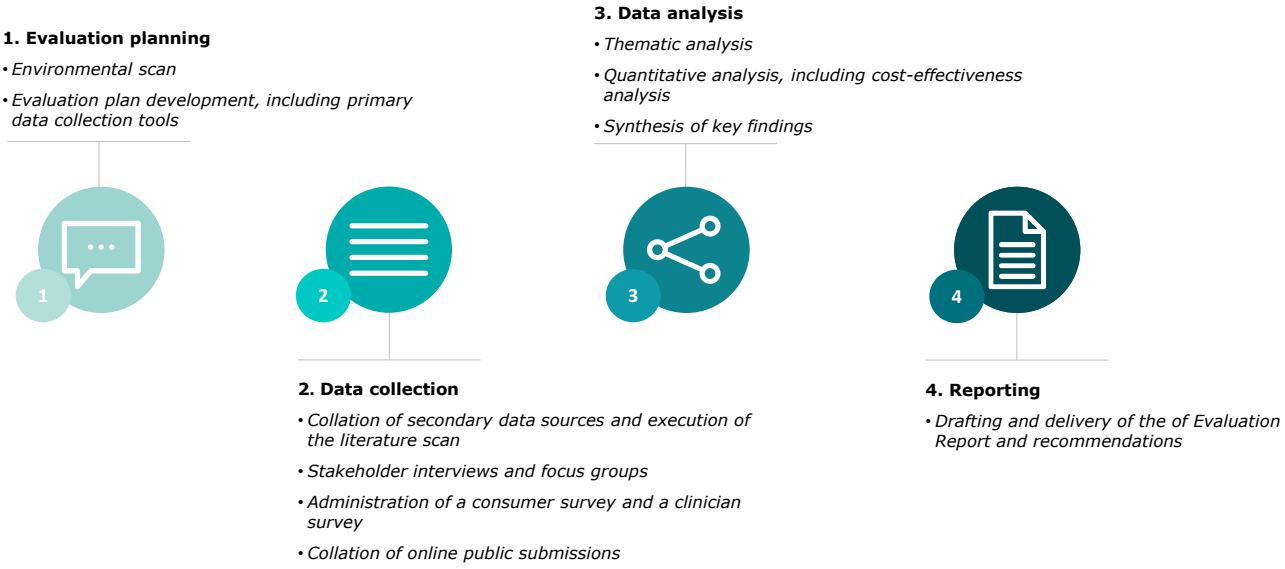
Diagnosis (part of usual care model)
If the colonoscopy detects abnormalities, a specialist and GP will discuss the results with the participant and suggest options for follow-up as part of 'usual-care' protocol. This clinical care continues outside of the Program. If the colonoscopy detects no abnormalities, a specialist and GP will discuss the results with the participant; the participant will be re-invited to screen four years following the negative colonoscopy.

Treatment and outcomes
Following a positive colonoscopy, the participant will undergo clinical care outside of the screening pathway. Stage at diagnosis and mortality outcomes will be assessed, with details recorded in the Australian Cancer Database (ACD) and jurisdictional cancer registries according to reporting guidelines.

1.4 Methodology

Deloitte Access Economics undertook a four-step approach to inform the review over the period September 2020 to April 2021. Figure 1.3 provides an overview of this approach, with additional detail provided in subsequent paragraphs.

Figure 1.3: Overview of approach to the review



Source: Deloitte Access Economics.

1.4.2 Evaluation planning

During the project inception phase, an Evaluation Plan was co-designed with the Department. The Evaluation Plan included a program logic, set out the key lines of investigation to pursue as part of the evaluation, and identified data sources to inform each area of the investigation. The Evaluation Plan canvassed both an implementation evaluation and an outcome evaluation. The key questions assessed underneath each evaluation type is outlined in Table 1.1.

Table 1.1: Evaluation questions used to guide the scope of the review

Domain	Evaluation question(s)
Implementation evaluation	
Appropriateness	To what extent is the Program facilitating the provision of timely, appropriate, high-quality, and safe diagnostic assessment services for Program participants?
Fidelity	Was the Program delivered as it was intended? To what extent did Phase Four address the recommendations of the previous evaluation? To what extent are governance structures operating effectively?
Awareness and adoption	To what extent is the Program achieving participation levels that maximise the population benefit of early detection of bowel cancer in the target population (50 to 74-year olds)?
Sustainability	Are there opportunities to improve the Program and maximise its ability to meet its policy objectives?
Outcome evaluation	
Effectiveness	To what extent is the Program maximising the benefits and minimising harm to individuals participating in the Program?

Domain	Evaluation question(s)
	Are there opportunities to change or enhance the role of states and territories to better support the achievement of NBCSP outcomes?
Equity	To what extent is the Program enabling equitable access for the target population, irrespective of their geographic, socioeconomic, disability or cultural background, to achieve representative participation?
Efficiency	To what extent is the Program cost effective?

1.4.3 Data collection

Following the planning phase, data collection occurred over the period November 2020 to January 2021. A mixed-methods approach was adopted, drawing upon a range of primary and secondary data sources. The sections below provide an overview of this mixed-methods approach.

Secondary data collection

The review drew upon the following secondary data sources:

Australian Institute of Health and Welfare (AIHW) Program Monitoring and Operational Reports. These reports routinely record data on the Program against the KPIs listed in the Phase Four Policy Framework, including participation rates, timeliness of follow-up, compliance with the clinical pathway, and adverse events (data permitting).

National Cancer Screening Register. The NCSR is a register containing a single electronic record for each person in Australia who receives an invitation to participate in the NBCSP. Data from the NCSR was used to measure indicators relating to participation rates, compliance with the clinical pathway, as well as the impact of the PFUF officers on follow-up rates.

Literature scan on best practice approaches. A literature scan was undertaken to identify and appraise similar cancer screening programs in local and overseas jurisdictions, with a view of drawing comparisons and learnings. Additionally, the literature scan identified and appraised alternative testing options, screening intervals and age brackets. The literature scan comprised 82 articles, addressing one of more of the following questions:

- for comparable screening programs, how do they perform against key implementation performance indictors (e.g. participation, timeliness etc.)?
- what opportunities or innovations can be learned from comparable programs to inform improvements to the NBCSP?
- what is the diagnostic value of alternative testing options to the iFOBT?
- what is the most appropriate screening interval and target population for the NBCSP?

Primary data collection

The objective of the primary data collection was to gain a holistic understanding of the Program's implementation and outcomes, by soliciting a broad range of views, gauging opinion and gathering important qualitative insights across a diverse group of stakeholders.

Stakeholders were consulted through a virtual semi-structured interview or focus group. In total, 67 consultations were undertaken with a total of 117 stakeholders participating. Stakeholders consulted included:

- members of the Clinical Advisory Group (CAG)
- members of the Program Delivery Advisory Group (PDAG)
- relevant federal department branches and divisions
- PFUF officers
- vendors

- clinicians
- government agencies
- time-limited Program working groups
- Primary Healthcare Networks (PHNs)
- peak bodies
- academics
- non-government organisations
- state and territory policy officers.

A complete list of organisations consulted is provided in Appendix A. In addition, a consumer survey and a clinician survey were administered.

The **consumer survey** was administered by a market research provider in December 2020 and remained in field for a period of two months. Respondents to the survey were sourced from the market research provider's panel, where the provider runs "open enrolment" and "by-invitation-only" recruitment campaigns. Participation was voluntary, with any respondents below the age of 50 screened out. The sample included Program participants and non-participants, including those who screened via other methods.

The survey achieved a sample of over 2,000 responses, with a further sample of 200 respondents who identified as Culturally and Linguistically Diverse (CALD). Prior to analysis, the sample was standardised to the Australian population by age and gender. Responses were complete, and thus statistical techniques to deal with missing data were not employed.

The **clinician survey** was administered in December 2020 and remained in field for a period of two months. The clinician survey achieved a sample of 147 completed responses[xiii], comprising: GPs (36 per cent), colorectal surgeons (21 per cent), practice nurses (20 per cent), Primary Health Network officers (5 per cent), other public health and/or policy officers (3 per cent), general surgeons (3 per cent), and other (13 per cent).

Online submissions were also received through the Department's website. A total of 36 submissions were received from a range of stakeholders including non-government organisations, professional bodies, clinicians, and consumers.

It should be noted that primary data collection to inform the review was carried out over the period October 2020 to February 2021. The calendar year 2020 included unique challenges and changes which affected the Program's business as usual processes. This included the impact of the 2019/2020 bushfires and COVID-19 on Program operations, as well as the migration to the NCSR. While stakeholders were asked to reflect on the complete Phase Four period, observations from stakeholders should be considered in light of these factors.

1.4.4 Data analysis

The analytical techniques used to mine, synthesise and summarise the key findings across each of the data sources is described below.

Analysis of qualitative data

All insights gathered through the various qualitative data collection activities (i.e. interviews, literature scan, qualitative questions in surveys) were analysed thematically using a structured process of review, reflection, and refinement:

- **review:** collation of information, and coding of topics and key issues
- **reflection:** team discussion of the key emergent themes, including an assessment of their 'substantive significance'
- **refinement:** describing the key themes clearly and concisely.

[xiii] The clinician survey also received 90 in-progress responses, which were not included in the subsequent analysis.

Analysis of quantitative data

The analytical approaches used to analyse quantitative data included:

- descriptive statistics to identify key trends and patterns over time
- benchmarking of results across regions and subgroups
- correlation analysis to understand drivers of outcomes (e.g. participation rates)
- cost-effectiveness analysis (using a cohort Markov model) to understand the cost per Disability Adjusted Life Year (DALY) averted as a result of the Program compared to the comparator of no screening, with sensitivity analysis performed to assess the impact of alternative age brackets, participation rates and diagnostic assessment rates.

1.4.5 Reporting

The emergent findings were synthesised across all data sources and summarised by each evaluation question in the Evaluation Report (this document). In response to the key findings generated through the review, the report culminates in a set of opportunities to guide the ongoing improvement and sustainability of the Program.

1.5 Limitations of the review

The review of Phase Four of the Program was limited by the following factors:

Data Quality: A longstanding challenge to the Program is the non-compulsory provision of data related to participant outcomes from stakeholders. While the NCSR is able to capture data related to activities where the Department has direct oversight (e.g. invitations and iFOBT results), participant follow-up with primary health care providers and specialists is not systematically captured. This issue affects the reporting of key Program performance indicators, notably diagnostic assessment rates, adenoma and colorectal cancer detection rates, interval rates, and adverse events. Data reporting issues associated with these indicators are summarised annually in the AIHW's publicly available Program Monitoring Reports.

Consequently, the review had limited ability to reliably report on participant follow-up rates, colonoscopy outcomes and adverse events.

Inability to compare cancer-related outcomes for participants vs. non-participants: To assess outcomes of the Program, data linkage is required between:

- information on Program participants and non-participants in the NCSR
- diagnosis information from jurisdictional cancer registries
- death records from the National Death Index.

An updated data linkage study was not in scope for the review. The most recent project of this nature was the 2018 AIHW report: *Analysis of bowel cancer outcomes for the National Bowel Cancer Screening Program*, which used data from Program invitees between 2006 and 2010. In addition, significant lag times are required between the cohort under analysis and the project study date in order to compare incidence and mortality outcomes for Program participants and non-participants. This precluded the ability to report cancer-related outcomes specifically linked to Phase Four. In the absence of Phase Four-specific data, the review instead refers to the 2018 AIHW report as an indication of the impact of the Program on earlier detection and better survival.

1.6 Structure of this report

The remainder of the report is structured as follows:

Chapter 2: Appropriateness. This chapter addresses the appropriateness of the Program design, including the clinical pathway, alternative pathway pilots, and diagnostics.

Chapter 3: Fidelity. This chapter addresses the extent to which the Program was implemented as intended, canvassing Program delivery and data collection and reporting aspects, as well as the efficacy of Program governance structures.

Chapter 4: Awareness and adoption. This chapter addresses the extent to which consumers and clinicians are aware of, and have adopted, the Program.

Chapter 5: Effectiveness. This chapter addresses the extent to which the Program was effective in achieving its stated objectives, including in supporting earlier detection and reducing mortality.

Chapter 6: Efficiency. This chapter addresses the cost-effectiveness of the Program relative to no screening, across different age brackets and participation rates.

Chapter 7: Concluding remarks and opportunities for improvement. This chapter provides concluding remarks on the Program and summaries the key opportunities for improvement to maximise benefit for the population.

Note: A separate chapter focused on the domain of Equity is not included, as equity considerations are included in the Chapter 2 (section 2.1.1.2 and section 2.1.1.6) and Chapter 4 (section 4.1.3). A separate chapter on Sustainability is not included as each chapter concludes by considering the key opportunities to improve the Program. In addition, a consolidated summary of the key opportunities to improve the Program is included in Chapter 7.

2 Appropriateness

This chapter addresses the appropriateness of the Program design, including the clinical pathway, alternative pathway pilots, and diagnostics.

2.1 To what extent is the Program facilitating the provision of timely, appropriate, high-quality, and safe diagnostic assessment services for Program participants?

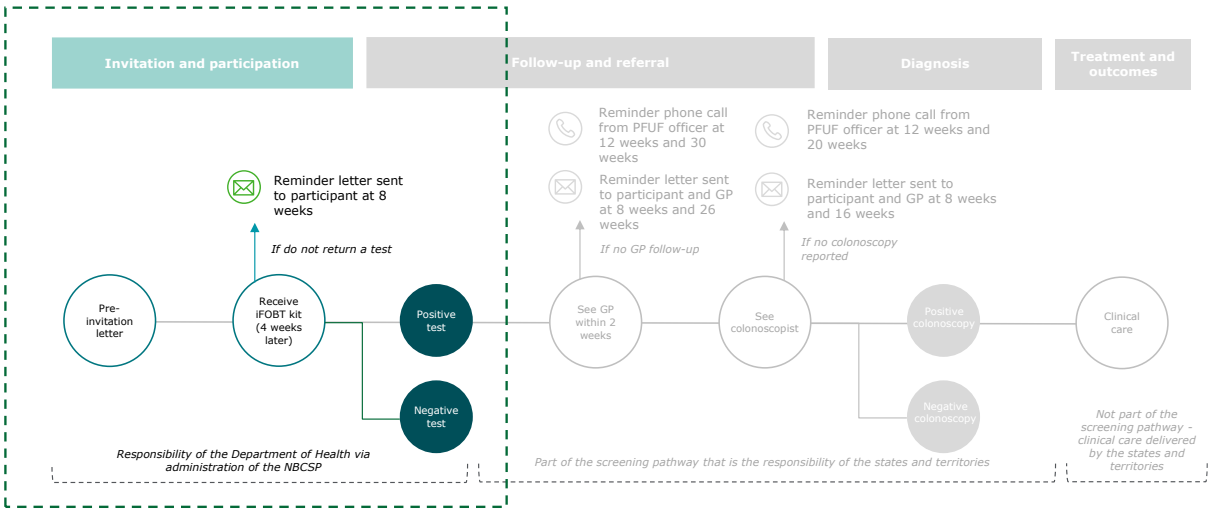
This section outlines the appropriateness of different aspects of the clinical pathway, encompassing:

- invitation and participation
- follow up and referral
- diagnosis.

2.1.1 Invitation and participation component of the pathway

This subsection outlines the appropriateness of the invitation and participation component of the clinical pathway, including the age bracket and screening interval, kit distribution methods, kit instructions, as well as the diagnostic appropriateness of the iFOBT.

Figure 2.1: Invitation and participation component of the NBCSP participant pathway



Source: Deloitte Access Economics using Department of Health information.[12]

2.1.1.2 Age bracket and screening interval

The current age bracket and screening interval reflects best practice and the economic evidence at a whole-of-population level.

The Program's age bracket and screening interval (biennial for people aged between 50 and 74) is aligned with the NHMRC-approved *Clinical practice guidelines for the prevention, early detection, and management of colorectal cancer*. The Guidelines (last updated in 2017 and approved until October 2022), recommends iFOBT testing every two years, starting at age 50 and continuing to age 74 for those with average risk of bowel cancer and without relevant symptoms.[13]

With regard to the economic evidence, a cost-effectiveness analysis was undertaken as part of the current review (presented in Chapter 6). The analysis found that commencing screening at age 50 was more cost-effective than commencing screening at age 45, when evaluated from a healthcare

system perspective, but slightly less cost-effective when evaluated from a societal perspective. However, overall, across both perspectives, there was a marginal difference between the cost-effectiveness ratios for both screening entry ages.

These results are consistent with an Australian study from 2018 which found that starting screening at age 50 was the most cost-effective entry age, when evaluated from a healthcare system perspective.[14] This study also highlighted the burden to colonoscopy services if the age bracket was expanded, estimating a demand increase of 3 to 14 per cent if the age bracket was lowered to 45.

When compared with other countries using FOBT kits via a mail-out method, Australia already targets the widest age bracket, with most countries targeting individuals aged 60 to 74, or 65 to 74 (see section 4.1.3 for a more complete overview of the characteristics of comparable overseas programs). It is noted that the target age bracket for the colonoscopy-based screening program in the United States was recently lowered to age 45, however there are several country-specific factors underlying this change (as described in Box 1).

Regarding stakeholder sentiment, stakeholders broadly agreed that Program resources may be more optimally invested in increasing participation in the existing cohort (i.e. reaching older unscreened individuals) rather than expanding the age bracket.

Box 1: Insights from the recent age bracket expansion in the United States compared to Australia

In October 2020 the US Preventative Services Taskforce recommended lowering the age bracket for colonoscopy-based colorectal cancer screening from 50 to 74 to 45 to 74. The draft recommendation was based on data showing that bowel cancer incidence in 45 to 49-year olds is similar to the incidence rates for those aged 50-years and older (before accounting for the effect of screening).[15]

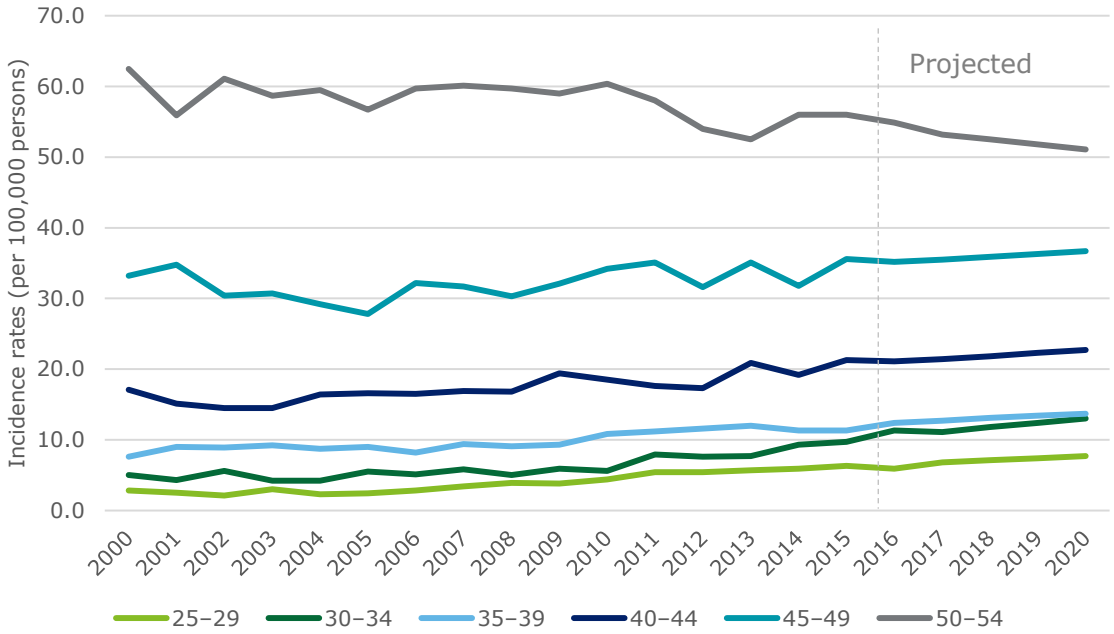
However, it should be noted that in comparison to the Australian Program, participation in the United States Program is relatively high, at 67 per cent of eligible adults in 2016, supporting the investment in younger age groups.

With bowel cancer incidence rates rising in younger age groups, the appropriateness of the target age bracket should continue to be monitored over time.

Stakeholders consulted agreed that while the current target age bracket is appropriate, there is a trend of rising bowel cancer incidence rates for younger age groups (shown in Chart 2.1), and the appropriateness of the target age bracket should continue to be monitored.

AIHW statistics show that the incidence rate for those under the age of 50 has increased at a faster rate than for those over the age of 50, however the current rates are still relatively low compared to the rates for older age groups. For example, in 2020, the incidence of bowel cancer in 50 to 54-year olds was 51 per 100,000 persons, compared to 37 per 100,000 persons for 45 to 50-year olds.[16] This is noted with the caveat that trends over time are not directly comparable between age brackets over and under age 50, as recent rates for people over age 50 are affected by the impact of the Program on adenoma detection, which leads to a reduction in cancer incidence.

Chart 2.1: Bowel cancer incidence rates, by age, 2000 to 2020



Notes: Trends over time are not directly comparable between age brackets over and under age 50, as recent rates for people over age 50 are affected by the impact of the Program on adenoma detection, which leads to a reduction in cancer incidence.

Source: AIHW, *Cancer data in Australia*, November 2020.

Stakeholders noted that if the age bracket was lowered, a risk-stratified approach could be considered. However, it was agreed that more evidence is required to determine what physiological and behavioural factors could be used to objectively identify those at elevated risk (noting those with family history should already be undergoing surveillance with colonoscopy).

Consider feasibility of lowering screening entry age to 40 or 45 for Aboriginal and Torres Strait Islander people, coupled with scale up of the Alternative Pathway pilot for this group.

Table 2.1 shows that bowel cancer incidence rates are lower for Aboriginal and Torres Strait Islander people relative to non-Aboriginal and Torres Strait Islander people, however survival rates are poorer. Worse survival outcomes may reflect cancer being detected at a more advanced stage.[17] Evidence from the NSW Cancer Registry also showed that Aboriginal and Torres Strait Islander people were diagnosed an average of seven years younger than the non-Indigenous population.[18]

Recognition of worse outcomes in Aboriginal and Torres Strait Islander people diagnosed with bowel cancer has prompted research regarding whether lowering the age bracket may be beneficial in this cohort. Please refer to section 6.1.5 for a review of Lew et al. (pre-published) on this issue. Any decision to lower the age bracket for Aboriginal and Torres Strait Islander people should consider the existing barriers to participation in this cohort, and associated investment in alternative pathways to optimise participation across the screening pathway.

Table 2.1: Bowel cancer incidence (per 100,000 persons) and five-year relative survival rates in 2016, by age, Indigenous and non-Indigenous Australians

Age	Indigenous population	Non-Indigenous population
25 to 44	Incidence: 8.7 Five-year survival: 50.4%	Incidence: 9.1 Five-year survival: 71.8%
45 to 64	Incidence: 64.1 Five-year survival: 61.1%	Incidence: 70.4 Five-year survival: 72.1%
65+	Incidence: 242.5 Five-year survival: 55.1%	Incidence: 295.6 Five-year survival: 64.7%

Source: AIHW, *Cancer in Aboriginal and Torres Islander people in Australia*, March 2018.

2.1.1.3 Kit distribution methods

The mail-out approach (with pre-invitation letter) is considered broadly appropriate.

The mail-out approach with pre-invitation letter is consistent with best practice as a way of increasing participant readiness and promoting participation.[19] Many stakeholders agreed that a mail out approach is appropriate, noting that other methods of kit provision would not achieve broad coverage of the population in an equitable manner. In addition, as people are mailed kits directly, there is no reliance on people's awareness of bowel cancer screening or motivation to seek out more information to participate in the Program.

Despite the merits of the mail-out approach, there are some indications that not all eligible Australians are receiving their kits. The consumer survey found that 9 per cent of eligible participants (who did not opt-out of the Program) had not received a kit in the past two years. Potential contributing factors cited through stakeholder consultations and program advisers included:

- **Incorrect addresses in Medicare**. It was noted that people are often unaware of the importance of updating Medicare details or checking that Medicare details are up to date.
- **Postal issues for individuals residing in rural and remote locations**. Stakeholders noted that postal services do not deliver to certain remote regions and that consumers are often not aware they can update their address for kit delivery to a PO box.

A Healthcare Provider Portal (HPP) linked to the NCSR was implemented in October 2020. The portal allows healthcare practitioners to access and submit screening data electronically. With patient consent, the HPP also allows practitioners to update participant details, nominate an alternative postage address (e.g. a GP or community health centre), order a kit (or replacement) for an eligible participant, and to opt-in or opt-out their patients to the Program. Integration between the NCSR and practice software started in Phase Four and is ongoing. The capability of the NCSR has also expanded to include a Participant Portal, which offers similar features to participants.

The HPP provides an important mechanism for reducing the rate of kits not received by participants, and thereby, a more accurate assessment of the true participation rate. However the benefit of the HPP is contingent on education of the primary care sector to ensure stakeholders understand how and when to use the HPP to confirm participant contact details.

There is an opportunity to combine the mail-out approach with opportunistic provision and return of kits through GPs, pharmacies and/or other trusted practitioners.

Results from the consumer survey (described further in section 4.1.4.2) and insights gleaned from clinicians consulted suggest that the inflexibility of the mail-only approach to kit distribution with strict return post requirements, may have contributed to:

- the use of alternative kits that are more accessible

- lack of support available for participants to fully understand the importance of the Program in the detection and prevention of bowel cancer, and what would be involved in the screening pathway
- difficulty complying with the return post requirements i.e. the need to post the kit at a post-office during business hours, or if via a post box, in the afternoon before 6pm.

Opportunistic issuing and/or return of kits via GPs, pharmacies or other trusted practitioners in addition to the current mail-out approach (i.e. a mixed-method approach) could help to overcome these barriers. The consumer survey found that this was one of the key Program changes that would encourage non-completers to complete the kit next time. This is discussed further in section 4.1.4.

2.1.1.4 The Hot Zone policy

The Hot Zone policy is appropriate for the logistical challenges of administering the Program in Australia.

The iFOBT test used by the Program (i.e. Eiken OC Sensor) is listed on the Australian Register for Therapeutic Goods, alongside a set of requirements for appropriate use. Of particular relevance to Program administration are conditions related to temperature, to which the Program must adhere. The OC-Auto Sampling Bottle has storage instructions of 1-30 ° Celsius (C), and the following recovery rate of haemoglobin has been reported by the manufacturer in Table 2.2.[20] As shown, sample storage temperatures below 30 °C have a higher haemoglobin recovery rate, which reduces the risk of false negative results.

Table 2.2 Performance testing of Program iFOBT

Sample storage temperature (°C)	Storage length (days)	Haemoglobin recovery rate (% ± 2 standard deviations)
2-10	28	95 ±14.7 %
25	7	96 ±20.4 %
	14	93 ±23.5 %
30	7	89 ±20.5 %
	14	84 ±23.6 %

Source: In-house data from Eiken Chemical Co., Ltd.

Note: The pathology provider reports the interval from participant sample collection to sample testing, as well as the time from receipt of the sample to testing as part of internal Program reporting processes. Participants whose first sample is taken more than 14 days prior to pathology testing are sent a new kit and asked to re-test.

Kits are considered temperature-stable from the time of transport to invitees until they are inoculated with faecal samples. Once this occurs, to comply with the listing requirements participants are given instructions regarding storage of samples, as well as how to mail the samples back for analysis. Details regarding these processes are contained in the invitation letter, user instructions in the test kit and an information leaflet available online at the Department of Health website.

The Program has also instituted a Hot Zone policy. Invitees living in postcodes where the average monthly temperature is greater than 30 degrees Celsius are not sent invitations/kits in these months. Instead, they are sent in cooler months of the year. This policy covers approximately 1000 postcodes, primarily impacting North Queensland, Northern Territory and Western Australia. The Program uses 30-year data from the Bureau of Meteorology to make assessments about invitation timing. Given that the Program cannot prevent an invitee completing a kit during a hot time of the year, a hot-weather flier is distributed to invitees affected by the policy regarding methods to keep the kit cool during the sampling and mailing phase.

Overall, given the temperature sensitivity of the iFOBT test, the Program has designed appropriate policies and reporting processes in place to oversee this challenge. The Program should continue to

monitor positivity results from postcodes affected by the Hot Zone, in order to determine whether further amendments to the policy are required.

2.1.1.5 Kits messaging and reminders

The simplified kit instructions are associated with improved rates of valid kit returns. However, there is scope to consider how the kit messaging and method for reminders could be modified and tailored to optimise participation.

Program pathology statistics show that the rate of valid kits returned has improved since the kit instructions were updated in 2018. Across January, April, August and December of 2016, the proportion of returned iFOBT kits that could not be tested was between 8 and 10 per cent, for reasons including incorrect completion or kit expiry. This figure had declined to less than 5 per cent in the same months of 2019 (Table 2.3). These statistics were supported by insights gleaned from stakeholders who generally agreed that the change in iFOBT kit (including kit instructions) in 2018 was an improvement on the earlier iteration.

Table 2.3: Rate of invalid kits returned in January, April, August and December of specified year

Year	Rate of invalid kits returned
2016	8.0% to 9.6%[a]
2019	0.5% to 4.1%[b]

Source: [a]Dorevitch NBCSP pathology reports; [b]Sonic MBCSP pathology reports.

Despite this, there are opportunities to consider how the kit messaging and instructions could be tailored for people from CALD backgrounds and first-time screeners, with a view to overcoming their unique attitudinal and behavioural barriers. These are discussed in more detail in section 4.1.4.

In addition, the consumer survey showed that reminders may be more effective in promoting participation if they were in in digital form, as compared to a mailed letter. This was supported by insights gleaned from consultations that reminders via mail will soon be outdated as the eligible population relies more on technology for communications. A more detailed exploration of digital forms of reminders is provided in section 4.1.4.3.

Timing intervals for reminders should be reviewed with clinical input.

A review of the NHMRC-approved clinical practice guidelines, the NBCSP Quality Framework and input from PDAG members indicates there is scope to explore the clinical implications of refining the timing of reminder intervals.

Table 2.4: Reminder timing intervals

Reminder	GP reminders	Colonoscopy reminders (from date of GP visit)
1 – letter	8 weeks	8 weeks
2 – PFUF phone call	12 weeks	12 weeks
3 – letter	26 weeks	16 weeks
4 – PFUF phone call	30 weeks	20 weeks

This is based on the following observations:

- **Access to GPs.** The NHMRC-approved clinical practice guidelines and the NBCSP Quality Framework advise participants with a positive iFOBT to see their GP 'preferably within two weeks'. However, as shown in Table 2.4, the Program follow-up intervals allow the participant initially 8, and then up to 30 weeks to consult a GP (as opposed to 8 and then up to 20 weeks for the colonoscopy reminders). Analysis of NSCR data indicates that the most significant delay in timely access to diagnostic assessment is due to extended wait times for colonoscopy after a

GP consultation (discussed further in section 2.1.2.3). It may therefore be appropriate to shorten the time allowed for GP consultation to better align with the drivers of timely access to diagnostic assessment.

- **Colonoscopy waitlists.** Under the current participant screening pathway, the relatively short interval between the second and third, and then third and fourth reminders (both four weeks), means that participants may still be on a waitlist when they receive subsequent reminders. This causes wastage and has the potential to cause anxiety in participants.

Shortening GP reminder intervals and increasing colonoscopy reminder intervals may be appropriate based on any understanding of the key access barriers along the screening pathway. However, it is important that the suitability of any change is tested and validated with advisory groups and representatives from jurisdictional colorectal departments, given their unique understanding of colonoscopy waitlists and other clinical implications associated with a change of this nature.

2.1.1.6 The alternative pathway pilot

Alternative distribution and completion pathways for Aboriginal and Torres Strait Islander people have shown to be highly effective.

To improve participation rates among people from Aboriginal and Torres Strait Islander backgrounds, the Department partnered with Menzies School of Health Research to implement the Alternative Pathway in 2015. The Alternative Pathway involved 36 Indigenous primary health care centres offering kits directly to their patients aged 50 to 74, as an alternative to the usual mail-out out method. Other aspects of the pathway were tailored in the following ways:

- cultural training for practitioners including face-to-face training, online training module, information sheets and links to online content
- tailored resources to address health literacy gaps, for example modifying the instructions
- in-clinic recommendations by GPs
- kit packaging using Indigenous designs and colours and messaging that had been test through focus groups and found to resonate with Indigenous people
- understanding cultural protocols to facilitate communication about bowel cancer screening.

Outcomes from the pilot of the Alternative Pathway highlight the efficacy and appropriateness of the model for this cohort. The pilot resulted in an Aboriginal and Torres Strait Islander participation rate of 40 per cent (similar to the rate for all Australians) compared to 23 per cent in the traditional pathway. In addition, the median number of days in which kits were returned was 13 days for the Alternative Pathway compared to 34 days in the traditional pathway.[21,22]

Insights gleaned from consultations supported these findings, with strong sentiment that the model is an appropriate method for reaching people from Aboriginal and Torres Strait Islander backgrounds. There was consensus that the model could be scaled to other Aboriginal and Torres Strait Islander communities and/or other groups such as people from CALD backgrounds. This was noted with the caveat that, in any decision to scale, the target population's unique access barriers should be considered, and approaches and resources from the Alterative Pathway tailored, as appropriate.

2.1.1.7 The diagnostic value of the test

The iFOBT is considered the most accurate and easy-to-use at-home test available. The diagnostic value of Australia's two-sample test is higher than the tests used in many comparable programs overseas and is considered a strength of the Program.

Evidence in the literature on diagnostic test accuracy shows that the iFOBT is the most accurate test on the market when compared with alterative at-home tests (e.g. guaiac faecal occult blood test (gFOBT), especially in the detection of advanced adenomas.[23,24,25] Outside of diagnostic value, the literature shows that the iFOBT is superior to other at-home tests from an ease-of-use perspective, as participants are not required to change their diets or stop taking certain medications.[26,27]

The diagnostic value of Australia's two-sample iFOBT is higher than the iFOBT tests used in comparable programs overseas, as most other countries use a one-sample iFOBT.[28] While the two-

sample test results in enhanced detection of lesions (higher sensitivity) with a lower colonoscopy workload (higher specificity), stakeholders observed that it may also contribute to a reduction in the participation rate[xiv], owing to the challenge in collecting and refrigerating two samples over multiple days.[29,30] Despite this, stakeholders agreed that the accuracy of Australia's two-sample test is a strength of the Program, and extensive clinical research and stakeholder engagement should occur before considering transition to a one-sample test.

The efficacy of emerging testing technologies should continue to be monitored.
Although the two-sample iFOBT is currently considered best practice, the suitability of new technology and diagnostic methods should be reviewed in collaboration with Health Technology Assessment committees.

For example, emerging evidence shows the sensitivity of liquid biopsies for detecting early stage bowel cancer may be superior to the iFOBT, with a pilot study currently in progress at the Royal Marsden Hospital in the United Kingdom.[31] Liquid biopsies aim to detect circulating tumor cell-free DNA to detect cancer. However, the use of liquid biopsies as a screening technology (as opposed to its use in diagnosed cancer cases) requires multiple criteria to be met. Firstly, if the test is designed to detect multiple cancers, it must be able to determine the tissue of origin with reasonable accuracy, to avoid patients undergoing a series of expensive diagnostic procedures as a result. The false positive rate would also need to be low to avoid large diagnostic costs, and the test would be required to perform adequately in asymptomatic populations. Finally, the prospect of liquid biopsies as a screening tool for multiple cancers may also require a comprehensive cost-effectiveness evaluation examining many facets of the Australian health system. This would be due to the cancer-screening programs already in place for breast, bowel and cervical cancer, alongside the personalised diagnostic journeys that Australians currently face for other cancers which may be in scope for the test.

In addition, new simple blood test methods are emerging for groups who are not able to complete faecal testing easily (e.g. those with benign bleeding, those who are visually impaired and those with mobility or cognitive issues).[32] Diagnostic strategies for these tests include measuring the concentration of protein biomarkers in order to determine a 'risk score' for bowel cancer. However, these tests are in the early stages of commercialisation and evidence of cost-effectiveness would rely on the expense of the equipment required to complete testing, as well as the sensitivity and specificity at detecting disease. Reliable evidence on efficacy is also limited at this stage.

In any decision to transition to a new test type, it is important that the test is approved by the Therapeutic Goods Administration (as per the guidance in the NBCSP Quality Framework) and a cost-effectiveness analysis is performed using reliable estimates of test sensitivity and specificity, as compared with the current iFOBT.

Emerging overseas research regarding innovative use of iFOBT results to support personalised diagnostic pathways.
Research in European and Asian national cancer screening programs have shown that interval cancers (i.e. missed cancers) predominantly occur in people with a high-negative iFOBT result.[33,34] This suggests that iFOBT results, which are habitually reported in a dichotomised manner (i.e. below or above a pre-specified threshold), could be used in a more nuanced way to improve Program outcomes. For example, the full iFOBT reading could be used to inform stratified diagnostic pathways (e.g. those with a high-negative could be rescreened annually and/or receive targeted follow up at the next screening interval to improve adherence with the screening pathway).

Researchers in various countries including Taiwan, Netherlands, Italy and Spain are now considering how these findings should be put into practice in organised screening programs.[35,36,37] Before considering changes to the Australian Program pathway, there is a need to validate this research in Australian settings using pathology data from historical participants, the ACD and state

[xiv] Attribution of the higher participation rate observed in other jurisdictions (discussed further in Section 4.1.3) to their use of a one-sample test is complicated by differences in the administration of their screening programs, including more centralised control over the screening pathway.

and territory cancer registries. Pathologists consulted agreed that this research should be a priority for the Program and would further support Australia's eminence in bowel cancer screening.

2.1.1.8 Screening positivity rate

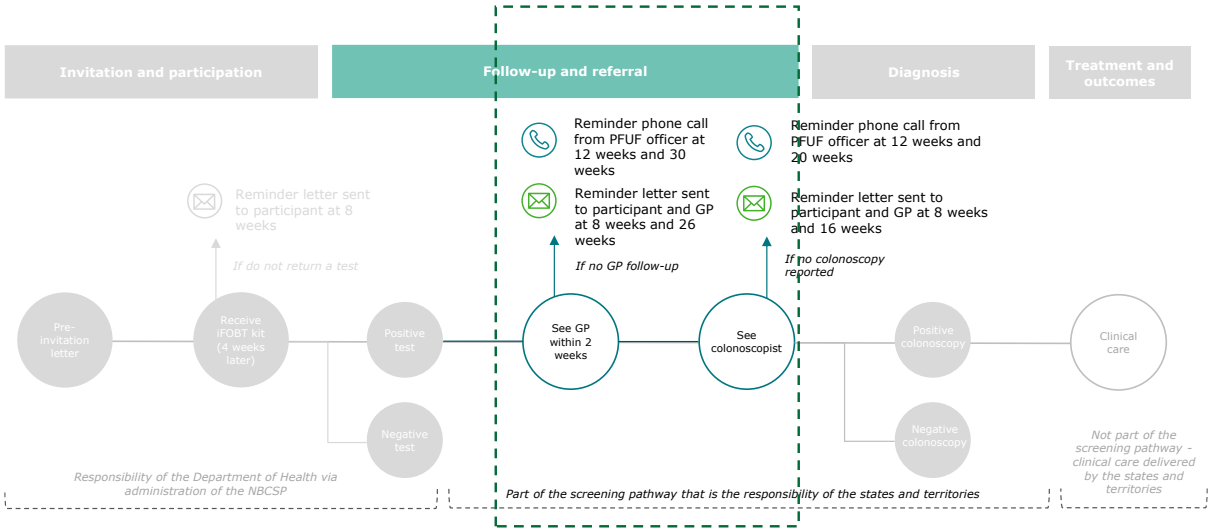
The screening positivity rate is an indicator collected as part of the National Bowel Cancer Screening Program Performance Reporting Framework. It is an important metric, as it determines the volume of diagnostic follow-up and participant follow-up that the Program is required to undertake. Sudden changes in the overall positivity rate may also indicate faults with the underlying testing procedure, which require investigation. The AIHW Annual Monitoring Report reports the screening positivity rate by sex, age, screening round, state and territory, remoteness, Indigenous status, language spoken at home and disability status.

In 2014, Health engaged the AIHW to develop statistical process controls regarding the screening positivity rate, to create a more systematic approach to this issue. These process controls were updated for the introduction of the current test kit in 2018. Broadly, participants are grouped by sex, location, age group and month, with an upper and lower bound for positivity established. In the event that the median positivity rate is outside of these bounds, the cohort is flagged. Further statistical methods are then employed to review the number of cohorts flagged each month.

2.1.2 Follow-up and referral component of the pathway (part of usual care model)

This subsection outlines the appropriateness of the follow-up and referral component of the clinical pathway, including current follow-up rates, enablers and barriers to follow-up. The participant follow-up function is addressed in section 2.1.3.

Figure 2.2: Follow-up and referral component of the NBCSP participant pathway



Source: Deloitte Access Economics diagram, using Department of Health information.[38]

2.1.2.2 Program follow-up rates

Low rates of diagnostic assessment may limit the benefits of the Program, particularly for those in greatest need.

AIHW statistics show that the overall (colonoscopy) diagnostic assessment rate for participants with a positive iFOBT is 66 per cent, a decline from 75 per cent in 2012 when the screening interval was five-yearly.[39] Given the wide expansion of the Program since 2012, the supply of colonoscopies required to maintain a stable diagnostic assessment rate has increased over time. As well, because provision of colonoscopy reports to the NCSR by colonoscopy providers is not mandatory, the current rate of 66 per cent is likely to be underestimated. Participants may also not proceed to a colonoscopy for variety of clinical reasons, as determined by a GP or specialist.

The overall diagnostic assessment rate is relatively low when compared to overseas programs using at-home kits via a mail-out method (as shown in Table 2.5), however these programs are characterised by different design features which may contribute to higher rates of diagnostic

assessment. Examples include responsibility for the full screening pathway by the Program and/or national healthcare provider, as well as the use of using nurse navigators or primary care practitioners to schedule colonoscopies for those with a positive result.

The diagnostic assessment rate in Australia varies across sub-groups, as shown in Table 2.5 with rates as high as 70 per cent in metropolitan regions and as low as 53 per cent in very remote regions. Follow-up rates are lower than average for individuals with a disability, those from Aboriginal and Torres Strait Islander backgrounds, and those residing in low socioeconomic areas. This is despite higher test positivity rates observed among many of these groups.

Table 2.5: NBCSP follow-up rates, comparative analysis

Type	Assessment rate	Positivity rate
Overall NBCSP follow-up rates		
Diagnostic assessment rate	65.5% *72.1% private facilities* *17.5% public facilities* *10.4% not known*[a]	6.7%[a]
Diagnostic assessment rate for sub-populations within the NBCSP		
Female	65.0%[a]	5.6%[a]
Male	66.0%[a]	7.9%[a]
Disability	51.2%[a]	10.1%[a]
Indigenous	47.7%[a]	9.9%[a]
Metro	69.5%[a]	6.4%[a]
Inner regional	59.1%[a]	7.0%[a]
Outer regional	58.1%[a]	7.6%[a]
Remote	52.8%[a]	8.1%[a]
Very remote	42.7%[a]	8.0%[a]
Low socioeconomic areas	59.4%[a]	7.9%[a]
High socioeconomic areas	74.3%[a]	5.4%[a]
Overseas programs		
England	83%[b]	
Sweden	85.6% to 92.4%[c]	
Denmark	91.7%[d]	
New Zealand	82.3% to 85.7%[e]	

Notes: Green shading indicates a diagnostic assessment rate better than the overall average, while red shading indicates a worse rate.

Source: [a]AIHW, *NBCSP Monitoring Report*, July 2020; [b]Logan, R; Patnick, J; et al 'English Bowel Cancer Screening Evaluation Committee. Outcomes of the Bowel Cancer Screening Programme (BCSP) in England after the first 1 million tests', *Gut*, 2012. 61(10):1439-46. [c]Blom, J; Kilpelainen, S et al 'Five-year experience of organized colorectal cancer screening in a Swedish population – increased compliance with age, female gender, and subsequent screening round', *Journal of Medical Screening,* 2014. [d]Kaalby, L; Rasmussen, M, et al 'Time to colonoscopy, cancer probability, and precursor lesions in the Danish colorectal cancer screening program', *Clinical Epidemiology*, 2019, 11, 659-667. [e]Ministry of Health NZ, *National Bowel Screening Programme,* 2018.

Insights from the consumer survey (discussed further in section 4.1.4), and supported by research in the literature indicate that people from low socioeconomic backgrounds are less likely to participate in bowel cancer screening programs due to:

- lower levels of health literacy
- lack of knowledge about the meaning of a positive iFOBT and the next steps in the screening pathway
- lack of social support and perceived cost or lack of private health insurance.[40,41,42,43]

This may partially explain lower rates of diagnostic assessment for these groups.[xv]

2.1.2.3 Access to colonoscopy

For Program participants, timely access to colonoscopy in the public healthcare system remains a challenge.

Timely access to colonoscopy was cited as a barrier to timely transition through the screening pathway in the previous Program review. This challenge was again highlighted as part of the current review and is a priority issue given that research has shown prognosis can worsen if the time between GP referral and colonoscopy exceeds 120 days.[44,45,46]

The NBCSP Quality Framework recommends that diagnostic assessment should occur within 44 days of a positive iFOBT, and a GP consultation should occur within two weeks.[47] Table 2.6 shows that for participation in 2018, the median time to GP consultation outperformed the benchmark, however the median time to colonoscopy underperformed the benchmark.

The median time between positive iFOBT and diagnostic assessment was 51 days overall; however, this varied among different population groups. For example, for those treated in the public healthcare system, the median was 77 days. The median time was also longer for Aboriginal and Torres Strait Islander people (69 days) and for those living in very remote areas (66 days).

These results may be partially driven by the dispersion of the trained workforce within Australia. As of 2016, 58 per cent of gastroenterologists and hepatologists practised in the private sector.[48] Consequently, the availability of publicly funded colonoscopies may be a downstream consequence of these workforce dynamics. Longer wait times in rural and regional areas are expected given geographical barriers. For example, in the Northern Territory, colonoscopies are only available in four public hospitals, three of which are located in the Top End and one located in Central Australia.[49]

Because of access barriers in the public system, there appears to be a higher number of colonoscopies occurring in the private system (72 per cent) relative to the proportion of the Program's target population with private health insurance (54 per cent).[50] This may reflect public colonoscopies occurring through private providers (e.g. as part of wait list management strategies), as well as patients choosing to incur out-of-pocket costs to access colonoscopy in a timely manner.

[xv] Please note: In reporting on population sub-groups of interest, the AIHW uses participant residential postcode and the ABS Index of Relative Socioeconomic Disadvantage to aggregate participants by their residency in a low or high socioeconomic area. The Program objectives however specify socioeconomic *background* as a cohort of interest regarding equity considerations. The consumer survey sought to identify the respondent's socioeconomic background via an index of variables, including whether they were unemployed but looking for work, their household income band and highest level of education. Consequently, results from the consumer survey refer to the socioeconomic background of the participant. The NCSR does not collect participant labour data or financial information, and as such the consumer survey represents a unique spotlight on this cohort of interest which is not impacted by the ecological fallacy.

Table 2.6: Time between positive iFOBT and diagnostic assessment

Type	Time
Median time to GP-follow-up	
Benchmark based on Quality Framework	14 days
Overall (January 2019 to December 2020)	9 days[a]
Median time to diagnostic assessment	
Benchmark based on Quality Framework	44 days (i.e. 30 days following GP follow-up)
Overall (2018)	51 days[b]
Overall (2007)	54 days[b]
Public healthcare system	77 days[b]
Private healthcare system	45 days[b]
Indigenous	69 days[b]
Very remote	66 days[b]
Major cities	50 days[b]
90th percentile, time to diagnostic assessment	
Overall (2018)	144 days[b]
Public system	178 days[b]
Private system	129 days[b]

Notes: Green shading indicates a median time to diagnostic assessment rate better than the overall 2018 average, while red shading indicates a median time to diagnostic assessment worse than the 2018 overall average.

Source: [a]NCSR data January 2019 to December 2020, July 2020; [b]AIHW, *NBCSP Monitoring Report*, July 2020.

The volume of low-value colonoscopies for average-risk patients likely contributes to barriers in achieving timely access to colonoscopy for Program participants.

Stakeholders noted that challenges with access to a publicly funded colonoscopy in Australia partly stem from the high volume of low-value colonoscopies for first-line screening outside of the Program (i.e. people undergoing surveillance colonoscopy contrary to the NHMRC-approved clinical practice guidelines). More than 900,000 colonoscopies are performed in Australia annually with only a small proportion (5 per cent in 2015) performed on people who received a positive iFOBT through the NBCSP.[51] In addition, the Improving Colonoscopy Services in Australia Quality Working Group Report showed that colonoscopy capacity in Australia is sufficient to support the Program.[52]

These findings suggest that the problem may not be capacity but overuse of low-value colonoscopies. In 2019, after consultation with the sector the Medicare Benefits Schedule (MBS) Taskforce made multiple changes to the MBS item codes relating to colonoscopy. These changes were designed to reflect the latest evidence-base and reduce the number of colonoscopies occurring of low value. The full impact of this measure on colonoscopy access across public and private settings will require several years to understand.

Sectorial stakeholders (e.g. advocacy groups, peak bodies, and other relevant non-government organisations) noted that to improve the prioritisation of colonoscopies, the Program could work with PHNs and peak bodies to promote the NHMRC-approved clinical practice guidelines among GPs and/or with hospital intake hubs (e.g. electronic referral forms could reiterate the NHRMC approved clinical practice guidelines).

2.1.3 The Participant Follow-Up Function

While the Program has undertaken participant follow-up since Phase One, a nationalised and consistent function was incorporated from Phase Two onwards, referred to as the Participant Follow-Up Function (PFUF). The objective of the PFUF is to encourage Program participants who have received a positive iFOBT result to progress through the screening pathway. Participants are followed up if they have no record of GP and/or colonoscopy activity in the NCSR within set time intervals (Table 2.7). As such, the extent to which pathway progression (or reasons for drop out) are provided to the NCSR by GPs and specialists has a downstream influence on the volume and nature of PFUF activity.

Table 2.7: Participant follow-up function reminders

Reminder	GP reminders	Colonoscopy reminders (from date of GP visit)
1 – Letter	8 weeks	8 weeks
2 – PFUF phone call	12 weeks	12 weeks
3 – Letter	26 weeks	16 weeks
4 – PFUF phone call	30 weeks	20 weeks

Source: Department of Health information.

The function is funded by the Department and delivered by the states and territories under a National Partnership Agreement, which is due to expire on 30 June 2022. To comply with the terms of the Schedule, the Commonwealth's roles and responsibilities include identifying Program participants who require follow-up and providing states and territories with an Annual Reporting Template. The states and territories provide the specified outputs:[53]

- delivery of an agreed follow-up service for relevant NBCSP participants and/or their relevant health professionals who are identified through the NCSR
- timely updates to a participant's NCSR record.

States and territories also report on outputs using the Annual Reporting Template, as payments are contingent on this process.

2.1.3.2 Evaluating the PFUF function

The PFUF was reviewed in relation to:

- **Effectiveness**, the contribution of the output to the successful progression of the participant through the screening pathway, and timely updates to a participant's NCSR record.
- **Efficiency**, the input required to produce an output of a successful contact. Successful contacts are broadly defined as the officer successfully reaching the intended recipient.

To assess the effectiveness and efficiency of the PFUF function, a data extract of from the NCSR was provided by the NCSR vendor. Unit-level records relating to PFUF interactions were available from November 2019 at the earliest (due to the transition of the NCSR) to December 2020. As such, this time period was used for analysis related to the proportion of interactions by contact type, and the rate of successful contacts by contact type.

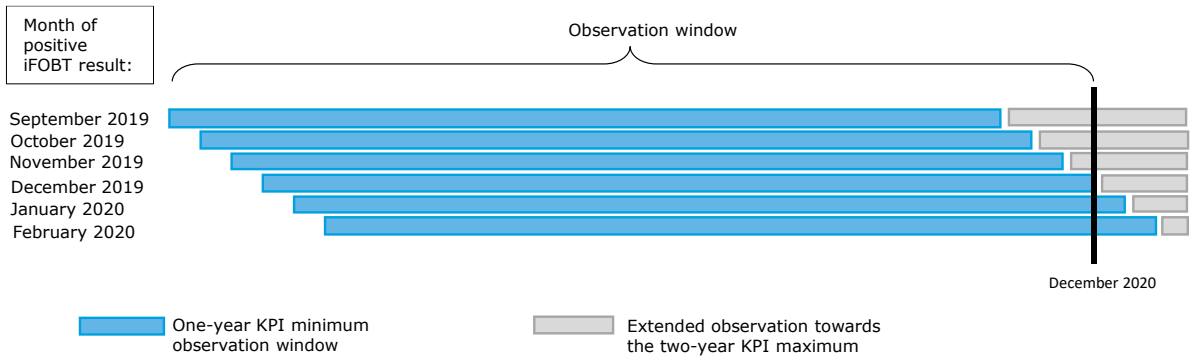
A second line of inquiry aimed to follow a cohort of participants with a positive iFOBT through the screening pathway, to understand the timing of pathway progression and any association between PFUF contact and likelihood of progression. Positive iFOBT results recorded more than eight weeks prior to November 2019 were considered unsuitable for inclusion, as accompanying PFUF records would be incomplete. The overall timeframe chosen was participants recording a positive iFOBT between 1 September 2019 and 29 February 2020, with a sample size of 4,158 participants. The following contextual factors are noted about this analysis:

- The COVID-19 pandemic is likely to have altered participant behaviour, particularly the access to, and completion of, follow-up appointments. The lockdowns and focus on essential services during this period may have also contributed to a reduction in assessments. The effectiveness

of PFUF interactions to encourage GP/colonoscopy appointments should therefore be considered within the context at the time.

- In the AIHW Annual Monitoring Report, calculation of the diagnostic assessment KPI has a minimum participant observation window of one year and a maximum of two years. As shown in Figure 2.3, the minimum and maximum observation windows to calculate a diagnostic assessment rate for individuals in this analysis was shorter (at 11 months and 16 months, respectively), and therefore the diagnostic assessment rate cannot be directly compared with the AIHW's figures.

Figure 2.3: Cohort observation window



2.1.3.3 Effectiveness of the PFUF function

The number of participants with a GP follow-up date recorded that may have been influenced by the second phone call and/or reminder letter was low, thus supporting the idea that timing intervals for reminders should be reviewed.

GP appointment

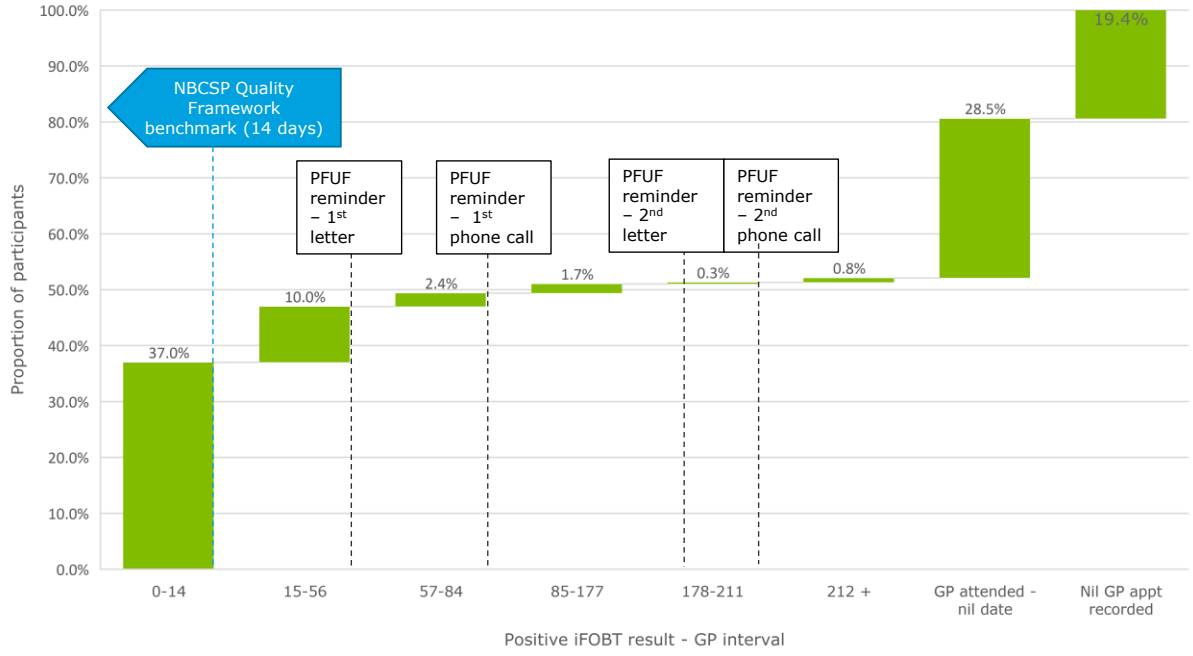
The first trigger for PFUF intervention is the timely progression from a positive iFOBT result to a GP appointment. Overall, 81 per cent of participants had evidence recorded in the NCSR of a GP follow-up. This consultation rate represents a minimum estimate, given that reporting to the NCSR is voluntary. The consultation rate was calculated as the sum of:

- participants with a GP appointment date in their NCSR record
- participants without a GP appointment date in their NCSR record, but with a colonoscopy date in their record (assuming GP engagement would have preceded the recorded colonoscopy)
- PFUF information in a participant's NCSR record which indicated a future GP appointment date had been set
- PFUF information in a participant's NCSR record which indicated that a clinical or personal decision had been made regarding progression to a colonoscopy.

When considering the results in relation to the NBCSP Quality Framework benchmark, 37 per cent of participants with a positive iFOBT had a recorded appointment occurring within 14 days. Excluding participants without a GP appointment date recorded, this is equivalent to 71 per cent of recorded appointment dates occurring within 14 days. Overall, the distribution is described in Chart 2.2, with PFUF intervals indicated.

From the chart it can be seen that the number of participants with a GP follow-up date recorded that may have been influenced by the second phone call and/or reminder letter was low. This finding supports the recommendation discussed in section 2.1.1.4 that the timing intervals for reminders should be reviewed with clinical input. Given the accessibility of GP services, there is an opportunity to better align the first PFUF letter/phone call with the NBCSP Quality Framework benchmark.

Chart 2.2: Participant progression to GP appointment



Source: Deloitte Access Economics calculations from NCSR data, November 2019 to December 2020.

Participants that were eligible for PFUF intervention related to the GP milestone include:

- those without a GP appointment date recorded in the NCSR (or any additional information indicating an appointment had occurred)
- those without a GP appointment date recorded prior to the established PFUF intervention intervals of 56 days, 84 days, 182 days and 210 days.

It is important to analyse the extent to which PFUF officers interacted with the 19 per cent not recording any indication of a GP follow-up. Of this group:

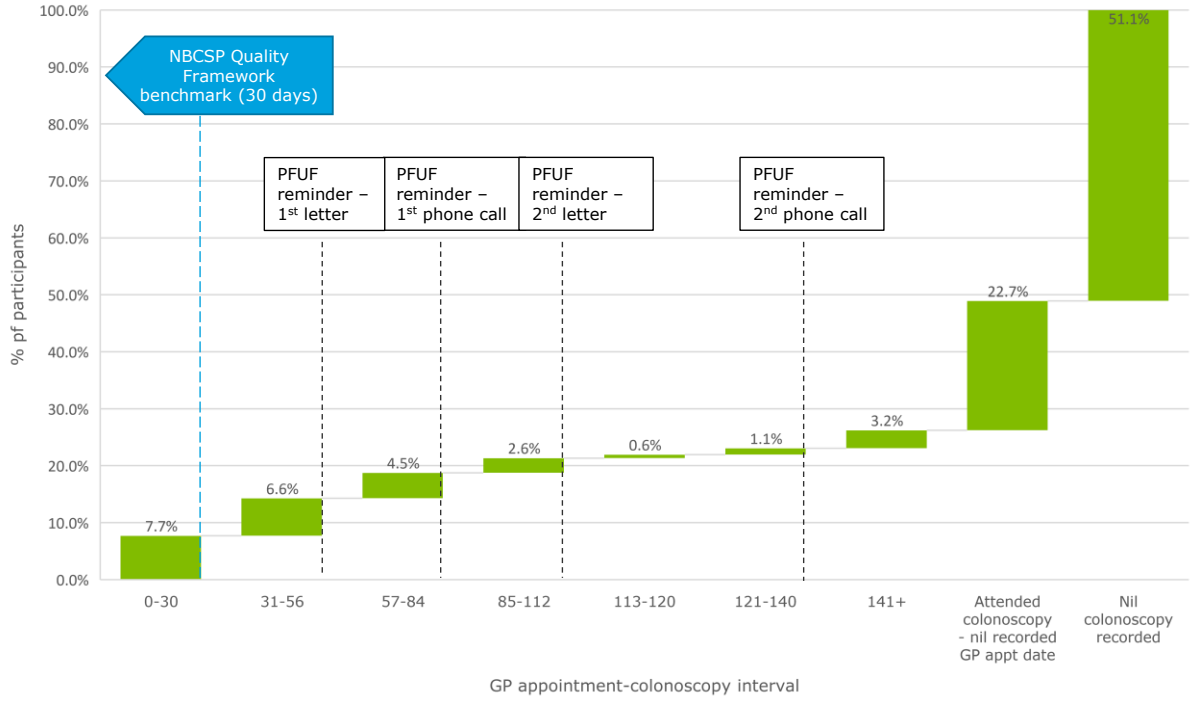
- 81 per cent of participants did not have any PFUF interaction recorded against their case (approximately 650 people)
- 5 per cent had only unsuccessful contacts recorded
- 13 per cent had at least one successful contact recorded.

It is not able to be determined from the data provided whether those who did not have any PFUF interaction recorded against their case were due to missing contact details and/or due to incomplete lists.

Colonoscopy

For the diagnostic assessment part of the screening pathway, 49 per cent of participants had a procedure recorded in the NCSR in the period studied. Participants that had both a GP appointment and colonoscopy date recorded were able to have the interval between these dates calculated, to examine colonoscopy wait times. These results are shown in Chart 2.3. In relation to the NBCSP Quality Framework benchmark, 29 per cent of participants who could have their wait time established, underwent a colonoscopy within 30 days of their GP appointment.

Chart 2.3: Participant progression from GP appointment to colonoscopy



Source: Deloitte Access Economics calculations from NCSR data, November 2019 to December 2020

Participants that were eligible for PFUF intervention related to the diagnostic assessment milestone include:

- those without a procedure date recorded in the NCSR
- those without a procedure date recorded prior to the established PFUF intervals of 56 days, 84 days, 112 days and 140 days from GP contact.

It is important to analyse the extent to which PFUF officers interacted with the 51 per cent not recording any indication of a colonoscopy. Of the participants recording a GP appointment but no colonoscopy:

- 43 per cent did not record any PFUF interaction related to colonoscopy (822 participants)
- 4 per cent recorded only unsuccessful contacts
- 53 per cent recorded at least one successful contact.

As per the GP interactions, it is not able to be determined from the data whether those who did not have any PFUF interaction recorded against their case were due to missing contact details and/or due to incomplete lists.

2.1.3.4 Efficiency of the PFUF follow-up function (by recipient type)

Nearly half of all PFUF interactions recorded were attempted contact with a participant, however specialists and healthcare professionals are more likely to be successfully contacted.

To consider the efficacy of PFUF interactions (including by recipient type), observations between November 2019 and December 2020 were analysed for the number of successful and unsuccessful interactions. Overall, 73 per cent of PFUF interactions were successful. The proportion of total PFUF interactions aimed at each recipient type was also considered, shown in Table 2.8.

Table 2.8: PFUF analysis by recipient type

Contact type	Proportion aimed at contact type (%)
Participant	44%
Personal representative	2%
Healthcare Professional	18%
Specialist	19%
Other	17%

Source: Deloitte Access Economics calculations from NCSR data, November 2019 to December 2020.

Healthcare professionals and specialists were more likely to be successfully contacted, whereas participants and personal representatives were more evenly divided between successful and unsuccessful interactions. In consultation, stakeholders cited the practical limits of PFUF officers, noting their operational hours are within typical business hours. This challenges their ability to make successful contact with participants, given that most people they are targeting are within working age.

Another possible explanation for this phenomenon is participants and/or their personal representatives declining to answer calls from unrecognised numbers. In the case of health care professionals and specialists, administrative support in their workplace may facilitate successful contact during office hours, improving the efficiency of the PFUF process.

Given that nearly half (44 per cent) of all PFUF interactions are aimed at participants, methods of communication which increase the likelihood of successful contact with this recipient type may help to improve the efficiency of the follow-up function. As such, consideration could be given to communication modes that do not require simultaneous availability between the PFUF officer and the participant (e.g. text message or email).

Current Program reporting could utilise NCSR data to more accurately reflect progression to a diagnostic assessment.

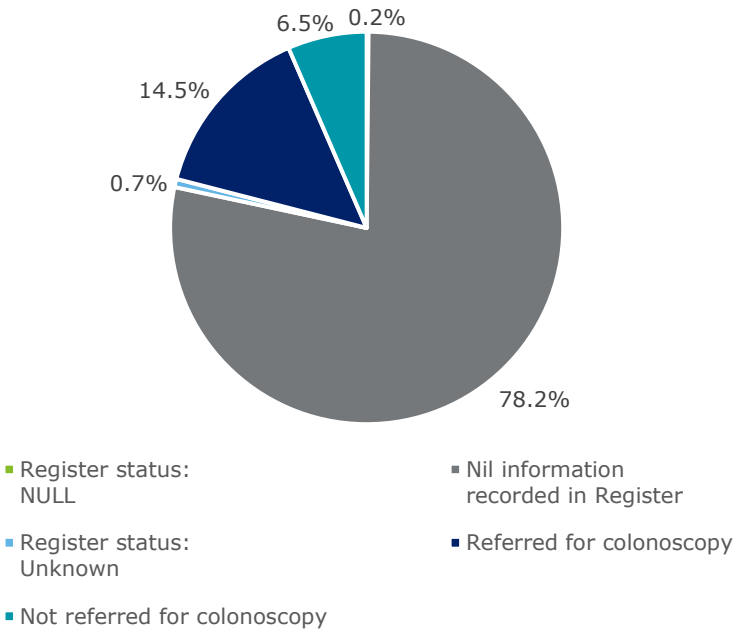
For the Program to maximise benefits and minimise harms, it is important to optimise the number of participants with positive iFOBT completing a diagnostic assessment, where clinically appropriate and where the participant has made a personal decision to proceed. Program KPIs include the positivity rate and the diagnostic assessment rate, however less is known about the circumstances in which participants do not progress through to a diagnostic assessment.[xvi]

In the cohort of participants that had evidence of a GP follow-up but no colonoscopy recorded, the referral status of the participant is shown below in Chart 2.4.

[xvi] Clinical suitability: In situations where the participant is found to be clinically unsuited for diagnostic assessment by a GP or specialist, the Program has functioned appropriately, and potential harms have been minimised.

Personal decision: Patients may personally elect not to proceed to a colonoscopy for a variety of reasons, including their perceived view of the risk of adverse events, or logistical challenges including distance required to travel and financial concerns.

Chart 2.4: Information contained in the NCSR regarding a participant's current referral status for a colonoscopy

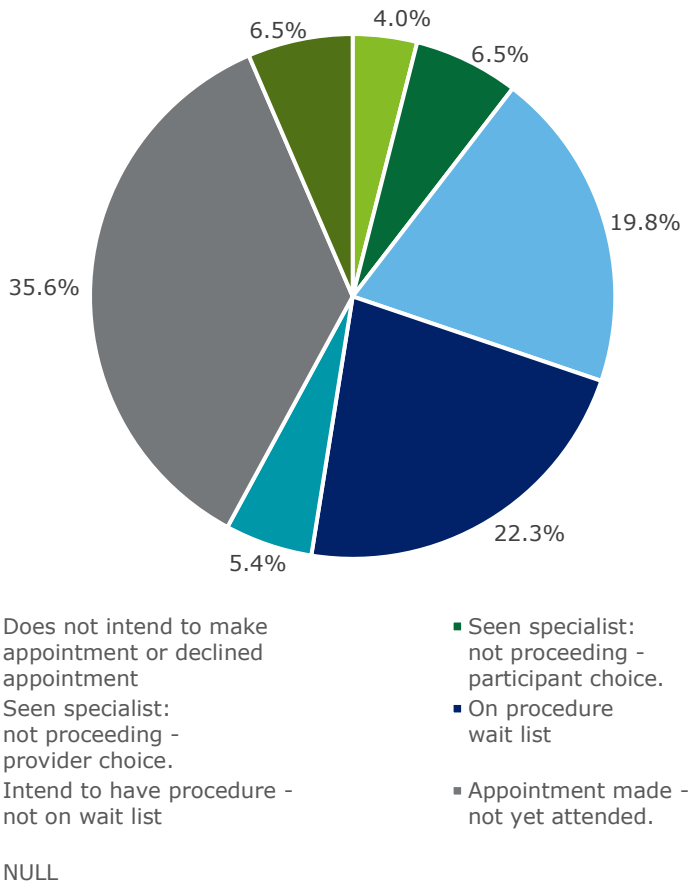


Source: NCSR data November 2019 to 31 December 2020.

Note: 'Nil information recorded in NCSR' includes participants who proceeded from a positive iFOBT result to a colonoscopy without the requirement of a PFUF interaction.

As shown in Chart 2.4, 6.5 per cent of these participants were not referred for colonoscopy. For the 14.5 per cent of patients referred for colonoscopy (shown in dark blue in Chart 2.4), the distribution of outcomes is displayed below in Chart 2.5. Of those referred for colonoscopy, 30.3 per cent are not expected to undertake a diagnostic assessment, due to either clinical unsuitability or as a result of personal decision-making. Consequently, when considering the entire cohort of patients recorded as having a GP follow-up but no colonoscopy date recorded, one in ten participants (10.9 per cent) exited the pathway and will not complete the diagnostic assessment.

Chart 2.5: Information contained in the NCSR regarding a participant's current colonoscopy appointment status



Source: NCSR data November 2019 to 31 December 2020.

Ideally, participants who exit the screening pathway would be removed from the calculation of relevant KPIs, particularly the diagnostic assessment rate, which may be interpreted by external stakeholders as a function of colonoscopy access. Estimating the diagnostic assessment rate in this way would provide a more accurate picture of Program functioning and utilise data already collected by the NCSR. It is noted that PFUF officers currently play a valuable role in the collection of data of this type.

NCSR data gaps limit the efficiency of the PFUF role.

Because clinical practitioner data entry in the NCSR regarding participant engagement is voluntary, data is incomplete. As a result, PFUF officers may follow up participants who are proceeding through the pathway, but their clinician interactions have not been recorded (i.e. making reminder phone calls to participants who have already visited a GP and/or a specialist).

The extent to which PFUF officers' time is spent performing data entry tasks to update the participant's record is difficult to determine precisely, however NCSR data can be evaluated for a selection of scenarios. For example, from an analysis of the cohort recording a positive iFOBT between 1 September 2019 and 29 February 2020, 27 per cent of total interactions recorded occurred after the date recorded for the participant's colonoscopy.

There is an opportunity to consider how the PFUF role could be reshaped by drawing on learnings from innovative nurse-led colonoscopy access models.

Innovative follow-up models implemented in Australian and international contexts have shown that follow-up roles which have an expanded scope of practice (e.g. nurse navigators who schedule colonoscopies and triage patients) have the ability to achieve high diagnostic assessment rates, reduce waiting times and increase patient satisfaction (see Box 2 below).

Stakeholders noted that the Queensland PFUF is relatively well integrated within the Health and Hospital Services (HHSs), as PFUF officers are Queensland Health employees with access to key systems. This is contrast to other jurisdictions, particularly Victoria where the PFUF is outsourced to a private provider. This may partly explain why the diagnostic assessment rate in Queensland (78 per cent) is higher than other jurisdictions including Victoria (61 per cent) and Western Australia (59 per cent).[54]

In summary, the PFUF officer's scope of practice (which is currently limited to *encouraging* compliance across the entire pathway) may be more effective in improving the rate and timelines of diagnostic assessment if it was expanded to include activities such as scheduling and prioritising colonoscopies; however, this needs to be balanced with the potential additional cost.

Box 2: Innovative colonoscopy access models

Direct Access to Colonoscopy models

The Direct Access Colonoscopy (DAC) model uses a nurse telephone triage to eliminate the initial gastroenterologist consultation appointment for low or average risk individuals who meet clinical criteria. These individuals are then fast-tracked to a procedural colonoscopy, with the appointment scheduled by the triage nurse.

These models have typically been based at hospital intake hubs. As a result, as an added benefit, the nurse triages patients who do not need a colonoscopy at all, i.e. low value colonoscopies for average risk patients screening outside of a national screening program, thereby addressing the issue of inappropriate colonoscopies, freeing up service capacity and further reducing colonoscopies wait times.[55]

This model has demonstrated success in NSW, England and Scotland.[56,57,58] To cite one example, Campbelltown Hospital's median time from GP referral to colonoscopy following a positive iFOBT test decreased from 100 days to 36 days as a result of the model.[59] In the Far West Local Health District in NSW, prior to implementation of the DAC model, no patients attended a colonoscopy within the NHMRC recommended timeframe. By June 2018, 74 per cent of DAC patients attended within the 120-day recommendation.[60]

Austin Health model

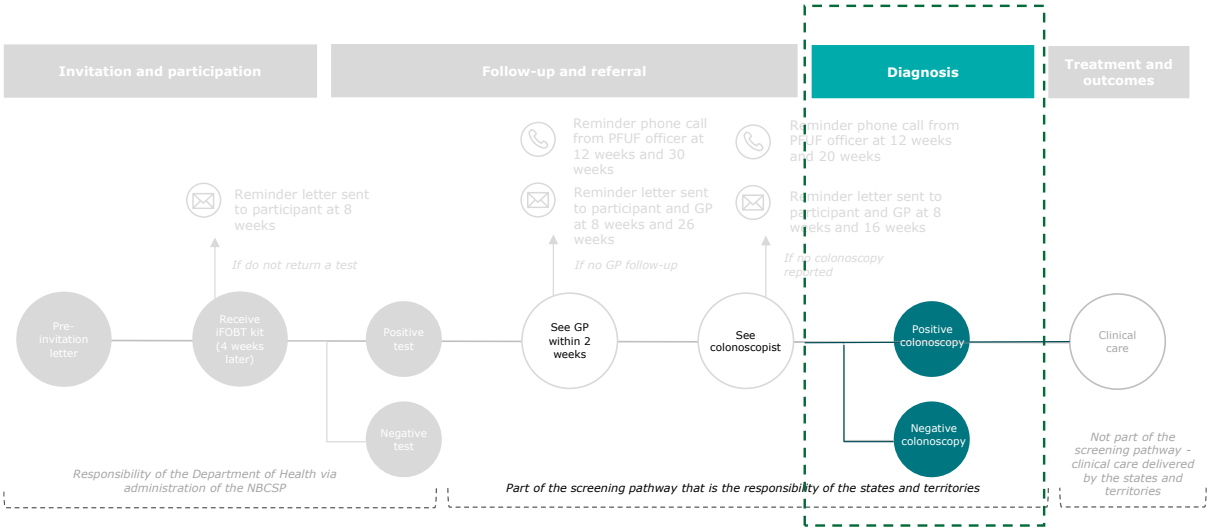
A separate model, similar to the model of nurse navigators used in the United Kingdom's national bowel cancer screening program (whereby a participant with a positive result receives a call from a Program dedicated gastrointestinal nurse and a colonoscopy is scheduled), was implemented at Austin Health during the pilot of the NBCSP. Several stakeholders consulted referred to the strength of this model in increasing diagnostic assessment rates and the time to diagnostic assessment and suggested it should be considered for future implementation.

The Austin Health model used a dedicated nurse coordinator (based at, and employed by, the hospital) to receive referrals from GPs, undertake pre-procedure assessment by phoning the participant, directly scheduling the colonoscopy, undertaking post-procedure follow up and ensuring completion of data collection. The nurse contacted individuals within two days of receiving a referral (faxed from a GP) to schedule a follow up colonoscopy within three weeks. The model resulted in strong follow-up rates and consumer satisfaction, as the nurse also helped to reduce anxiety over a positive result.[61]

2.1.4 Diagnostic component of the pathway (part of usual care model)

This subsection outlines the appropriateness of the diagnostic component of the clinical pathway.

Figure 2.4: Diagnosis component of the NBSP participant pathway



Source: Deloitte Access Economics diagram, using Department of Health information.[62]

Implementation of the Colonoscopy Clinical Care Standard is a positive step in addressing variation in the quality of colonoscopy.

Colonoscopy is considered the gold standard for detection of bowel cancer with an average sensitivity rate of 95 per cent and is therefore the most appropriate form of diagnosis as part of the screening pathway.[63,64,65]

Despite this, stakeholders consulted noted that Australia has historically not used colonoscopy accreditation or national quality standards. As a result, *some* participants may have received poor bowel preparation prior to the procedure, shorter withdrawal times, and low caecal intubation, which can contribute to missed cancers. Poor quality colonoscopy can create additional risk of interval cancers, as participants with a clear colonoscopy will skip a round of screening, creating a four-year window.

Stakeholders observed that the Australian Commission on Safety and Quality in Health Care's (ACSQHC) 2018 development and implementation of the Colonoscopy Clinical Care Standard (CCCS) is a positive step in addressing this issue. Another positive change cited was the establishment of a National Colonoscopy Recertification Program governed by the Gastroenterological Society of Australia (GESA). It is noted that certification brings Australia in line with overseas trends in maintaining standards and support for practising specialists.[66]

Each clinical care standard in the CCCS is linked to several indicators that can be used by health service organisations to monitor how well they are implementing the care recommended. These align with the performance indicators for certification and recertification developed by GESA (e.g. withdrawal time, intubation distance, adenoma detection rates, bowel preparation scores). Stakeholders suggested these indicators should be monitored on an ongoing basis to inform targeted quality improvement at the diagnostic stage of the screening pathway.

2.2 What are the key identified opportunities to improve the appropriateness of the Program?

In reflecting on the key findings that emerged related to the appropriateness of the Program, the following opportunities for Program enhancement were identified.

The Program

1. **Consider feasibility of lowering screening entry age to 40 or 45 for Aboriginal and Torres Strait Islander people, coupled with scale up of the Alternative Pathway pilot for this group.**

This decision should consider the existing barriers to participation in this cohort, and associated investment in alternative pathways to optimise participation across the screening pathway. Please refer to section 6.1.5.

2. **Review the appropriateness of timing intervals for GP and colonoscopy follow-up reminders with clinical input.**

Proposals to decrease timeframes for GP follow-up reminders and increase timeframes for colonoscopy follow-up reminders may be appropriate based on an understanding of the key access barriers along the screening pathway. However, the suitability of the exact timings should be tested and validated with advisory groups and other representatives from jurisdictional colorectal departments.

3. **Consider alternate forms of PFUF communication which do not require simultaneous availability of the PFUF officer and recipient (e.g. email/SMS).**

Email/SMS reminders may allow the Program to reach participants more efficiently, noting that these communication methods would need to comply with relevant privacy legislation as well as the legal framework of the NCSR, and the data would need to be available to support this method of communication.

Colonoscopy

4. **Engage with PHNs and professional bodies (e.g. Royal Australian College of General Practitioners and Royal Australian College of Physicians) to promote a comprehensive set of educational materials which describe the NHMRC-approved clinical practice guidelines, the Program's full alignment with biennial screening recommendations, and recent changes to the MBS item codes for colonoscopy.**

Funding was provided during Phase Four of the Program for the revision of the following NHMRC-approved guidelines:

- *Clinical practice guidelines for the prevention, early detection and management of colorectal cancer (updated in 2017)*
- *Clinical practice guidelines for surveillance colonoscopy – in adenoma follow-up; following curative resection of colorectal cancer; and for cancer surveillance in inflammatory bowel disease (updated in 2019)*

Collectively, these guidelines provide clinical advice to GPs and specialists regarding the appropriate use of colonoscopy for bowel cancer screening, diagnostic assessment and ongoing surveillance depending on the patient's risk profile. These guidelines also improve understanding regarding recent changes to MBS item codes. Consequently, increasing awareness and uptake of the guidelines among relevant health professionals may minimise the volume of low-value colonoscopies currently perceived to be contributing to capacity issues.

Given that a core function of PHNs is provision of practice support to health professionals, they are well placed to leverage their relationships and knowledge of local contextual factors to promote the guidelines in an effective manner. This could also be achieved by encouraging hospital intake hubs to reiterate the NHMRC-approved clinical practice guidelines in GP electronic referral forms.

Note: Detailed opportunities to improve the invitation and participation component of the pathway are described in section 4.2 below.

5. **States and territories to pilot innovative colonoscopy access models.**

To improve compliance with the diagnostic component of the screening pathway, states and territories should trial innovative colonoscopy access models, tailored to their jurisdictions. It is envisaged these pilot models would involve reshaping the role of the PFUF officer to a scope of practice which directly facilitates the process of colonoscopy follow-up.

Reshaping the PFUF scope of practice may also change the expected role of GPs in the screening pathway (as a referrer). As a result, the design of pilot initiatives will require GP representation, and plans for communication and education ahead of implementation.

This opportunity would require consultation with the states and territories to create stakeholder buy-in and facilitate integration with local colorectal departments. In addition, future *National Partnership Agreements* should contain suitable performance requirements for jurisdictions that elect to undertake pilot projects.

6. **Support the ACSQHC with its implementation of the CCCS and monitor performance against colonoscopy quality standards.**

The Department should continue to support the ACSQHC with its implementation of the CCCS, as required, given its importance in standardising the delivery of appropriate evidence-based colonoscopy care. The Department should also endeavour to monitor performance against the quality indicators set in the CCCS to inform targeted quality improvement. However, it is acknowledged that systematic assessment of colonoscopy quality across geographies and sites is challenged by the absence of a national minimum dataset.

3 Fidelity

This chapter addresses the extent to which the Program was implemented as intended, canvassing Program delivery, data collection and reporting aspects, as well as the efficacy of Program governance structures.

3.1 Was the Program delivered as intended?

This section outlines the extent to which the Program was delivered as intended, encompassing:

- delivery aspects of the Program
- data collection and reporting.

3.1.1 Program delivery aspects of the Program

The Program was broadly delivered as in intended in Phase Four, with some deviations associated with kit reach and delays to the NCSR migration.

Overall, it appears the Program was broadly delivered as intended in Phase Four. The focus of Phase Four was to fully transition to biennial screening for people aged 50 to 74, which was achieved earlier than expected in 2019. Other notable activities delivered as intended included the Alternative Pathway pilot, the introduction of a new iFOBT kit in 2018 (including new instructions), the introduction of a new pathology service (Sonic Healthcare), the roll out of the HPP for healthcare practitioners, and the provision of funding grants to GESA to establish the National Colonoscopy Recertification Program.

With regard to kit distribution, in 2019 (the year the Program became fully biennial) the volume of invitations sent was only marginally lower than Australian Bureau of Statistics' (ABS) estimate of the size of the eligible population aged 50 to 74, suggesting kit distribution broadly met the Program requirements. The difference in numbers may be attributed to opt-outs and removal of people from the invite list who had recently undergone a screening colonoscopy. Despite this, there were indications that some kits may not have reached invitees, with the consumer survey indicating that 9 per cent of invitees had not received a kit in the past two years. Possible explanations for invitees not receiving a kit include (as described further in section 2.1.1.3):

- incorrect addresses in Medicare
- postal issues for those residing in rural and remote areas.

Table 3.1: Volume of NBCSP invitations sent in 2019 vs. eligible Australian population

Data element	Number
Invitations sent	2,938,841[a]
Eligible Australian population	3,511,434[b]
Proportion of eligible Australians receiving an invitation	83.7%

Note: Eligible Australian population is calculated as Estimated Residential Population at 30 June 2019.

Source: [a]AIHW, *Cancer screening programs: quarterly data*, December 2020; [b]ABS, *National state and territory population*, 2021.

Migration to the NCSR from the original register housed by Services Australia was postponed for two years to allow the complete migration to the NCSR for the National Cervical Cancer Screening Program, which involved the merging of eight separate state and territory cancer registries into

one national register. However, as of November 2019, the Program had fully migrated to the NCSR.

3.1.2 Data collection and reporting mechanisms

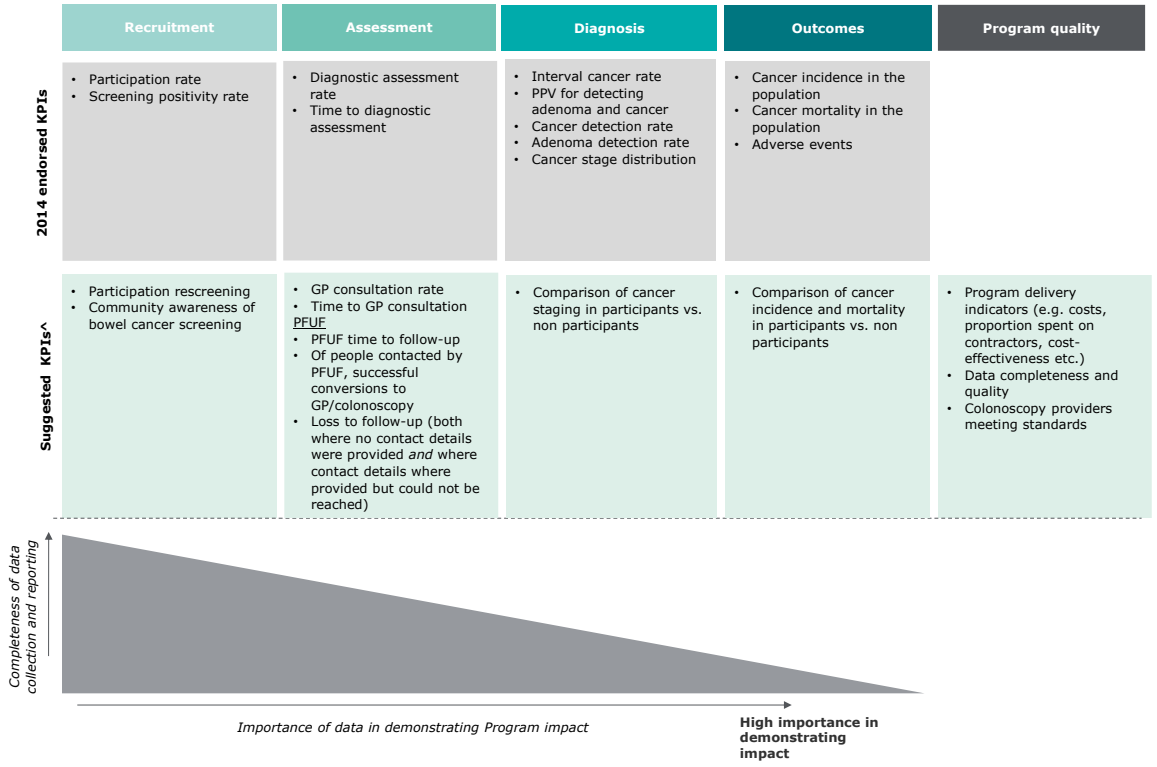
There are strong data collection and reporting mechanisms for assessment of participation and positivity rates, however complete and reliable data to demonstrate Program outcomes is limited.

The previous review of the NBCSP recommended that Program KPIs should be developed to enhance Program monitoring and transparency. In response, a set of Program KPIs were agreed and endorsed, as outlined in the AIHW's 2014 *Key performance indicators for the National Bowel Cancer Screening Program technical report*. Reporting against these KPIs is included, where possible, in the AIHW's annual Monitoring Reports.

In 2018, a KPI working group was convened to review the endorsed KPIs and identify opportunities to address data gaps. At the time of the review, only preliminary progress was made. Despite this, working papers from the group show that many of the existing KPIs are appropriate, yet the key challenge lies in the feasibility of reporting due to data completeness issues. The working group expressed a view that all KPIs should be reported on, even where they are considered 'aspirational', and initiatives to address data gaps should be prioritised.

A summary of the 2014 endorsed KPIs, as well as others identified as important by the KPI working group and through consultation with clinicians and sectorial stakeholders, is shown in Figure 3.1 across each stage of the screening pathway. Many of the endorsed and/or proposed KPIs that are most important in demonstrating the impact of the Program cannot be reported due to data gaps. This is reflected in Figure 3.1, which shows that data collection (and reporting for the endorsed KPIs) is relatively complete at the screening pathway entry point, but gradually declines across the continuum as the KPIs become more important in demonstrating Program impact.

Figure 3.1: Key KPIs vs. degree of data collection by stage of the screening pathway



^Note: Suggested KPIs are based on suggestions from stakeholders, KPIs reported in overseas Programs and those discussed in the KPI Working Group documentation provided as part of the review. All indicators would ideally be captured and reported for different ages and demographic groups. Also note, separate indicators would need to be developed to report on any alternative pathways.
Source: Deloitte Access Economics diagram, using Department of Health information.[67]

An overview of each broad KPI area coupled with an assessment of the calculation approach and data availability to inform the indicator is provided in Table 3.2. This assessment was based on information provided in AIHW Monitoring Reports and insights gleaned through stakeholder consultation.

Table 3.2: Overview of each broad KPI area

Participation *Data availability* The participation (KPI 1) is captured in the NCSR and reported in the AIHW Monitoring Reports. *Calculation* The true participation is likely underestimated due to the provision of kits to those using other forms of screening (e.g. other at-home kits and surveillance coloscopy) and those not suitable for participation in the Program (i.e. where a colonoscopy is not considered appropriate due to the risks). As noted in Chart 4.6, results from the consumer survey showed that 10 per cent of all invitees do not participate because they completed another form of screening. The recent update to integrate the NCSR with the Medicare Benefits Schedule (MBS) to ensure those undergoing surveillance colonoscopy do not receive a kit, was cited as a positive step in supporting a more reliable estimate of the true participation rate. However, this will only capture those undergoing colonoscopy in the private system. Using GPs to 'opt-out' individuals who may not be appropriate for the Program would further support a more accurate estimate of the true participation rate; this could be facilitated through the HPP, as suggested in section 2.1.1.3. Currently, participation rates are reported in the AIHW's Annual Monitoring Reports for Program invitees from two years prior. The benefits of the current length of observation include: • allowing a long timeframe for participants to return their kit (which recognises the time to expiry of the kit) • accounting for participants requesting multiple kits • aligning conceptually with biennial screening intervals. Consequently, any decision to shorten this window will likely lower the reported participation rate. However, it may allow for the impact of interventions which encourage prompt participation to be recognised more clearly. As such, the approach to measuring participation could be revised in a manner which reports the rate at shorter intervals, for example: • participants invited to screen between January and June of 2021 that return a kit by December 2021 • participants invited to screen between July and December 2021 that return a kit by June 2022. A revised participation rate could then be calculated (using the prior method of a longer window) and reported in the Annual Monitoring Report, to provide comparable statistics over time. However, an appropriate window would need to be discussed and agreed with the AIHW. As well, altering the participation rate indicator to report on a more frequent basis would require an additional administrative workload.
Positivity rate *Data availability and calculation* The iFOBT positivity rates is captured in the NCSR and reported through the AIHW Monitoring Reports in a reliable manner.

Diagnostic assessment rates (and timeliness of assessment)

Data availability

Rates and timeliness of diagnostic appointments with specialists (following a positive iFOBT) are partially captured in the NCSR and reported through the AIHW Monitoring Reports (KPI 3 and 4). However, the data captured is incomplete, owing to the voluntary nature of information provision to the NCSR by clinicians; this is unlike the National Cervical Cancer Screening Program, where clinician reporting is mandatory.

Underreporting contributes to an inaccurate estimate of the true diagnostic assessment rate and limits the extent to which this indicator can be used to inform quality improvement. In addition, it creates inefficiencies in the PFUF role due the inability to reliably target individuals who have not had a diagnostic assessment (as described in section 2.1.3).

Clinicians and peak body organisations expressed concerns that the proposed removal of monetary reimbursement for the provision of clinical information to the NCSR in early 2021 will create additional data gaps. It was noted that while the removal of reimbursement is coupled with a transition to digital rather than paper-based reporting, clinicians still incur time costs associated with the preparation of this information, and the lack of incentives may result in high rates of non-submission.

Stakeholders agreed that to address data gaps related to diagnostic assessment, integration between the NCSR and colonoscopy software is an area that should be prioritised by the Department.

Calculation

As described in section 2.1.3.4, analysis of a cohort of participants that had evidence of a GP follow-up but no colonoscopy recorded (Chart 2.4 and Chart 2.5), showed that one in ten participants (10.9 per cent) exited the pathway and will not complete the diagnostic assessment. Ideally, these participants would be removed from the calculation of the diagnostic assessment rate, which may be interpreted by external stakeholders as a function of colonoscopy access.

Colonoscopy detection rates and outcomes, positive predictive value and interval rates

Data availability and calculation

Information on colonoscopy outcomes such as the incidence and size/stage of detected lesions is only partially captured in the NCSR, owing to the voluntary nature of information provision to the NCSR by histopathology providers and the need for data linkage with state and territory cancer registries and/or the ACD.

As a result, the AIHW Monitoring Reports do not routinely report (or report with significant caveats), the following endorsed Program KPIs (KPI 5 to 8): adenoma detection rates, iFOBT positive predictive value (PPV) of detecting adenoma, iFOBT PPV of detecting colorectal cancer, interval cancer rates, and cancer stage at detection.

Cancer incidence and mortality (KPI 10 and 11) are reported in the AIHW Monitoring Reports based on information supplied from the ACD, however the data takes approximately five years to be collated and verified before it can be used.

Stakeholders agreed that integration between the NCSR and histopathology software is an area that should be prioritised by the Department and the NCSR vendor to address data gaps. In addition, a working group should be convened to identify priority projects for routine data linkage, for example with the ACD, to further support the feasibility of reporting on these indicators.

Current calculation methods are appropriate, however should be reviewed as data gaps are addressed.

Adverse events following colonoscopy

Data availability and calculation

Adverse events following a colonoscopy are partially captured in the NCSR (KPI 9). While data fields exist in the NCSR to capture the type of adverse event and follow-up care required, this data is underreported due to the voluntary nature of information provision from colonoscopy providers.

The AIHW Monitoring Reports include high-level statistics related to unplanned admissions within 30 days of a procedure, however the AIHW notes that these figures should be interpreted with caution as they underrepresent the true rate of adverse events (e.g. due to underreporting of the true volume of unplanned admissions, and no reporting on adverse events not resulting in an admission).

Stakeholders agreed that in the absence of reliable information provision from specialists on adverse events, there is a strong opportunity to engage in data linkage with jurisdictional inpatient datasets to inform a more accurate view of this indicator. A pilot project of this nature has recently commenced by the AIHW.

Other suggested KPIs

Figure 3.1 provides a summary of additional suggested indicators. A detailed description is provided below for two of these indictors that are considered a priority, based on stakeholder consultation and the KPI working group documentation.

GP assessment rates (and timeliness of assessment)

The GP consultation is the first step in the pathway for participants that receive a positive iFOBT result. Rates and timeliness of GP follow-up are captured in the NCSR, however they are underreported owing to the voluntary nature of information provision by GPs. These metrics are not included as indicators under the current endorsed Program KPIs, and they are therefore not reported as part of the AIHW Monitoring Reports.

Reporting against these indicators would aid an understanding of where in the screening pathway participants drop-off, which could then be used to inform targeted quality improvement efforts. For example, the diagnostic assessment rate (and time to diagnostic assessment) is currently calculated using a denominator of the number of patients returning a positive iFOBT. If all participants that did not complete a diagnostic assessment *did not complete a GP assessment*, Program efforts should be focused toward encouraging the initial GP appointment. However, if all patients that did not complete a diagnostic assessment *had visited a GP*, colonoscopy access is more likely to be a contributing factor. The recent integration between GP clinical software and the HPP may support the feasibility of capturing and reporting this indicator in a more reliable manner moving forward.

Stage at detection and mortality rate – comparisons between screened and unscreened

An assessment of cancer incidence and mortality can only demonstrate the impact of the Program on earlier detection and better survival if these metrics are compared between participants and non-participants to derive relative risk/odds-ratio estimates. Working papers from the KPI Working Group suggest that KPI 10 and 11 could be rephrased in a way to enable this assessment.

This is noted with the caveat that even if these KPIs were rephrased to enable this assessment, their feasibility is contingent on routine data linkage with the NCSR, state and territory cancer registries, and the Australian Death Index.

It is acknowledged that the Department has commissioned two bespoke projects of this nature in 2014 and 2018, however stakeholders agreed that this information should be generated more frequently, and used in media and communications strategies to promote the benefits of the Program to non-participants. As well, this information is valuable for use in academic clinical research as well as economic analyses of the Program, to better inform policy recommendations.

In summary, development of endorsed Program KPIs are a positive step in promoting accountability and transparency of the Program. However, several of the endorsed KPIs and others proposed for potential inclusion, particularly those most important in demonstrating Program impact, cannot be reported owing to data gaps. These gaps could be addressed through better integration between the NCSR and practitioner software, as well as routine data linkage with jurisdictional cancer and inpatient datasets.

3.2 To what extent did Phase Four address the recommendations of the previous evaluation?

The previous Program review evaluated Phase Two of the Program in 2012. The review recommended a suite of opportunities to improve the Program. An assessment of the extent to which the key recommendations of the previous review were addressed is outlined in Table 3.3. In summary, the recommendations were largely addressed, with partially implemented activities related to facilitation of outcome data and the need for a consistent national message across the Department and sectorial stakeholders.

Table 3.3: Assessment of the extent to which the recommendations of the previous Program review were implemented

Assessment	Notes
Develop strategy to support expansion of the Program	
Implemented as planned	The previous review recommended the development of a strategy for full implementation of the Program by 2019. Since this time, the Department accelerated the phased approach to implementation of biennial screening, resulting in the full implementation in 2019. The previous review also recommended development of an Alternative Pathway pilot for Aboriginal and Torres Strait Islander participants. In 2015, the Department announced funding for an Alternative Pathway pilot for Aboriginal and Torres Strait Islander people, which was implemented in 2018. The Alternative Pathway is discussed further in Section 2.1.1.6.
Revise governance and advisory structures (to align with proposed new structure)	
Implemented as planned	The previous review recommended a revised governance and advisory structure to align with the structure shown in Figure 3.2. Under this structure, the Minister for Health has the decision-making authority, with the Department responsible for Program management. The original Program Advisory Group and a Program Delivery Group were to be replaced by two standing advisory committees: a "Clinical Reference Group" (now known as CAG) and a "Program Delivery Group" (now known as PDAG). It was recommended that sitting below these two advisory committees are time-limited working groups. This recommendation was subsequently implemented. The CAG provides clinical advice to the Department, while PDAG provides advice on the operational aspects of the Program. Additionally, during Phase Four, two time-limited working groups were established: the KPI Working Group and the Alternative Pathway Working Group. This efficacy of the current governance structure is explored in section 3.3.
Develop a quality management plan, and revise information packages for primary healthcare providers	
Implemented as planned	The previous review suggested the Program implement a quality management plan or quality assurance framework at a national level. A Quality Framework was published in 2016. The Framework states the desired quality outcomes for each element of the

Assessment	Notes
	pathway. The Quality Framework is referenced throughout this report, including performance against desired follow-up timeliness targets, as defined in the Quality Framework. The previous evaluation highlighted the need for information packs for primary healthcare providers. A NBCSP Primary Healthcare Engagement Strategy was published in October 2016. In addition, with the move to the HPP, the Department has invested in development of a suite of information packages targeted at GPs advising how and when the HPP should be used to support uptake of the Program.
Develop KPIs and address gaps in data relating to outcomes post diagnosis	
Partially implemented	The previous review recommended the development of KPIs and highlighted to the need to address data gaps on participant outcomes post diagnosis. A set of Program KPIs were agreed and endorsed, as outlined in the AIHW's 2014 *Key performance indicators for the National Bowel Cancer Screening Program* technical report. Despite this, several of the endorsed KPIs, particularly those related to participant outcomes, cannot be reported owing to data gaps. A time-limited working group was established in 2018 to identify opportunities to address these data gaps, however only preliminary progress was made. A more detailed discussion on Program KPIs is provided in section 3.1.2.
Work with NGOs and communities to develop a consistent, national messaging to promote screening awareness and capture information regarding non-NBCSP screening	
Partially implemented	The previous review highlighted the need to capture information on individuals screening outside of the Program and to develop a consistent national message across the Department, non-government organisations (NGOs) and local communities. Consultations indicated limited engagement with NGOs to progress this recommendation. There was strong sentiment across stakeholders consulted that better integration and coordination with cancer charities is an action that should be prioritised in the next phase of the Program.

3.3 To what extent are governance structures operating effectively?

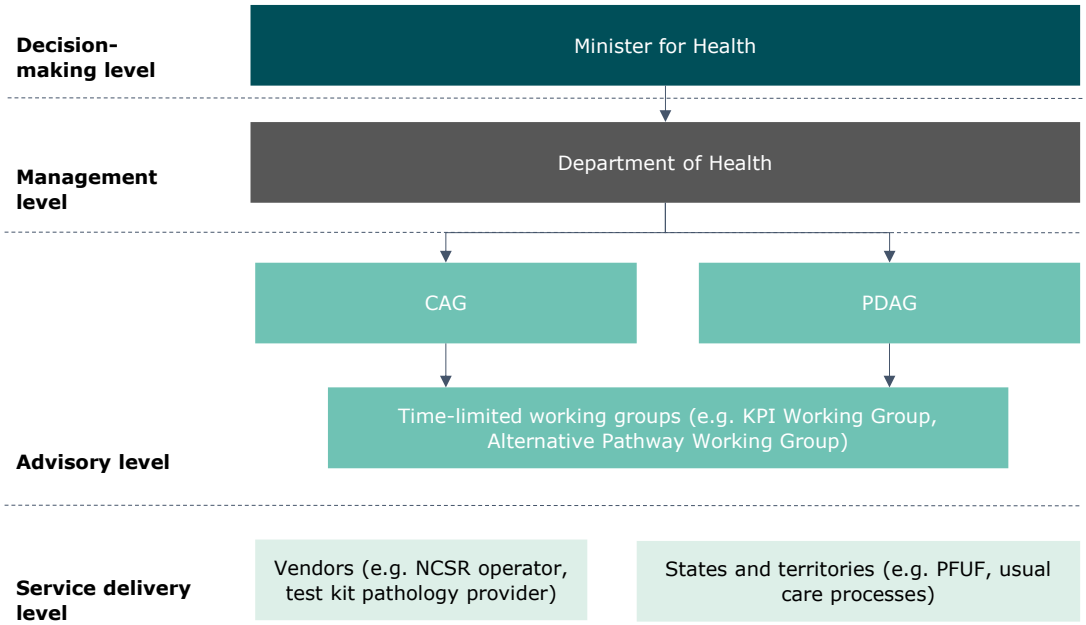
The following sections discusses the current governance arrangements and their operations, as well as the Program's engagement with other stakeholder groups.

3.3.1 Program governance

The Program is an Australian Government program that is delivered with cooperation and support from state and territory governments. This is a key aspect of the Program that makes it distinct from comparable programs delivered in the United Kingdom or New Zealand, where the complete screening pathway is delivered by the national healthcare provider.

The current Program governance structure is outlined Figure 3.2.

Figure 3.2: Summarised NBCSP governance structure, as outlined in the Phase Four Policy Framework



Source: Deloitte Access Economics diagram, using Department of Health information.[68]

The Department is responsible for Program management and governance, policy development, and expenditure of Program funds (e.g. iFOBT screening and partnership follow-up support delivered via states and territories).

State and territory governments have responsibility for: providing usual care services for Program participants following a positive screening test; local coordination of the Program, including health system workforce and colonoscopy capacity; and other support activities to improve awareness of the Program and increase participation and follow-up.

State and territory governments have an advisory role in Program policy and management through the PDAG, which comprises jurisdictional Program managers, and representation by vendors as needed. Terms of reference for the PDAG includes provision of advice and input on:

- policy development
- reviews and monitoring activities
- Program delivery issues
- population screening, relevant settings and monitoring of KPIs, including participation targets
- development of policy documents including position statements
- jurisdictional and key stakeholder agency perspectives and advice, and act as a conduit for consultation and collaboration between the relevant agencies.

The other advisory group is the CAG, who provides clinical advice on the Program. The group is comprised of clinical representatives including epidemiologists, pathologists, primary care practitioners, colorectal surgeons, and gastroenterologists. Terms of reference for the CAG include:

- review, monitor and advise on clinical outcomes and performance issues for the NBCSP
- advise on issues of safety and quality (e.g. Program colonoscopy outcomes, test sensitivity and specificity)
- provide clinical and technical input into monitoring of KPIs, new and emerging bowel screening technologies, position statements, and the development of enhanced data collection
- review adverse events resulting from participation in the NBCSP and, if relevant, provide clinical advice
- act as a conduit for consultation and collaboration with clinical stakeholder agencies.

Program advisory functions provide valuable advice on how to optimise the Program from an operational and clinical perspective.
Among stakeholders consulted that were aware of the Program's governance structures, there was agreement that the operational and clinical aspects of the advisory functions provide important and unique insights to guide Program delivery.

It was observed that separation between CAG and PDAG can make it difficult to progress new ideas or actions, that require both clinical and operational input, in a timely manner. There was strong sentiment that the integrated forum between the groups (which currently occurs annually) should be retained, as it is important for a sense of connectivity and streamlining the process for gathering shared input.

Stakeholders noted that the establishment of time-limited working groups to address opportunities raised through CAG and PDAG is a strength of the Program. There was a perception that the status of the working groups implemented in Phase Four were not always clear or well communicated across and between CAG, PDAG, the Department and the working group itself. However, meeting minutes provided by the Department demonstrated that meetings included standing agenda items for updates on working group progress at Advisory Group meetings.

This finding related to working groups was consistent with a finding from the previous review of the Program, which observed *"there was a lack of clarity around the current status of the various Working Groups that had operated during Phase Two".*

Given variation in perceptions across the stakeholders involved in Program governance, it may be useful to reset working relationships to ensure needs are being met in regard to the purpose of each group and expectations on information sharing.

With an increased focus on supporting access to timely colonoscopy, there is scope to consider broader representation from the jurisdictions on PDAG.
PDAG is currently represented by Program managers and vendors, with jurisdictional representatives acting as a conduit to other relevant jurisdictional agencies, as defined in the PDAG Terms of Reference.

As noted in section 2.1.2.3, access to colonoscopy for Program participants is a challenge that has persisted for a number of years, suggesting the conduit model may not be the most effective mechanism for understanding colonoscopy barriers and potential solutions.

Given this, it may be worthwhile to consider more direct representation from jurisdictional colorectal departments as part of PDAG. This is suggested in the context that any initiative to improve access to colonoscopy (e.g. rescoping aspects of the PFUF role to become more integrated within Local Health Districts [LHD] or HHSs, as described in section 2.1.3) would require buy-in and operational support from these agencies.

Opportunity to better align external research with the Program's priority research areas.
Program, sectorial and academic stakeholders consulted noted the importance of commissioning research targeted at improving the Program. It was noted that to date, there has been a limited number of Randomised Controlled Trials or other observational research studies conducted, with the intent of examining changes to Program design and its impact on uptake and outcomes. Research of this nature is important for establishing an evidence-base before deciding to change a Program feature at scale.

It was noted that now the Program is fully biennial, the next phase of the Program can shift from a focus on Program expansion to a focus on optimising Program design. In addition, transition to the NCSR provides the enabling infrastructure to better support targeted research. A number of opportunities to pursue research grants already exist (e.g. through the NHMRC or elsewhere), and external researchers should be encouraged to use these mechanisms to address the Program's key research objectives.

3.3.2 Stakeholder engagement

The Program engages with a variety of external stakeholder groups in different ways to support the Program. This is summarised below by stakeholder type:

PHNs. PHNs are an important enabler in promoting participation in the Program, and in encouraging and supporting GPs to recommend screening. PHN's perform this function by developing local resources and tools, as well as pilot initiatives with specific GP practices such as the LaTrobe Cancer Screening Collaborative run by Gippsland PHN (described in Box 3 in Section 4.1.4.2).

Peak bodies. The Program collaborates with peak bodies in a variety of ways. As noted in section 3.1.1, as part of Phase Four, the Program provided funded grants to GESA to establish the National Colonoscopy Recertification Program. Further, the Program engaged with RACGP to discuss the scope of the HPP and the role of GPs as part of the transition. The Program also commissioned the Cancer Council to deliver a national media and communications campaign in 2019.

As noted in section 2.2, there is an opportunity for the Program to engage with PHNs and professional bodies (e.g. RACGP and RACP) to promote a comprehensive set of educational materials which describe the NHMRC-approved clinical practice guidelines.

NGO advocacy groups. Representatives from relevant bowel cancer related NGO advocacy groups are invited to participate in governance groups for special projects, where relevant and appropriate.

As noted in section 4.2, there is an opportunity to strengthen engagement with NGO advocacy groups to develop a consistent national message regarding bowel cancer screening. In addition, as noted in section 3.4, improving visibility of participation in screening using other at-home kits operated by NGOs such a Bowel Cancer Australia, would support estimating a more accurate participation rate.

Other government agencies. The Program is enabled by support from other government agencies such as the AIHW and Australia Post. As noted in section 3.1.2, the AIHW uses Program data to report against the Program's endorsed KPIs in Annual Monitoring Reports and engages in bespoke projects to address key Program areas of interest on an ad hoc basis. Australia Post has responsibility for delivering Program kits to invitees.

3.4 What are the key identified opportunities to improve governance and data collection?

In reflecting on the key findings that emerged related to Program implementation, data collection and reporting mechanisms, and the efficacy of governance structures, the following opportunities for Program enhancement were identified.

Data collection

1. **Reconvene a working group with the goal of prioritising initiatives to address data gaps and agree on any required changes to the endorsed set of KPIs.**

The Department should reconvene a working group with the goal of improving data collection and reporting against Program indicators. The purpose of this group should be two-fold:

- confirm an agreed revised set of KPIs and calculation approaches, considering those outlined in section 3.1.2
- improve the feasibility of reporting against each indicator by prioritising initiatives and/or dedicated resourcing to address data gaps, such as data linkage or clinical interoperability, noting that a number of these initiatives would require detailed workplans and dedicated funding for the AIHW or Telstra Health.

This group should be set-up over a medium to long term period, given the timeframes, effort and stakeholder engagement required to oversee initiatives to improve data quality and completeness. The group should include representation from CAG, PDAG, AIHW, Telstra Health and as well custodians of relevant jurisdictional datasets (e.g. inpatient data or cancer registries).

2. **Improve visibility regarding the target population's participation in other forms of bowel cancer screening.**

The Department should aim to improve visibility regarding the extent to which the target population is undertaking other forms of screening (particularly via the use of other iFOBT kits). At present, the Program incurs a cost associated with unreturned kits, and the improper inclusion of invitees who have already engaged in other forms of screening reduces the reported participation rate.

Governance

3. **Re-configure PDAG to include jurisdictional representatives that can provide operational advice on contextual issues related to colonoscopy access.**

Given the critical role of timely colonoscopy access to the successful delivery of the Program, it may prove beneficial to include representation from jurisdictional colorectal departments on PDAG. These representatives would be able to provide operational advice related to contextual barriers and enablers. In addition, it is envisioned that these representatives will play a key intermediary role in relation to pilot initiatives which are trialled in their states and territories.

4. **Promote the Program's research priorities to external researchers.**

External researchers should be encouraged to pursue research which is a priority of the Program. Current Program-related priority research areas should include the pilot projects suggested in the review to improve participation (described further in section 4.2) and opportunities to validate emerging overseas innovations related to quantitative iFOBT readings in the Australian context (described in section 2.2).

External researchers should be encouraged to seek grant opportunities through the NHMRC or elsewhere to address these research areas. To do this, the Department should promote the Program's key research priorities and the Program data available to inform such research (e.g. in the NCSR) to academic organisations. External researchers can then develop research protocols and HREC submissions that align with the Program's research objectives.

Where external researchers do pursue Program-related research, updates should be included as part of CAG meetings to allow the group to determine how the research outcomes could be translated into Program modifications.

5. **Reset the working relationship with all advisory group stakeholders to ensure needs are being met in regard to the purpose of each group and expectations on information sharing.**

This would enhance clarity on the status of key actions and the work produced by advisory group functions and enhance the sense of partnership across and between all relevant stakeholders.

4 Awareness and adoption

This chapter addresses the extent to which consumers and clinicians are aware of, and have adopted, the Program.

4.1 To what extent is the Program achieving participation levels that maximise the population benefit of early detection of bowel cancer in the target population (50 to 74-year olds)?

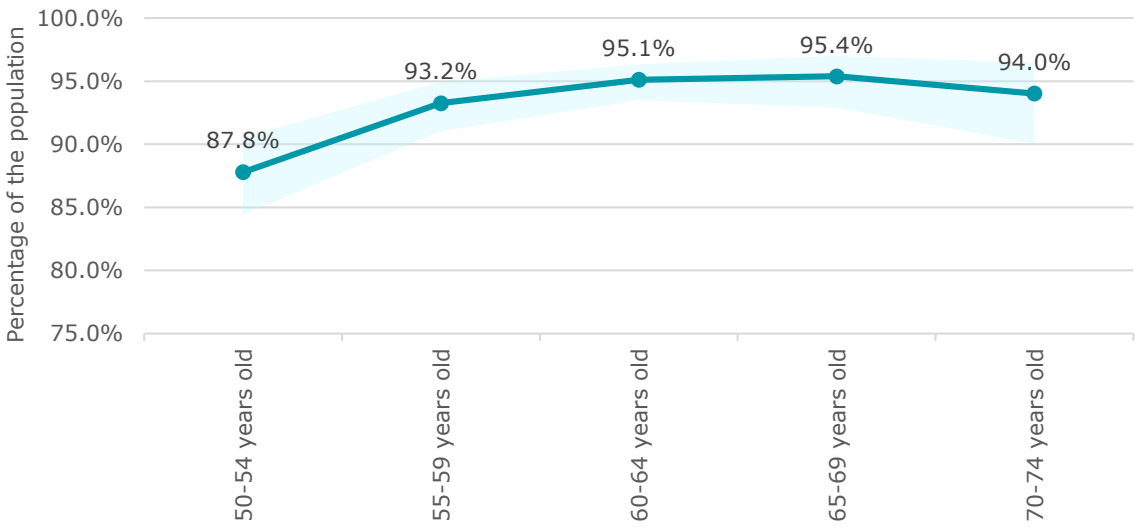
This section outlines findings related to awareness of the Program, bowel cancer and the benefits of screening among the eligible population. It also explores trends in participation rates over time and concludes by considering the key drivers and barriers to participation across different sub-groups.

4.1.1 Program awareness and among consumers

There is a relatively strong degree of public awareness of the Program among consumers. However, awareness is relatively low among people aged 50 to 54.

The consumer survey showed that approximately 92 per cent of Australians aged 50 to 74 years were aware of the NBCSP in 2020. Awareness was higher in cohorts that are more health conscious, based on factors such as likelihood to visit a GP for general check-ups as well as general health behaviours, such as smoking. Awareness was lower in people from CALD backgrounds and low socioeconomic status. Further, awareness was approximately five percentage points lower for people aged 50 to 54 years compared to people 55 or older (see Chart 4.1).

Chart 4.1: Consumer survey: 'Before today, had you heard of the National Bowel cancer Screening Program?', percentage by age group



Note: Shading represents a 95 per cent confidence interval.

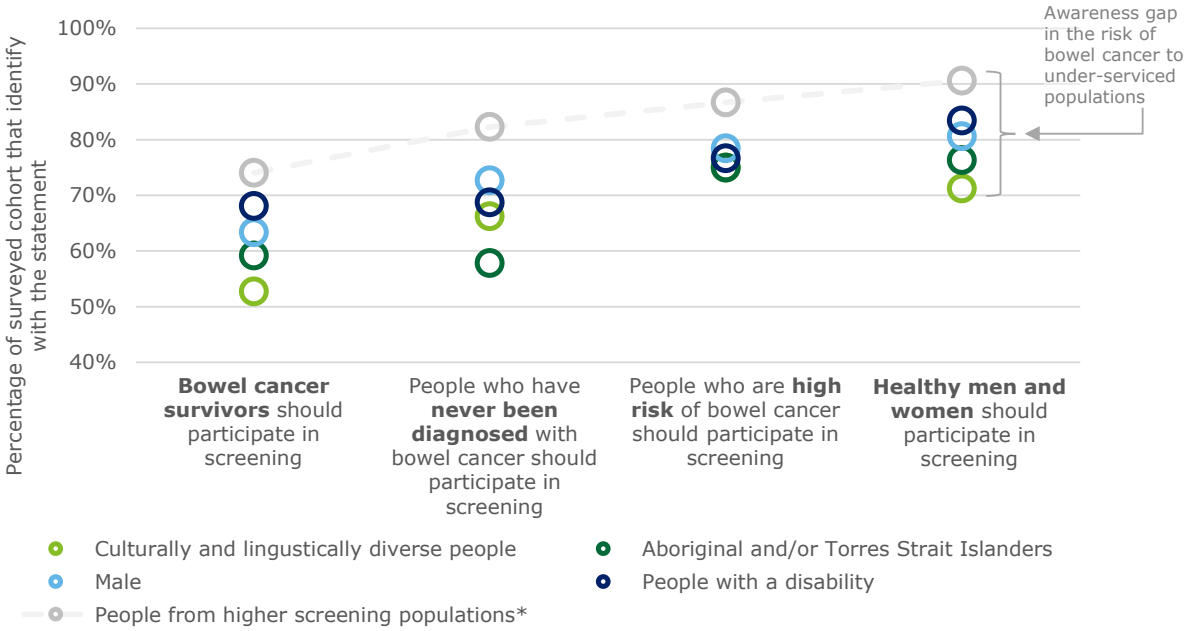
Source: Deloitte Access Economics NBCSP Consumer Survey, 2020.

Stakeholders consulted agreed that there is good awareness of the Program among the public, however it was noted that poor transparency on key Program updates/changes can contribute to confusion regarding the scope and timing of kit distribution. Examples cited included the shift from a strict biennial kit distribution interval based on birth date to two years after an individual completed their previous test, as well as the hot zone policy affecting kit distribution timing in some areas.

The understanding of personal cancer risk and the benefits of bowel cancer screening varies by population sub-group.

Evidence in the literature shows that people may underestimate their risk of developing cancer, which can reduce the perceived benefits of participating in screening.[69] The findings from the consumer survey support this finding, showing that population groups with low NBCSP participation rates were less likely to agree with statements such as: 'people who have never been diagnosed with bowel cancer should participate in screening' (Chart 4.2).

Chart 4.2: Consumer survey: agreement with statements related to cancer risk, percentage by population group



Source: Deloitte Access Economics NBCSP Consumer Survey, 2020.

4.1.2 Program awareness among clinicians

There is a relatively strong degree of understanding of the Program among respondents to the clinician survey, however understanding of the screening interval is mixed.

Of the respondents to the clinician survey, 71 per cent agreed that had a very good understanding of the Program.[xvii] This was supported by insights gleaned from consultations which indicated good practitioner awareness of the Program; however, it was noted that there is some confusion regarding the Program screening interval. Stakeholders attributed this to the incremental implementation of the Program, coupled with the absence of media campaigns promoting the complete transition to biennial screening.

In addition, stakeholders reported some confusion among primary care providers regarding appropriate clinical management for 'non-typical' patients, such as those who:

- have had a negative colonoscopy following a positive NBCSP iFOBT test (i.e. the 'skip round' policy, where if a patient receives a negative colonoscopy result, they will skip one screening round and be invited to re-screen in four years)
- are undertaking surveillance colonoscopies that do not meet the NHRMC clinical practice guidelines.

Stakeholders agreed that now the Program is aligned with the NHMRC-approved clinical practice guidelines, this will help clarify the messaging around best clinical practice to the Australian public.[70] It was also noted that with the transition to biennial screening now complete, the next 12

[xvii] Clinicians who reported their understanding of the Program as an 8 to 10 on a 10 point scale (1 = very limited understanding and 10 = very strong understanding), were classified as having a 'very good' understanding of the Program.

to 24 months present an opportune time to raise awareness, which may include the development of decision-making tools/resources for GPs regarding eligibility, screening interval and appropriate management for different types of participants.

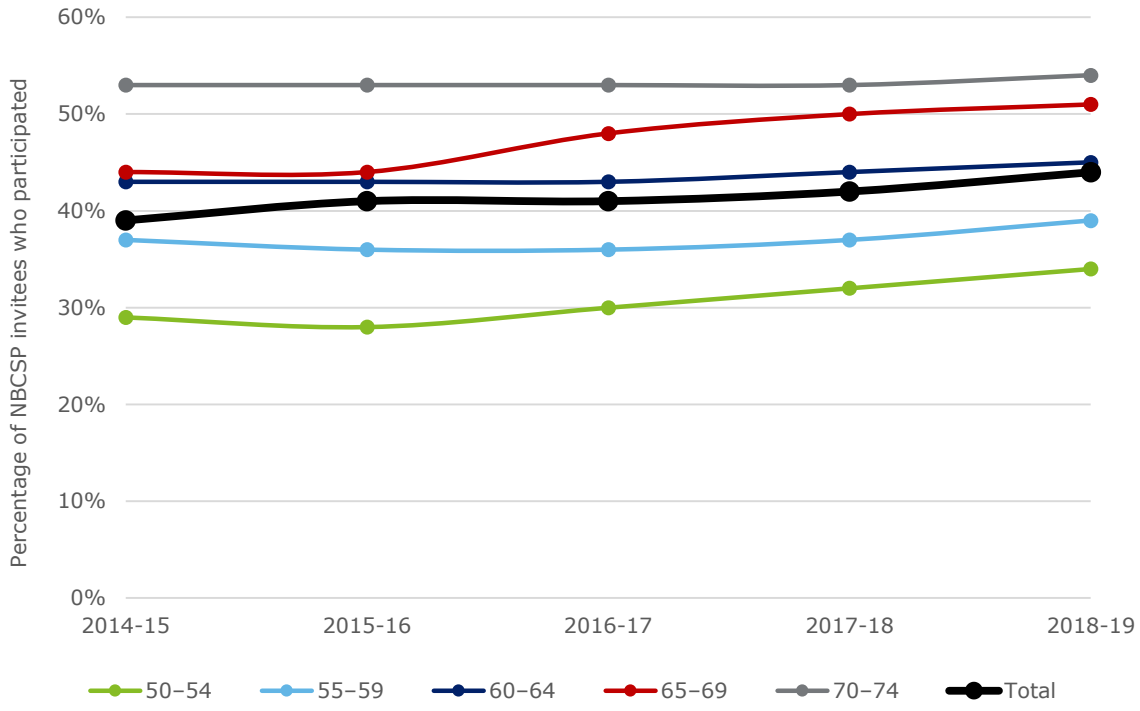
4.1.3 Program participation rates

Participation rates have gradually increased over time; however, they remain low relative to comparable cancer screening programs, both locally and overseas.

The overall Program participation rate for 2018-19 was 44 per cent, compared to 41 per cent in 2015-16, as shown in Chart 4.3. The participation rate has gradually increased year-on-year since 2012-13.

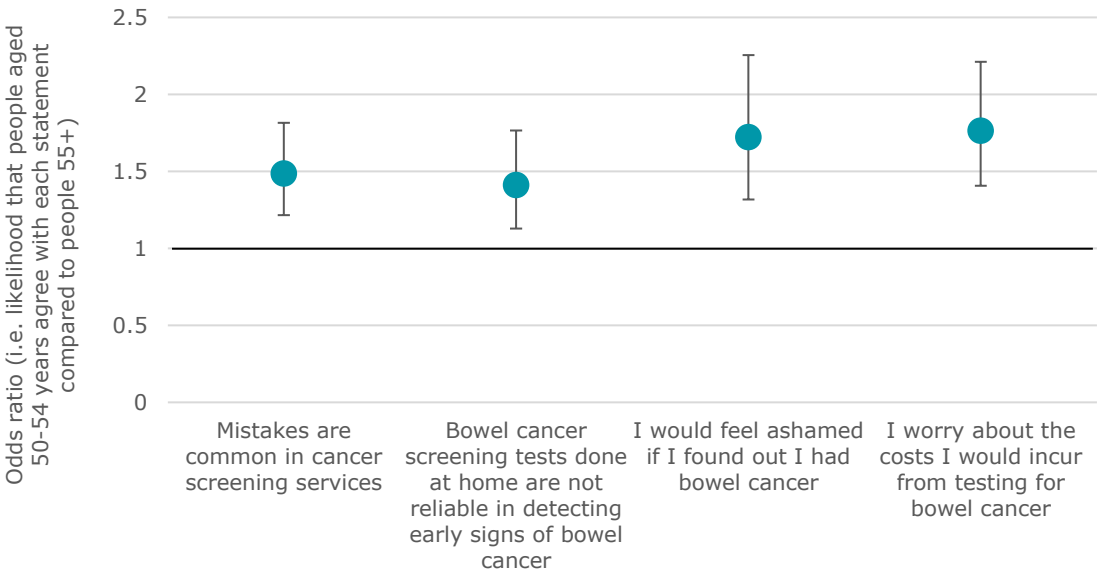
The statistics also shows that each year since Program commencement, the participation rate was positively correlated with age. In 2018-19, the participation rate ranged from 34 per cent for people aged 50 to 54 to 54 per cent for people aged 70 to 74. This likely reflects an attitudinal and awareness barrier among younger cohorts on the perceived need for screening. Consumer survey findings indicate that people aged 50 to 54 years were more likely to be concerned about the costs of bowel cancer screening (1.8 times), would feel ashamed if they received a positive diagnosis (1.7 times), and show scepticism in the reliability of at home screening kits (1.4 times), as compared with people above 55 or older (Chart 4.4).

Chart 4.3: NBCSP participation rate, by age, over time



Source: AIHW, *Cancer Screening programs: quarterly data* (2020).

Chart 4.4: Consumer survey: Odds ratios of the likelihood that people aged 50 to 54 years agree with the following statements, compared to people aged 55 to 74



Notes: Agreement with the following statements was rated on a 7-point Likert scale. Scores of 5 and above were categorised as 'agreement'. An odds ratio of greater than one indicates that the 50 to 54-year cohort are more likely to agree with the statement. Bars indicate a 95 per cent confidence interval.

Source: Deloitte Access Economics NBCSP Consumer Survey, 2020.

Participation rates in the NBSCP are relatively low compared to those observed in other Australian cancer screening programs. For example, in the year 2018-19, BreastScreen reported a participation rate of 55 per cent and the National Cervical Screening Program reported a rate of 46 per cent (see Table 4.1). Higher rates of participation in these programs may be driven by the following factors:

- the female only target cohort, with females generally more likely than males to participate in cancer screening programs[71]
- not facing the perceived hygiene barrier associated with iFOBTs.

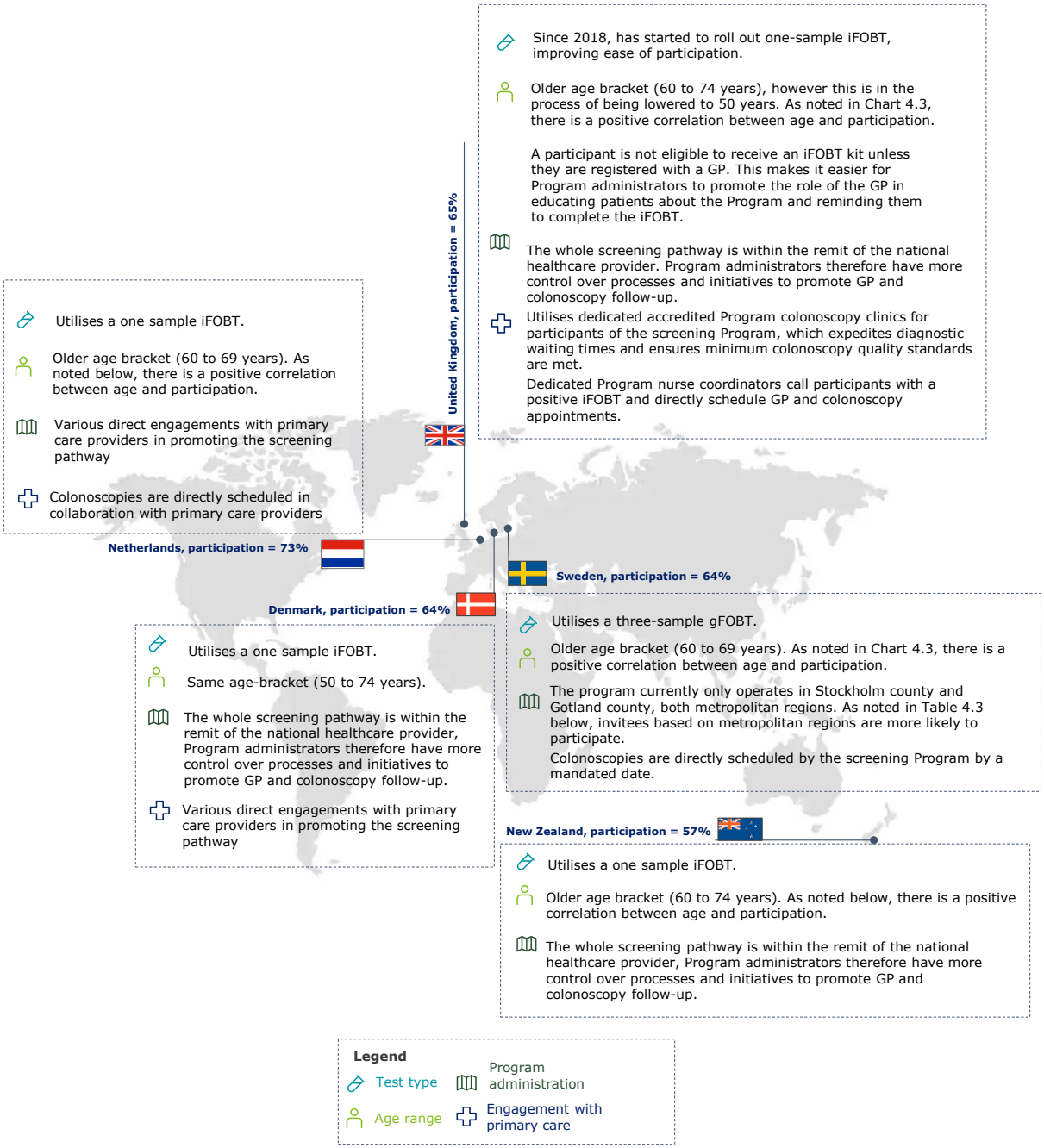
Table 4.1: Participation rates in other Australian cancer screening Programs and overseas bowel cancer screening Programs

Program	Overall participation rate
NBCSP	43.8%[a]
Other Australian cancer screening Programs	
BreastScreen	54.8%[a]
National Cervical Screening Program	46.3%[a]
Overseas bowel cancer screening Programs	
England	64.5%[b]
Sweden	64.0%[c]
Denmark	64.0%[d]
Netherlands	73.0%[e]
New Zealand	56.8% to 58.1%[f]
Scotland	64.1%[g]
Ireland	41.4%[h]

Source: [a]AIHW, *Cancer screening programs: quarterly data*, December 2020; [b]Public Health England, *Screening KPI data summary factsheets*, June 2020; [c]Blom, J; Kilpelainen, S et al 'Five-year experience of organized colorectal cancer screening in a Swedish population – increased compliance with age, female gender, and subsequent screening round', *Journal of Medical Screening,* 2014; [d]Larsen, M; Njor, S et al 'Effectiveness of Colorectal Cancer Screening in Detecting Earlier-Stage Disease-A Nationwide Cohort Study in Denmark', *Gastroenterology,* 2018, 155(1), 99-106.; [e]Toes-Zoutendijik, E; Portillo, I, et al 'Participation in faecal immunochemical testing-based colorectal cancer screening programmes in the northwest of Europe', *Journal of Medical Screening*, 2019, 27(2), 68-76; [f]Ministry of Health NZ, *Bowel Screening Pilot results,* 2018.; [h]Public Health Scotland, *Scottish Bowel Screening Program KPI Report*, August 2019. [g]National Screening Service, *BowelScreen Programme Report 2016-17*, 2017.

As shown in Table 4.1, the overall participation rate is also relatively low compared to mail-out bowel cancer screening programs overseas. However, these programs have different characteristics and features, which may explain higher participation rates, as shown in Chart 4.5. This chart is presented in table format with references in Appendix C.

Chart 4.5: Characteristics of overseas mail-out cancer screening Program



Source: Deloitte Access Economics informed by a literature scan. References are provided in Table C.1.

Unique access barriers exist for people in rural and remote areas, from CALD backgrounds and Aboriginal and Torres Strait Islander people.

The Population Based Screening Framework includes criteria for screening programs to be implemented in a way that provides equitable access to the test and follow-up assessment regardless of remoteness, ethnicity, socioeconomic status, and disability status. The Program does provide universal, free access to screening for all people within the target cohort, however there are disparities in rates of Program participation and subsequent follow-up.

Table 4.2 illustrates the variable participation rate by different population groups. Groups with comparatively low participation rates are those from remote areas (37 per cent from remote areas, and 27 per cent from very remote areas) and those that identify as Aboriginal and Torres Strait

Islander (23 per cent). Other cohorts with relatively low participation rates are people with disabilities (36 per cent) and from low socioeconomic areas (40 per cent).[xviii]

An exploration of the access barriers specific to each of these groups is described in section 4.1.4.3.

Table 4.2: Participation rates by population sub-group, 2018

Type	Participation
Overall NBCSP participation rate	
NBCSP	43.8%[a]
Sub-populations within NBCSP	
Female	45.9%[a]
Male	41.6%[a]
Disability	35.7%[b]
Indigenous	22.9%[b]
Language other than English spoken at home (estimate)	23.8% to 32.8%[b]
Metro	41.2%[b]
Inner regional	45.4%[b]
Outer regional	42.4%[b]
Remote	37.3%[b]
Very remote	27.1%[b]
High socioeconomic area	44.6%[b]
Low socioeconomic area	39.6%[b]

Note: Red shading indicates the participation rate for this group is lower than the overall NBCSP participation rate; green shading indicates the participation rate for this group is higher than the overall NBCSP participation rate.

Source: [a]AIHW, *Cancer screening programs: quarterly data*, December 2020; [b]AIHW, *NBCSP Monitoring Report*, July 2020.

4.1.4 Drivers and barriers to Program participation

The key enablers and barriers to participation were identified through the literature scan, stakeholder consultation and the consumer survey. A synthesis of the key themes is provided below.

4.1.4.1 Key enablers to Program participation

Key enablers to Program participation include the pre-invitation letter, the simplified kit instructions, 'peace of mind' and culturally tailored pathways for people from Aboriginal and Torres Strait Islander backgrounds.

Key enablers to Program participation include:

Pre-invitation letter. A pre-invitation letter is considered best-practice in the mail-out cancer screening program literature and was cited by a number of stakeholders as important in increasing the readiness of participants (especially first time participants) to undertake screening.[72] Of nine potential strategies identified in a meta-analysis of mail-out colorectal cancer screening programs, interventions with the strongest positive association with increased uptake were: use of advanced

[xviii] Please refer to Footnote i in section 2.1.2.3 regarding the distinction between socioeconomic background and residency in a low/high socioeconomic area.

notification (e.g. pre-invitation letter), a GP endorsement letter, and telephone contact (from any person i.e. Program officer or health professional).[73]

While the letter is considered an enabler, GP endorsement (e.g. on GP letterhead or through a signed separate letter), may further increase the efficacy of the letter. For example, a South Australian study investigated the effect of GP endorsement on the invitation for bowel cancer screening. GP–endorsed invitations (invites featuring the invitee's medical practice letterhead and signed by the invitee's GP) resulted in an increase in participation of approximately 10 percentage points.[74]

Simplified instructions. As noted in section 2.1.1.3, there was consensus across stakeholders consulted that the update to kit instructions in 2018 was a positive step toward increasing participation. In particular, the use of plain English and illustrations were seen to be a significant improvement, particularly for people with low literacy levels.

Despite this, there are opportunities to consider how the kit messaging and instructions could be tailored for people from CALD backgrounds and first-time screeners, with a view to overcoming their unique attitudinal and behavioural barriers. These are discussed in more detail in section 4.1.4.

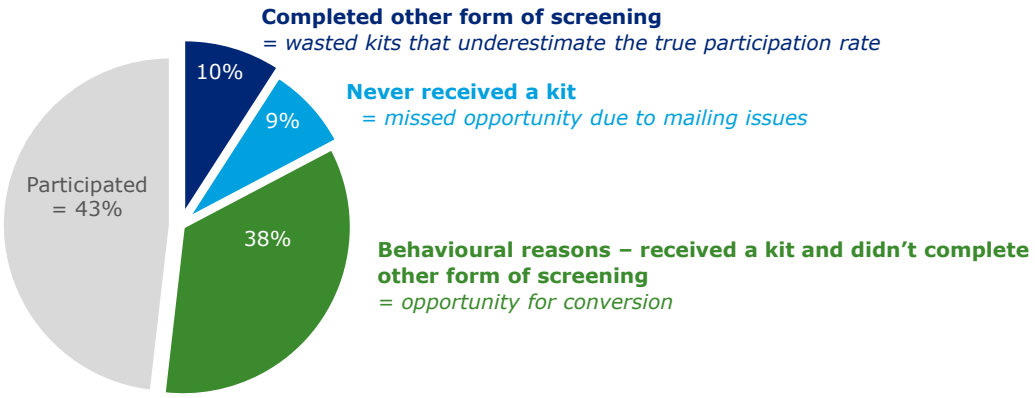
'Peace of mind' for those who understand the benefits of screening. Results from the consumer survey show that approximately eight in ten people who participated in the Program did so, in part, for *'peace of mind'*. This supports research in the literature, which shows that improving the degree to which people are aware of the risks of cancer increases the perceived benefits of engaging in cancer screening.[75]

Alternative distribution and completion pathways. As noted in section 2.1.1.7, the Alternative Pathway pilot was able to improve participation among Aboriginal and Torres Strait Islander people in line with those at an overall population level (from 23 per cent to 40 per cent).

4.1.4.2 Key barriers to Program participation (at an overall level)

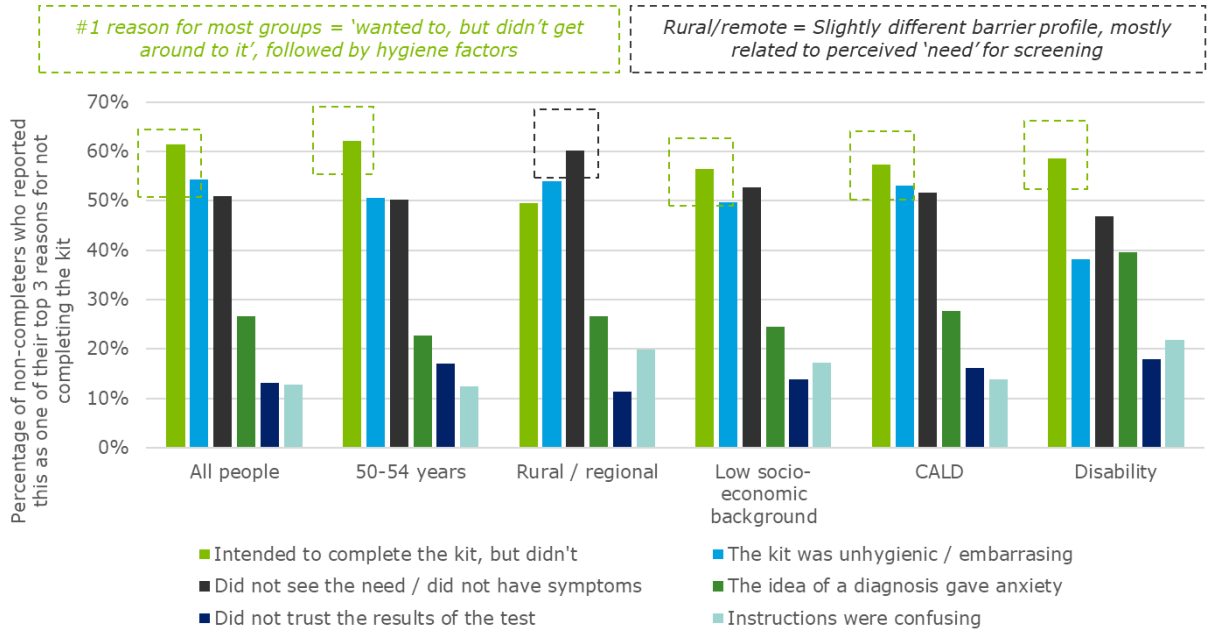
Most people who did not complete their NBCSP kit expressed an intention but lack of follow through, presenting opportunities for practical solutions to facilitate participation. The consumer survey provided useful insights into the drivers of non-participation, showing that of the 57 per cent of invitees who did not complete the kit, 38 per cent received a kit and did not complete another form of screening (see Chart 4.6). Of the remaining non-participants, 9 per cent never received the kit (representing the lost opportunity due to mailing issues) and 10 per cent completed another form of screening (with the majority undergoing colonoscopy).

Chart 4.6: Distribution of Program participants and non-participants (by reason for non-participation)



Source: Deloitte Access Economics NBCSP consumer survey, 2020.

Chart 4.7: Consumer survey: 'What were the three main reasons you decided not to complete the kit?', percentage by sub-group. *Asked of those who received a kit and did not complete another form of screening only.*



Source: Deloitte Access Economics NBCSP consumer survey, 2020.

Factors which may have contributed to the 38 per cent of people that received a kit and did not complete another form of screening, include:

Procrastination. For the cohort who received a kit and did not complete another form of screening, survey results showed that the number one reason for non-completion was *'wanted to do it but did not get around to it'* (61 per cent of non-completers, as shown in Chart 4.7). This presents a large opportunity for the NBCSP, as it indicates these people may be converted with the right 'nudging' or modifications to kit design.

Perceived hygiene concerns and personal embarrassment. The consumer survey found that the number two reason for non-completion was perceived hygiene of the kit and/or personal embarrassment (54 per cent of non-completers, as shown in Chart 4.7). Stakeholders suggested that modifications to kit accessories could help overcome these attitudinal barriers, such as opaque fridge storage bags or non-latex gloves.

Underuse of primary care as a resource. Currently, GPs are not involved in the screening pathway until the participant has completed the kit. There was consensus across stakeholders consulted that GPs, or other practitioners such as practice nurses or pharmacists, could act as a 'trusted advisor' and encourage participation in the Program, through providing education about the benefits of screening and encouraging compliance.

GPs and practice nurses could also be used a resource to identify and 'opt-out' (via the HPP) patients for whom screening may not be appropriate (e.g. those with overt bleeding or where a colonoscopy is considered too risky) or those who have recently used other forms of screening. This would inform a more accurate assessment of the true participation rate.

Engagement with primary care to promote participation has proven effective in England, Sweden and Denmark, as described in Chart 4.5. In addition, evidence shows these models can work in an Australian context, as shown in Box 3.

Box 3: Australian insights on use of primary care to promote bowel cancer screening

New South Wales

A randomised controlled trial conducted in New South Wales tested the effect of a GP promotion intervention on iFOBT uptake.[76] The intervention involved GP endorsement, printed screening advice and point-of-care iFOBT provision by the GP. Those involved in the intervention were ten times more likely to complete an iFOBT, when compared to those not involved in the intervention.

Victoria

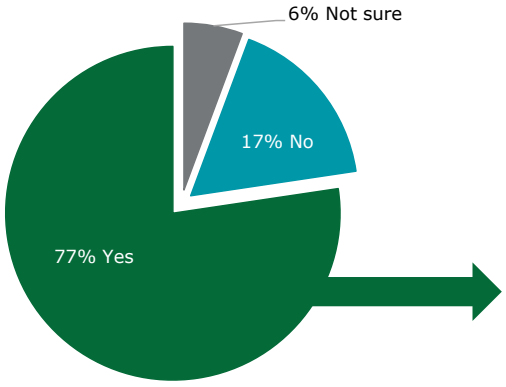
The Latrobe Cancer Screening Collaborative (the Collaborative) pilot project was developed in May 2019 to increase patient cancer screening rates within four Latrobe general practices. The practices worked together to achieve improved cancer screening rates, by participating in activities including webinars, workshops, and in-clinic systematic approaches for reminders. By the end of the project, the average NBCSP participation rates rose from 32.7 per cent (June 2019) to 36.2 per cent (February 2020), an increase of 9.7 per cent for the period.[77]

Single mode of kit distribution. Insights gleaned from stakeholder consultations suggest that the single mode of kit distribution (via the mail) may have contributed to the use of alternative at-home kits. It was noted that GPs and pharmacists often promote screening as part of routine health checks, yet the timing of NBCSP kit receipt may not align with the timing of these health checks, contributing to the use of more accessible kits through GPs and pharmacies.

The clinician survey showed that only 21 per cent reported 'always' initiating conversations about the NBCSP with a new patient aged 50 to 74 (and then every two years, as appropriate), yet 77 per cent of GPs surveyed had recommended a kit other than the NBCSP at least once in their practice (see Chart 4.8). Reasons cited referred to use for younger cohorts, as well as convenience and ease of access.

Stakeholders noted that the full implementation of biennial screening should contribute to a reduction in the use of alternative kits, as the Program's screening interval now aligns with the NHMRC-approved clinical practice guidelines.

Chart 4.8: Clinician survey: 'Have you ever recommended another at-home bowel cancer screening kits?', percentage. *Asked of GPs only.*



Why?

GP's commonly cited:

- people not eligible for the NBCSP (i.e. younger)
- availability of the kits in their practice rooms
- convenience (including automatic entry into the patient's medical record)
- patients who were not able to access an NBCSP kit in the moment (kits were thrown out/not completed, patient preference for annual screening).

Source: Deloitte Access Economics NBCSP clinician survey, 2020.

Box 4 highlights research showing the potential benefits to involving GPs and/or pharmacies in the provision of kits for the general population.

Box 4: Insights from the literature on alternative methods for kit distribution

Research commissioned on drivers of participation in France, the United Kingdom, Northern Europe and Australia all found that an active role of the GP or another 'trusted' practitioner in kit distribution and completion is important for uptake.[78, 79, 80, 81] Other studies in the Australian context have highlighted the potential role of community pharmacies in promoting and administering kits.[82] The involvement of GPs and pharmacies in the potential distribution of the testing kits offer the following benefits:

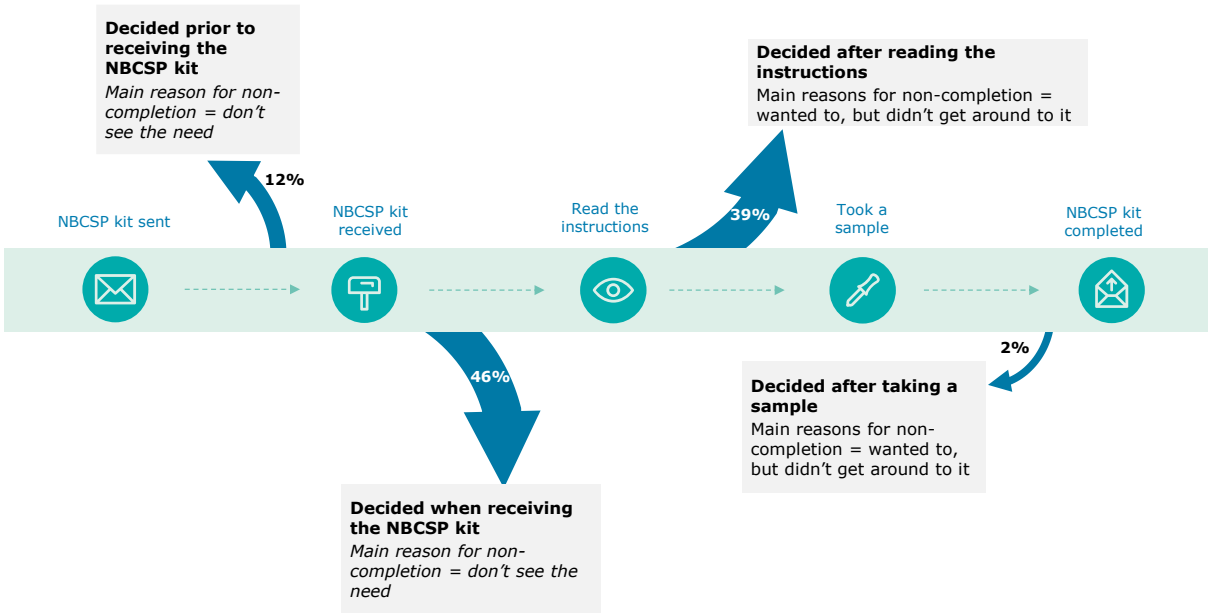
- ability for kits to be personalised based on the needs of the participants, for example, providing a culturally appropriate kit, or a kit in the participant's preferred language (see 'accessibility for CALD groups in section 4.1.4.3)
- the promotion of the NBCSP compared to alternative bowel screening kits: currently alternative kits are promoted due to availability for opportunistic issuing, and usually incur an out-of-pocket cost to consumers
- support the trusted advisor model, through GPs and/or pharmacists being able to address any questions and concerns regarding the use of the kit and provide additional advice or information about the Program and bowel cancer.

This is currently done in a similar manner through the Australian National Diabetes Services Scheme, in which people with diabetes are able to access services, support and subsidised diabetes products through 'Access Points'. Access Points are predominately community pharmacies and some health centres, clinics, and hospitals.

The letter content and kit design. As shown in Chart 4.9, almost half of non-completers decide to not complete the kit after reading the instructions. This suggests that the kit and instructions are an important hook, but can also act as a participation deterrent.

Stakeholders suggested that kit modifications could overcome some of the common behavioural and attitudinal barriers. To overcome procrastination, the instructions could include practical advice (e.g. an action plan for kit completion such as putting the kit in the bathroom within reach). Modifications to overcome the perceived hygiene concerns are described above under 'perceived hygiene concerns and personal embarrassment'.

Chart 4.9: Consumer survey: 'When did you decide not to complete the kit?', percentage. *Asked only of those who received a kit, did not complete it and did not complete another form of screening.*



Source: Deloitte Access Economics NBCSP consumer survey, 2020.

Fragmented and time-limited media and communications. Evidence in the literature shows that public health media and communications campaigns are effective in facilitating behaviour change at their peak, but their benefits gradually diminish over time.[83,84]

The Program has historically provided funding to states and territories to undertake their own time-limited marketing campaigns, rather than investing in long-term media and communications campaigns at a national level. Stakeholders acknowledged that a reason for this was the staged implementation of the Program, which was a barrier to long-term consistent and clear public messaging.

Following implementation of biennial screening, the Department provided funding to the Cancer Council to conduct a national media campaign. The campaign was successful, achieving a participation rate of 57 per cent, a 13 percentage point improvement on the baseline participation levels of 44 per cent at the time.[85] However, the campaign was time-limited and therefore the benefits were only realised in a cross section of the population at the time of the campaign.

4.1.4.3 Key barriers to Program participation (at a sub-group level)

In addition to common barriers across the board, evidence indicates some more pronounced challenges in particular population cohorts that further limit participation and contribute to inequities of access.

Key barriers identified at a sub-group (i.e. sociodemographic) level included:

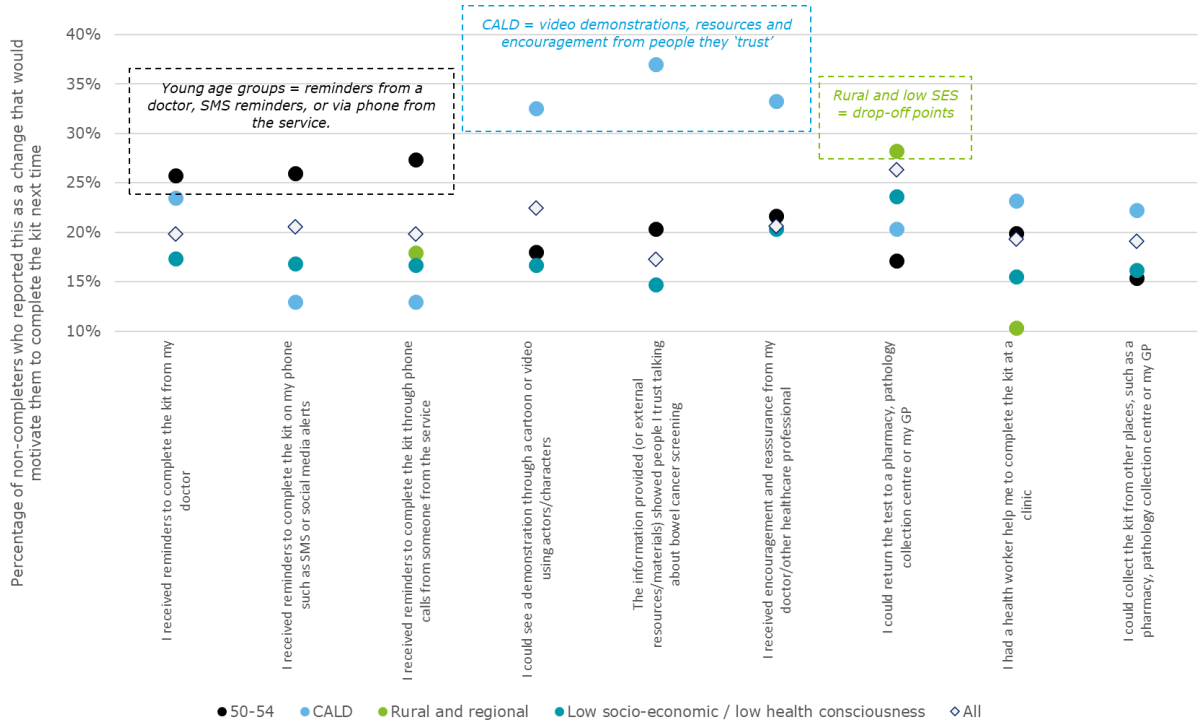
Health literacy. The consumer survey showed that people located in rural and remote regions and from low socio-economic status were more likely to cite *'did not see the need'* as a reason for non-completion, as compared with other low-participating groups.

The survey also showed that people in these groups were more likely to decide not to complete the kit before reading the instructions, suggesting that mechanisms to overcome this barrier should occur outside of modifications to the kit itself (e.g. via education from a healthcare professional, through media campaigns or through messaging modifications to the pre-invitation letter, the packaging of the kit or the kit).

Single mode of kit return. The consumer survey showed that the number one change to the Program that would encourage people from rural and remote regions to complete a kit next time was, *'I could return the test to a GP, pharmacy or pathology collection centre'* (28 per cent, as shown in Chart 4.10).

Insights gleaned from consultations provide important context to this finding. Stakeholders cited the challenges associated with strict return postage requirements for those located in rural and remote regions (i.e. the need to use post offices during business hours or mailboxes in the afternoon before 6pm), and the impact of delays to postage on kit expiry.

Chart 4.10: Consumer survey: 'Which of the following would motivate you to complete the kit next time?', percentage by sub-group. *Asked of those who received a kit but did not complete another form of screening.*



Source: Deloitte Access Economics NBCSP consumer survey, 2020.

Findings from a 2015 New Zealand trial of bowel cancer screening kit 'drop-off' collection points support this observation, finding that 26 per cent of participants used the drop-off location. The effect of the drop off option on participation varied by age, gender and ethnicity. There was a statistically significant increase in participation among groups with low baseline participation, such as Māori and Pacific Islander people (plus 3 per cent), men (plus 2 per cent) and participants under 60 (plus 2 per cent).[86]

Accessibility for CALD groups. The consumer survey showed that the number one change to the Program that would encourage non-completers from CALD backgrounds to complete a kit next time was '*the information provided showed someone I trust talking about screening'*, followed by *'I could see a demonstration through a cartoon or video'* (as shown in Chart 4.10).

Stakeholders consulted highlighted that Program participation by people from CALD communities is impeded by communication difficulties and the ability to understand the materials received. It was noted that the existing instruction video that is available on the Program's website provides an animated demonstration, however the narration is in English and available translations are not immediately obvious on the landing page. It was suggested that instructions should be pictorial to address this issue. More broadly, it was noted that the organisation of translated resources on the website is difficult to navigate.

Accessibility for people with disabilities. Stakeholders consulted highlighted participation barriers for people with disabilities including vision impairment and disabilities affecting mobility and dexterity. Eligible participants with disability related to their vision, dexterity or mobility may face challenges:

- writing their details on sample tubes
- completing the participant form
- opening collection tubes
- collecting samples
- returning the sample swab to the collection tube.

People with vision impairment may have the added challenge of not being able to read the instructions.

4.2 What are the key identified opportunities to improve Program participation?

Key opportunities for Program enhancement have been identified drawing on evaluation findings relating to awareness and adoption.

1. Use the primary care sector as a resource to promote participation through education and opportunistic provision of kits.

Primary care professionals such as GPs, practice nurses and pharmacists, are important in promoting patient participation in the Program and counselling and advising patients throughout the screening, diagnosis, and treatment process. Chart 4.10 shows that counselling from a trusted health professional is the key Program change that would encourage non-completers from younger cohorts and CALD backgrounds to complete the kit next time.

Further, education on the personalised risk of bowel cancer and the benefits of screening would overcome the attitudinal barrier relating to the perceived 'need' for screening, as well as beliefs relating to the costs associated with a positive iFOBT.

As noted in section 2.1.1.3, the HPP and its integration with primary care management software provides important enabling infrastructure to facilitate the role of primary care in promoting participation. The HPP could be used:

- **Within existing Program parameters.** For example, by initiating conversations about bowel cancer screening, confirming eligibility to participate and appropriate postage details, and following-up patients who have been sent a kit but not completed it. In addition to improving participation rates, each of these factors would also inform a more accurate assessment of the true participation rate for reporting purposes.
- **Beyond current Program parameters.** For example, invitees could collect a kit from a registered community pharmacy or a GP, and their participation could be recorded by a practitioner who notifies the NCSR through the HPP. Alternatively, the pre-invitation letter could include a voucher to collect the kit from a pharmacy or a practice.

The utility of the HPP in promoting participation in its current form should be evaluated, and additional features could be considered.

2. Consider piloting sample drop-off points.

Chart 4.10 shows that the ability to drop off iFOBT samples at a collection point was the number one Program change that would encourage non-completers to complete the kit next time. This was a proposed change that was most profound for non-completers residing in rural and remote locations due to their unique challenges in complying with the strict return postage requirements.

To ensure a change of this nature is feasible, consideration should be given to sufficient dedicated refrigeration at the collection point, and the logistics of ensuring that all samples arrive at the laboratory from the collection point prior to expiry.

3. Scale up the Alternative Pathway pilot, as appropriate in other population groups.

The Alternative Pathway pilot demonstrated success in increasing participation in Aboriginal and Torres Strait Islander communities. Feasibility of scaling the pilot to other Aboriginal and Torres Strait Islander communities should be explored. In addition, consideration should be given to how the pilot could be tailored and adapted to meet the unique needs and access barriers for people from CALD backgrounds.

4. Explore utilisation of the NCSR to improve participation.

There are several ways the NCSR could be utilised to improve communication methods and engagement with the target cohort, and thereby, overcome common barriers to participation. Examples include:

- **Electronic reminders.** Chart 4.10 shows that digital reminders are one of the key Program changes that would encourage non-completers from younger cohorts to complete the kit next time.
- **Streamlined processes for completion of the personal details form or access to in-language communications.** For example, personal details forms could be pre-populated based on information previously collected, a QR code could be used to take invitees to an electronic mode of form completion, a QR code could be used to take invitees direct to in-language communications and express preferences for modes of communication etc.
- **Personalised invitations that seek to overcome specific sub-group attitudinal or behavioural barriers.** For example, information on the benefits of screening could be targeted at first-time screeners (both those receiving a kit for the first time and those who have received kits previously but never participated).

  Modifications to the information provided could have a profound impact on improving participation given that almost one in two non-completers decide not to complete the kit after reading the instructions (Chart 4.9).

5. Modify kit contents and accessories to mitigate common reasons for non-completion.

Chart 4.7 shows that the number one reason for non-completion was *'wanted to do it but did not get around to it'* followed by perceived hygiene concerns. This suggests that modifications to kit design that seek to overcome these attitudinal barriers may promote participation. Suggestions cited by stakeholders included:

- an action plan in the instructions (e.g. advice to put the kit in the bathroom in a reachable position, and to plan to complete the kit on days when you are at home).
- provision of accessories such as a completely opaque bag for fridge storage or non-latex gloves.

6. Implement sustained and coordinated media and communications campaigns.

As noted in section 4.1.4.2, long-term communications strategies are needed to achieve sustained levels of awareness that contribute to sustained improvements in participation rates. National media and communications campaigns, such as the Cancer Council's 2019 strategy, have proven highly effective, with up to 101,800 extra kits returned and 600 lived saved over the next 30 years.[87] Longer-term implementation of these campaigns targeted at both consumers and primary healthcare practitioners (as reinforcement) should be considered to overcome the limitations of time-limited campaigns.

These campaigns should be considered at a national level, and as part of an integrated communications framework (in partnership with cancer charities and community groups) to promote a coordinated message that minimises fragmentation and duplication of effort.

5 Effectiveness

This chapter addresses the efficacy of the Program in maximising the benefits and minimising the harms to participants.

5.1 To what extent is the Program maximising the benefits and minimising harms to individuals participating in the Program?

AIHW analysis of longitudinal cancer data demonstrates that the Program achieves earlier detection and better survival from bowel cancer.

As noted in section 3.1.2, to assess the Program's impact on achieving its overarching goal of facilitating earlier detection and better survival from bowel cancer, an assessment of cancer incidence, staging and mortality should be assessed for participants versus non-participants.

Any analysis of this nature requires data linkage between the ACD and the NCSR, which was out of scope for the review. Other factors that limited the feasibility of this analysis included:

- **The recency of the data in the ACD.** Cancer incidence statistics are only available in the ACD up to the year of 2016. Mortality statistics are only available in the ACD up to the year 2018.
- **The availability of staging data.** Cancer staging data is only available in the ACD for the year 2011.

Given these limitations, to assess the impact of the Program on earlier detection and better survival, reference is made to the AIHW's 2018 report *Analysis of bowel cancer outcomes for the National Bowel Cancer Screening Program*. This report linked data from Program invitees between 2006 and 2010 to people diagnosed with bowel cancer from 2006 to 2015. The report observed:

- **Stage at detection.** Among invitees, those with screen-detected bowel cancers were more likely to be diagnosed at an earlier summary stage (1.71 times as likely), compared with bowel cancers later diagnosed in the invitees who did not participate.
- **Survival.** Among Program invitees diagnosed with bowel cancer, the risk of death from bowel cancer was over two times greater in non-participants compared to participants whose cancer was screen-detected.[88]

These findings confirm that Phase One and Two of the Program effectively contributed to reducing morbidity and mortality from bowel cancer in Australia. These estimates also closely align with our modelled estimates (provided in section 6.1.3) of the impact of the Program on cancer incidence and mortality used in the cost-effectiveness analysis (Chapter 4). Data from more recent years, following the transition to biennial screening and increased rates of participation, is likely to demonstrate an even greater benefit for Australians.

Australia uses a test with a high diagnostic value to minimise harms associated with screening, however efforts to address data gaps on adverse events and the test PPV would inform a more robust assessment of Program harms.

A harm associated with any bowel cancer screening program is the chance of an adverse event following a screening colonoscopy (including perforation and death). For Program participants who proceed to a diagnostic assessment, unplanned hospital admissions within 30 days of diagnostic assessment is reported in the AIHW Monitoring Reports (shown in Table 5.1). However, given that reporting of adverse events is voluntary, the AIHW states a concern about the level of data completeness, noting an unknown level of under-reporting.

When compared with the overall rates of adverse events post colonoscopy reported in *Colonoscopy Clinical Care Standard (2020),* the Program's rates appear lower, however this comparison should be interpreted with caution given that even a small level of Program under-reporting could have a significant impact on comparability.

As noted in section 3.1.2, data linkage with inpatient datasets would support a more accurate assessment of the rate of adverse events and should be prioritised as part of addressing KPI data gaps.

Table 5.1: Rates of selected diagnostic assessment complications (per 10,000 screening colonoscopies)

Group	Rate
General population	
• perforations	4.0[a]
• major bleeding events	8.0[a]
• colonoscopy-specific mortality	0.7[a]
NBCSP (2020)	1.2[b]
NBCSP (2019)	3.0[c]
NBCSP (2018)	6.0[d]
NBCSP (2017)	9.0[e]

Source: [a]ACSQHC, *Colonoscopy Clinical Care Standard*, 2020 [b]AIHW, *NBCSP Monitoring Report*, July 2020; [c]AIHW, *NBCSP Monitoring Report*, July 2019; [d]AIHW, *NBCSP Monitoring Report*, July 2018; [e]AIHW, *NBCSP Monitoring Report*, July 2017.

Other common harms associated with any cancer screening program are the risk of false positive or false negative screening results. In the context of bowel cancer screening, false positive results contribute to unnecessary colonoscopies, which are associated with risks of adverse events and patient distress and anxiety. Conversely, false negative results may delay a diagnosis of cancer.

As discussed in section 2.1.1.7, the Program minimises harm in this respect, as it uses a test with a high diagnostic value, relative to overseas bowel cancer screening programs. However, as noted in section 3.1.2, the Program does not routinely report the PPV of the test in detecting cancer or adenoma due to data gaps. Efforts to improve the feasibility of this indicator would support a more accurate assessment of the Program's harm caused by iFOBT false positives and should be prioritised as part of addressing KPI data gaps.

5.2 Are there opportunities to change or enhance the role of states and territories to better support the achievement of NBCSP outcomes?

Several opportunities to enhance the role of the state and territories to better support the achievement of Program outcomes were identified through the review and are discussed throughout this report. These opportunities are predominantly related to colonoscopy access, as summarised below:

- **Innovative colonoscopy access models.** Trial pilot projects that reshape the PFUF role to align with innovative nurse-led colonoscopy access models that prioritise and schedule appointments for participants. As discussed in section 2.2, this would require buy-in and input from primary care stakeholders (as referrers to the model) and stakeholders from hospital colonoscopy departments (as facilitators of access to coloscopy waitlists and appointments).
- **Representation on PDAG by jurisdictional colorectal departments.** Reconfigure representation on PDAG to involve key jurisdictional contacts representing colonoscopy departments. This would facilitate buy-in to any proposed models involving integration with LHDs/HHSs that seek to improve colonoscopy access, as described in section 3.4.

5.3 What are the key identified opportunities to improve the effectiveness of the Program?

A note on the opportunities associated with this chapter:

Each of the opportunities identified in section 2.2, section 3.4 and section 4.2 serve to increase the efficacy of the Program on improving earlier detection of bowel cancer and better survival. As highlighted in Table 3.2, more routine data linkage with cancer outcomes datasets such as the ACD and jurisdictional cancer registries would improve the ability to demonstrate the impact of the Program on these outcomes.

6 Efficiency

This chapter addresses the cost-effectiveness of the Program relative to no screening, across different age brackets and participation rates.

6.1 To what extent is the Program cost-effective?

A cost-effectiveness analysis (CEA) is performed to assess the value for money of a particular policy or program. A CEA calculates the incremental net costs and benefits of an intervention relative to a comparator, by providing evidence to answer the question – *do the extra benefits outweigh the extra costs?*

A CEA was performed to assess the value of the current configuration of the Program (biennial screening for those aged 50 to 74) relative to no screening at 2020 age-specific participation rates (equating to a weighted average participation rate of 44%). In addition, scenarios were performed on different eligible age ranges and participation rates to assess how changes to Program scope and uptake may impact cost-effectiveness.

This analysis was conducted from multiple perspectives. Many evaluations of healthcare interventions are conducted from a healthcare system perspective, as payers are charged with the responsibility of achieving maximum output within their limited budget. However, there is merit in also considering a broader set of monetisable societal benefits associated with a cancer screening program. These include the impact of earlier detection and better survival on improved productivity for patients and informal carers, as well as a reduction in patient out-of-pocket costs. Therefore, the modelling adopted:

- **A societal perspective**, in the primary analysis. This includes the cost of health-related resource use, out-of-pocket patient costs, and productivity costs for patients and informal carers.
- **A healthcare system perspective**, in the scenario analysis. This only includes the cost of health-related resource use.

6.1.1 Existing research and what this analysis adds

Previous literature has examined the cost-effectiveness of the Program. Deloitte Access Economics conducted the first CEA on the Program in 2007 and found that biennial screening for people aged 50 to 74 was more cost-effective than biennial screening for people aged 55 to 74, when evaluated from a societal perspective.[89] More recently, a 2018 study by Lew et al. evaluated the cost-effectiveness of different target age ranges from a healthcare system perspective. The research found that commencing screening at age 50 was more cost-effective than commencing screening at age 45, across a range of different participation scenarios. In addition, the study found that starting screening at age 45 would increase colonoscopy demand for Program-related colonoscopies by 3 per cent to 14 per cent.[90]

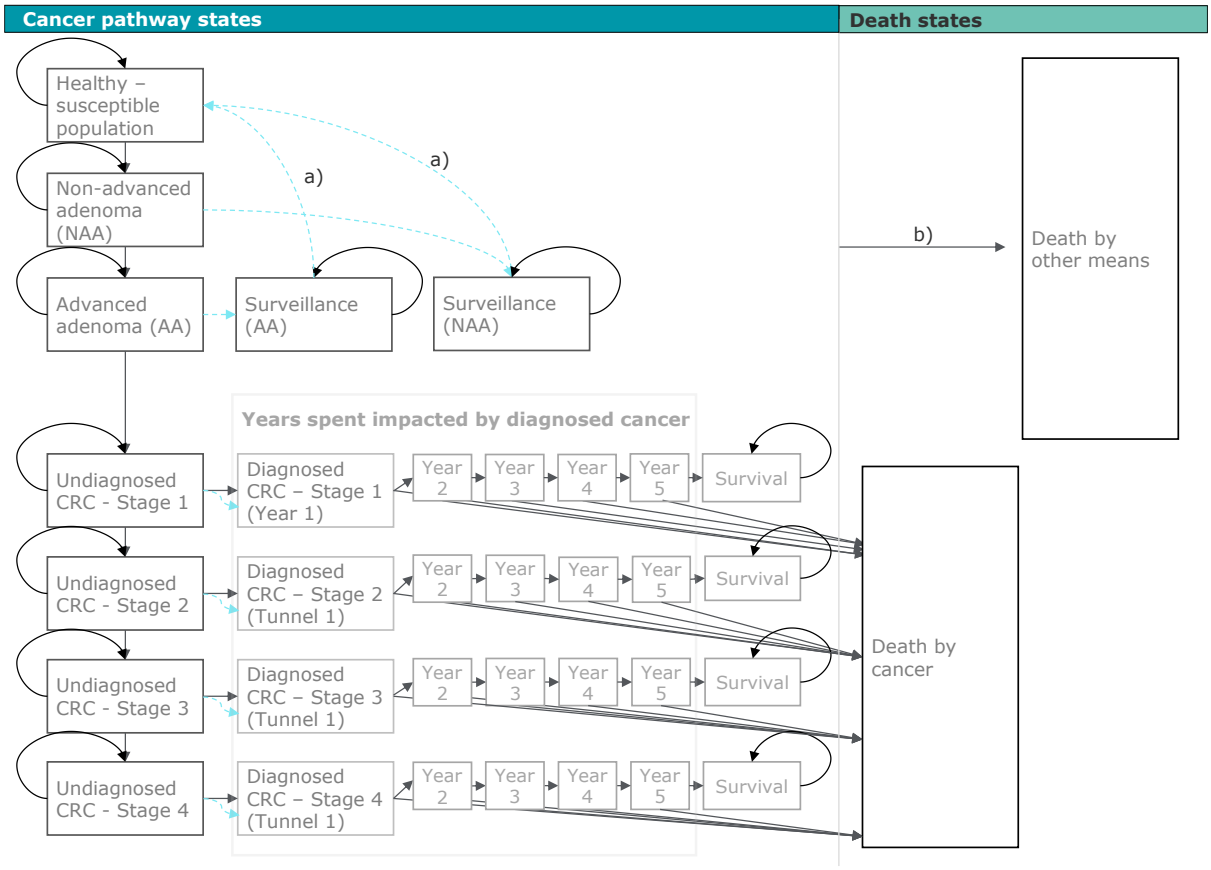
These papers did not consider Program administrative costs or evaluate the cost-effectiveness of a screening entry age of 45 or 40 from a societal perspective. The modelling conducted in this paper adds to the evidence base by addressing both gaps.

6.1.2 Methodology and approach

The CEA was conducted using a Markov cohort model to reproduce the natural history of bowel cancer overlayed with a decision-tree model to account for the effect of screening. This approach is consistent with the approach used by Lew et al. (2018) and is representative of a 'deep model' as described in Silva-Illanes' (2018) critical analysis of Markov models used for the economic evaluation of colorectal cancer screening.[91,92]

The Markov-chain includes 35 health states which a person moves through over time (see Chart 6.1). Each health state represents a state in the natural history of adenoma and bowel cancer development. In the base case, the population enters the model at age 50, and transitions from one state to another each period, defined as a year, until each person dies or reaches 90 years of age.[xix] The probability that a person will move from one state to another is based on transition probabilities drawn from the literature.

Chart 6.1: Schematic overview of the natural history and screening pathways



Notes: a) This arrow indicates that a proportion of people within the Surveillance stage do not comply with the surveillance guidelines at all, and therefore they return to the 'Healthy – susceptible population' state. b) All states in the 'cancer pathway' can transfer to the 'Death by other means' state.

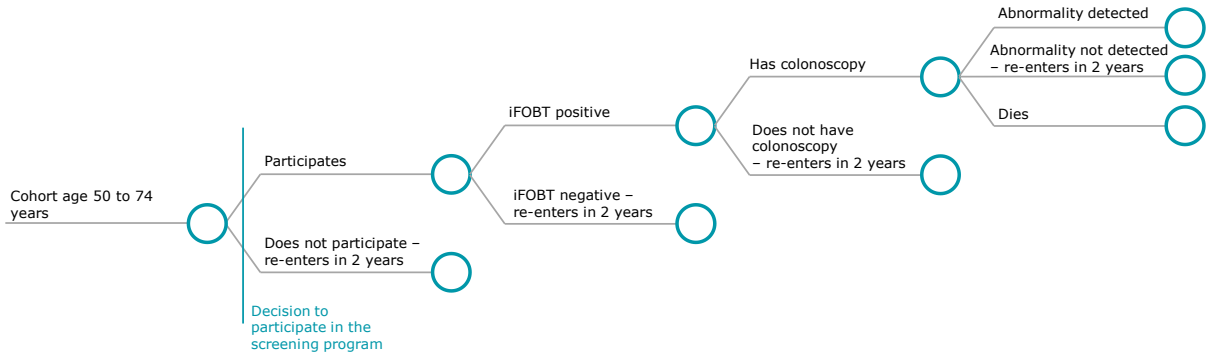
Source: NBCSP Policy Framework, 2017.

Costs and disability-adjusted life years (DALYs) are applied to each state to determine the costs and outcomes associated with a person living in a given state for a year. Costs and DALYs are accrued annually over time as each person in the cohort cycles through the model.

To account for the benefit of screening on earlier detection, a decision-tree model is superimposed on the natural history model every second year (to account for biennial screening) over the target age range (see Chart 6.2). This model represents the screening strategy and is governed by participation rates, iFOBT sensitivity rates, diagnostic assessment rates, colonoscopy sensitivity rates, and colonoscopy adverse event rates. This model is used to adjust transition probabilities to account for the effect of screening on 'intercepting' the natural progression of bowel cancer and reducing the probability that cancer will be detected (i.e. through detection at the adenoma stage) or detected at an advanced stage.

[xix] The age at which people enter the model is based on the scenario being tested. For example, for a Program with a commencement age of 40 years, people enter the base case and scenario models at the age of 40.

Chart 6.2: Screening pathway decision tree



Source: Deloitte Access Economics

To estimate the incremental impact of screening vs. no screening, a cohort of Australians is simulated through the model both with (screening arm) and without (no screening) the decision-tree model. Costs and DALYs are summed and compared between these two simulations. Results are then reported in the form of an incremental cost-effectiveness ratio (ICER).

Refer to Appendix B for a more in-depth description of the methodology.

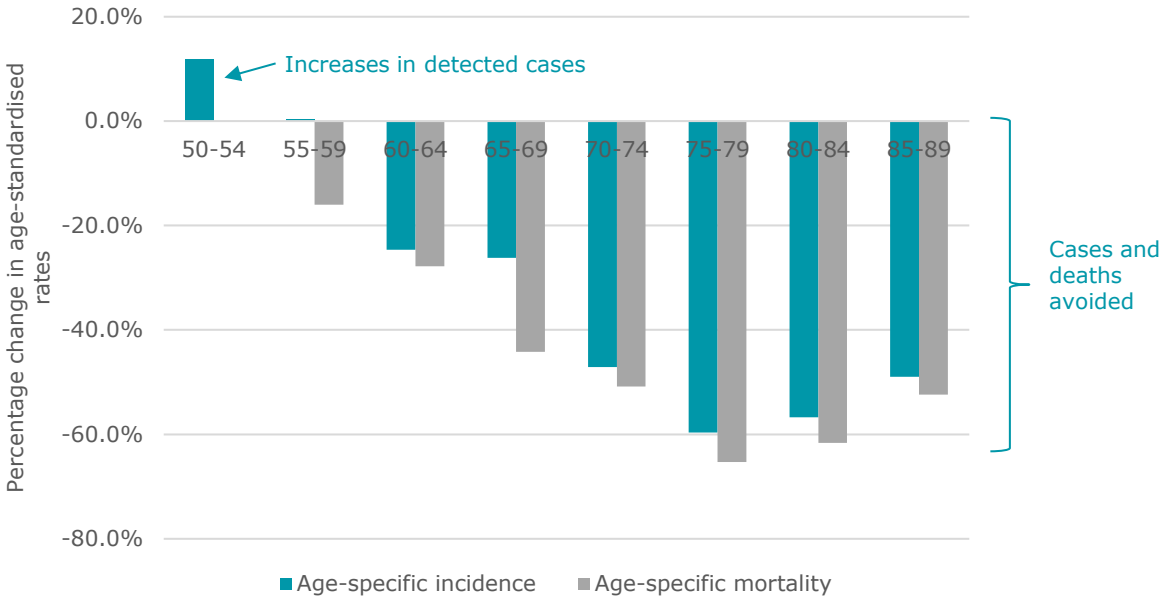
6.1.3 Base case results

Overall, the CEA results show that the Program is highly cost-effective compared to a no screening scenario.

Under the base case, from a societal perspective, biennial screening for those aged 50 to 74 resulted in an ICER of $1,931 per DALY avoided (Table 6.1), when compared to a comparator of no screening. This value is considerably lower than Australian estimates for a government-based willingness-to-pay threshold of $50,000 per Quality Adjusted Life Year (QALY) gained, indicating that the Program is highly cost-effective.[93]

In terms of clinical benefit, over the lifetime of the invited cohort, the model estimates that biennial screening for those aged 50 to 74 years reduces cancer incidence by approximately 40 per cent and cancer-related mortality by approximately 47 per cent (Chart 6.3). However, in the short-term, the Program is estimated to increase cancer incidence rates while having no material impacts on cancer-related deaths. This is because, in the short-term, the Program increases the rate at which cancer is diagnosed, as compared with symptomatic detection. Further, a lag time of approximately 5 to 10 years is required before the increased rate of detection (at an earlier stage) leads to a reduction in mortality, as compared with symptomatic detection.

Chart 6.3: Percentage reduction in age-standardised cancer incidence and mortality rates

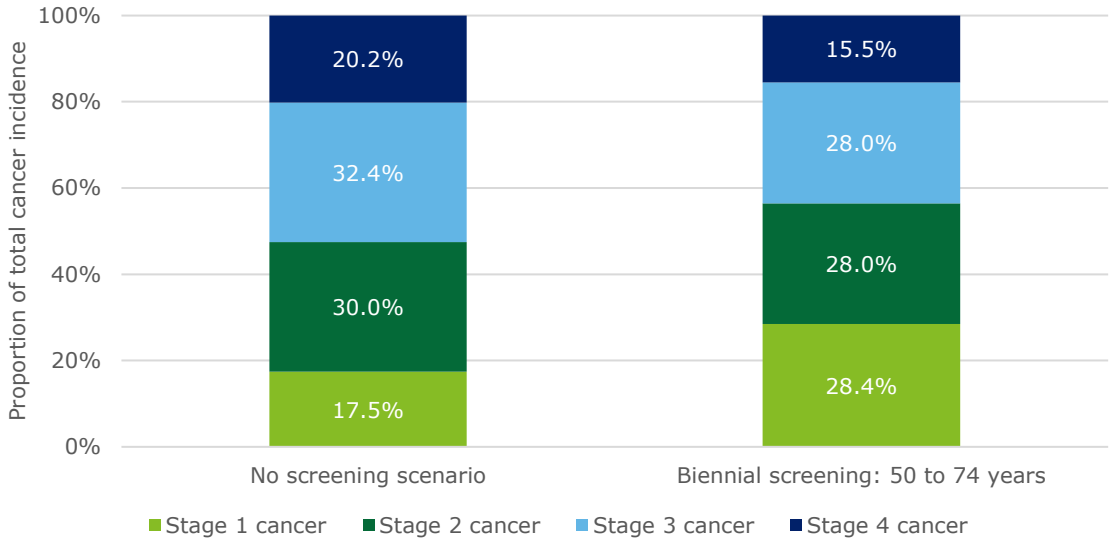


Notes: Analysis assumes current age-specific participation rates reported by AIHW.

Source: Deloitte Access Economics analysis and AIHW Cancer data in Australia (2020).

The reduction in cancer-related mortality attributable to screening is primarily a result of earlier stage at detection, where survival rates are better (see B.3 for five-year relative survival rates by stage at detection). As shown in Chart 6.4, of all cancer diagnoses, the proportion diagnosed at Stage 1 is approximately 28 per cent under the screening scenario (biennial screening for those aged 50 to 74) compared to 18 per cent under the no screening scenario.

Chart 6.4: Stage at cancer detection



Source: Deloitte Access Economics analysis.

When conducted from a societal perspective, the model estimates that lowering the screening entry age to 45 years is slightly more cost-effective than starting screening at age 50.[xx]

When the model was adjusted to assess the cost-effectiveness of lowering the screening entry age to 45 compared to no screening, the ICER was marginally lower at $1,381 per DALY avoided, evaluated from a societal perspective. This result shows that commencing screening at age 45 has a slightly lower cost per DALY avoided, signalling a moderate increase in cost-effectiveness. The main contributing factor to this result is the value of lost lifetime earnings due to premature mortality. When commencing screening at age 45, the cost of lost productivity is reduced by 14 per cent when compared with no screening. This figure is only 8 per cent under a scenario where screening commences at 50.

By lowering the screening entry age to 45, it would save society an additional $1,529 per DALY avoided compared with the current Program configuration (commencing screening at age 50). However, because this analysis was conducted from a societal perspective, not all cost-savings accrue directly to the healthcare system.

Across the three age scenarios assessed (50 to 74, 45 to 74 and 40 to 74), commencing screening at age 40, was the least cost-effective scenario, when evaluated from a societal perspective.

Table 6.1: Summary of base-case CEA results; societal perspective

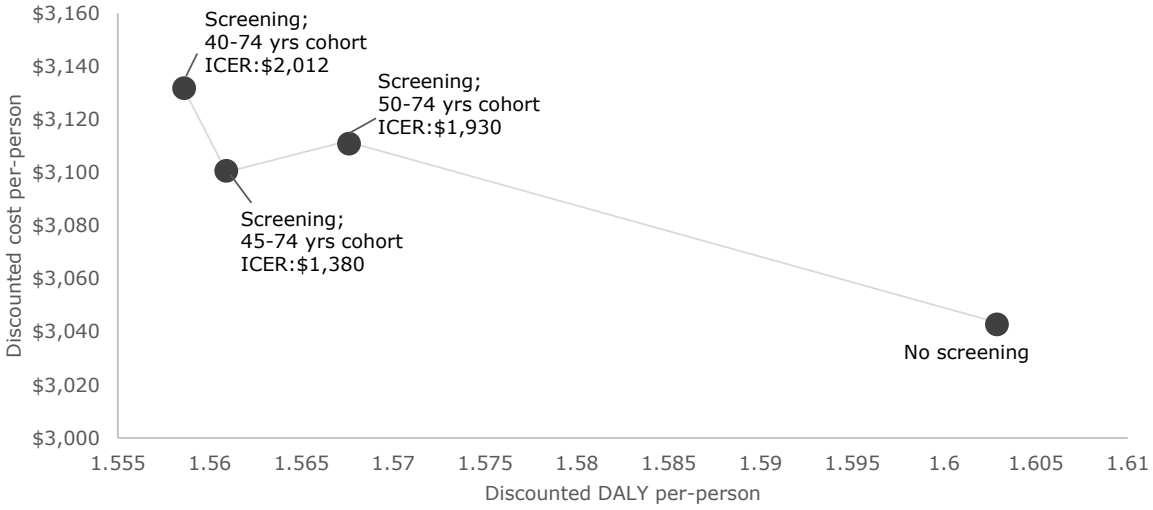
Scenario	Reduction in cancer incidence[a]	Reduction in deaths[a]	Discounted costs per person	Discounted DALY per person	ICER[a]
No screening	-	-	$3,042	1.60	-
Biennial screening for 50 to 74 years	-39.6%	-46.7%	$3,111	1.57	$1,931
Biennial screening for 45 to 74 years	-41.4%	-48.6%	$3,100	1.56	$1,381
Biennial screening for 40 to 74 years	-41.7%	-48.8%	$3,131	1.56	$2,012

Notes: (a) Variables are estimates compared to the no screening scenario.

Source: Deloitte Access Economics analysis.

[xx] For the 45 to 49 year cohort, a participation rate of approximately 29 per cent was used. This was estimated using the coefficient from the linear relationship between age and participation based on AIHW statistics for people aged 50 to 74.

Chart 6.5: ICER plane of CEA results; societal perspective



Source: Deloitte Access Economics analysis.

6.1.4 Scenario analysis

This section explores the change to the ICER results under the following scenarios:

- adjusting the perspective of the model to consider a narrower set of benefits that accrue only to the healthcare system (i.e. a healthcare system perspective)
- an increase in the participation rate to 60 per cent across all age brackets
- an increase in the diagnostic assessment rate following a positive iFOBT to 90 per cent across all age brackets.

When a healthcare system perspective is adopted, the model estimates that lowering the starting screening age to 45 is *less* cost-effective than starting screening at age 50.

When compared to the no screening scenario, adopting a narrower healthcare system perspective increases the ICER for biennial screening of those aged 50 to 74 to $8,992 per DALY avoided, from $1,931 per DALY avoided when using a societal perspective. In other words, when the economic modelling perspective is narrowed to remove cost-savings not accruing by the healthcare system, the cost-effectiveness of the Program decreases.

When the model is adjusted to lower the starting screening age to 45 and 40, under a healthcare system perspective, the results show commencing screening at age 45 and 40 is *less* cost-effective than starting screening at 50 (an ICER of $9,936 and $12,021 per DALY avoided, respectively, versus $8,992 per DALY avoided, when compared with no screening, respectively). These findings are consistent with Lew et al.'s 2018 economic modelling conducted from a healthcare system perspective, which found that commencing screening at age 45 and 40 is less cost-effective than commencing screening at age 50.[94]

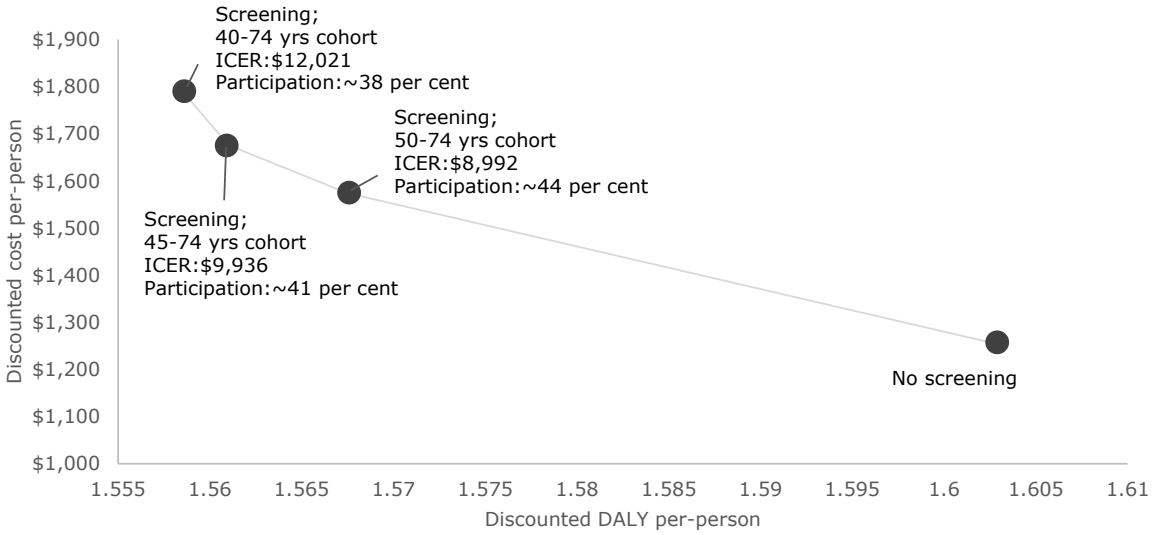
Table 6.2: Summary of CEA results; healthcare system perspective

Scenario	Reduction in cancer incidence[a]	Reduction in deaths[a]	Discounted costs per person	Discounted DALY per person	ICER[(a)]
No screening	-	-	$1,257	1.60	-
Biennial screening for 50 to 74 years	-39.6%	-46.7%	$1,574	1.57	$8,992
Biennial screening for 45 to 74 years	-41.4%	-48.6%	$1,674	1.56	$9,936
Biennial screening for 40 to 74 years	-41.7%	-48.8%	$1,789	1.56	$12,021

Notes: (a) Variables are estimates compared to the no screening scenario.

Source: Deloitte Access Economics analysis.

Chart 6.6: ICER plane of CEA results; healthcare system perspective



Notes: Participation rates are weighted average participation rates across the simulation. They are weighted by population size at each age.

Source: Deloitte Access Economics analysis.

Increasing Program participation could increase the cost-effectiveness of the Program. Participation is a key driver of the cost-effectiveness of the Program. Increasing participation to 60 per cent across all age cohorts, all else being equal, is estimated to reduce the ICER from $1,931 per DALY avoided (using current participation rates) to $1,223 per DALY avoided, under a societal perspective. The cost required to avoid one DALY is thus lowered, signalling improved cost-effectiveness.

However, it should be noted that increasing participation to 60 per cent across all ages is likely to required investment by the Program, which has not been modelled.

Table 6.3: Summary of CEA results with participation of 60 per cent; both perspectives

Scenario	Reduction in cancer incidence[a]	Reduction in deaths[a]	Discounted costs per person	Discounted DALY per person	ICER[a]
Societal perspective					
No screening (base case)	-	-	$3,042	1.603	-
Biennial screening for 50 to 74 years	-48.3%	-56.0%	$3,098	1.555	$1,223
Healthcare payer perspective					
No screening (base case)	-	-	$1,257	1.603	-
Biennial screening for 50 to 74 years	-48.3%	-56.0%	$1,653	1.555	$8,581

Notes: (a) Variables are estimates compared to the no screening scenario.

Source: Deloitte Access Economics analysis.

Increasing the diagnostic assessment rate could increase the cost-effectiveness of the Program.

The diagnostic assessment rate following a positive iFOBT is another key driver of the cost-effectiveness of the Program. Increasing the diagnostic assessment rate to 90 per cent across all age cohorts is estimated to reduce the ICER from $1,931 per DALY avoided (using current diagnostic assessment rates) to $1,427 per DALY avoided, under a societal perspective. The cost required to avoid one DALY is lowered, signalling improved cost-effectiveness. As with participation rates, it should be noted that increasing diagnostic assessment rates across all ages is likely to required investment by the Program, which has not been modelled.

Table 6.4: Summary of CEA results with diagnostic assessment rate of 90 per cent; both perspectives

Scenario	Reduction in cancer incidence[a]	Reduction in deaths[a]	Discounted costs per person	Discounted DALY per person	ICER[a]
Societal perspective					
No screening (base case)	-	-	$3,042	1.603	-
Biennial screening for 50 to 74 years	-46.7%	-54.4%	$3,102	1.559	$1,427
Healthcare payer perspective					
No screening (base case)	-	-	$1,257	1.603	-
Biennial screening for 50 to 74 years	-46.7%	-54.4%	$1,618	1.559	$8,558

Notes: (a) Variables are estimates compared to the no screening scenario.

Source: Deloitte Access Economics analysis.

6.1.5 Review of Lew et al. (pre-published) regarding Program cost-effectiveness for Aboriginal and Torres Strait Islander people

To maximise benefits and minimise harms to individuals participating in the Program, the target population needs to be defined in a way that balances the likelihood of early detection of adenomas/bowel cancer, while limiting the number of people undertaking unnecessary colonoscopies. Aboriginal and Torres Strait Islander people represent a distinct cohort within the broader Australian population in relation to their experience of bowel cancer. Of note:

- Aboriginal and Torres Strait Islander people that participate in the Program have a higher positivity rate than non-Indigenous participants (9.9 per cent compared to 6.6 per cent in 2018).[95]
- Aboriginal and Torres Strait Islander people have a lower recorded incidence of bowel cancer (2001 Australian population age-standardised rate of 116.5 per 100,000 people compared to 121.2 per 100,000). This statistic may have several possible underlying causes including reduced likelihood of diagnosis due to the availability of culturally appropriate health care.[96]
- Aboriginal and Torres Strait Islander people diagnosed with bowel cancer were more likely to be diagnosed at an advanced stage, compared to the non-Indigenous population.[97]
- Aboriginal and Torres Strait Islander people diagnosed with bowel cancer had a 5-year survival rate of 58 per cent between 2007 and 2014, compared with 67 per cent in non-Indigenous Australians.[98]
- The average age at diagnosis for Aboriginal and Torres Strait Islander people was 7.2 years younger than non-Indigenous Australians.[99]

Consequently, there is merit to analysing cost-effectiveness considerations for Aboriginal and Torres Strait Islander people separately.

In a pre-published report '*The potential for tailored screening to reduce bowel cancer mortality for Aboriginal and Torres Strait Islander peoples in Australia: modelling study*', Lew et al. analysed the cost-effectiveness of different target age ranges for the Aboriginal and Torres Strait Islander cohort. Age cohorts tested included 50 to 74, 45 to 74 and 40 to 74, as well as participation rates of ~20 per cent (the current Aboriginal and Torres Strait Islander participation rate) and ~40 per cent.

The paper uses the *Policy-1 Bowel* model, with natural history and screening inputs parameterised and calibrated to Aboriginal and Torres Strait Islander-specific data where available. The model takes a health service perspective when calculating cost-effectiveness and does not include promotional/administrative Program overhead costs. As such, the cost-effectiveness values found by Lew et al. are not able to be directly compared with Deloitte Access Economics' healthcare system or societal analysis provided for the overall Australian population. Lew's cost-effectiveness results are estimated in 2018 $AUD. Results are framed within the context of a benchmark willingness-to-pay threshold of $50,000 per life-year saved.

6.1.5.1 Economic considerations for Program policy settings

Overall, Lew et al. reports that the Program is cost-effective for the Aboriginal and Torres Strait Islander cohort at $11,927 per life-year saved compared to a baseline of no-screening, though this estimate is higher than the cost per life-year saved attributed to the broader Australian Program cohort in previous Lew et al. papers. Contributing factors for this result include lower modelled incidence rates, lower participation and lower diagnostic assessment rates in the Aboriginal and Torres Strait Islander cohort.

Lew also modelled scenarios to assess the cost-effectiveness of increasing the Aboriginal and Torres Strait Islander participation rate, as well as extending the screening age cohort for this population. With an accepted cost-effectiveness threshold of $50,000 per life year saved, the following results were reported:

- At the current participation rate, extending the screening age cohort from 50 to 74 (the status quo) to 45 to 74 was cost effective at $28,145 per life year saved.[xxi]
- With the current screening age cohort, increasing the participation rate from ~20 per cent to ~40 per cent was also cost-effective at $25,636 per life-year saved.[xxii]

Lew concludes, "The evidence … supports cost-effective screening for Aboriginal and Torres Strait Islander people in their forties, but not for the general population in their forties" (p5).[100]

6.2 Conclusions

Overall, the CEA results show that the Program is highly cost-effective compared to a no screening scenario. The analysis found that the most cost-effective entry age varied slightly depending on the perspective taken, however, overall, there was a marginal difference between starting screening at age 45 or 50. Deciding which entry age is most cost-effective depends on the extent of value placed on a societal perspective versus a healthcare system perspective.

Future Program investment should prioritise efforts to improve Program participation and the rate of diagnostic assessment, as both factors are associated with improved outcomes and cost-effectiveness ratios. For example, improving participation to 60 per cent, all else being equal, could reduce deaths due to bowel cancer by an estimated 7 percentage points, when compared with current rates. Improving the diagnostic assessment rate to 90 per cent, all else being equal, could reduce deaths due to bowel cancer by an estimated 9 percentage points, when compared with current rates.

Based on Lew et al.'s (pre-published) findings and conclusions, it is also worthwhile to consider lowering the starting screening age for Aboriginal and Torres Strait Islander people. When considering a policy change to the Program it is necessary to consider both value for money *and* equity of access considerations with a view to closing gaps in health disparities for certain population sub-groups. It is on this basis the review supports Lew et al.'s conclusion that there is an opportunity to consider lowering the starting screening age for Aboriginal and Torres Strait Islander people but not the general population.

Given the important role of the Alternative Pathway Pilot in increasing participation for Aboriginal and Torres Strait Islander people it is prudent to consider coupling any lowering of the screening starting age for Aboriginal and Torres Strait Islander people with a scale up of the Alternative Pathway Pilot for this group. This is particularly important given there is a positive correlation between age and participation, and Lew et al.'s modelling was conducted on the basis that participation rates for Aboriginal and Torres Strait Islander people in their forties would be consistent with those aged 50. Therefore, without efforts to increase participation, the benefits of lowering the screening age may not be realised. Further, those that participate once are more likely to participate again, supporting the investment in increasing participation among younger age groups.

[xxi] At the current Aboriginal and Torres Strait Islander participation rate, Lew also reports an incremental cost-effectiveness ratio of $30,384 per life-year saved for a 40 to 74 screening age cohort, compared to a 45 to 74 screening age cohort. However, given the current Program policy settings of a 50 to 74 screening age cohort, ICERs using 50 to 74 as the comparator are the most relevant for the Program at this stage.

[xxii] A participation rate of ~40 per cent reflects the current overall participation rate in the Program. As well, any costs associated with strategies to improve the participation rate were not included in the modelling process.

7 Concluding remarks and opportunities

This chapter provides concluding remarks on the Program and summarises the key opportunities for improvement.

7.1 Concluding remarks

Overall, the Program is a major strength of Australian's public health system. The Program has contributed toward improved population health for Australians through earlier detection of bowel cancer and better survival. Since the Program's inception in 2006, it has played a key role in Australia's eminence in bowel cancer screening and prevention for the following reasons:

- Australia was one of the first countries to offer free screening for bowel cancer to a national population
- Australia was one of the first countries to collect quantitative iFOBT results, which is now used globally as best-practice
- Australia offers screening to the widest age range of all countries utilising FOBT screening via a mail out method.

Phase Four of the Program saw the Program become fully biennial for people aged 50 to 74, following staged implementation since 2006. The Program's screening interval and age bracket is now consistent with the NHMRC-approved clinical practice guidelines for bowel cancer screening. The cost-effectiveness analysis conducted as part of the review found that the most cost-effective entry age varied slightly depending on the perspective taken, however, overall, there was a marginal difference between starting screening at 45 or 50. The analysis also highlighted the importance of optimising Program uptake and compliance, with results showing that improved participation and diagnostic assessment rates each improve cost-effectiveness.

Further research is required to assess the feasibility of lowering the age bracket for groups at elevated risk, such as Aboriginal and Torres Strait Islander people.

Outside of achieving full implementation of biennial screening, the review identified several key strengths of the Program in Phase Four, including:

- **Awareness of the program.** There is a high degree of awareness of the Program among consumers and clinicians.
- **Alternative distribution and completion pathways for Aboriginal and Torres Strait Islander people**. Offering alternative pathways for kit access coupled with culturally tailored resources improved participation rates among this cohort in line with overall participation rates.
- **Simplified kit instructions.** The simplified kit instructions (updated in 2018) were associated with improved rates of valid kit returns.
- **Diagnostic value of the iFOBT.** Australia's use of a two-sample test results in enhanced detection of lesions with a lower colonoscopy workload compared to a one-sample test, which is used in most other countries.
- **Transition to a national cancer screening register with a healthcare provider portal.** The transition to the NCSR allows for more efficient data collection and reporting and allows for invitee data to be updated and monitored by practitioners (through the HPP). With the migration now complete, the Program can shift to a focus on enhancing the completeness of data throughout the diagnostic and cancer care pathway continuum, as described below.

- **Consistency with best-practice elements of bowel cancer screening programs.** Most facets of the Program broadly align with best practice features of bowel cancer screening Programs, including the participant screening pathway, the mail-out approach to kit distribution to achieve equitable access, the use of colonoscopy for diagnosis, and the suite of endorsed KPIs. However, opportunities to enhance many of these features were identified and are described below.

Now that the Program is fully biennial, the next phase of the Program can shift from a focus on expansion to optimisation. To support optimisation, the review identified several opportunities for improvement, as summarised below:

- **Participation.** Participation is low relative to comparable Programs overseas and could be addressed through better integration with primary care, innovative kit modifications and sustained media and communications campaigns (described further in section 4.2).
- **Colonoscopy access.** Low rates of diagnostic assessment rates and long wait times limit the benefits of the Program. These challenges may be addressed by improving awareness of the NHMRC-approved clinical practice guidelines and reshaping the PFUF officer role to include colonoscopy prioritisation and scheduling (described further in section 2.2).
- **Completeness of data.** Complete data to demonstrate Program impact is limited and could be addressed through targeted initiatives to address data gaps along the diagnostic and cancer care continuum (described further in section 3.4).
- **Maximising advisory group functions and promoting the Program's research agenda.** There is an opportunity to consider reconfiguring the PDAG to include representation from jurisdictional colorectal departments to support the Program's initiatives to address colonoscopy access barriers. In addition, there is an opportunity to encourage researchers to pursue research grants in areas that align with the Program's key research priorities.

7.2 Identified opportunities for improvement

The findings generated through the review identified several actions to guide the key opportunities for improvement as part of the next phase of the Program, as listed below:

Appropriateness of the Program

1. Consider feasibility of lowering screening entry age to 40 or 45 for Aboriginal and Torres Strait Islander people, coupled with scale of the Alternative Pathway pilot for this group.

2. Review timing intervals for reminders with clinical input.

3. Consideration should be given to alternate forms of communication which do not require simultaneous availability of the PFUF officer and recipient (e.g. email/SMS).

Appropriateness of colonoscopy

4. Support the ACSQHC with its implementation of the CCCS and monitor colonoscopy performance against colonoscopy quality standards.

5. Encourage states and territories to pilot projects that reshape the PFUF role in line with innovative colonoscopy access models.

6. Engage with PHNs and professional bodies (e.g. RACGP and RACP) to promote a comprehensive set of educational materials which describe the NHMRC-approved clinical practice guidelines, the Program's full alignment with biennial screening recommendations, and recent changes to the MBS item codes for colonoscopy.

Governance

7. Re-configure PDAG to include jurisdictional representatives that are able to provide operational advice on contextual issues related to colonoscopy access.

8. Promote the Program's research priorities to external researchers.

9. Reset the working relationship with all stakeholders to ensure needs are being met in regard to the purpose of each group and expectations on information sharing.

Data collection

10. Reconvene a working group with the goal of prioritising initiatives to address data gaps and agree on any required changes to the endorsed set of KPIs. This group should be set-up over the medium to long term to manage the stakeholder engagement, effort and time required to implement and oversee initiatives to address data gaps.

11. Improve visibility of the target population's participation in other forms of bowel cancer screening, including via over-the-counter iFOBT kits or kits provided by clinicians. Identifying invitees in the target population deemed to be at higher risk for bowel cancer (who may be undergoing surveillance colonoscopies) would also allow a more accurate measure of the true Program participation rate.

Participation

12. Implement sustained and coordinated media and communications campaigns. Campaigns should be national in nature (across jurisdictional and cancer charities, where possible) to promote a coordinated message that minimises fragmentation and duplication of effort.

13. Use the primary care sector as a resource to promote participation through education and opportunistic provision of kits. GPs, practice nurses and pharmacists are well placed to promote and provide counselling regarding Program participation.

14. Consider piloting sample drop-off points. Trials of this nature should initially be targeted at people in regional areas due to their unique challenges in complying with the strict return postage requirements.

15. Scale up the Alternative Pathway pilot, as appropriate in other population groups. This includes other locations targeted at Aboriginal and Torres Strait Islander people, as well as exploration of how the pilot could be tailored to address access barriers faced by invitees from CALD backgrounds.

16. Explore utilisation of the NCSR to improve participation. This could include electronic reminders, streamlined processes for completion of personal details, access to in-language communications, as well as personalised invitations based on Program screening history and/or demographic factors. However, given phone/email contact information is unavailable for first-time screeners, mechanisms to collect this information from other government databases, such as MyGov, may be required.

17. Modify kit contents and accessories to mitigate common reasons for non-completion. This may include an action plan for completion contained in the kit instructions (to overcome the procrastination barrier), and/or provision of accessories such as an opaque bag for fridge storage (to overcome perceived hygiene concerns). Please refer to the 'Supplementary information' section for further information.

Appendix A Stakeholders consulted

A.1. List of organisations consulted

As part of the evaluation Deloitte Access Economics conducted 67 interview or focus group consultations with 117 stakeholders from 46 organisations. The list of organisations is provided in Table A.1). Additional organisations provided online written submissions to the public consultation website.

Table A.1: List of organisations consulted

Name of organisation
Peak bodies
Australian Association of Practice Management
Australian College of Rural and Remote Medicine
Australian Medical Association
Australian Pathology
Consumers Health Forum
Gastroenterological Society of Australia
National Aboriginal Community Controlled Health Organisation
National Association of Aboriginal and Torres Strait Islander Health Workers and Practitioners
Pathology QLD
Pharmaceutical Society of Australia
Public Pathology of Australia
Royal Australasian College of Surgeons
Royal Australian College of General Practitioners
Royal College of Pathologists of Australasia
The Pharmacy Guild of Australia
Advisory groups
NBCSP Clinical Advisory Group
NBCSP Program Delivery Advisory Group
Federal Departments and branches
Commonwealth Department of Health
Services Australia
Relevant government agencies
Australian Commission on Safety and Quality in Health Care
Australian institute of Health and Welfare
National Pathology Accreditation Advisory Council

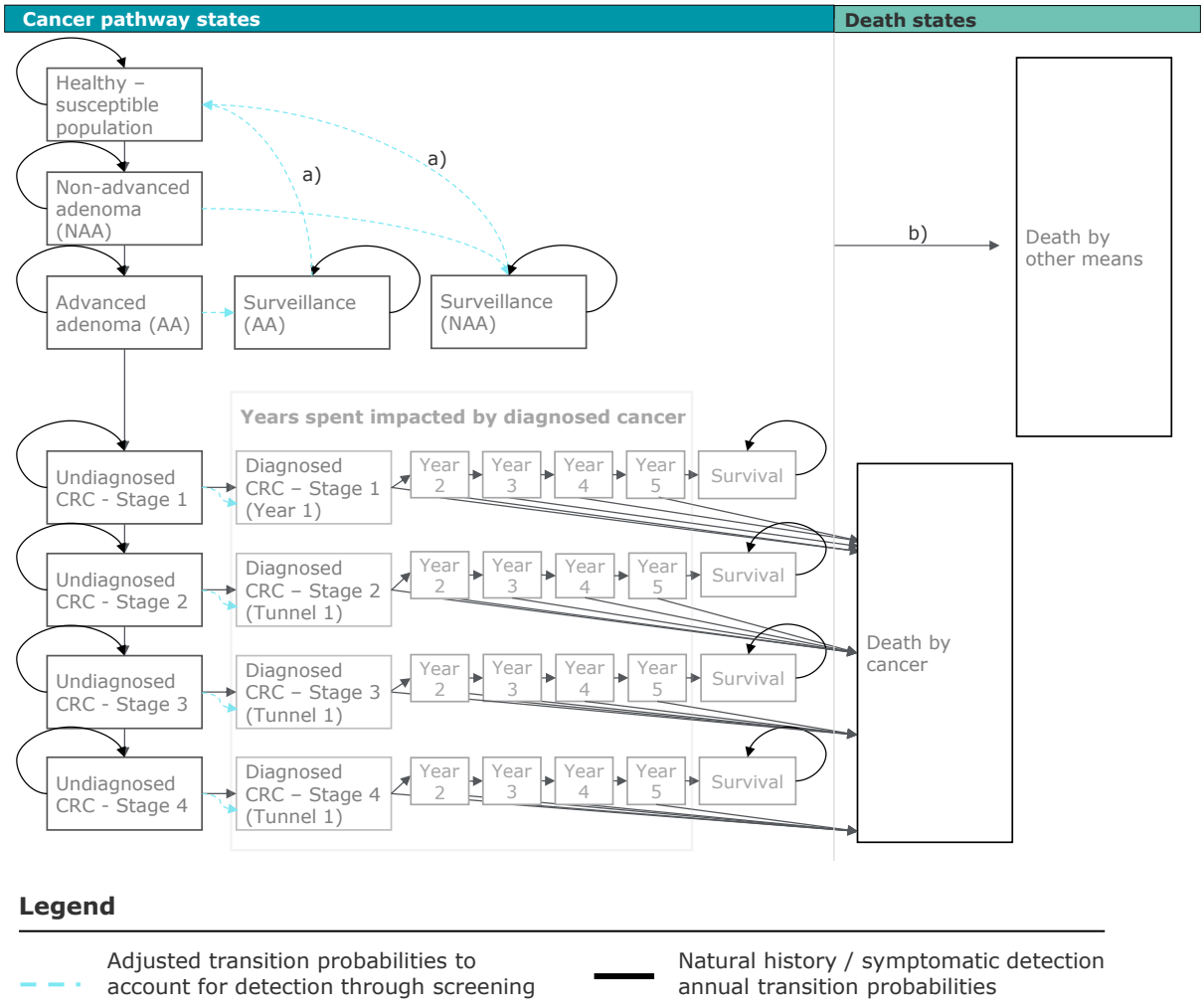
Name of organisation
State Departments and branches
QLD Department of Health
Tasmanian Health Service
Victorian Department of Health and Human Services
WA Department of Health
NGOs
Bowel Cancer Australia
Cancer Council Australia
Cancer Council NSW
Cancer Council QLD
Cancer Council SA
Cancer Council TAS
Cancer Council VIC
Cancer Council WA
Jodi Lee Foundation
Let’s Beat Bowel Cancer (Cabrini)
VCS Foundation
Time limited working groups
Alternative Pathway Pilot Evaluation Committee
NBCSP KPI Working Group
Other
Rhythm Biosciences
Sonic Healthcare
Telstra Health
The Menzies School of Health Research

Appendix B CEA methodology

B.1. Methodology

The CEA was conducted using a Markov cohort model to reproduce the natural history of bowel cancer overlayed with a model to account for the effect of screening (see a schematic of the model provided in Figure B.1.). This approach is consistent with the approach used by Lew et al. and representative of a 'deep model' as described in Silva-Illanes' (2018) critical analysis of Markov models used for the economic evaluation of colorectal cancer screening programs.[101,102]

Figure B.1: Schematic overview of the natural history and screening pathways



Notes: a) This arrow indicates that a proportion of people within the Surveillance stage do not comply with the surveillance guidelines at all, and therefore they return to the 'Healthy – susceptible population' state. b) All states in the 'cancer pathway' can transfer to the 'Death by other means' state.

Source: Deloitte Access Economics.

The model simulated the impact of the Program on costs and outcomes of bowel cancer over a person's lifetime (or by the time they turned 90, whichever occurred first) for a representative cohort of Australians. The discounted outcomes and costs associated with screening were

compared to a scenario in which no screening occurred. A base case of a health care system in which no coordinated screening strategy is in place was chosen to understand the cost-effectiveness of the current configuration of the screening program.

Outcomes were measured as disability adjusted life years (DALY) averted, and costs were measured in 2020 AUD. A 5 per cent discount rate was used. Results were reported using an Incremental Cost Effectiveness Ratio (ICER), from both a healthcare system and a societal perspective.

The model assumes that bowel cancer always develops through the adenoma-carcinoma pathway, due to limited evidence regarding development via the serrated pathway.

B.1.1. The Markov-chain simulation

The Markov-chain process models the movement of individuals through various health states, based on the probability that a person will transition from one state to another.

The Markov-chain includes 35 health states through which a person moves over time. Each health state represents a state in the natural history of adenoma and bowel cancer development, including but not limited to: 'healthy', 'advanced adenoma', 'undetected cancer' (by stage), 'detected bowel cancer stage' (by stage), 'survival' and 'death'. In the base case, the population enters the model at age 50, and moves from one state to another each period, defined as a year, until each person dies or reaches 90 years. The probability that a person will move from one state to another is based on transition probabilities drawn from the literature on adenoma incidence rates, low to high risk adenoma progression rates, cancer progression rates, cancer survival rates, all-cause mortality rates etc.

Costs and DALYs are applied to each state to determine the costs and outcomes associated with a person living in a given state for a year. Costs and DALYs are accrued annually over time as each person in the cohort cycles through the model. Costs include:

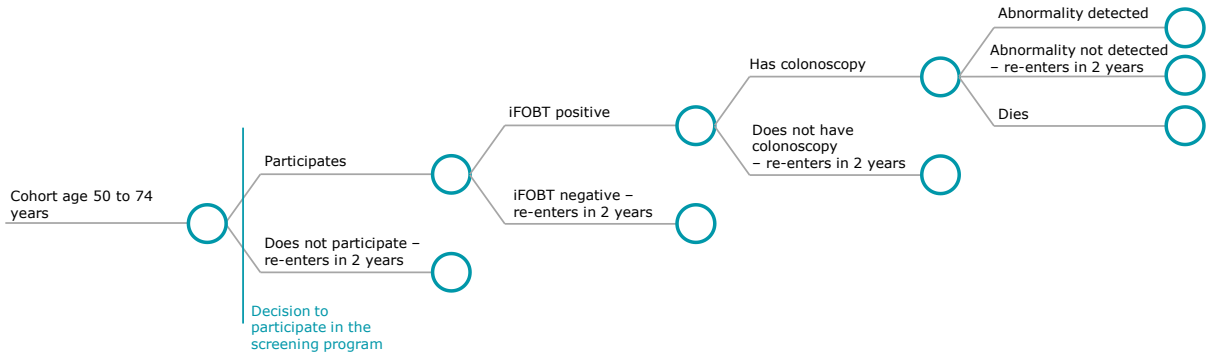
- medical costs associated with bowel cancer treatment
- diagnostic costs, such as GP follow-up and colonoscopy to diagnose bowel cancer
- costs of administrating the Program, such as development of the NCSR, costs of manufacturing and distributing Sonic kits, and costs of pathology
- productivity costs due to change in employment status and premature loss of life (*calculated in the societal perspective scenario only*)
- costs of informal care provided to cancer patients (*calculated in the societal perspective scenario only*)

Disutility associated with each health state, or DALYs, take a value of between 0 and 1, where 1 equals a complete loss of quality life (or death), and 0 means that a person is completely healthy. DALYs were also applied to diagnosed cancer stages, as well as during cancer survival due to the possibility that a cancer survivor requires a permanent stoma. These values were drawn from AIHW's Australian Burden of Disease study.[103]

B.1.1.1. Superimposing the screening strategy

To account for the benefit of screening on earlier detection, a second model using a decision tree structure (Figure B.2) is superimposed on the natural history model every second year (to account for biennial screening) over the target age range. In the base case this is age 50 to 74.

Figure B.2: Screening pathway decision tree



Source: Deloitte Access Economics.

This model represents the screening strategy and is governed by participation rates, iFOBT sensitivity rates, diagnostic assessment rates, colonoscopy sensitivity rates, and colonoscopy adverse event rates. This model is used to adjust transition probabilities to account for the effect of the screening Program on 'intercepting' the natural progression of bowel cancer and reducing the probability that cancer will be detected (i.e. through detection at the adenoma stage) or detected at an advanced stage.

This is achieved by applying the decision tree to the undiagnosed adenoma and cancer health states. This is reflected in the dotted arrows of Figure B.1, which represent modified transition probabilities that account for the effect of screening.

B.1.1.2. Calculation approach

To estimate the incremental impact of screening vs. no screening, a cohort of Australians is simulated through the model both with (screening arm) and without (no screening) the decision-tree model. In the base case, the population enters at age 50, and DALYs and costs are accrued until each person dies (or turns 90, whichever occurs first).

Costs and DALYs are summed and compared between these two simulations, and results are reported in the form of an ICER. This ratio is calculated as the difference between the discounted costs of the two simulations, over the difference between the discounted DALY's. It is interpreted as the additional cost required to avoid one DALY. If this value if less than approximately $50,000, it is decided that the screening program is cost-effective.

B.1.2. Limitations of the CEA

The CEA analysis results should be considered within the limitations of the modelling. Notably, the analysis relies on available data from older studies within Australia and in other jurisdictions (where high-quality data was not available in the Australian context).

Key parameters drawn from overseas literature include adenoma incidence rates and transition probabilities associated with the natural progression of cancer. Adenoma incidence rates are based on a Dutch randomised trial conducted in 2003. Other transition probabilities associated with the natural development of cancer were estimated from Lew et al., where the authors applied a calibration approach to results from a trial conducted in the Netherlands in 2012.

These parameters were identified as the most appropriate estimates of the natural development of cancer for our study as there were no equivalent data available in the Australian context. Further, it was not possible to estimate current age-specific adenoma incidence rates (i.e. the likelihood of progression from no lesion to adenoma in a year) using AIHW bowel cancer incidence data, as the NBCSP has been in place since 2006. Consequently, AIHW rates are not reflective of the natural rate of detection under a no screening scenario, which is required for the natural progression model.

As a method of validating the modelling approach and the inputs used, model estimates of the age-specific incidence of bowel cancer (i.e. outputs of the model) was compared to actual AIHW

bowel cancer incidence data pre-screening Program (i.e. in 2006). The results show that modelled estimates of age-specific cancer incidence and mortality in a scenario where no screening program exists broadly aligns with the AIHW statistics from 2006 (See section B.2).

While this validation check implies robustness of the model, the absence of current age specific adenoma incidence rates in an Australian setting remains a limitation, given that that AIHW statistics show moderate changes to incidence rates for younger cohorts over time.

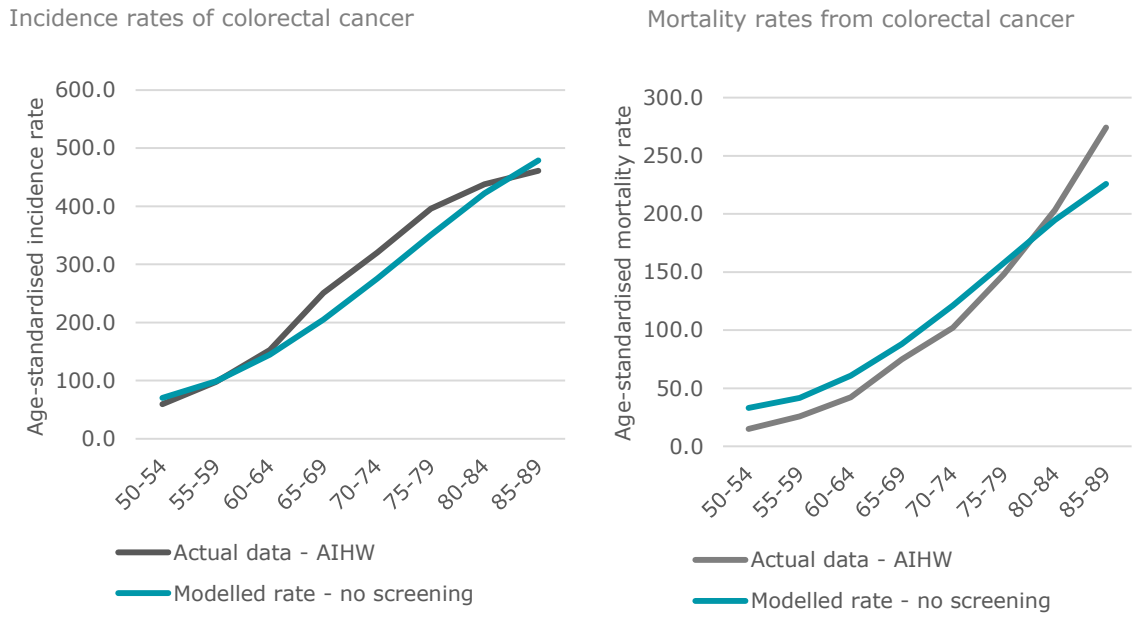
B.2. Model calibration and validity

This section assesses the validity of the CEA results by comparing modelled outputs on incidence and mortality rates to actual rates observed in AIHW data. The results of the analysis are also compared to results reported in comparable modelling studies.

B.2.1. Calibration with observed rates

Actual and modelled bowel cancer incidence and mortality rates are displayed in Chart B.1. The modelled rates are based on the no screening scenario, while the actual rates were sourced from AIHW's 2006 cancer statistics; the year the Program was first implemented. The model captures cancer incidence and mortality to a reasonable degree of accuracy. The model predicts a lifetime risk of bowel cancer for people aged 50-years of approximately 8.0 per cent, and a lifetime risk of dying of bowel cancer of 3.5 per cent. This is compared to AIHW lifetime risk statistics measured between 2001 to 2010 of 7.7 per cent and 3.2 per cent respectively.

Chart B.1. Actual age-standardised incidence and mortality rates for bowel cancer vs. modelled estimates under the no screening scenario



Notes: a) Actual age-standardised rate from 2006 used to control for the impact of the NBCSP on cancer incidence and mortality over the period 2006-2020

Source: Deloitte Access Economics analysis and AIHW Cancer data in Australia (2020).

B.2.2. Comparison with Lew et al.'s economic evaluation

The modelling results conducted from a healthcare system perspective are compared against Lew et al.'s results in Table B.1. To enable direct comparison between the outputs of each study, the model was adjusted to remove Program costs, and DALYs associated with reduced morbidity, as neither of these were included in the Lew et al. study.

Overall, our base-case ICER results comparing biennial screening for individuals aged 50 to 74 to a scenario of no screening is slightly higher than the results reported by Lew et al. In addition, our analysis comparing different screening starting ages is consistent with Lew et al., with both studies

concluding that commencing the Program at age 50 is more cost effective than commencing screening at age 45, when evaluated from a healthcare system perspective.

Table B.1: Comparison of ICERs for scenarios between this study and Lew et al.

Scenario	Lew et al. (low scenario)	This study
Healthcare system perspective: ICER per life-year saved compared to no screening		
Biennial screening for 50 to 74 years	$2,984	$6,514
Biennial screening for 45 to 74 years	$5,471	$6,993
Biennial screening for 40 to 74 years	$8,264	$7,764

Notes: Results for Lew's 'low scenario' are used in this analysis. This scenario assumes ~40% screening participation rate.

Source: [a]Deloitte Access Economics, [b]Lew JB, St John J, Xu X-M, et al 'Supplementary Files - Long-term evaluation of benefits, harms, and cost-effectiveness of the National Bowel Cancer Screening Program in Australia: a modelling study' (2017) 2(7), *The Lancet*, 331.

Differences in base-case results can be attributed to several factors. First, Lew et al. simulates the development of bowel cancer through both the conventional adenoma-carcinoma and serrated pathways. The serrated pathway describes the development of cancer through serrated polyps, such as sessile serrated adenomas. By comparison, this study only captures the conventional adenoma-carcinoma pathway due to limited evidence to inform parameters on the development of bowel cancer through the serrated pathway.

Second, Lew et al. includes different mortality rates by stage for individuals with bowel cancer detected through screening vs. symptomatic detection. By comparison, this study does not adjust the stage-dependant mortality rates by detection type due to limited evidence to support this difference in an Australian setting. As a result, our modelling takes a more conservative perspective on the potential impact of screening on better survival.

Third, the analysis in this study draws on more recent data. Therefore, several inputs differ between studies, such as the time-value of money, participation rates, as well as the use of different data sources where new research has been made available since 2017.

B.3. Model parameters

Table B.2. below summarised the key model parameter assumptions.

Table B.2: Model parameters informing the CEA

Parameter	Value	Source
Cohort characteristics		
Size and gender distribution of cohort	320,448 (50.3% Female, 49.7% Male)	ABS[104]
Natural mortality rate	Age dependent	ABS[105]
General model parameters		
Initial commencement distribution across health states	Stage dependant	Bishop et al[106] These rates were adjusted for a cohort starting at 40 years, based on

Parameter	Value	Source
		differences in incidence rates of bowel cancer by age, sourced from AIHW[107]
Adenoma incidence, by age	Age dependent	Jahn et al[108] Note: Adenoma incidence rates used by Jahn et al. were taken from a study conducted by Goede et al. dated 2013.
Natural pathway transition probabilities for health states	Stage dependent	Lew et al[109] Note: The transition probabilities estimated by Lew et al. were results of calibration to align with observed from the COCOS trial dated 2012 (see Stoop et al. 2012).
Disutility associated with cancer Stage and time since diagnosis	Stage dependent	AIHW[110]
Disutility associated with full health	0.00	Assumption
Disutility associated with death	1.00	Assumption
Disutility associated with permanent stoma	0.09	AIHW[111]
Colonoscopy parameters		
Colonoscopy costs (health care payer / societal)	Minor complexity: $1,915 / $1,945 Major complexity: $9,860 / $10,015	Queensland Government[112] This study used national rates, which were reported by the Queensland Government as benchmarks for state rates.
Compliance to recommended surveillance regime (Non-advanced adenoma / advanced adenoma)	Percentage of people who screen at least once within a 10-year period – 83.9% / 93.9% Compliance with screening regime guidelines (i.e. frequency of screening) 50% / 50%	Taylor et al[113] Tran et al[114]
Negative impacts of colonoscopy (death and perforation)	Death – 1.6 per 10,000 Perforation – 5.0 per 10,000	Rutter et al[115]
Colonoscopy diagnostic assessment rate	Age dependant	Lew et al[116]
Cancer-stage parameters		
5-year survival rate from colorectal cancer	Stage 1: 86.9% Stage 2: 73.0% Stage 3: 42.4% Stage 4: 9.5%	Lew et al[117]
Medical costs (health care payer / societal)	Stage 1: $30,145 / $38,721 Stage 2: $39,249 / $50,414 Stage 3: $72,976 / $93,735 Stage 4: $72,031 / $92,522	Ananda et al[118] Gordon et al[119]

Parameter	Value	Source
Probability of requiring a permanent stoma	Cancer stages 1 to 3: 2.3% of survivors Cancer stage 4: 11.5% of survivors	Estimated using Enker et al[120] and Gessler et al[121]
NBCSP Program parameters		
iFOBT sensitivity	Non-advanced adenoma: 15.2% Advanced adenoma: 41.5% Cancer: 58.6%	Lew et al[122]
iFOBT false positive rate	4.4%	Hubbard et al[123]
Participation rate (NBCSP)	40 to 44: 25.3% 45 to 49: 29.4% 50 to 54: 33.9% 55 to 59: 39.0% 60 to 64: 44.9% 65 to 69: 51.0% 70 to 74: 54.2%	AIHW[124] Rate for 40 to 49 years was calculated based on the relationship between age and participation.
GP follow-up costs	Health care payer: $38.75 Societal: $46.30	MBS[125] and AIHW[126]
Total annual administrative, register and Program costs for one cohort in a screening year. Costs associated with starting screening at age 50.	$1,878,816	Department of Health program data. Costs per cohort estimated by dividing total costs by number of cohorts. This value is increased by approximately 15% for the scenario where the commencement age is dropped to 45 years to account for the increase in size of the cohort.
NCSR build	$7,978,798	Department of Health program data.
Program unit administrative costs per invitee	$8.6	Department of Health program data. Sonic commercial workbook.
Program unit laboratory costs per participant	$15.1	Department of Health program data. Sonic commercial workbook.
Productivity costs and costs of informal care		
Labour force characteristics	Age dependant	ABS[127]
Median income post-tax, by age	44 to 44: $44,724 45 to 49: $44,169 50 to 54 years: $43,298 55 to 59 years: $35,447 60 to 64 years: $24,994 65 to 69 years: $5,812 70 to 79 years: $2,906	ABS[128] Income estimates are post-tax estimates. A flat 20% tax rate was used.
Costs of informal care	Costed using the human capital method Age and stage dependent	ABS[129,130]
Costs of loss of employment	Age and stage dependent	ABS[131,132]

B.4. Methodology used to estimate costs of lost productivity and informal care

To perform the modelling from a societal perspective, this study estimates three types of productivity costs associated with cancer treatment and premature death from cancer, including:

- loss of income associated with premature death
- loss of income associated with change in employment status due to a cancer diagnosis
- the economic cost of informal care for those with a cancer diagnosis.

Data sources included the ABS' income and labour force data and the Survey of Disability, Ageing and Carers (SDAC) microdata.

B.4.1. Loss of productivity associated with premature death

Death due to bowel cancer prior to retirement causes a loss of economic productivity associated with a person's forgone labour contribution to the economy. The annual loss of income due to premature death was calculated by estimating income earned per person per annum during their working life, using ABS income statistics. The chance of being employed is accounted for by taking age-dependant unemployment and labour force participation rates from ABS detailed labour force statistics.

B.4.2. Loss of productivity due to change in employment status

A cancer diagnosis also impacts a person's ability to participate in the workforce. This may be due to increased sick-leave and absenteeism to receive treatment, the need for people to take a longer leave of absence, or to retire prematurely due to the debilitating nature of their condition.

The impact of a cancer diagnosis on participation in the workforce was estimated using the ABS' SDAC. This dataset allows for analysis of the employment status of people with and without cancer. Due to the small sample size of people with bowel cancer at the time of the survey, people with either breast, bowel or prostate cancer were considered in the analysis. The impact of cancer on presenteeism (i.e. where a person continues to work but is less productive due to their condition) was not estimated in this analysis due to absence of reliable data.

The estimated impact of cancer on a person's work-status was estimated from a direct comparison of the work status of people with cancer (by stage of cancer) and those without cancer. The impact of cancer on employment status by stage of cancer was drawn from the SDAC. While the SDAC does not identify a person's stage of cancer, the survey does ask questions regarding the impact of the condition on their general mobility. This study categorised each stage of cancer by their level of general mobility, assuming that each cancer stage is associated with decreased mobility. Further, costs to employment were assumed to occur in the first year post-diagnosis and reduce linearly over the next four years before returning to general population levels.

Overall, it was estimated that cancer reduced the probability that someone aged between age 45 to 74 years would be employed, in any capacity. Specifically, the probability that someone aged between 45 and 55 years with cancer was employed was approximately 45%, compared to approximately 80% for those that did not have cancer. Further, the probability that someone aged between 55 and 65 years with cancer was employed was approximately 35%, compared to approximately 65% for those that did not have cancer. This impact was monetised using ABS age-sex wage statistics, less taxable income.

B.4.3. Informal carer productivity losses

Carers are people who provide informal care to others in need of assistance or support. For example, carers may take time off work to accompany people with cancer to medical appointments, stay with them in hospital, or care for them at home. While informal care is provided free of charge, it is not free in an economic sense, as time spent caring is time that cannot be directed to other activities such as paid work, unpaid work or leisure. As such, informal care is a use of economic resources.

SDAC provides the most recent and comprehensive profile of Australians with cancer and the people who provide them with assistance and support. Only a proportion of cancer patients were

identified to require informal care assistance due to cancer, which was estimated from the proportion of people with cancer that required some informal care support within the SDAC. The number of hours of informal care provided to each person was estimated from a direct comparison of the informal care hours received by people with cancer (by stage of cancer) and those without cancer, to control for other possible conditions that may increase the need for informal care, such as age. As above, this study categorised each stage of cancer by the patient's level of general mobility, assuming that each cancer stage is associated with decreased mobility. Further, costs to employment were assumed to occur in the first-year post-diagnosis and reduce linearly over the next four years before returning to general population levels.

Overall, it was estimated that a cancer diagnosis increases the need for informal care by approximately 48 per cent. The value of informal care was monetised using ABS age-sex wage statistics. The value of informal care was only costed at this rate for a proportion of persons, after accounting for the age-dependant chance of being employed. For others, the value of leisure time was used (i.e. one-third of the value of the average hourly work wage).[133]

B.5. Sensitivity analysis on discount rate

Sensitivity analysis was conducted to assess the robustness of the CEA results to variations in the discount rate. The results of the analysis are presented below for adjustments in the discount rate of between 0 and 10 per cent.

B.5.1. Societal perspective

From the societal perspective, all configurations of the Program remain cost-effective across all variations of the discount rate, when compared to the commonly used willingness-to-pay threshold of $50,000 per DALY averted (Table B.3.).

A commencement age of 45 to 74 years remains the most cost-effective configuration of the Program for all discount rates, except for a 10 per cent discount rate. At the 10 per cent discount rate, the Program with a commencement age of 50 to 74 years is the most cost-effective configuration. This is because additional benefits due to a commencement age tend to occur further in the future (such as increased life expectancy), while costs tend to occur in the present or near future (associated with greater program screening costs).

A discount rate of between zero and two per cent results in a negative ICER across all Program configurations. A negative ICER indicates that the Program results in a negative cost per DALY avoided (i.e. it is cost saving). This occurs when total discounted costs and total discounted DALYs are lower in the Program when compared to the base case. This indicates that a Program is avoiding DALYs in addition to reducing costs within a system.

Table B.3: Sensitivity analysis of ICER to discount rates; societal perspective

Discount rate	Commencement age		
	40 to 74 years	45 to 74 years	50 to 74 years
0%*	-$3,695	-$4,868	-$4,524
2%*	-$2,277	-$3,195	-$2,703
5%	$2,012	$1,381	$1,941
7%	$7,317	$6,699	$6,938
10%	$21,609	$20,106	$18,803

Notes: *Negative ICER results indicate that the Program results in a negative cost per DALY avoided. This occurs when total discounted costs and total discounted DALYs are lower in a Program when compared to the base case. Green shading highlights the program configuration that is most 'cost-effective' for each discount rate.

Source: Deloitte Access Economics analysis

B.5.2. Healthcare system perspective

From the healthcare system perspective, all configurations of the Program remain cost-effective across all variations of the discount rate, when compared to the commonly used willingness-to-pay threshold of $50,000 per DALY averted (Table B.4.).

A commencement age of 50 to 74 years remains the most cost-effective configuration of the Program for all discount rates.

Table B.4: Sensitivity analysis of ICER to discount rates; healthcare system perspective

Discount rate	Commencement age		
	40 to 74 years	45 to 74 years	50 to 74 years
0%	$1,355	$997	$453
2%	$4,307	$3,579	$3,070
5%	$12,021	$9,936	$8,992
7%	$20,653	$16,656	$14,729
10%	$42,190	$32,493	$26,986

Notes: Green shading highlights the program configuration that is most 'cost-effective' for each discount rate.

Source: Deloitte Access Economics analysis

B.6.

Appendix C Other bowel cancer screening programs

C.1. Characteristics of other bowel cancer screening programs

Chart 4.5 is presented below in table format with references.

Table C.1: Characteristics of other screening programs

Country	Characteristics of overseas mail-out bowel cancer screening Programs
England	• Since 2018, has started to roll out one-sample iFOBT, improving ease of participation. • Older age bracket (60 to 74 years), however this is in the process of being lowered to 50 years. As noted in Chart 4.3, there is a positive correlation between age and participation. • A participant is not eligible to receive an iFOBT kit unless they are registered with a GP. This makes it easier for Program administrators to promote the role of the GP in educating patients about the Program and reminding them to complete the iFOBT. • The whole screening pathway is within the remit of the national healthcare provider. Program administrators therefore have more control over processes and initiatives to promote GP and colonoscopy follow-up. • Utilises dedicated accredited Program colonoscopy clinics for participants of the screening Program, which expedites diagnostic waiting times and ensures minimum colonoscopy quality standards are met. • Dedicated Program nurse coordinators call participants with a positive iFOBT and directly schedule GP and colonoscopy appointments.
Sweden	• Utilises a three-sample gFOBT [134] • Older age bracket (60 to 69 years). As noted in Chart 4.3, there is a positive correlation between age and participation. • The program currently only operates in Stockholm county and Gotland county, both metropolitan regions. As noted in Table 4.2 below, invitees based on metropolitan regions are more likely to participate.
Denmark	• Utilises a one sample iFOBT.[135] • Same age-bracket (50 to 74 years). • The whole screening pathway is within the remit of the national healthcare provider, Program administrators therefore have more control over processes and initiatives to promote GP and colonoscopy follow-up. • Various direct engagements with primary care providers in promoting the screening pathway.[136] • Colonoscopies are directly scheduled by the screening Program by a mandated date.[137]
Netherlands	• Utilises a one sample iFOBT.[138] • Older age bracket (60 to 69 years). As noted below, there is a positive correlation between age and participation.

Country	Characteristics of overseas mail-out bowel cancer screening Programs
	• Various direct engagements with primary care providers in promoting the screening pathway.[139] • Colonoscopies are directly scheduled in collaboration with primary care providers.[140]
New Zealand	• Utilises a one sample iFOBT.[141] • Older age bracket (60 to 74 years). As noted below, there is a positive correlation between age and participation. • The whole screening pathway is within the remit of the national healthcare provider, Program administrators therefore have more control over processes and initiatives to promote GP and colonoscopy follow-up.

Appendix D Findings related to Indigenous cohorts

D.1. Findings related to Indigenous cohorts

A summary of findings that emerged through the review for people from Aboriginal and Torres strait Islander backgrounds is presented below.

Table D.1: Summary of findings related to Indigenous cohorts

Chapter	Relevant findings
Appropriateness	Bowel cancer incidence rates are lower for Aboriginal and Torres Strait Islander people relative to non-Aboriginal and Torres Strait Islander people; however, survival rates are poorer. Alternative distribution and completion pathways for Aboriginal and Torres Strait Islander people have shown to be highly effective. The Alternative Pathway pilot resulted in an Indigenous participation rate of 40 per cent (similar to the rate for all Australians) compared to 23 per cent in the traditional pathway. In addition, the median number of days in which kits were returned was 13 days for the Alternative Pathway compared to 34 days in the traditional pathway.[142,143] Insights gleaned from consultations supported these findings, with strong sentiment that the model is an appropriate method for reaching people from Aboriginal and Torres Strait Islander backgrounds. There was consensus that the model could be scaled to other Aboriginal and Torres Strait Islander communities and/or other groups such as people from CALD backgrounds. This was noted with the caveat that, in any decision to scale, the target population's unique access barriers should be considered, and approaches and resources from the Alterative Pathway tailored, as appropriate. Based on a review of Lew et al.'s (pre-published) findings and conclusions, it is also worthwhile to consider lowering the starting screening age for Aboriginal and Torres Strait Islander people. Changes to Program policy require a consideration of both value for money *and* equity of access considerations, with an overall view to closing gaps in health disparities for certain population sub-groups. It is on this basis the review supports Lew's conclusion that there is an opportunity to consider lowering the starting screening age for Aboriginal and Torres Strait Islander people, but not the general population. This decision should consider the existing barriers to participation in this cohort, and associated investment in alternative pathways to optimise participation across the screening pathway. Opportunity: Consider the feasibility of lowering screening entry age to 40 or 45 for Aboriginal and Torres Strait Islander people, coupled with scale up of the Alternative Pathway pilot for this group.

Fidelity	As intended, as part of Phase Four, the Department successfully implemented the Alternative Pathway program to enhance access to the Program for Aboriginal and Torres Strait Islander people.
Awareness and adoption	Program participation rates are comparatively low for Aboriginal and Torres Islander backgrounds (23 per cent, compared to 44 per cent overall, in 2018). Opportunity: Scale up the Alternative Pathway pilot, as appropriate in other population groups. The Alternative Pathway pilot demonstrated success in increasing participation in Aboriginal and Torres Strait Islander communities. Feasibility of scaling the pilot to other Aboriginal and Torres Strait Islander communities should be explored. In addition, consideration should be given to how the pilot could be tailored and adapted to meet the unique needs and access barriers for people from CALD backgrounds.

Endnote

[1] Department of Health, *National Bowel Cancer Screening Program- Participant Screening Pathway*, (2019)

[2] Senore C, Zappa M, Campari C et al 'Faecal haemoglobin concentration among subjects with negative FIT results is associated with the detection rate of neoplasia at subsequent rounds: a prospective study in the context of population based screening programmes in Italy' (2019) 69 *Gut* 523

[3] Buron A, Roman M, Auge JM et al 'Changes in FIT values below the threshold of positivity and short-term risk of advanced colorectal neoplasia: Results from a population-based cancer screening program'(2019) 107 *European Journal of Cancer* 53.

[4] Department of Health, *National Bowel Cancer Screening Program Key Performance Indicator Review*, (2019)

[5] Martini A, Morris J, Preen D. 'Impact of non-clinical community-based promotional campaigns on bowel cancer screening engagement: An integrative literature review' (2016) 99(10), *Patient Education and Counselling*, 1549

[6] Wakefield, Loken B, Hornik R. 'Use of mass media campaigns to change health behaviour' (2014), 376(9748), *Lancet*, 1261.

[7] Lew J-B, St John J, Macrae F et al 'Evaluation of the benefits, harms and cost-effectiveness of potential alternatives to iFOBT testing for colorectal cancer screening in Australia' (2018) 143(2) *International Journal of Cancer,* 269.

[8] Lew et al. (pre-published) *The potential for tailored screening to reduce bowel cancer mortality for Aboriginal and Torres Strait Islander peoples in Australia: modelling study*.

[9] Australian Institute of Health and Welfare, *Cancer data in Australia*, (2021).

[10] Australian Institute of Health and Welfare, *Cancer data in Australia*, (2020).

[11] Department of Health, *National Bowel Cancer Screening Program- Participant Screening Pathway*, (2019)

[12] Ibid.

[13] National Health and Medical Research Council, *Clinical practice guidelines for the prevention, early detection, and management of colorectal cancer* (2017)

[14] Lew J-B, St John J, Macrae F et al 'Benefits, Harms, and Cost-Effectiveness of Potential Age Extensions to the National Bowel Cancer Screening Program in Australia' (2018) 29(12), *Cancer Epidemiology, Biomarkers & Prevention* 1450.

[15] US Preventatives Services Task Force, *Draft Recommendation Statement: Colorectal Cancer Screening* (2020)

[16] Ibid.

[17] Cancer Australia, *Stage at diagnosis by type (breast, prostate, colorectal, lung)* (2021), https://ncci.canceraustralia.gov.au/stage-diagnosis/stage-diagnosis-type.

[18] Cancer Council Australia, *Colonoscopy outcomes in Aboriginal and Torres Strait Islander peoples* (2019),

https://wiki.cancer.org.au/australia/Clinical_question:What_colonoscopic_surveillance_is_available_to_indigenous_people_for_CRC_resection,_polyp_removal,_IBD%3F.

[19] Libby G, Bray J, Champion J et al 'Pre-notification increases uptake of colorectal cancer screening in all demographic groups: a randomized controlled trial' (2011) 18(1), *Journal of Medical Screening*, 24.

[20] Eiken Chemical Co., Ltd, *Instructions for use* (2019), https://www.eiken.co.jp/uploads/380094E_OC-Auto3_V-PH18%20V-PH33.pdf.

[21] Menzies School of Health Research, *National Indigenous Bowel Screening Pilot Final Report* (September 2020)

[22] AIHW, *National Bowel Cancer Screening Program Monitoring Report* (June 2020)

[23] Barry M. 'Faecal occult blood testing for colorectal cancer: a perspective' (2002) 13(1), *ANNALS of Oncology* 61.

[24] Lu M, Luo X, Chen H et al 'Diagnostic Accuracy of Faecal Occult Blood Tests For Detecting Proximal Versus Distal Colorectal Neoplasia: A Systematic Review And Meta-Analysis' (2019) 11 *Clinical Epidemiology,* 943.

[25] Lew J-B, St John J, Macrae F et al above n 4.

[26] Parkin C, Bell S, Mirbagheri N. 'Colorectal Cancer Screening in Australia' (2018) 47(12) *Australian Journal of General Practice*.

[27] Rabeneck L, Rumble RB, Thompson F et al 'Faecal immunochemical tests compared with guaiac fecal occult blood tests for population-based colorectal cancer screening' (2012) 26(3) *Canadian Journal of Gastroenterology and Hepatology* 131.

[28] Schreuders E, Ruco A, Rabeneck L et al 'Colorectal cancer screening: a global overview of existing programmes' (2015) 64 *Gut* 1637.

[29] Young G, Woodman R, Ang F, Symonds E 'Both sample number and test positivity threshold determine colonoscopy efficiency in detection of colorectal cancer with quantitative faecal immunochemical tests' (2020) 159(4) *Gastroenterology* 1561

[30] Young G, Woodman R, Symonds E, 'Detection of advanced colorectal neoplasia and relative colonoscopy workloads using quantitative faecal immunochemical tests: An observational study exploring the effects of simultaneous adjustment of both sample number and test positivity threshold' (2020), 7(1) *BMJ Open Gastroenterology*

[31] Liu MC, Oxnard GR, Klein EA et al 'Sensitivity and Specificity of Multi Cancer Detection and localisation using methylation signatures in cell fee DNA' (2020) 31(6) *Annals of Oncology* 745.

[32] Rhythmn Biosciences, *ColoSTAT*, 2020

[33] Senore C, Zappa M, Campari C et al 'Faecal haemoglobin concentration among subjects with negative FIT results is associated with the detection rate of neoplasia at subsequent rounds: a prospective study in the context of population based screening programmes in Italy' (2019) 69 *Gut* 523

[34] Buron A, Roman M, Auge JM et al 'Changes in FIT values below the threshold of positivity and short-term risk of advanced colorectal neoplasia: Results from a population-based cancer screening program'(2019) 107 *European Journal of Cancer* 53.

[35] Chen L, Yen A, Chiu SY. 'Baseline faecal occult blood concentration as a predictor of incident colorectal neoplasia: longitudinal follow-up of a Taiwanese population-based colorectal cancer screening cohort' (2011) 12(6) *Europe PMC*, 551

[36] Buron A, Roman M, Augue JM et al above n 29

[37] Senore C, Zappa M, Capmari C, et al above n 28

[38] Department of Health above n 8

[39] AIHW, *National Bowel Cancer Screening Program: monitoring report 2020* (July 2020)

[40] Javanparast S, Ward P, Young G et al 'How equitable are colorectal cancer screening programs which include FOBTs? A review of qualitative and quantitative studies' (2010) 50(4) *Preventative Medicine* 165.

[41] Molina- Barceló A, Salas Trejo D, Peiró-Perez R et al 'To participate or not? Giving voice to gender and socio- economic differences in colorectal cancer screening programmes' (2011) *European Journal of Cancer Care*, 669.

[42] Frederiksen BL, Jørgensen T, Brasso K et al 'Socioeconomic position and participation in colorectal cancer screening' (2010) 103 *British Journal of Cancer* 1496

[43] Von Wagner C, Good A, Wright D et al 'Inequalities in colorectal cancer screening participation in the first round of the national screening programme in England' (2009) 101(2) *British Journal of Cancer* 60

[44] Tørring ML, Frydenberg M, Hamilton W, et al 'Diagnostic interval and mortality in colorectal cancer: U-shaped association demonstrated for three different datasets', (2012) 65(6) *Journal of Clinical Epidemiology* 669.

[45] Pruitt SL, Harzke AJ, Davidson NO, et al 'Do diagnostic and treatment delays for colorectal cancer increase risk of death?' (2013) 24(5) *Cancer Causes Control* 961.

[46] Singh H, Shu E, Demers A et al 'Trends in time to diagnosis of colon cancer and impact on clinical outcomes' (2012) 26(12) *Cancer Journal of Gastroenterology* 877.

[47] Australia Department of Health, *National Bowel Cancer Screening Program- Quality Framework* (October 2016)

[48] Australian Government Department of Health (2016), *Gastroenterology & Hepatology 2016 Factsheet*.

[49] Northern Territory, 'Bowel Cancer', *Northern Territory Government* (2021), < https://nt.gov.au/wellbeing/cancer-services/bowel-cancer>

[50] AIHW, *Private Health Insurance* (July 2020)

[51] ACSQHC, *Colonoscopy Clinical Care Standard* (2018)

[52] *Improving Colonoscopy Services in Australia Report from the National Bowel Cancer Screening Program Quality Working Group* (July 2009)

[53] Commonwealth of Australia, *The National Bowel Cancer Screening Program – Participant Follow-up Function: National Partnership Agreement on Specified Projects*, (2018)

[54] AIHW, *National Bowel Cancer Screening Program Monitoring report*, (2020)

[55] Cancer Institute NSW, *Direct access colonoscopy model of care*, 2020

[56] Ibid.

[57] Beggs A, Bhate R, Irukulla S et al 'Straight to colonoscopy: the ideal patient pathway for the 2-week suspected cancer referrals?', (2011) 93(2) *Annals of the Royal College of Surgeons of England* 114

[58] Ahmed J, Mehmood S, Khan, S et al 'Direct access colonoscopy in primary care: is it a safe and practical approach?' (2013) 58(3) *Scottish Medical Journal*, 168.

[59] Verdon, C, 'Improving access to colonoscopy in South Western Sydney public hospital for patients with positive faecal test'*,* (2018) *Cancer Institute*

[60] Far West Local Health District, *Innovation in Colonoscopy Services: Direct Access Colonoscopy Clinic* (2019)

[61] Australian Department of Health and Ageing, *The Australian Bowel Cancer. Screening Pilot Program and Beyond: Final Evaluation Report* (2005)

[62] Department of Health above n 8

[63] Leaper M, Johnston MJ, Barclay M et al 'Reasons for failure to diagnose colorectal carcinoma at colonoscopy', (2004) 36(6), *Endoscopy* 499.

[64] Robertson DJ, Greenberg ER, Beach M, et al 'Colorectal cancer in patients under close colonoscopic surveillance' (2005) 129(1), *Gastroenterology*, 34.

[65] Singh H, Turner D, Xue L et al 'Risk of developing colorectal cancer following a negative colonoscopy examination: evidence for a 10-year interval between colonoscopies' (2006) 295(20), *JAMA*, 2366.

[66] Kelly N, Moorehead J, Tham T 'Is the 'driving test' a robust quality indicator of colonoscopy performance?' (2010) 2(4), *World Journal of Gastrointestinal Endoscopy*, 112.

[67] Department of Health, *National Bowel Cancer Screening Program Key Performance Indicator Review*, (2019)

[68] Department of Health, *National Bowel Cancer Screening Program Policy Framework Phase Four (2015-2020)*, (2017)

[69] Atkinson, T., Salz, T., Touza, K., Li, Y., Hay, J. Does corectal cancer risk perception predict screening behavior? A systematic review and meta-analysis. (2015) 38(6). *Journal of Behavioural Medicine*.

[70] NHRMC, *Clinical Practice Guidelines For the Prevention, Early Detection and Management of Colorectal Cancer,* 2017

[71] Davis J, Buchanan K, Katz R, et al 'Gender differences in cancer screening beliefs, behaviors, and willingness to participate: Implications for health promotion' (2012) 6(3), American *Journal of Mens Health*, 211.

[72] Cole, S; Smith, A; Wilson, C; Turnbull, D; Esterman, A; Young G. 'An advance notification letter increases participation in colorectal cancer screening', 2007, 14(2) *Journal of Medical Screening*, p.73-75

[73] Goodwin B, Ireland M, March S et al. 'Strategies for increasing participation in mail-out colorectal cancer screening programs: a systematic review and meta anlaysis.'(2019), 8(257) *Systematic Reviews.*

[74] Zajac I, Whibley A, Cole S et al 'Endorsement by the Primary Care Practitioner Consistently Improves Participation in Screening for Colorectal Cancer: A Longitudinal Analysis', (2010) 18(1), *Journal of Medical Screening* 19.

[75] Curry SJ, *Fulfilling the Potential of Cancer Prevention and Early Detection*, (2003) 6.

[76] Dodd N, Carey M, Mansfield E et al 'Testing the effectiveness of a general practice intervention to improve uptake of colorectal cancer screening: a randomised controlled trial' (2019) 43(5) *Australian and New Zealand Journal of Public Health* 464.

[77] PHN Gippsland, *LaTrobe Cancer Screening Collaborative*, (2019)

[78] Moutel G, Duchange N, Lièvre A et al 'Low participation in organized colorectal cancer screening in France' (2019) 28(1) *European Journal of Cancer* 27.

[79] Benton S, Butler P, Allen K et al, 'GP participation in increasing uptake in a national bowel cancer screening programme: the PEARL project' (2017) 116(12), *British Journal of Cancer* 1551. Benton S, Butler P, Allen K et al n above xviii

[80] Flander L, Paauw L, Deckler E et al 'Increasing Bowel Cancer Screening Participation in Australia: Can We Learn from Successful Northern European Programs' (2017) University of Melbourne.

[81] Lofti-Jam K, O'Reilly C, Feng C et al 'Increasing bowel cancer screening participation: integrating population-wide, primary care and more targeted approaches' (2019) 29(2) *Public Health Research Practice*.

[82] Sendall M, Ostermann L, Brown C et al 'Health promotion of bowel cancer and breast cancer screening in community pharmacies: Pharmacists' perceptions of their role, knowledge and confidence' (2018) 16(4) *Pharmacy Practice* 1275

[83] Martini A, Morris J, Preen D. 'Impact of non-clinical community-based promotional campaigns on bowel cancer screening engagement: An integrative literature review' (2016) 99(10), *Patient Education and Counselling*, 1549

[84] Wakefield, Loken B, Hornik R. 'Use of mass media campaigns to change health behaviour' (2014), 376(9748), *Lancet*, 1261.

[85] Cancer Council, *Promoting participation in the NBCSP- Cancer Council Australia's national bowel screening communications strategy* (2020)

[86] Sandiford P, Buckley A, Robinson T et al 'A community laboratory drop-off option for bowel screening test kits increases participation rates: results from an interrupted time series analysis', (2017), 40(2) *Journal of Public Health*, 133

[87] Cancer Council, *Promoting participation in the NBCSP – Cancer Council Australia's national bowel screening communications strategy* (2020)

[88] AIHW, *Analysis of bowel cancer outcomes for the National Bowel Cancer Screening Program,* (2018)

[89] Access Economics, *National Bowel Cancer Screening Program Economic Evaluation* (report commissioned by Department of Health and Ageing, 2007)

[90] Lew J-B, St John J, Macrae F, et al 'Benefits, Harms, and Cost-Effectiveness of Potential Age Extensions to the National Bowel Cancer Screening Program in Australia', (2018) 27(12), *Cancer Epidemiology Biomarkers and Prevention*, 1450.

[91] Ibid.

[92] Silva-Illanes N, Espinoza M. 'Critical Analysis of Markov Models Used for the Economic Evaluation of Colorectal Cancer Screening: A Systematic Review' (2018) 21(7), *Value Health*, 858.

[93] Wang S, Gum D & Merlin T. 'Comparing the ICERs in Medicine Reimbursement Submissions to NICE and PBAC – Does the Presence of an Explicit Threshold Affect the ICER Proposed?' (2018) 21(8), *Value in Health*, 938.

[94] Ibid.

[95] AIHW, *National Bowel Cancer Screening Program Monitoring report*, (2020)

[96] AIHW (2018), Cancer in Aboriginal and Torres Strait Islander people of Australia, https://www.aihw.gov.au/reports/can/109/cancer-in-indigenous-australians/contents/cancer-type/colorectal-cancer.

[97] Cancer Australia (2020), https://ncci.canceraustralia.gov.au/stage-diagnosis/stage-diagnosis-type.

[98] AIHW (2018), Cancer in Aboriginal and Torres Strait Islander people of Australia, https://www.aihw.gov.au/reports/can/109/cancer-in-indigenous-australians/contents/cancer-type/colorectal-cancer.

[99] AIHW, *National Bowel Cancer Screening Program Monitoring report*, (2020)

[100] Lew et al. (pre-published) *The potential for tailored screening to reduce bowel cancer mortality for Aboriginal and Torres Strait Islander peoples in Australia: modelling study*.

[101] Lew JB, St John J, Xu X-M, et al 'Long-term evaluation of benefits, harms, and cost-effectiveness of the National Bowel Cancer Screening Program in Australia: a modelling study' (2017) 2(7), *The Lancet*, 331.

[102] Silva-Illanes N, Espinoza M. 'Critical Analysis of Markov Models Used for the Economic Evaluation of Colorectal Cancer Screening: A Systematic Review' (2018) 21(7), *Value Health*, 858.

[103] AIHW, *Australian Burden of Disease Study- Impact and causes of illness and death in Australia* (2015)

[104] ABS, *National, state and territorial population tables,* (2020)

[105] ABS, *Life tables* 2017-2019, (2020)

[106] Bishop J, Glass P, Tracey E et al 'Health Economics Review of Bowel Cancer Screening in Australia', (2008) *Cancer Institute NSW Monograph*.

[107] AIHW above 40.

[108] Jahn B, Sroczynski G, Bundo M. et al 'Effectiveness, benefit harm and cost effectiveness of colorectal cancer screening in Austria' (2019) 19, *BMC Gastroenterology*

[109] Lew JB, St John J, Xu X-M, et al, above 86.

[110] AIHW, *Australian Burden of Disease Study*, (2015).

[111] Ibid.

[112] Queensland Government, *Health Funding Policy and Principles 2019/2020*, (2020).

[113] Taylor D, Cannon-Albright L, Sweeney C, et al 'Comparison of compliance for colorectal cancer screening and surveillance by colonoscopy based on risk', (2011) 13, *Genetics in Medicine*, 737

[114] Tran B, Keating C, Ananda S. et al 'A preliminary analysis of the cost-effectiveness of the National Bowel Cancer Screening Program – demonstrating the potential value of comprehensive real-world data', (2012) 42(7), *Internal Medicine Journal*, 794.

[115] Rutter C, Johnson E, Miglioretti D, et al 'Adverse Events after Screening and Follow-up Colonoscopy' (2011) 23(3), *Cancer Causes Control* 289.

[116] Lew JB, St John J, Xu X-M, et al, above n 86.

[117] Lew JB, St John J, Xu X-M, et al, above n 86.

[118] Ananda S, Kosmider S, Tran B et al 'The rapidly escalating cost of treating colorectal cancer in Australia: Rising cost of colorectal cancer' (2015) 12(1), *Asia-Pacific Journal of Clinical Oncology*, 33.

[119] Gordon L, Elliott T, Olsen C, et al 'Out-of-pocket medical expenses for Queenslanders with a major cancer' (2018) 208(11), *The Medical Journal of Australia*, 497.

[120] Enker E, Merchant N, Cohen A, et al 'Safety and Efficacy of Low Anterior Resection for Rectal Cancer', (1999) 230(4), *ANNALS of Surgery*, 544.

[121] Gessler B, Haglind E, Angenete E. 'Loop ileostomies in colorectal cancer patients--morbidity and risk factors for non-reversal', (2012) 178(2), *Journal of Surgical Research* 708.

[122] Lew JB, St John J, Xu X-M, et al, above n 86.

[123] Hubbard R, Johnson E, Hsia R et al 'The cumulative risk of false-positive faecal occult blood test after 10 years of colorectal cancer screening' (2013) 22(9), *Cancer Epidemiology, Biomarkers and Prevention*, 1612.

[124] AIHW, above n 47.

[125] MBS, *Item 23*, (2020)

[126] AIHW, *Patients' out-of-pocket spending on Medicare services 2016-17*

[127] ABS, *Labour Force, Australia*, (2020)

[128] ABS, *Household Income and Wealth, Australia*, (2019)

[129] ABS, *Survey of Disability, Ageing and Carer, Australia.* (2019)

[130] ABS, *Household Income and Wealth, Australia*, (2019)

[131] ABS, *Survey of Disability, Ageing and Carer, Australia.* (2019)

[132] ABS, *Household Income and Wealth, Australia*, (2019)

[133] Cadilhac D et al. (2009). The Economic Benefits of Reducing Disease Risk Factors. Melbourne, Australia: Deakin Health Economics Group, Deakin University and National Stroke Research Institute.

[134] Blom J, Kilpelainen S et al 'Five-year experience of organized colorectal cancer screening in a Swedish population – increased compliance with age, female gender, and subsequent screening round' (2014) 21(2) *Journal of Medical Screening* 144.

[135] Larsen M, Njor S, Ingeholm P et al 'Effectiveness of Colorectal Cancer Screening in Detecting Earlier-Stage Disease—A Nationwide Cohort Study in Denmark' (2018) 155(1) *Gastroenterology* 99.

[136] Flander L et al above n 75

[137] Ibid.

[138] Toes-Zoutensijk E, van Leerdam M, Dekker E.et al 'Real-Time Monitoring of Results During First Year of Dutch Colorectal Cancer Screening Program and Optimization by Altering Fecal Immunochemical Test Cut-Off Levels' (2018) 152 *Gastroenterology*, 767

[139] Flander L et al above n 75

[140] Flander L et al above n 75

[141] 'Doing the bowel screening test', *Time to Screen NZ* (2020) < https://www.timetoscreen.nz/bowel-screening/doing-the-bowel-screening-test/>

[142] Menzies School of Health Research, *National Indigenous Bowel Screening Pilot Final Report* (September 2020)

[143] AIHW, *National Bowel Cancer Screening Program Monitoring Report* (June 2020)

Supplementary Program participant personae information

The following infographics were designed to offer further insights into the attitudes and behaviours of the Program's target population, alongside the development of participant and non-participant personas.

Infographic 1

For the attitude and behaviour segments, consumer survey respondents were sorted according to whether they participated in the Program (behaviour) and whether they believed that healthy people should screen (attitude).[23] Given the Program's aim of screening asymptomatic eligible Australians, the extent to which the target population believe that healthy people should screen is meaningful in understanding ways to encourage (or retain) participation in the Program. Consumers that understand that healthy people should screen, but do not currently participate, are considered the easiest segment to target to improve participation.

Infographic 2

For consumers, the value of the kit is an outcome of the recipient of benefit (self or others) and whether the motivation to complete is intrinsic or extrinsic. The most important value driver of Program participation found in the consumer survey was emotional (pride, relief, protection, safe). This persona is characterised by intrinsic motivation and seeking benefits for self. Consequently, ensuring that the benefits of screening are clear on Program materials may encourage participation among those who are reluctant.

Infographic 3

From the consumer survey, non-participants were able to be characterised as 'aspirer non-screeners' (who believe that healthy people should screen) and 'resistant non-screeners' (who do not believe that healthy people should screen). Resistant non-screeners may be further segmented into:

- **apprehensive resistant**: perceives the process as unhygienic/embarrassing, and/or does not trust the result, and/or has anxiety of a diagnosis.
- **indifferent resistant**: does not see the need, and/or doesn't have symptoms.

These personas may be motivated to participate using different strategies, as shown in Infographic 3.

[23] Note: Percentages do not add to 100% as some people use other screening pathways.

Infographic 1: Attitudes and behaviour

Bowel Cancer Screening Attitude/Behaviour segments

Segmentation strategy

Value proposition strategy - *Resistant screeners*

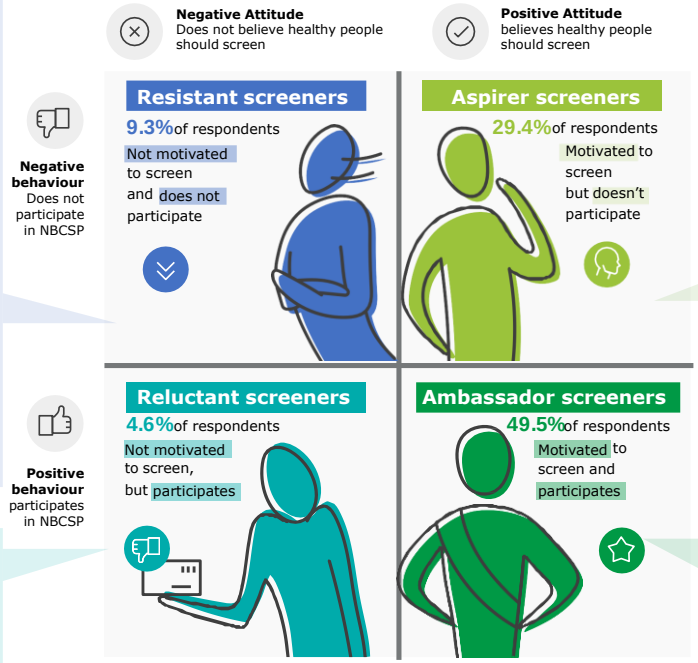
- Communication that demonstrates value of screening for healthy people
- Provide transparency about the rigour of the test results to increase trust
- Two sub-groups for 'Resistant' – Apprehensive & Indifferent
- Build trust and reduce stigma through credible advocate/s
- Myth-busting/Fact Check re costs, efficacy, why it's important, kit [and test analysis] is free (Govt funded), process (esp. post-transaction)
- Simplify instructions further (Ikea-style option: pictorial with minimal text)

Note: It's early days with the revised instructions and there has already been an increased uptake

Segmentation strategy

Reinforcement strategy *incentivise Reluctant screeners*

- Provide incentives to address negative attitude to avoid cessation of participation or negative word of mouth
- Send 'reward' communication after completed screen is sent e.g. SMS or email



Notes: *Percentages do not add to 100% as some people used other screening pathways. Respondents includes current screeners and non-screeners.*

Segmentation strategy

Low hanging fruit strategy *engage Aspirer screeners*

- Identify if barrier is communication or kit-based and make improvements.
- Reminders and strategies to reduce procrastination: (i.e reminder of the expiry date of kit)
- Modification to kit to be more convenient and practical to use

Segmentation strategy

Leverage strategy *leverage Ambassador screeners*

- Use testimonials from current users to endorse kit usage
- Offer support for use and advice for partner, friends and family

Adopting a segmented approach to increasing participation

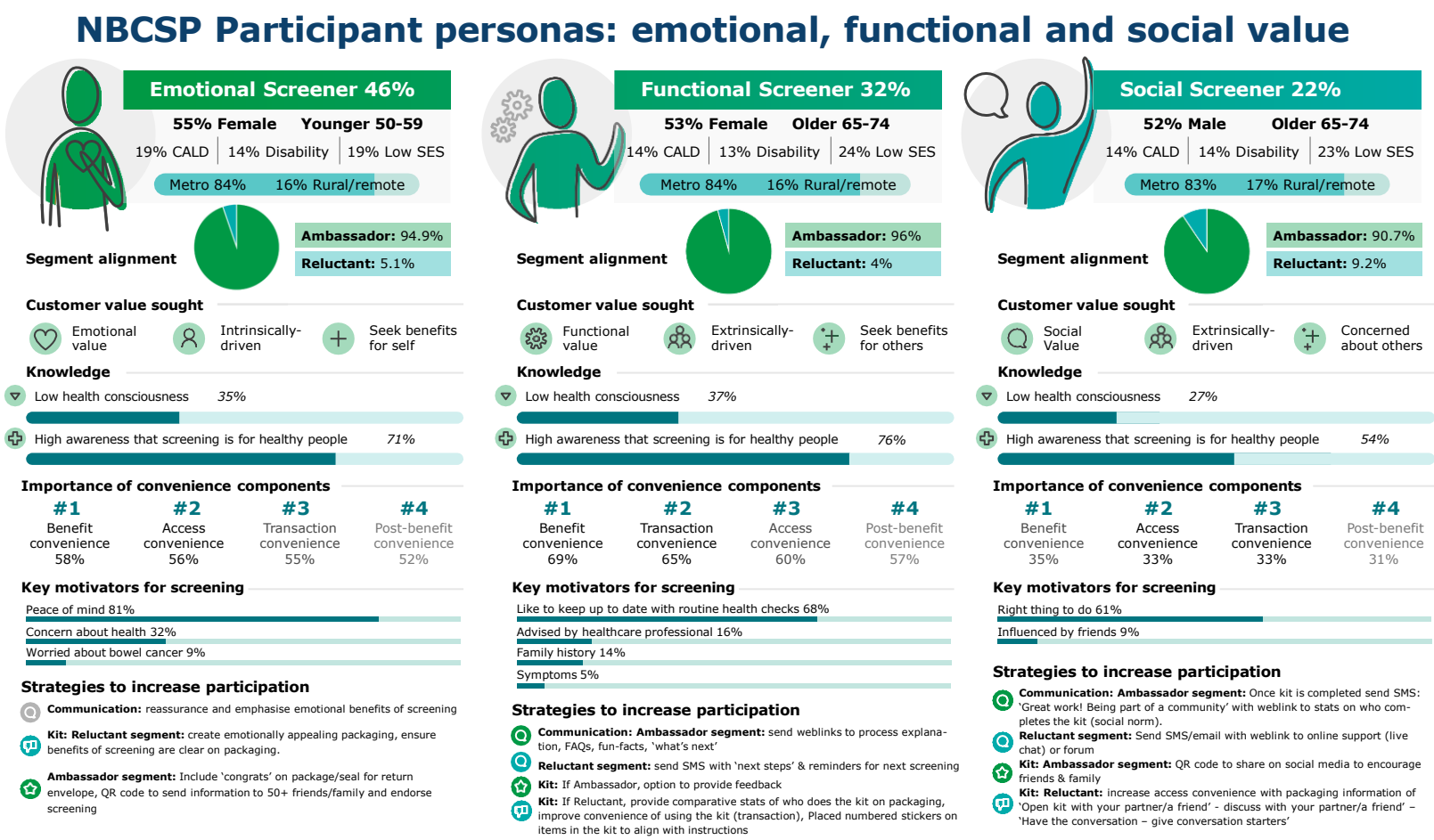
Attitudes x behaviour segmentation
Identifying customers with varying attitudes and behaviours allows for a strategic approach to aligning marketing strategies with the needs of program participants.

Evidence-based
The attitude x behaviour segmentation approach is derived from evidence that shows understanding both psychological and behavioural motivators and barriers is critical for behaviour change.

Communication and kit improvements
Messaging and kits could be improved by avoiding a one-size-fits all approach and designing for different segments to increase uptake.

Relationship Development
The NBCSP is a direct impersonal strategy and while this offers benefits, there is no relationship with the users. Involving key intermediaries such as healthcare providers to encourage, support and follow-up screening would increase particaiption. Relationship development through direct and personalised communication would also assist.

Infographic 2: Participant personas



Infographic 3: Non-participant personas

NBSCP Non-participant Personas

Aspirer Non-screeners

Younger: mean 59yrs | 56.1% Female
Gender role bias: 12.8% | Low SES 19.1%
Rural/regional 14.7% | CALD 17.9%

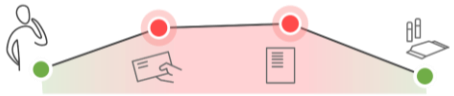
Customer value sought

- Emotional value
- Intrinsically-driven
- Seek benefits for self

Barriers to screening

- Intended to complete the kit but didn't get around to finishing.
- Low interest , 29.4% motivated to screen
- Instructions difficult or inconvenient

Customer journey pain points



I had already decided before I got the kit:	On receiving the invitation and test kit:	After reading the instructions:	After taking the sample:
9.7%	41.4%	44.8%	4.1%

Importance of convenience components

#1	#2	#3	#4
Access convenience (high): 66.6%	Benefit convenience (high): 60.1%	Transaction convenience (high): 62.3%	Post-benefit convenience (high): 61.1%

Strategies to increase participation

- Communication: SMS/email reminders once kit has been sent, notify GP kit has been sent and GP call or SMS encouragement
  Increased access to collection centres
- Kit: Highlight expiry date of the kit on packaging for urgency
- Kit: Simplify instructions and use visuals (e.g. Ikea-style option: pictorial with minimal text). Placed numbered stickers on items in the kit to align with instructions

Apprehensive Resistant Non-screeners

Younger: mean 59 years | Female 60.1%
Gender role bias: 21.4% | Low SES 20.0%
Rural/regional 27.7% | CALD 18.2%

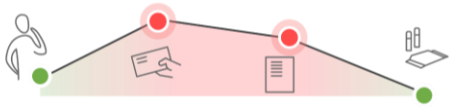
Customer value sought

- Functional value
- Extrinsically-driven
- Seek benefits for self

Barriers to screening

- Perceived kit as unhygienic
- Screening was embarrassing
- Lack of trust in results
- Anxiety about a diagnosis
- Low interest, 9.3% not motivated to screen

Customer journey pain points



I had already decided before I got the kit:	On receiving the invitation and test kit:	After reading the instructions:	After taking the sample:
10.3%	51.2%	38.4%	0%

Importance of convenience components

#1	#2	#3	#4
Access convenience (high): 62.3%	Post benefit convenience (high): 61.2%	Transaction convenience (high): 57.6%	Benefit convenience (high): 56.0%

Strategies to increase participation

- Communication: Use credible message sources/advocates to build trust and reduce stigma, send SMS reminders with motivational prompts, provide weblinks to videos showing kit analysis to make scientific rigour of analysis transparent
- Increased access to collection centres
- Increased guidance & support from HCPs
- Kit: Provide gloves & opaque fridge bag to reduce embarrassment

Indifferent Non-screeners

Younger: mean 58 years | Male 52.9%
Gender role bias: 25.5% | Low SES 26.3%
Rural/regional 26.4% | CALD 19.8%
Low SES and less aware that kit is free

Customer value sought

- Social
- Extrinsically-driven
- Concerned about others

Barriers to screening

- Don't see the need or don't have symptoms
- Concerns of cost of treating bowel cancer
- Low knowledge
- Low self-efficacy
- Low interest, 9.3% not motivated to screen

Customer journey pain points

I had already decided before I got the kit:	On receiving the invitation and test kit:	After reading the instructions:	After taking the sample:
21.2%	58.3%	19.6%	0%

Importance of convenience components

#1	#2	#3	#4
Access convenience (high): 86.2%	Post-benefit convenience (high): 85.3%	Benefit convenience (high): 82.3%	Transaction convenience (high): 81.2%

Strategies to increase participation

- Communication: provide awareness of free to do kit and cost of treating any detecting cancer, dispel myths about kit is for people with symptoms, providing the facts ie costs, service process, kit [and analysis] is free (Govt funded), process (esp. post-transaction)
- Involve healthcare providers as support
- Increased access to collection centres
- Kit: Simplify instructions (Ikea-style option: pictorial with minimal text)

Limitation of our work

General use restriction

This report is prepared solely for the internal use of the Department of Health. This report is not intended to and should not be used or relied upon by anyone else and we accept no duty of care to any other person or entity. The report has been prepared for the purpose of the Review of the National Bowel Cancer Screening Program. You should not refer to or use our name or the advice for any other purpose.