cutting through complexity™

Review of the National Bowel Cancer Screening Program (Phase 2)

Final report, part one

November 2012

Department of Health and Ageing

Disclaimers

Inherent Limitations

This report has been prepared as outlined in the Introduction Section. The services provided in connection with this engagement comprise an advisory engagement, which is not subject to assurance or other standards issued by the Australian Auditing and Assurance Standards Board and, consequently no opinions or conclusions intended to convey assurance have been expressed.

References to 'review' throughout this report have not been used in the context of a review in accordance with assurance and other standards issued by the Australian Auditing and Assurance Standards Board.

The findings in this report are based on a qualitative study and the reported results reflect the sample surveyed, being the Department of Health and Ageing's (DoHA) approved representative sample of stakeholders. Any projection to the wider stakeholder is subject to the level of bias in the method of sample selection.

No warranty of completeness, accuracy or reliability is given in relation to the statements and representations made by, and the information and documentation provided by, DoHA and other stakeholders consulted as part of the process.

KPMG have indicated within this report the sources of the information provided. We have not sought to independently verify those sources unless otherwise noted within the report.

KPMG is under no obligation in any circumstance to update this report, in either oral or written form, for events occurring after the report has been issued in final form.

The findings in this report have been formed on the above basis.

Third Party Reliance

This report is solely for the purpose set out in the Introduction Section and for DoHA's information, and is not to be used for any other purpose or distributed to any other party without KPMG's prior written consent.

This report has been prepared at the request of DoHA in accordance with the terms of the Official Order between DoHA and KPMG dated 23rd December 2011. Other than our responsibility to DoHA, neither KPMG nor any member or employee of KPMG undertakes responsibility arising in any way from reliance placed by a third party on this report. Any reliance placed is that party's sole responsibility.

Electronic Distribution

This KPMG report was produced solely for the use and benefit of DoHA and cannot be relied on or distributed, in whole or in part, in any format by any other party. The report is dated 6 August 2012 and KPMG accepts no liability for and has not undertaken work in respect of any event subsequent to that date which may affect the report.

Any redistribution of this report requires the prior written approval of KPMG and in any event is to be complete and unaltered version of the report and accompanied only by such other materials as KPMG may agree.

Responsibility for the security of any electronic distribution of this report remains the responsibility of DoHA and KPMG accepts no liability if the report is or has been altered in any way by any person.

Table of contents

Executive summary

This report outlines the findings from the review of the National Bowel Cancer Screening Program, Phase Two, including identified opportunities to improve the program and increase participation rates (within current program parameters), and considerations for the future evaluation of the whole National Bowel Cancer Screening Program in 2013-14. The framework for the future evaluation is provided as a separate document.

The review of Phase Two was conducted between December 2011 and June 2012. The review considered the following aspects:

- Operation of the program during Phase Two
- Extent to which Phase Two activities and outcomes contributed to meeting the overall program objectives
- Opportunities to improve the program and to increase participation rates
- Key considerations for the future evaluation, as identified through the review.

The following methods were used to gather the information for the review:

- Interviews with a range of program stakeholders
- Secondary analysis of program data, as reported in the Australian Institute of Health and Welfare (AIHW) program monitoring reports
- Thematic analysis of consumer and practitioner experiences and perceptions of the program, provided to the review by the Department
- Review of program and related documents
- Review of various journal articles and reports about the program
- Literature scan of good practice approaches to engaging consumers and health professionals in screening programs and pathways; and best practice for managing screening programs.

Operation of the program during Phase Two

Screening pathway alignment with policy: The overarching policy framework for screening programs such as the NBCSP is the Population Based Screening Framework (2008). The review found that the NBCSP screening pathway is consistent with the pathway outlined in the framework.

Delivery models: The review notes that several stakeholders (primarily jurisdictions) did not support the provision of assessment colonoscopy through *mainstream health services* (the 'usual care' model), and pointed to the example of the UK Bowel Cancer Screening Programs, and BreastScreen in Australia as their preferred model for assessment services. Other stakeholders suggested that a usual care model was the most feasible approach to delivery of assessment under NBCSP at its current stage of implementation and given the current levels of participation. The review notes that it is open to jurisdictions to organise assessment and care services under a dedicated resources approach if they wish to do so.

Governance: The review found that there was considerable crossover and duplication in purpose, function and work between the Program Managers' Group and the Program Advisory Group. This appears to contribute to a lack of clarity amongst committee members as to the exact role and purpose of each committee. There was also a lack of clarity around the current status of the various working groups that had operated during Phase Two.

Specific Phase Two initiatives: The review found that five of the eight specific Phase Two initiatives had been implemented:

- Expansion of the eligible age group to include the 50 year old cohort
- Introduction of the pre-invitation letter
- Introduction of the PFUF role
- Alternative service delivery pilots
- Consumer and primary health care practitioner experiences and perceptions of the program).

Another two initiatives were partially implemented: quality framework and projects; and improved program data collection).

One initiative was not implemented, although considerable preliminary work was done (communication strategy).

It would be appropriate to consider some of these activities in the evaluation or to revisit some of that work as part of an overall strategy for the development of the program to meet the clinical guidelines and evidence based practice.

- In particular, now that remediation is complete and the program has ongoing funding, it may be timely to revisit the communication framework and the alternative pathways pilots, with a view to exploring ways to expand entry points for hard-to-reach groups.
- Revisiting the quality framework should also be a priority, to ensure alignment with the population based screening framework (discussed further in the next section).

Extent to which Phase Two contributed to program objectives

Maximise early detection: The program is aiding the early detection of bowel cancer. The extent to which this is 'maximised' is difficult to say at the current stage of program maturity.

Equitable access: The program is universally available within the eligible age cohorts but participation in screening and recorded follow-up of positive results is lower for traditionally 'hard-to-reach' groups. Pilot projects have shown variable but promising results for alternative pathways into the program for Aboriginal and Torres Strait Islander peoples, which could be explored further.

Assessment colonoscopy timeliness: 69.4 per cent of participants recorded as undergoing a colonoscopy received that service within 26 weeks of notification of their positive result, although there is no program benchmark or performance indicator against which to assess that period as a measure of timeliness.

It is also not clear how long the waiting time is between primary health care practitioner referral and actual conduct of the colonoscopy, as opposed to time between notification of the positive FOBT and reported conduct of the colonoscopy.

There may be accessibility issues in relation to colonoscopy services, with access inequitably favouring those with private health insurance or the ability to pay for privately delivered care.

Maximise benefits and minimise harm: Early detection of cancers for participants is evidence that the program is maximising benefits, but there may be a potential harm of participants being re-assured by a negative iFOBT if they do not also understand the need to undergo re-screening after two years. More evidence of participant behaviour in this regard is needed (that is, whether participants take the initiative to re-screen after two years if they are not prompted to do so).

Opportunities to improve the program

Program alignment with policy: The NBCSP in its current configuration does not fully align with the overarching policy outlined in the national population based screening framework.

Alignment with good practice design and service delivery: The NBCSP program design and service delivery approach is largely consistent with common international practice for bowel cancer screening, including:

- Recruitment methods
- Screening modality (FOBT)
- Use of colonoscopy for follow-up assessment/investigation
- Monitoring and evaluation frameworks.

The key area where the NBCSP has not mirrored common international practice is the screening interval – however, the 2012-13 Budget announcement that biennial screening program will be progressively phased-in for the program will address this issue.

Alignment with good practice program management and governance: The current advisory committees structure lack clarity and duplicate functions. The review proposes a refreshed committee structure for consideration.

Service delivery: There are no tangible opportunities to improve service delivery within current program parameters.

Data collection and monitoring: Improving data capture along the screening pathway should be a priority. Move to electronic reporting should assist in this goal.

Key gaps in the current data collection include:

- Data around the levels of non- NBCSP related FOBT testing undertaken by the target population.
- Outcomes for program participants diagnosed with bowel cancer.

Opportunities to increase participation rates

Participation rates: The overall participation rate in Phase Two was 38.4 percent, which was similar to Phase One. The review suggests that, overall, the participation rates achieved during Phase Two, particularly the increasing participation of older cohorts, is a positive achievement. More meaningful interpretation of participation rates would be aided by having a published target participation rate.

Evidence of mass media campaigns as a tool to increase screening participation is not strong. Evidence suggests that a combination of small media interventions, promoting GP endorsement of screening, and provision of patient navigation or coaching for participants, can be effective.

Currently, there are a number of charities and community based organisations involved in raising awareness of bowel cancer and screening. The message is somewhat fragmented, with some of these organisations promoting screening for people aged 40 or even younger (which is not consistent with NHMRC guidelines).

Summary of opportunities to improve the program and increase participation

The review has identified the following opportunities to improve the program and increase participation rates:

- Develop a strategy to support the future expansion of the program in line with the 2012-13 Budget announcement.
- Revise program governance and advisory structures.
- Develop a quality management plan.
- Review and finalise the draft communications framework, including consideration of a number of small media interventions
- Review, revise and re-distribute information packages to primary health care practitioners
- Work with charities and community groups promoting bowel cancer screening to develop a consistent, national message promoting bowel cancer and screening awareness and to capture information regarding the level of non-NBCSP screening taking place.
- Develop KPIs and targets for participation and outcomes to enhance program monitoring and continuous improvement. The review notes that this work is already planned.
- Address the gap in the data relating to outcomes for participants after cancer diagnosis / resection. The review notes that this work is already planned.

Summary of key considerations for the future evaluation

The review has identified the following key considerations for the future evaluation:

- Effectiveness of the program data collection and monitoring framework, including comparisons to other cancer screening programs.
- Accessibility of screening and follow-up services for 'hard to reach' groups.
- Colonoscopy capacity, distribution and accessibility.
- Comparison to international benchmarks for timeliness and quality of colonoscopy.
- Comparison of different service delivery approaches in the jurisdictions.
- Participation trends over time and future projections.
- Bowel cancer and screening awareness levels in the target population (comparison at time of evaluation to point in time information collected during the pilot and during Phase Two).
- Reasons for higher participation rates in inner regional and outer regional areas.
- Cost effectiveness.

These are addressed in the evaluation framework.

1. Introduction

The Department of Health and Ageing ('the Department') engaged KPMG to undertake a review of Phase Two of the National Bowel Cancer Screening Program (NBCSP), and to develop a framework for the future evaluation of the program. The review of Phase Two was conducted between December 2011 and June 2012.

This report sets out the findings of the Phase Two review, and provides an evaluation framework for the future whole-of-program evaluation. The report is set out in two parts:

- Part One sets out the Phase Two review findings and conclusions (this document);
- Part Two is the evaluation framework.

1.1 Purpose of this report

Part one of the report sets out the findings and conclusions of the Phase Two review. The report addresses three overarching review questions:

1 To what extent have Phase Two initiatives contributed to meeting the NBCSP objectives?

2 Are there any opportunities to improve the program (within current program parameters)?

3 Are there opportunities to increase program participation rates?

1.2 Background

Bowel cancer (also called colorectal cancer) is the second most common form of cancer in Australia, and causes the second highest number of deaths.[1] Around 80 Australians die each week from the disease. Bowel cancer can be treated successfully if detected in the early stages

In 1997, the Australian Health Technology Advisory Committee conducted a systematic review of the evidence for bowel cancer screening and concluded that screening for bowel cancer with faecal occult blood testing (FOBT) was efficacious. It recommended that a national population based bowel cancer screening program be introduced, subject to pilot and feasibility testing[2].

In 2000-01, the Australian Government funded a four-year pilot bowel cancer screening program to improve knowledge about early detection of bowel cancer. The Pilot commenced in November 2002 and continued until June 2004. Approximately 57,000 people aged between 50-74 years of age were invited to participate. Evaluation of the pilot found that a national, co-ordinated screening program would be feasible, acceptable and cost effective. [3,4]

---

[1] Cancer Australia (2010) *Review of national cancer control activity in Australia*, Commonwealth of Australia: Canberra.

[2] Australian Health Technology Advisory Committee (1997) *Colorectal Cancer screening,* Department of Health and Family Services: Canberra.

[3] M-Tag (2004) *Cost effectiveness evaluation of a national bowel cancer screening program*, Submitted to the Population Screening Division, Department of Health and Ageing (unpublished)

[4] Department of Health and Ageing (2005) *The Australian Bowel Cancer Screening Pilot Program and Beyond: Final Evaluation Report*, Commonwealth of Australia: Canberra.

In 2005-06, the Australian Government established Phase One of the National Bowel Cancer Screening Program (NBCSP), with people turning 55 and 65 years old between 1 May 2006 and 30 June 2008, as well as those people who had participated in the pilot, invited to screen. A cost effectiveness analysis based on Phase One data was conducted which modelled a base case and different future scenarios for the program (expanded age cohorts, screening intervals, participation rates). The analysis found that the base case (biennial testing) was very cost effective. The greatest net financial benefit from modelled scenarios would be biennial testing of all 50-74 year olds, with a first round participation rate of 60 per cent.[5].

In 2007-08, the Australian Government funded the program for a further three years and expanded the eligible population to include 50 year olds. In 2011-12, the Australian Government continued funding for a further four years to 2014-15, giving the NBCSP the status of an ongoing program. Phase Two, which is the key focus of this review, encompasses the period from 1 July 2008 to 30 June 2011.

On 11 May 2009, the program was suspended following identification of a fault with new FOBT kits which had been introduced in December 2008. The program resumed on 2 November 2009 with a new kit and a remediation plan offering re-testing to affected participants.

In the 2012-13 Budget, the Australian Government announced that the program would be expanded over a period of years to increase the frequency of bowel cancer screening available to all people aged 50-74 years. Under the budget measure, screening will be expanded to include people turning 60 years of age from 2013, and to people turning 70 years of age from 2015. The budget measure also provides for the progressive phasing-in of a biennial screening interval from 2017-18, starting with people aged 72 years.

Table 1 sets out the key dates in the NBCSP program development.

---

[5] Access Economics (2007) *National Bowel Cancer Screening Program economic evaluation*, for the Department of Health and Ageing (unpublished)

Table 1: NBCSP Timeline

Phase	Dates	Description
Pilot	Nov 2002 – Jan 2004	Approx. 57,000 people aged 50-74 invited to participate in the pilot
One	Aug 2006 – Jun 2008	Approx 1 million people aged 55 and 65 years, plus those involved in the pilot, invited to participate
Two	Jul 2008 – Dec 2010	Program eligibility expanded to include the 50 year old cohort.
Suspension	11 May 2009	Program suspended due to faulty iFOBT kits. Remediation plan developed.
Two (resumed)	2 November 2009	Program resumed with new iFOBT kits, Affected participants invited to re-screen.
Two (continued)	1 July 2011	Invitations commenced for people turning 50, 55 or 65 from 1 January 2011.
Three	1 July 2013	Eligibility expanded to 60 year olds. Progressive phasing in over 21 years of biennial screening for people aged 50-74.

Source: Department of Health and Ageing and 2013-14 Budget Papers

Further detail about the program design, including goal and objectives, key features, and specific Phase Two activities, is included in chapter 2 of this report.

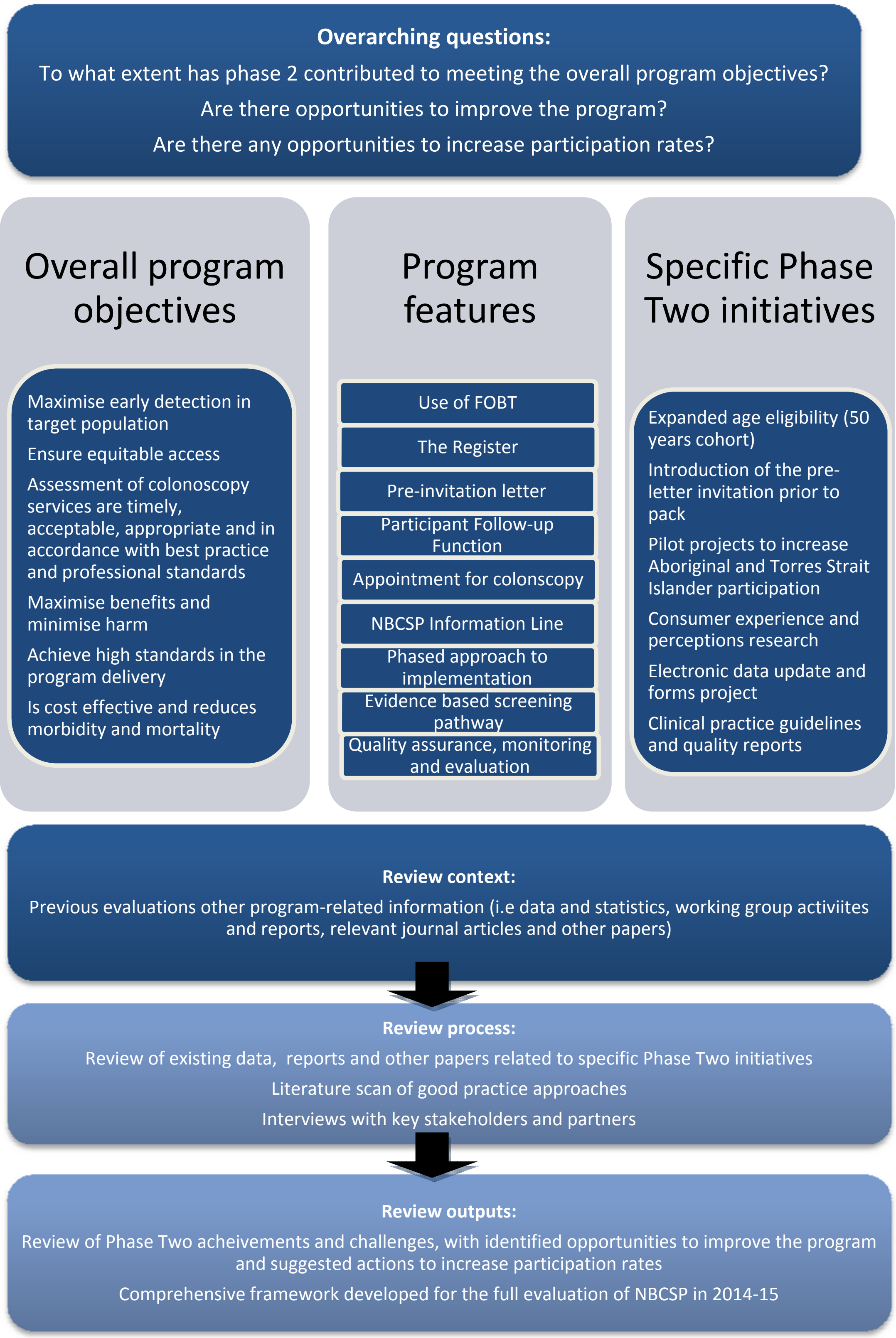
1.3 Review of Phase Two

The purpose of this review is to:

- Assess the extent to which Phase Two initiatives have been delivered, and the contribution of those activities to meeting the overall NBCSP program objectives
- Identify opportunities (within current program parameters) for program improvements, including opportunities to improve participation rates or achieve efficiencies
- Develop a framework, based on the review findings, for the future evaluation of the NBCSP.

Figure 1 provides a diagrammatic overview of the review approach.

Figure 1: Overview of review approach



Overarching questions:

To what extent has phase 2 contributed to meeting the overall program objectives?

Are there opportunities to improve the program?

Are there any opportunities to increase participation rates?

Overall program objectives

- Maximise early detection in target population
- Ensure equitable access
- Assessment of colonoscopy services are timely, acceptable, appropriate and in accordance with best practice and professional standards
- Maximise benefits and minimise harm
- Achieve high standards in the program delivery
- Is cost effective and reduces morbidity and mortality

Program features

- Use of FOBT
- The Register
- Pre-invitation letter
- Participant Follow-up Function
- Appointment for colonscopy
- NBCSP Information Line
- Phased approach to implementation
- Evidence based screening pathway
- Quality assurance, monitoring and evaluation

Specific Phase Two initiatives

- Expanded age eligibility (50 years cohort)
- Introduction of the pre-letter invitation prior to pack
- Pilot projects to increase Aboriginal and Torres Strait Islander participation
- Consumer experience and perceptions research
- Electronic data update and forms project
- Clinical practice guidelines and quality reports

Review context:

Previous evaluations other program-related information (i.e data and statistics, working group activiites and reports, relevant journal articles and other papers)

Review process:

Review of existing data, reports and other papers related to specific Phase Two initiatives

Literature scan of good practice approaches

Interviews with key stakeholders and partners

Review outputs:

Review of Phase Two acheivements and challenges, with identified opportunities to improve the program and suggested actions to increase participation rates

Comprehensive framework developed for the full evaluation of NBCSP in 2014-15

Source: KPMG

The following methods were used to gather the information for the review:

- Interviews with a range of program stakeholders, primarily drawn from the membership of the NBCSP Program Advisory Group and its various working groups. This included state and territory representatives and clinical representatives, as well as other program stakeholders such as the Australian Institute of Health and Welfare, the Department of Human Services (formerly Medicare Australia), and Dorevitch Pathology
- Secondary analysis of program data, as reported in the Australian Institute of Health and Welfare (AIHW) program monitoring reports
- Thematic analysis of consumer and practitioner experiences and perceptions of the program, provided to the review by the Department
- Review of program and related documents provided by the Department, including: program governance and management documents; previous evaluation and review reports; program information and communication materials; and various research and project reports
- Review of various journal articles and reports about the program
- Literature scan of good practice approaches to: engaging consumers in screening programs (including hard-to-reach consumers, and those in particular age cohorts); engaging health professionals in screening programs and pathways; and managing screening programs to facilitate early detection of cancer, and to maximise benefits and minimise harm.
- Validation of key findings with the Department of Health and Ageing and the NBCSP Program Advisory Group.

1.4 Outline of this report

Chapter	Title	Content	Page
2	Operation of the NBCSP, Phase Two	Discusses the NBCSP policy framework, program design and delivery during Phase Two of the program	11
3	Extent to which Phase Two has contributed to NBCSP objectives	Outlines findings in relation to Phase Two outputs and outcomes, and performance against objectives	32
4	Opportunities to improve the program	Considers program alignment with the policy framework, governance, service delivery and monitoring	46
5	Opportunities to increase participation rates	Considers communication/promotion, including targeting of hard to reach groups and health professionals	59
6	Conclusions	Discusses achievements and issues, opportunities for improvement, and key considerations for the evaluation	68

Part Two of the report (the evaluation framework) is provided in a separate document.

2. Operation of the NBCSP, Phase Two

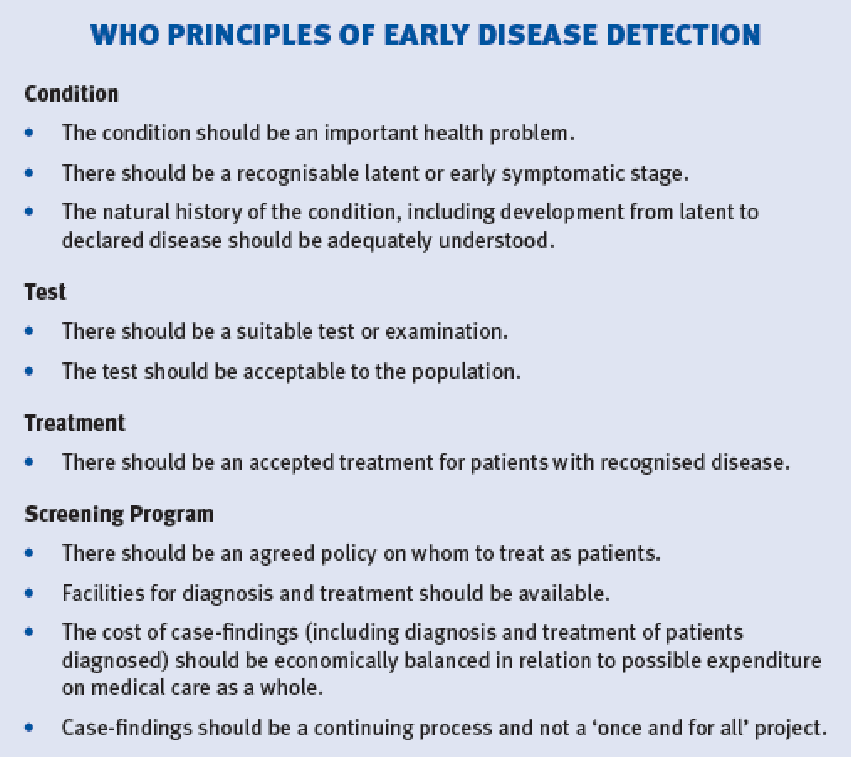
This chapter describes the NBCSP policy framework, program design and program delivery during Phase Two. It includes a discussion of the various aspects of the program, and some broad interim review findings in relation to each of those aspects. The main review findings are outlined in chapters 3 to 5 of this report.

2.1 Policy framework

Screening refers to the performance of tests on people who do not have symptoms, in order to identify those at risk of a disease or a condition, or to detect those who have early disease.[6] The major benefit of screening for diseases such as bowel cancer is that the likelihood of treatment being successful is significantly higher if the disease is identified at an early stage. It also allows for the detection and removal of pre-cancerous growths before they develop into cancer.

The World Health Organization has long-established principles for screening which governments, including Australian governments, have used in deciding whether or not to establish a screening program.

Figure 2: World Health Organisation principles of screening



WHO PRINCIPLES OF EARLY DISEASE DETECTION

Condition

- The condition should be an important health problem.
- There should be a recognisable latent or early symptomatic stage.
- The natural history of the condition, including development from latent to declared disease should be adequately understood.

Test

- There should be a suitable test or examination.
- The test should be acceptable to the population.

Treatment

- There should be an accepted treatment for patients with recognised disease.

Screening Program

- There should be an agreed policy on whom to treat as patients.
- Facilities for diagnosis and treatment should be available.
- The cost of case-findings (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole.
- Case-findings should be a continuing process and not a 'once and for all' project.

Source: Population Based Screening Framework (2008)

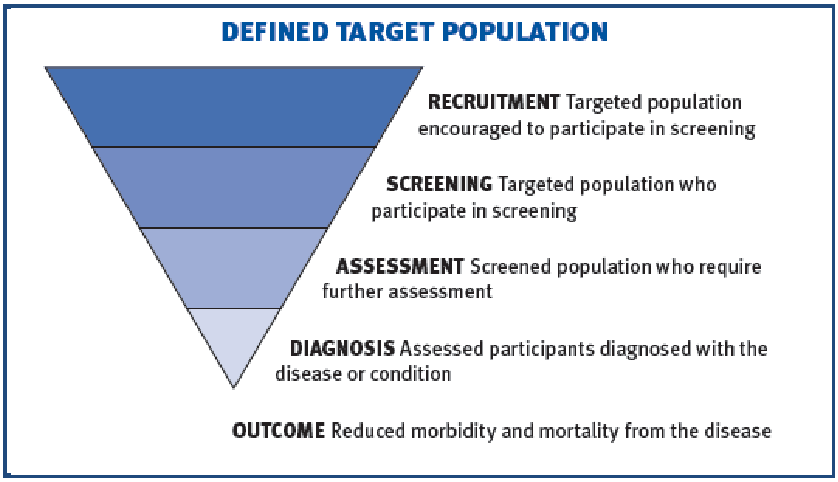
---

[6] Cancer Australia (2010) *Review of national cancer control activity in Australia*, Commonwealth of Australia: Canberra

The NBCSP is a population based screening program (also referred to as an organised or mass screening program).These programs systematically offer screening to all individuals in a defined target group. In Australia, there are three national population based cancer screening programs: BreastScreen Australia, the National Cervical Cancer Screening Program, and the NBCSP.

National policy framework: The core policy which underpins population based screening in Australia is the *Population Based Screening Framework*[7] ('the screening framework'). Based on the WHO principles, the framework describes a screening pathway, criteria for assessing a proposed new screening program, and principles for implementation and management.

Figure 3: Population based screening pathway



Source: Population Based Screening Framework (2008)

The NBCSP pathway aligns to the generic screening pathway as follows:

- *Recruitment:* Eligible persons are identified by a national Register through Medicare and Department of Veterans' Affairs enrolment records and invited, by mail, to participate.
- *Screening:* Eligible persons submit a pathology sample for testing. The participant (and their nominated primary health care practitioner) is advised of the results by return mail.
- *Assessment:* Participants with a positive result are encouraged to see their primary health care practitioner and may be referred for assessment colonoscopy. The colonoscopy is provided under a usual care model in the public or private health system[8].
- *Diagnosis:* Histopathology is undertaken through a usual care model. Participants diagnosed with bowel cancer receive treatment under a usual care model.
- *Outcome:* Individual outcomes, as well as global bowel cancer morbidity and mortality rates, are included within the NBCSP monitoring framework.

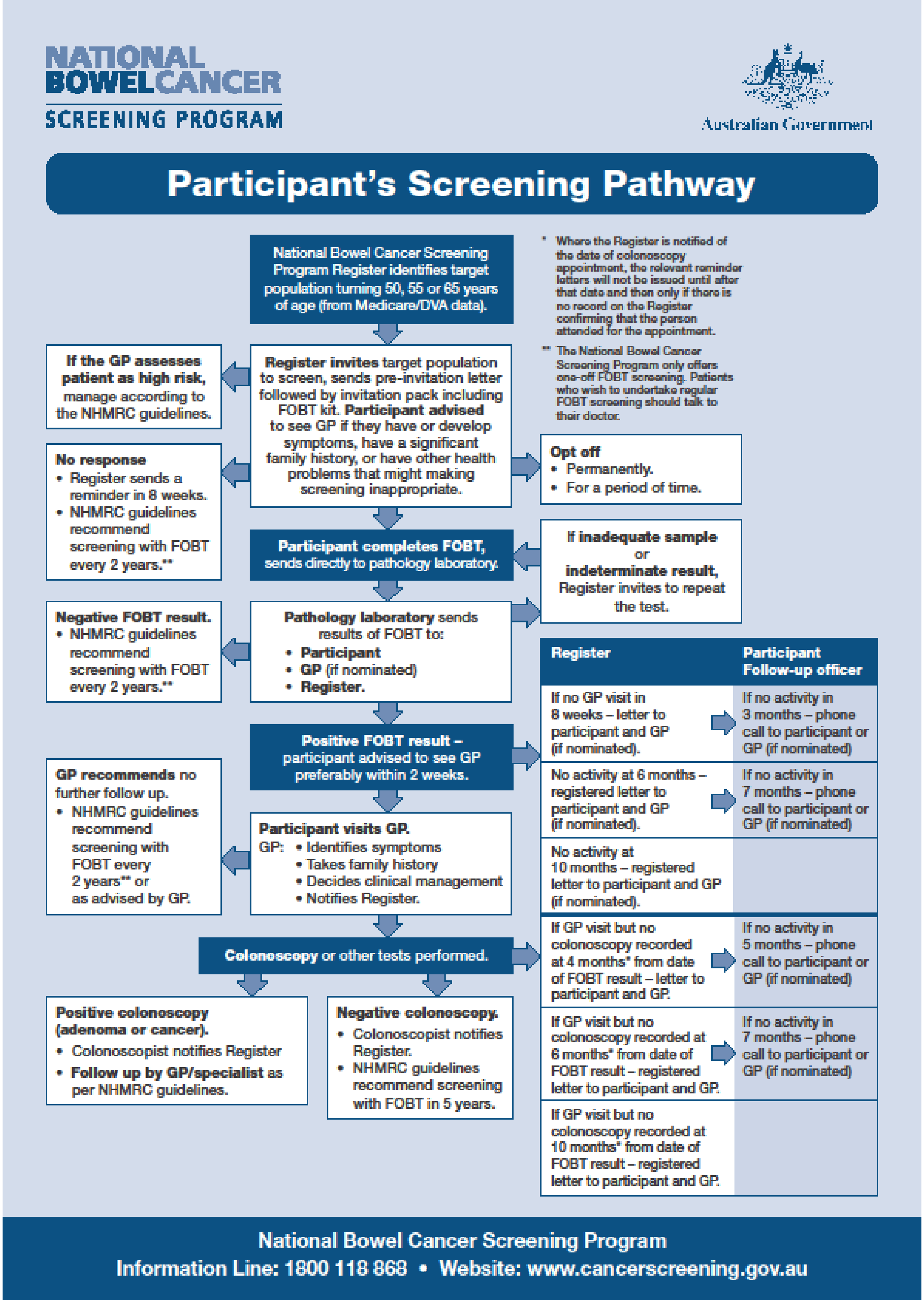
---

[7] AHMAC Australian Population Health Development Principal Committee, Screening Subcommittee (2008) *Population based screening framework*, Commonwealth of Australia: Canberra

[8] Queensland operates a dedicated resources care model for assessment colonoscopy, and Victoria operates a semi-dedicated resources model for assessment colonoscopy. These are funded by state resources.

Figure 4 shows the NBCSP screening pathway.

Figure 4: NBCSP Screening Pathway



NATIONAL BOWEL CANCER SCREENING PROGRAM

Australian Government

Participant's Screening Pathway

National Bowel Cancer Screening Program Register identifies target population turning 50, 55 or 65 years of age (from Medicare/DVA data).

If the GP assesses patient as high risk, manage according to the NHMRC guidelines.

Register invites target population to screen, sends pre-invitation letter followed by invitation pack including FOBT kit. **Participant advised** to see GP if they have or develop symptoms, have a significant family history, or have other health problems that might making screening inappropriate.

No response
- Register sends a reminder in 8 weeks.
- NHMRC guidelines recommend screening with FOBT every 2 years.**

Opt off
- Permanently.
- For a period of time.

Participant completes FOBT, sends directly to pathology laboratory.

If inadequate sample or **indeterminate result,** Register invites to repeat the test.

Negative FOBT result.
- NHMRC guidelines recommend screening with FOBT every 2 years.**

Pathology laboratory sends results of FOBT to:
- **Participant**
- **GP** (if nominated)
- **Register.**

Positive FOBT result – participant advised to see GP preferably within 2 weeks.

GP recommends no further follow up.
- NHMRC guidelines recommend screening with FOBT every 2 years** or as advised by GP.

Participant visits GP.
GP:
- Identifies symptoms
- Takes family history
- Decides clinical management
- Notifies Register.

Colonoscopy or other tests performed.

Positive colonoscopy (adenoma or cancer).
- Colonoscopist notifies Register
- **Follow up by GP/specialist** as per NHMRC guidelines.

Negative colonoscopy.
- Colonoscopist notifies Register.
- NHMRC guidelines recommend screening with FOBT in 5 years.

Register	**Participant Follow-up officer**
If no GP visit in 8 weeks – letter to participant and GP (if nominated).	If no activity in 3 months – phone call to participant or GP (if nominated)
No activity at 6 months – registered letter to participant and GP (if nominated).	If no activity in 7 months – phone call to participant or GP (if nominated)
No activity at 10 months – registered letter to participant and GP (if nominated).	
If GP visit but no colonoscopy recorded at 4 months* from date of FOBT result – letter to participant and GP.	If no activity in 5 months – phone call to participant or GP (if nominated)
If GP visit but no colonoscopy recorded at 6 months* from date of FOBT result – registered letter to participant and GP.	If no activity in 7 months – phone call to participant or GP (if nominated)
If GP visit but no colonoscopy recorded at 10 months* from date of FOBT result – registered letter to participant and GP.	

* Where the Register is notified of the date of colonoscopy appointment, the relevant reminder letters will not be issued until after that date and then only if there is no record on the Register confirming that the person attended for the appointment.

** The National Bowel Cancer Screening Program only offers one-off FOBT screening. Patients who wish to undertake regular FOBT screening should talk to their doctor.

National Bowel Cancer Screening Program
Information Line: 1800 118 868 • Website: www.cancerscreening.gov.au

Source: Department of Health and Ageing

The review found that the NBCSP screening pathway was consistent with the national screening framework. Stakeholder comments to the review supported this finding.

Program policy framework: The specific program policy and strategic direction for Phase Two of the NBCSP is outlined in the draft *National Bowel Cancer Screening Program Policy Framework August 2008 – June 2011*[9] ('the program policy framework'). This document was not finalised but it did form the general operating policy framework for the program and for the advisory committees.

The document sets out the features of Phase Two of the program, articulates roles and responsibilities for the management and delivery of the program, and also sets out an 'opportunities and challenges' work plan for Phase Two, including a range of actions to address particular issues that had been identified during the pilot and Phase One. These actions are:

- *Strategy:* proposed development of a joint Commonwealth/state-territory national framework for ongoing implementation of the program including workforce planning and quality assurance (the review notes that this did not occur)
- *Equitable access:* continued piloting of alternative service delivery models for Aboriginal and Torres Strait Islander people (the review notes that the pilots were concluded)
- *Quality of colonoscopy:* submission to AHMAC of a report on colonoscopy quality, with 'gradual implementation' of its recommendations[10], and completion of another project on colonoscopy workforce training and accreditation (the report was submitted to and endorsed by AHMAC in 2010; several follow-up quality projects were also conducted)
- *Quality framework:* development of a program quality framework with key performance indicators (a draft framework was developed, with the quality principles endorsed by the Program Advisory Committee, but no further action taken to further develop or implement the overall framework)
- *Participation:* development of a communication strategy (a draft strategy was developed but not implemented)
- *Monitoring:* work to improve capture of program data (considerable work has occurred in this area, which is discussed later in this report).

This work program was quite wide-ranging, and the various projects were not prioritised in the program policy framework. While action was commenced on most of these it was not completed during Phase Two.

---

[9] Department of Health and Ageing (2008) *National Bowel Cancer Screening Program: Policy framework August 2008 – June 2011* (unpublished).

[10] The report, *Improving Colonoscopy Services in Australia*, was commissioned as part of Phase One by AHMAC to advise on strategies to improve the quality, consistency, and availability of colonoscopy services in Australia. The report is available online at: http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/nbcs-imp-col-ser-0709-cnt

The NBCSP also has several operational policies and guidelines: the *Policy and Protocol Manual*[11], the *Participant Follow-Up Function Scope and Minimum Guidelines*[12], and the *Program Advisory Group Member Guidelines*[13]. These are not discussed in detail in this report.

Wider policy environment: Although not directly relevant to the review of Phase Two, there are several other initiatives and strategies within the wider national cancer control and health quality and safety environment which are noted here because of their possible relevance in considering improvements or refinements to the NBCSP later in this report.

Health Workforce Australia is currently developing a national cancer workforce strategy, which will include a national environmental scan and examine potential for national workforce innovation[14]. This includes consideration of the colonoscopy workforce.

Cancer Australia recently issued its consumer involvement framework, which is based on evidence that consumer outcomes and experiences are better when there is a high level of consumer involvement in cancer control activities, including respect of consumer expertise in all aspects of program design and service delivery[15]

The Australian Commission on Safety and Quality in Health Care leads and coordinates national safety and quality activities in health care. Its works includes national service standards and accreditation.

Several jurisdictions also have cancer control strategies, which include promotion of bowel cancer screening as an objective and increased uptake of screening as a measure of success.

2.2 Key features of the NBCSP, Phase Two

Key features of the program as delivered during Phase Two are:

- ***A single, national Register***, operated by DHS. The register invites eligible people to participate and monitors their progress through the screening pathway. It includes paper-based and semi-electronic options for health professionals to report outcome data (i.e. outcomes of consultations, colonoscopy and histopathology results following a positive screening result; where cancers are detected, the outcomes of cancer treatment are not included in the current data set).

---

[11] Australian Government (undated) *Supply and pathology analysis of FOBTs and support services for the National Bowel Cancer Screening Program: Policy and protocol manual* (unpublished).

[12] Department of Health and Ageing (2008) *National Bowel Cancer Screening Program Phase 2 Participant Follow-Up Function: Scope and minimum guidelines* (unpublished).

[13] Department of Health and Ageing (2011) *National Bowel Cancer Screening Program Advisory Group: Member Guidelines, November 2011* (unpublished)

[14] See: http://www.hwa.gov.au/news-and-events/newsletters/pulsecheck/2011/september/cancer-workforce-strategy

[15] Caner Australia and Cancer Voices Australia (2011) *National framework for consumer involvement in cancer control*, Commonwealth of Australia: Canberra.

  - The NBCSP Register was established in 2006, prior to Phase Two, and draws on Medicare Australia and Department of Veterans' Affairs enrolment records to determine the eligible population and issue invitations.
  - Aside from the ability to draw on these databases, the main rationale of a single, national register is that it ensures nationally consistent data elements and definitions, and avoids limitations and problems of state-based registers.
- ***Use of a pre-invitation letter***, followed by an invitation pack including the FOBT kit, which is sent directly to the eligible population from the Register.
- An ***Information Line***, operated by DHS. The line allows invitees to ask questions about the testing process, as well as to suspend or opt off the program. Some data is collected on reasons for suspension or opting off – often it is due to already receiving treatment and/or recent colonoscopy.
- Use of an ***immunochemical faecal occult blood test (iFOBT)*** for bowel cancer screening. This test allows participants to collect samples within their own home and send them through the post for pathology analysis. The FOBT kits and pathology are provided by Dorevitch Pathology. This provider also operates an information line for participants with specific questions about the test kit and process.
- A ***Participant Follow-Up Function*** (PFUF), delivered by the states and territories (except in New South Wales, where it is delivered by DHS) under a funding agreement with the Department of Health and Ageing. The PFUF workers contact and encourage participants to progress on the screening pathway following a positive screening result, where they have not been recorded on the Register as having a follow up with a health professional.
- A ***phased approach to implementation*** over a number of years, to ensure colonoscopy and treatment providers can meet increasing demand. In Phase Two, the 50 year old age cohort was included in the program (along with 55 and 65 year olds from Phase One).
  - During the course of this review, the 2012-13 Budget was released. The Budget announced that the NBCSP would be expanded over a 21 year period to increase the frequency of bowel cancer screening available to all people aged 50-74 years.
- Use of an ***evidence based screening pathway***, as shown in Figure 4 above, outlines the participant pathways from recruitment, through screening and assessment, to diagnosis and treatment, and outcomes. The program pathway is based on the generic pathway outlined in the screening framework, which was derived from international best practice and evidence.
- ***Quality assurance, monitoring and program evaluation***, the Quality Working Group was the key vehicle for quality assurance during Phase One and Phase Two of the program; monitoring is undertaken by the Australian Institute of Health and Welfare (AIHW), which produces detailed annual monitoring reports based on a national monitoring data set developed in consultation with key stakeholders; ongoing program evaluation has been built into the program from the pilot phase and has included pilot evaluation (including pilot process and outcomes, cost effectiveness and consumer experiences), Phase One cost

effectiveness evaluation, Phase Two consumer and primary health care practitioner research as well as this review. A full program evaluation is planned for 2014-15.[16]

2.3 Program design and service delivery

The Australian Government funds and manages the screening process; states and territories deliver follow-up assessment colonoscopy and treatment services in the public health system for those program participants returning a positive screening result and who, following a consultation with their nominated primary health care professional, choose to be treated through the public system. Participants can also receive assessment colonoscopy and treatment in the private health system (and in fact the majority of colonoscopies – within and outside of this program – are performed in the private system).

Public colonoscopy, histopathology and treatment services are provided through a 'usual care' service model by states and territories. Several states utilise a nominated provider system. The review notes that Queensland has committed significant additional funding to deliver its own dedicated resources model for assessment, which involves the employment of regional gastroenterological nurses to guide public patients on the post-screening steps of the pathway, regional promotion officers, state-wide coordination and quality management plan, with an authorised provider system for public colonoscopy providers which incorporates an accreditation process. Victoria also has a nominated provider system for public colonoscopy providers delivering assessment colonoscopy for NBCSP participants.

2.3.1 Goal and objectives

The goal of the NBCSP is to reduce morbidity and mortality associated with bowel cancer through the provision of high-quality, cost-effective and accessible population screening for bowel cancer, using faecal occult blood tests (FOBT) followed by referral to further clinical services.[17]

The objectives of the NBCSP are to:

1. Maximise the early detection of bowel cancer in the target population through FOBT screening followed, as appropriate, by assessment colonoscopy provided through mainstream health services
2. Ensure equitable access to the NBCSP for men and women in the eligible population irrespective of their geographic, socioeconomic, disability or cultural background
3. Ensure that colonoscopy services provided are timely, acceptable and appropriate, and are undertaken in accordance with professional standards for people requiring colonoscopy as a result of the Program

---

[16] Department of Health and Ageing (2008) *National Bowel Cancer Screening Program: Policy framework August 2008 – June 2011* (unpublished)

[17] Department of Health and Ageing (2008) *National Bowel Cancer Screening Program: Policy framework August 2008 – June 2011* (unpublished).

4 Maximise the benefits and minimise harm to the individual particularly in relation to assessment colonoscopy

5 Achieve high standards of program management, co-ordination, quality and safety, service delivery, monitoring and evaluation and accountability

6 Ensure the Program is implemented in a manner that is cost effective and will significantly reduce morbidity and mortality from bowel cancer. [18]

Consideration of the appropriateness of the goals and objectives was not within the scope of this review. However, the review has attempted to assess the performance of the program during Phase Two against each of these objectives, and in doing so it has identified some areas where the wording of the objectives might be re-considered to ensure that program performance can be measured against objectives. Overall, the objectives align with the screening policy framework and screening program best practice as identified in the literature, but specifically some of the objectives are difficult to measure because of the way they are worded. For example:

- Objective 1: Is it necessary or desirable to specify the use of ‘mainstream health services’ for the provision of colonoscopy (or any other kind of health services for that matter), if the intent of the objective is to simply maximise early detection? The current wording seeks to combine an objective with a delivery method. Delivery methods could change over time, but the objective should be worded in a way that it can be flexible and continuous irrespective of how the assessment services are delivered.
- Objective 3: Without an agreed national understanding of what ‘timely’ access to colonoscopy is, this objective is quite difficult to measure. Arguably, the objective of timely access is already implied within ‘acceptable and appropriate’ access. Until there is agreement on what constitutes timeliness, this objective remains difficult to assess.[19]
- Objective 3: There is also a question in terms of the extent to which the NBCSP can actually ‘ensure’ the timeliness, acceptability and appropriateness of assessment colonoscopy – given that these services are not directly funded or delivered under the program. Promotion and monitoring of assessment colonoscopy may be a more measurable objective.

At this point it is pertinent for the review to comment on the issue of ‘usual care’ versus ‘dedicated resources’ models of assessment and care delivery. The review notes that several stakeholders (primarily jurisdictions) did not support the objective of providing assessment colonoscopy through *mainstream health services* (the ‘usual care’ model), and pointed to the example of the UK Bowel Cancer Screening Programs[20], and BreastScreen in Australia as their

---

[19] The review notes that, at the time of writing, the Program is considering the issue of timely access to colonoscopy, with a recommendation that positive FOBT results should generate a category one referral (within 30 days) for colonoscopy.

[20] The approach to delivery of assessment services is not standard across the UK and Ireland: the Scottish Bowel Cancer Screening Program does not operate on a dedicated resources model. The English, Welsh and Northern Ireland programs do operate a dedicated resources model (with accredited assessment colonoscopy facilities). The Irish Bowel Cancer Screening Program, commencing this year, will also operate a dedicated resources model.

preferred model for assessment services.[21] Other stakeholders suggested that a usual care model was the most feasible approach to delivery of assessment under NBCSP at its current stage of implementation. The review did not identify any evidence in the literature which directly compared the effectiveness of a usual care versus dedicated resources models of bowel cancer screening program delivery. The review notes that it is open to jurisdictions to organise assessment and care services under a dedicated resources approach if they wish to do so.

2.3.2 Program management and service delivery

The NBCSP is administered by the Department of Health and Ageing to the point of FOBT result on the screening pathway.

The Department has agreements with the states and territories to perform the Participant Follow-Up Function (PFUF) for those participants who have received a positive FOBT result but who have not been recorded as having seen a health practitioner[22]. The Commonwealth Government provides financial support for the above activities and, through the Medicare Benefits Scheme, for consultations with medical practitioners that result from the Program; colonoscopies and histopathology provided in the private sector; and any other follow-up (such as specialist visits) provided in the private sector.

The Commonwealth also provides funding to state and territory governments for public hospital services including colonoscopies. Under the national system of activity based funding (ABF) arrangements which commenced on 1 July 2012 colonoscopies provided in public hospitals to admitted patients, or provided to outpatients in eligible Tier 2 non-admitted clinics, receive a Commonwealth ABF payment. The Commonwealth will increase its contribution to efficient growth funding for public hospital services, to 45 per cent in 1 July 2014, increasing to 50 per cent from 1 July 2017.

The Department has an agreement with the Department of Human Services (formerly Medicare Australia, hereafter as ‘DHS’) to provide the mail house and Register functions, as well as provide an information line for participants. Screening pathway data is also collected by the Register.

The Department has an agreement with a pathology provider for the provision of the FOBT kits and pathology analysis.

2.3.3 Governance

The Department of Health and Ageing is responsible for NBCSP program management and governance, policy development and funding. States and territories have an advisory role for the

---

[21] BreastScreen is a dedicated resources model with two components: Screening and Assessment Services, and Co-ordination Units at state and territory levels. All services are required to be accredited according to the which have been developed by professionals involved with the program. State and territory governments have primary responsibility for the implementation of the program at their local level. The Australian Government provides overall coordination of policy formulation, national data collection, quality, monitoring and evaluation. (cited from http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/breastscreen-about#how)

[22] See: http://www.federalfinancialrelations.gov.au/content/national_partnership_agreements/health.aspx

NBCSP through the Screening Subcommittee of the Australian Population Health Development Principal Committee, as well as the NBCSP Program Managers' Group and the NBCSP Program Advisory Group. Clinicians are also represented on the Program Advisory Group (PAG).

Program Advisory Group: The role of the PAG is to provide advice to the Department on issues relating to the NBCSP[23]. The member guidelines, dated November 2011, provide clear instruction regarding terms of appointment (to December 2012), meeting conduct (quorums, proxies, conflicts of interest, confidentiality) and administration (insurance, committee business, support, remuneration, travel and media contact).

There were 23 members of the PAG during Phase Two, comprising a chairperson, 8 jurisdictional representatives, 11 clinicians from various disciplines, two Departmental representatives, one consumer representative, one DHS representative and one AIHW representative.

Terms of reference for the committee are to provide:

1. Advice on bowel cancer screening policy issues including effectiveness of new and emerging screening technology and clinical developments, quality provision of colonoscopy, and cost-effective bowel cancer screening protocols
2. Input to program policy to maximise equitable access to the NBCSP for the eligible target group including those from rural and remote areas, non-English speaking backgrounds, Aboriginal and Torres Strait Islander backgrounds and those with a disability
3. Advice on relevant aspects of the NBCSP including monitoring, collecting and analysing of data on screening outcomes, including research and epidemiology evidence.

The *Phase Two Program Policy and Protocol Manual* suggests a slightly expanded advisory role for the PAG, including provision of advice on: 'bowel cancer screening policy; effective target group recruitment; development, refinement and implementation of cost-effective bowel cancer screening protocols including the screening pathway and economic evaluation of the program; consumer and health professional education; and informed consent.' The manual also flags that the PAG is time-limited and subject to review.

The PAG generally met on a biannual basis during Phase Two. The Department chairs the committee and provides secretariat support.

Quality Working Group: The QWG was convened prior to Phase Two and has operated for the life of Phase Two. It is comprised of 16 members including an independent clinician chairman.

Its terms of reference for Phase Two were to:

1. Finalise colonoscopy report for AHMAC
2. Develop a national framework for ongoing implementation of the program including quality agenda, workforce issues and an implementation plan
3. Report to the PAG on these matters.

---

[23] Department of Health and Ageing (2011) *National Bowel Cancer Screening Program Advisory Group: Member Guidelines, November 2011* (unpublished)

The colonoscopy report, *Improving colonoscopy services in Australia*, was completed in July 2009 and endorsed by AHMAC in March 2010. The report made a wide range of recommendations, including development of a national accreditation scheme for colonoscopy services using uniform national standards and performance indicators; adoption of national clinical standards for performance of colonoscopy; certification and re-certification processes for colonoscopy proceduralists; investigation of future training needs; and agreed minimum reporting systems for colonoscopy outcomes linked to accreditation[24].

Several other quality projects were also funded during Phase Two in response to the issues and recommendations identified in this report, including: development of an electronic-based colonoscopy system which is now widely used in Queensland and New South Wales public hospitals; development of certificate, diploma and master's degree courses at the University of Queensland for GE nurse training, and the provision of scholarships to promote enrolment when those courses commenced.

The proposed national framework for ongoing implementation of the program (also flagged in the program policy framework) did not occur during Phase Two.

Communications Strategy Working Group: This working group was formed to develop the draft communications strategy in 2008-09. There were 11 members of the working group, which was chaired by Cancer Council Australia. Its membership included Carroll Communications, Rotary, Cancer Voices, Bowel Cancer and Digestive Research Institute. The Department provided secretariat support. Its purpose was to develop a Communications Strategy to raise awareness of bowel cancer and the NBCSP, drawing together evidence of best communications practice, establishing key messages for various target groups, and making recommendations for appropriate communications strategies.

Its terms of reference were to:

1. Advise on the content of the framework including key messages, target audiences, methods of communication, evidence of best practice, and recommendations
2. Guide development of the framework document by giving professional opinion and relevant evidence and providing suggestions and feedback on drafts
3. Consider ways to encourage use of the framework document by a range of stakeholders.

The working group produced a draft framework in February 2009, which included a theoretical framework, key messages, potential strategies, potential research and evaluation methods, and linkages to other screening messages and campaigns.[25] The framework had not been finalised by the conclusion of Phase Two.

Program Managers Group: This group was established by jurisdictions in 2005, to discuss issues around implementation and planning of the NBCSP. The DHS also attends the meetings as

---

[24] National Bowel Cancer Screening Program Quality Working Group (2009) *Improving colonoscopy services in Australia*, Commonwealth of Australia: Canberra.

[25] Department of Health and Ageing (2009) *Draft communications framework for bowel cancer and the National Bowel Cancer Screening Program* (unpublished).

required. The group meets regularly by teleconference to discuss implementation, progress, monitoring and operational issues and to share information. The secretariat and chairing functions are rotated.

Whilst there are no formal ‘terms of reference’, the National Bowel Cancer Screening Program Managers Teleconference Service Guide, dated August 2007 (Phase One) does set out a purpose for the group to ‘discuss implementation, progress, reporting and operational issues arising from the Program Advisory Group…and to share individual state and territory experiences’.

The review found that there was considerable crossover and duplication in purpose, function and work between the Program Managers’ Group and the PAG.

2.4 Specific Phase Two activities

There were several amendments to the program and new initiatives introduced in Phase Two, which are discussed below. Progress on many of these activities was delayed or overridden by the remediation process described in section 0 below. The effect of this was that some of these activities were partially implemented during Phase Two.

2.4.1 Expanded age eligibility (50 year old age cohort)

The National Health and Medical Research Committee guidelines for the prevention, early detection and management of colorectal (bowel) cancer recommend that organised FOBT screening for asymptomatic persons commence at age 50. The Royal Australian College of General Practitioners’ guidelines for preventive medicine in general practice (‘the Red Book’) also recommend regular screening for bowel cancer using FOBT for people aged over 50 years.[26] Expansion of the eligible age cohort for participation to include 50 year olds (along with 55 and 65 years olds) is therefore in line with recommended clinical guidelines for age of commencement. It is also in line with the entry age in most other bowel cancer screening programs around the world.[27]

2.4.2 Pre-invitation letter

Research has shown that a preliminary letter providing advance notification of a forthcoming invitation to participate in bowel cancer screening has a positive impact on participation rates[28][29]. The inclusion of a pre-invitation letter, sent to eligible persons prior to the FOBT testing kit and instructions, was a new feature of Phase Two.

---

[26] Royal Australian College of General Practitioners (2009) *Guidelines for preventive activities in general practice,* 7th edition, RACP: Melbourne.

[27] Benson VS et al (2007) ‘Colorectal cancer screening: A comparison of 35 initiatives in 17 countries’, *International Journal of Cancer*, 122, 1357-1367.

[28] Cole, SR et al (2007) ‘An advance notification letter increases participation in colorectal cancer screening’, *Journal of Medical Screening*, 14, 73:75

[29] Courtney, RJ et al (2012) ‘Community approaches to increasing colorectal screening uptake: A review of the methodological quality and strength of evidence’, *Cancer Council Australia Cancer Forum*, http://www.cancerforum.org.au/Issues/2012/March/Forum/Community_approach_colorectal_screening.htm

Stakeholder views on the effectiveness of the pre-invitation letter were mixed. The Register found the letter to be effective, because it gave people an opportunity to contact the information line to postpone their kit or opt out of the program prior to a testing kit being mailed to them and thus preventing kit wastage (data on reasons for opting off the program is limited, but many people appear to opt off because they have already had a screening test or colonoscopy). Some jurisdictional and clinical stakeholders felt that the pre-invitation letter helped to relax and prepare participants. Other stakeholders noted that the impact of the pre-invitation letter on participation rates, specifically within the NBCSP, was unclear at this time. Some also felt the wording needed to be reviewed, because it did not instil a sufficient sense of urgency on the recipient.

The review notes that letter content is reviewed and revised regularly.

2.4.3 Participant Follow-up Function

Another new initiative in Phase Two was the instigation of the Participant Follow-up Function, or PFUF. The objective of this function is to encourage program participants, who have received a positive FOBT result but have not been recorded as attending a primary health care consultation or colonoscopy, to progress through the screening pathway. The function is funded by the Department and delivered by the states and territories under a funding agreement, except in New South Wales where it is delivered by DHS. The DHS Register continues to send follow-up and reminder letters to participants; the PFUF is an additional ‘safety net’.

Phase One follow up had been conducted by a small team of DHS officers based in the states and territories and included stakeholder and health professional educational activities. To plan and implement a consistent national follow-up function for Phase Two, a PFUF Working Group was established. The group formulated the minimum expectations and requirements of the roles. Several jurisdictions, DHS and the Department were represented on this working group

When asked about the PFUF role for this review, jurisdictional views varied. Most felt that the role offered a valuable service to ensure people did not ‘fall through the cracks’. Some PFUF officers reported that participants who had not progressed on the screening pathway genuinely appreciated receiving a personalised follow-up and having someone to help them with their concerns. Some PFUF officers had also taken on a role of following-up data returns with primary health care practitioners, colonoscopy providers and histopathology providers in their jurisdiction, and this has been associated with an improvement in data reporting in those areas.

Other stakeholders felt that the PFUF role, whilst valuable, was necessary only because of the failure of the program to routinely collect sufficient data from primary health care practitioners, colonoscopy providers and histopathology providers – these stakeholders reported that, often when a PFUF officer followed up with a participant, it turned out that they had progressed on the screening pathway but that it just had not been recorded due to the voluntary nature of data reporting under the program. Some stakeholders also suggested that the PFUF role would need to be reviewed as the program continued to expand.

Jurisdictional PFUF officers meet via bi-monthly (less frequently at times of decreased follow up activity) teleconferences to share experiences and ideas. They report that this has proven to be a valuable exercise. The operational issues discussed at teleconferences and discussions with DHS led to the PFUF working group being reconvened to re-consider roles and review possible barriers. DHS advised the review that a questionnaire completed by all jurisdictions delivering PFUF services had found that there was general consistency between jurisdictions adhering to the guidelines, and with some jurisdictions performing functions above the required minimum standard.

The review found that the PFUF role appears to be effective, but it should be considered in more detail as part of the future program evaluation. The ongoing sustainability of the role will need to be monitored as program participation continues to increase.

2.4.4 Communications strategy

As noted above, a working group was formed to develop a communications strategy in 2008-09.

The purpose of the strategy to raise awareness of bowel cancer and the NBCSP, drawing together evidence of best communications practice, establishing key messages for various target groups, and making recommendations for appropriate communications strategies. The draft strategy was completed in February 2009. No further work occurred on the strategy after that date.

2.4.5 Research on consumer and GP experience and perceptions

A number of research projects were funded during Phase Two to gain insight into consumer and GP experiences and perceptions of the NBCSP. These projects were completed and the reports were shared with stakeholders.

The review found that these reports provided valuable insights (several of them are quoted in later chapters of this report). The review suggests that incorporating ongoing research along these lines into the program would be helpful in terms of measuring trends over time in consumer and GP attitudes, perceptions and experiences. This would also help to set and interpret participation targets, and develop targeted communication approaches.

2.4.6 Alternative service delivery model pilot projects

A series of pilots were conducted with four jurisdictions during Phase Two of the Program to trial alternative, more effective ways of encouraging Aboriginal participation in bowel cancer screening. The pilots were conducted in selected communities in Queensland, Victoria, South Australia and the Northern Territory and managed by the relevant jurisdictional health department.

The pilots varied between jurisdictions, but the key difference from the 'standard' pathway in each of the pilots was the use of opportunistic recruitment measures at the point of invitation (the 'entry point' to the program), usually through local health clinics and often in conjunction with the conduct of a 'Well Health Check' provided for Aboriginal and Torres Strait Islander peoples. A key component of the alternative pathways is provision of training and support to healthcare workers involved in distributing the kits, to provide education on bowel cancer and screening to prospective participants at the point of invitation, and to provide sufficient continued support and information to the participant. The Queensland pilot was conducted between March 2008 and March 2009. The results of this project informed development of communication materials and pathways for the other pilot sites.

Remediation delayed the other pilots, but all pilots have since been completed. The results were variable: all pilots demonstrated improved participation, but there were some difficulties with health worker support. There was also a sense, in some cases, that bowel cancer is a relatively low priority for many Aboriginal and Torres Strait Islander people and for health workers in this area, because of the ‘competition’ from many other, earlier-onset diseases and chronic illnesses.

The review suggests that similar approaches might be worth exploring with culturally and linguistically diverse groups (experiences in breast cancer screening suggest this could be successful)[30] and the lower SES groups, both of which also have lower participation rates.

The AIHW suggested that it may be useful, for monitoring purposes, to flag participants in future pilots of this nature in the data returns.

2.4.7 Quality framework and colonoscopy quality projects

Quality framework: A draft quality framework for the NBCSP was prepared by a consultant for the Quality Working Group[31]. The proposed framework proposed had four objectives with underlying standards:

1. Consumer focus (objective): consumer needs are identified and addressed (standard)
2. Access and equity (objective): Access to the NBCSP is equitable and achieves maximum participation (standard)
3. Competence and performance (objective): All providers are competent and monitor and manage their performance (standard)
4. Good governance (objective): Governance facilitates the delivery of safe, high quality bowel cancer screening (standard).

The report proposed standards and supporting criteria and quality elements; and a proposed quality system for maintaining standards and establishing targets and performance indicators. It endorsed an accreditation-based approach to colonoscopy services, and recommended that a national colonoscopy registry should be implemented, following feasibility testing. The report also proposes a systematic process for collecting consumer feedback and monitoring the consumer experience.

A draft framework was presented to the PAG but it was not endorsed by the committee in its entirety; instead, the PAG endorsed the report’s proposed principles for a NBCSP quality framework, and agreed that further worked needed to be done to develop the standards and criteria.

The agreed principles are to:

- Focus on achieving the best possible experience and outcomes for consumers, including respecting their right of informed choice

---

[30] Aldridge, M (2011) ‘Can we increase screening participation for women from culturally and linguistically diverse backgrounds in South Australia – YES we can!’, *Paper to the BreastScreen Australia Conference*, 28-30 October, Melbourne.

[31] DLA Phliips Fox (2010) *Report on development of a quality framework for the National Bowel Cancer Screening Program, Draft 2.0,* Department of Health Victoria on behalf of the NBCSP Quality Working Group, October 2010.

- Be evidence-based and informed by research
- Build upon existing quality systems
- Promote accountability
- Be flexible, adaptive and sustainable in order to accommodate changes in program design
- Be transparent, relevant and practicable.

There had not been any further work on the proposed framework at the time of this review.

Colonoscopy quality in Australia: The Quality Working Group's extensive report on colonoscopy quality in Australia was endorsed by AHMAC in March 2010[32]. The report has also been released on the Department's NBCSP website.

The report explores several issues about the quality and consistency of colonoscopy services, particularly in light of the increasing numbers of procedures in recent years, the high number of low volume proceduralists, and suggestions that colonoscopy is being over-used as a form of inappropriate screening, contrary to NHMRC guidelines. The report found that services are generally of good quality, but workforce capacity and capability varied between metropolitan, rural and remote regions. The report recommended, inter alia, the development of a national accreditation scheme using uniform national standards and performance indicators, and credentialing of colonoscopy proceduralists.

A pilot of the proposed accreditation process was undertaken at four sites in Queensland and one site in South Australia. The sites chosen provided a cross section of service delivery settings: metropolitan standalone unit, regional integrated theatre/endoscopy unit, private standalone unit and metropolitan hospital-based unit.

The report of the pilots suggested that an accreditation scheme would be feasible for the wider endoscopy community in Australia, depending on a number of conditions, including identification of a national body to take responsibility for implementation of the accreditation standards, and buy-in by the relevant professional bodies, colleges and associations responsible for clinical and training standards.[33]

The review notes that the standards and accreditation process have considerable support from professional bodies, but at the time of the review they had not been fully adopted.

Colonoscopy training and certification: During Phase Two, funding was provided to the Gastroenterological Society of Australia (GESA) to pilot several proposed colonoscopy training methods and a proposed certification process, in response to issues raised in the NBCSP pilot evaluation concerning quality and consistency of colonoscopy training.[34] Outcomes of the project included development of a colonoscopy training curriculum; expansion of a National Endoscopic

---

[32] National Bowel Cancer Quality Screening Group (2009) *Improving colonoscopy services in Australia*, Department of Health and Ageing: Canberra.

[33] Shepherd, L (2011) *National Bowel Cancer Screening Program – Queensland Accreditation Pilot Project: Evaluation report*, June 2011 (unpublished)

[34] Gastroenterological Society of Australia (2011) *Towards a national approach to training and certification : Improving the quality of colonoscopy*, Report for the Department of Health and Ageing, June 2011.

Training Initiative (NETI) to set standards for endoscopists and training in endoscopy, Train-the-Colonoscopist-Trainer workshops; and development of courses and workshops for trainees in colonoscopy (around 300 trainees completed the courses nationally); changed processes for (voluntary) certification and re-certification of colonoscopists (managed by the Conjoint Committee for the Recognition of Training in Gastrointestinal Endoscopy); and development of web-based recording of training experience and competence. The project report anticipated that the training, certification and re-certification would progress on an ongoing self-funded basis.

2.4.8 Improved data collection (including electronic forms and submission)

Data collection is essential for the monitoring of a screening program. Data is collected at several points along the NBCSP screening pathway:

1 The Register records when an invitation is issued

2 Participants submit a personal particulars form with their FOBT sample, which is recorded on the Register via the pathology provider

3 The pathology provider also submits details of the FOBT result to the Register

4 Primary health care practitioners are asked to submit a form to the Register once they have undertaken an assessment of a participant with a positive FOBT result; return of this form is voluntary but does attract a $7.70 'information payment' from the Register – by way of comparison, this is the same amount as the information payment for immunisation reporting

5 Colonoscopy providers are asked to submit a form to the Register once they have performed an assessment colonscopy; the form provides details of the colonscopy outcome and various quality indicators; return of this form is voluntary but does attract an 'information payment' from the Register[35]

6 Histopathology providers are asked to submit a form with the result of histopathology testing to the Register; return of this form is voluntary.

The rates of data returns at those collection points where the returns are optional (that is, primary health care practitioners, colonoscopy providers and particularly histopathology providers) are relatively low. For example, the AIHW monitoring report notes that, of the 62,067 participants invited in Phase 2 who returned a positive FOBT result, 33,204 (or 53.5 per cent) had been recorded as attending a primary health care practitioner by 30 June 2011; using Kaplan-Meier estimates to minimise the effect of lag time, the AIHW estimated that 54.6 per cent of participants had consulted a primary health care practitioner within one year of their positive FOBT result. There were more colonoscopies recorded than primary health care practitioner visits, and, since referral from a primary health care practitioner is the usual pathway to colonoscopy, it is deduced that many primary health care visits are not being recorded. The AIHW noted return of assessment forms to the Register has improved over that recorded in previous monitoring reports, but that there is still room for improvement. All stakeholders agree that data returns must be improved to ensure effective monitoring of the program.

---

[35] There is an additional form which colonoscopists are asked to submit to report an adverse event experienced by an NBCSP participant. Return rates are very low and the AIHW considers the data unreliable.

During Phase Two, several initiatives were commenced by the Department to make data reporting easier and less cumbersome and more efficient for health providers, with the goal of improving overall data returns. At the same time, work was undertaken to make the extraction of program data by jurisdictions easier, so that they can better monitor the program.

Initially, all data returns to the NBCSP were paper-based, meaning that health providers had to obtain a supply of paper forms, manually complete a form for a participant, and manually send the form to the Register by mail or facsimile. The Register implemented an electronic reporting process for primary health care practitioners in 2008 but this was not very successful (with only 30 submissions over three years), and also did not target histopathology providers, which had the lowest return rates. During the remainder of Phase Two, the Department has led several initiatives aimed at improving data capture, especially histopathology, and also at improving the data available to monitor and manage the program.

The Department developed electronic versions of the NBCSP reporting forms (that is, PDF forms which can be downloaded, completed and then emailed to the Register; data is then manually input to the Register). About seven per cent of data returns are now submitted through this channel. The initial intention was to have these forms directly update into the Register but that was not possible. The current process has not been widely promoted.

The Department has also developed an NBCSP Data Hub, held on the Department’s system. It is capable of receiving data from providers in electronic format, and transmitting that data to the register. The process is currently being piloted by the Tasmanian Department of Health and Human Services: Tasmania will transmit live colonoscopy and histopathology data to the Hub, and that data will be sent to the Register and matched to the participant. This means that public colonoscopy and histopathology providers do not have to complete individual forms for patients. The intention is to then expand that process to software providers for private colonoscopy and histopathology services.

Ideally, the information would be provided directly into the Register, rather than through a Data Hub in the Department. The review understands that this approach was investigated but proved to be unfeasible. The Data Hub process will certainly be an improvement on the current process, which relies on cumbersome manual reporting and manual data entry.

Another data problem has been the desire by jurisdictions to have their data reported at regional rather than jurisdictional level. The Department now receives a monthly de-identified download of NBCSP Register data from DHS and, from this, provides a state-wide data level report to jurisdictions. The Department provides region-level data to jurisdictions on request (jurisdictions use the region-level data to assist with their service and workforce planning). At the time of this review, work was underway to develop processes allowing jurisdictions to access this region-level data directly.

The review notes that most jurisdictions expressed a preference for the NBCSP Register to be managed by them, just as the BreastScreen and National Cervical Cancer Screening registers are, rather than at a national level. However, because the NBCSP recruitment process relies on the use of Medicare (and DVA) enrolment data to identify eligible persons and issue the invitations, and there are strict privacy restrictions around the use of Medicare data, the review position is that it does not seem feasible under the current program structure for the register function to be devolved to jurisdictions. If the FOBT is superseded by another type of test with a different delivery mechanism, then the NBCSP screening pathway will need to be reviewed; this may well include reviewing the location and role of the Register (especially if recruitment is no longer dependent on Medicare data). However, it should also be noted that other stakeholders felt there were significant benefits for national reporting and monitoring in having a single register.

2.5 Summary of outcomes for Phase Two activities

Table 2 below providers a summary of outcomes for each of the Phase Two activities, at the time of this review.

Table 2: Summary of Phase Two activities – outcomes at time of this review

Phase Two Activity / Initiative	Status at time of review
Expansion of target group to include 50 year old cohort	*Implemented* Consistent with screening evidence and NHMRC guidelines.
Pre-invitation letter	*Implemented* Effectiveness of this function should be included as an aspect to consider in the evaluation
Participant follow-up function	*Implemented* Effectiveness of this function should be included as an aspect to consider in the evaluation
Communication strategy	*Not implemented* This could be revisited as part of a strategic planning process to support the future expansion of the program in line with the 2012-13 Budget announcement (hereafter this will be referred to as the '*strategic planning for full implementation of the program*')
Research on consumer and GP experiences and perceptions of the program	*Implemented* The research was conducted and distributed to jurisdictions. It provides useful insights to consumer and GP experiences and perceptions. There may be value in conducting similar research regularly, to monitor trends and assist in developing communications.

Phase Two Activity / Initiative	Status at time of review
Alternative service delivery pilot projects	*Partially implemented* The pilots were conducted. They showed promising results for alternative service delivery approaches. The pilots focused on Aboriginal and Torres Strait Islander participants, but may also be relevant to other groups where participation is notably lower (including culturally and linguistically diverse, low socioeconomic, and rural and remote). This work could be reviewed as part of the strategic planning for full implementation of the program.
Quality framework and projects	*Partially implemented* A draft framework was prepared and several quality assurance research and pilot projects were completed. This work could be reviewed as part of the strategic planning for full implementation of the program.
Improved data collection	*Partially implemented* Work has progressed and continues. There have been many delays and obstacles but stakeholders are supportive of this work.

Source: KPMG analysis

2.6 Remediation

The program was suspended from 11 May 2009 to 2 November 2009 due to lower than expected FOBT positivity rates in the screened population suggesting unreliability of the FOBT kits during hot weather. A remediation process was put in place following the TGA registration of a new FOBT kit. Actions included provision of replacement FOBT kits to affected participants and reminder letters to people who had received a negative result using the prior test.

The AIHW monitoring report for Phase Two outlines the number of participants affected by remediation. The FOBT positivity rate for the new test kit introduced in December 2008 was 3.5 per cent, which was statistically significantly lower than the rate of 6.5 per cent for the previous HemTube kits used during Phase Two.

All participants who had received a negative screening result with the new kit were offered a re-screening with the replacement kits as part of the remediation process in 2009. The AIHW reported that around 83 per cent of those who had received a negative screening result retested. The positivity rate for those with a previous negative and who retested was 5.5 per cent.

The review concluded that, overall, the remediation process was well-managed and effective. It demonstrated that there are sufficient clinical and program risk management processes in place. This finding was supported by comments from the majority of stakeholders interviewed. Many of them considered that the program suspension, testing of the replacement kits, and clear communications with affected participants demonstrated that the program's clinical risk management and monitoring was effective. However, some jurisdictional stakeholders felt that they had not been adequately consulted on the timing of the re-testing letters, with insufficient regard being given to the impact that would have on their colonoscopy resources given the time of year when the invitations to re-screen were issued.

2.7 Key points: Operation of Phase Two

Main findings

- The ***screening pathway*** aligns with the national framework. The ***goals and objectives*** are consistent with the national framework, although the wording of objectives 2 and 3 could be improved to ensure they are linked to measurable outputs.
- Overall, the ***remediation*** process was well-managed.
- There is a lack of clarity about the role and purpose of the ***advisory committees***.
  - It is not clear whether the membership of the Program Advisory Group is sufficient to provide expertise across all of its terms of reference (cost effectiveness, social marketing, education, expertise in Aboriginal and Torres Strait Islander health).
  - There appears to some duplication of function between the Program Managers' Group, the Program Advisory Group and the Screening Subcommittee.
- Some of the specific ***Phase Two activities*** were only partially implemented during Phase Two, due in large part to the remediation process. It would be appropriate to consider some of these activities in the evaluation (effectiveness of the pre-invitation letter and participant follow-up function; potentially also analysis of the cost effectiveness of including the 50 year old cohort) or revisit some of that work as part of the strategic planning for full implementation of the program (in line with the 2012-13 Budget announcement).
  - In particular, now that remediation is complete and the program has ongoing funding, it may be timely to revisit the ***communication framework*** and the ***alternative pathways pilots***, with a view to exploring ways to expand entry points for hard-to-reach groups.
  - Revisiting the ***quality framework*** should also be a priority, to ensure alignment with the population based screening framework (discussed further in the next chapter).

3. Extent to which Phase Two has contributed to NBCSP objectives

This chapter considers the extent to which Phase Two of the NBCSP has contributed to meeting the overall program objectives. It draws primarily on the document and secondary data review, and stakeholder interviews. It concludes with a summary of key points in relation to the meeting of program objectives, and a summary of issues to consider in the future evaluation.

3.1 Program outputs and outcomes

The AIHW monitoring report for Phase Two[36] reported the following key outputs for the NBCSP during Phase Two[37]:

- 2.1 million people were invited through the Register to participate during Phase Two.
- Of these, 38.4 per cent returned a completed bowel cancer screening kit for analysis. This overall participation rate was similar to the 38.7 per cent participation rate in Phase One.
    - The participation rate of 50 year olds was 33.9 per cent. The participation rate of 55 year olds was 38.6 per cent (up from 36.2 per cent in Phase One) and the participation rate of 65 year olds was 46.7 per cent (up from 42.6 per cent).
    - This indicates that participation is increasing in the older age cohorts, who are also more likely to have bowel cancer. It also suggests that program communications may need to be amended to reach the 50 year old cohort.
- It is interesting to note that the total participation rate for Phase One and Phase Two combined was 39.8 per cent (see Figure 5).

The AIHW reported the following outcomes for Phase Two:

- About 7.8 per cent of participants who returned a valid test had a positive screening result.
- Of these, 71 per cent were recorded as having a colonoscopy – the actual numbers of participants who received a colonoscopy is likely to be higher than this, due to relatively poor levels of outcome reporting to the Register by colonoscopy providers.
- One in 33 of the recorded colonoscopies performed diagnosed a confirmed or suspected cancer, whilst advanced adenomas (benign growths that have the potential to become cancerous) were found in a further one in 11 cases.
- The available data suggests that almost 80 per cent of the resected (removed) cancers identified through the NBCSP were in the earliest two of four cancer stages.

---

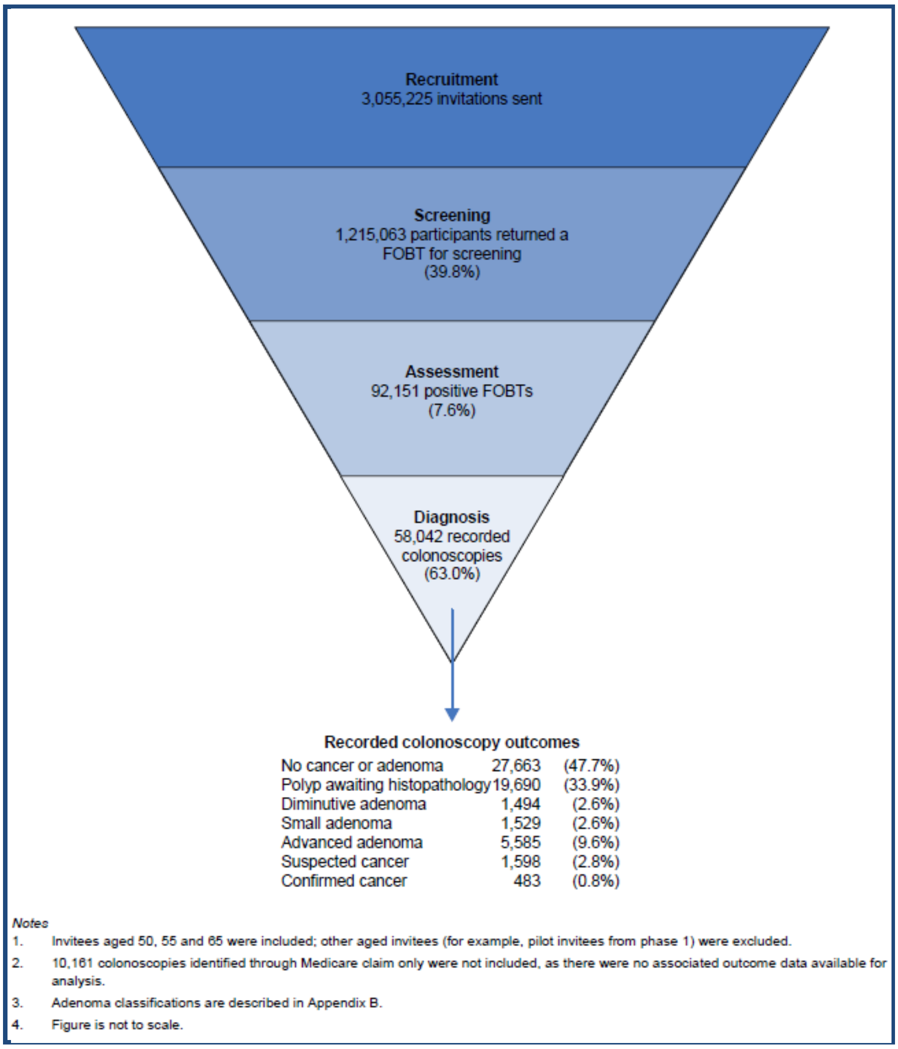
[36] Australian Institute of Health and Welfare (2012) *National Bowel Cancer Screening Program monitoring report: Phase Two, July 2008 – June 2011*, Commonwealth of Australia: Canberra

[37] Note that these figures have been adjusted by AIHW to take account of the remediation process, so that there is no 'double counting' of participants who were re-tested due to the faulty test kit.

The AIHW report notes that women were more likely than men to participate in screening (although men had higher rates of screen-detected cancer and overall bowel cancer incidence and mortality). Aboriginal and Torres Strait Islander participants, culturally and linguistically diverse participants, and participants living in lower socioeconomic postcodes had higher rates of positive screening results, yet lower rates of recorded follow-up colonoscopies. People from these groups also had lower screening uptake. These results suggest possible areas for future social marketing and bowel cancer awareness raising activities.

The review found two notable gaps in this data: the first is outcomes for program participants after they have a confirmed cancer and/or resection; the second is measurement of outcomes against program performance indicators / targets. The NBCSP does not have any (published) performance indicators / targets, so outputs and outcomes are reported by AIHW as general ‘performance measures’ which are compared to results from previous phases. There is no benchmark against which results can be measured to gauge program impact. The review notes advice from the Department that future work will focus on addressing these two issues.

Figure 5: Overall NBCSP outcomes for Phase One and Phase Two (August 2006 - June 2001)



Recorded colonoscopy outcomes

No cancer or adenoma	27,663	(47.7%)
Polyp awaiting histopathology	19,690	(33.9%)
Diminutive adenoma	1,494	(2.6%)
Small adenoma	1,529	(2.6%)
Advanced adenoma	5,585	(9.6%)
Suspected cancer	1,598	(2.8%)
Confirmed cancer	483	(0.8%)

Notes

1. Invitees aged 50, 55 and 65 were included; other aged invitees (for example, pilot invitees from phase 1) were excluded.
2. 10,161 colonoscopies identified through Medicare claim only were not included, as there were no associated outcome data available for analysis.
3. Adenoma classifications are described in Appendix B.
4. Figure is not to scale.

Source: NBCSP Phase Two Monitoring Report (AIHW, 2012)

Key points: Program outputs and outcomes

- The overall participation rate in Phase Two was 38.4 per cent, which was similar to Phase One. Fifty year olds in Phase Two were less likely to participate; participation rates for both the 55 and 65 year old cohorts increased from Phase One.
- There may be a need to amend or target program communication messages and methods to reach the 50 year old cohort
- There may be a need to target program communication messages and methods to reach Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, and people from lower socioeconomic postcodes.
- There is a gap in the data relating to outcomes for participants after cancer diagnosis / resection. The review notes advice from the Department that planned future work will address this issue.
- The lack of Key Performance Indicators and / or targets makes interpretation of program performance data and benchmarking of results difficult. The review notes advice from the Department that planned future work will address this issue.

3.2 Performance against program objectives

3.2.1 Maximise early detection in the target population

As noted above, the AIHW report indicates that around 80 per cent of the resected cancers first identified through the NBCSP were in the earliest two of four cancer stages.

The NBCSP has been shown to have had a measurable impact on the stage of bowel cancer at diagnosis[38]. Recent research into the stage of bowel cancer at diagnosis in South Australia has shown that bowel cancer detected through the NBCSP are down-staged (that is, earlier detection at a stage where the cancer is curable) relative to that detected through other pathways[39] [40].

---

[38] Ananda, S et al (2009) 'Initial impact of Australia's National Bowel Cancer Screening Program', *Medical Journal of Australia*, 191 (7), 378:381

[39] Young, GP et al (2011) *Cancer downstaging in the National Bowel Cancer Screening Program: Draft final report*, Flinders University: Adelaide

[40] Cole, SR et al (2011) 'Cancer downstaging as a consequence of the Australian National Bowel Cancer Screening Program', Paper to the *19th Annual European Gastroenterology Week Scientific Programme*, 22-26 October, Stockholm. Abstract available at http://uegw.congress-online.com/uegw2011/guest/AbstractView?ABSID=14410

Stakeholders also provided anecdotal evidence during the interviews for this review that cancers were being detected at earlier stages. Over time, this is further increasing primary health care practitioner acceptance of FOBT screening.

The evidence suggests that the program is effective in aiding early detection of cancer in the target population. The extent to which this is 'maximised' is difficult to say. The addition of program targets or KPIs would assist in measuring outcomes and trends over time, and in assessing the extent to which the program is maximising early detection.

3.2.2 Equitable access

The screening framework includes a criterion that programs must ensure equity of access for the entire population. Although the NBCSP provides universal, free access to screening for all people within the target age cohorts, there is inequitable uptake of this screening. National statistics show that males, people in the lower (50 and 55 years) age cohorts, people living in areas of lower socio-economic status, people from culturally and linguistically diverse backgrounds, and people from Aboriginal and Torres Strait Islander backgrounds were less likely to participate in screening.

A South Australian study of equity of access to the NBCSP found a number of barriers to uptake, including:

- Factors relating to the nature of the test: embarrassment, distaste or concern about the FOBT test
- Factors related to personal issues: beliefs (including cultural beliefs), low health literacy, fatalist ideas, lack of bowel cancer knowledge and awareness
- Systemic factors: inability to understand the instructions, lack of doctor's recommendation, concerns about the remediation publicity and the accuracy of the test

The main enablers of participation were cost, family history of cancer, ability to do the test privately at home, participation in other screening tests, doctor's recommendation, reminder letters, and trust of government bodies.[41]

Quantitative information on access

As noted in the previous chapter, around 38 per cent of invited eligible persons returned a completed bowel cancer screening kit for analysis. Around 3 per cent responded by opting off or suspending participation. Data suggests that the reason for opting off the program was often because people had already been screened outside of the program or had recently had a colonoscopy, but there is room for improvement in the collection of this information. A better understanding of why people do not participate would be helpful.

Of those participants who returned a valid FOBT, 7.8 per cent had a positive screening result, and 71 per cent of those were recorded as having undergone a colonoscopy.

---

[41] Ward, P et al (2010) *Equity of bowel cancer screening: An epidemiological and qualitative study: Final report*, August 2010, Flinders University: Adelaide.

FOBT participation: As previously noted, participants of Aboriginal and Torres Strait Islander origin, culturally and linguistically diverse background, those living in inner regional and outer regional areas, or those living in areas of lower socioeconomic status all had higher rates of positive screening results but lower rates of follow-up colonoscopies than other participants. Specifically, with regard to:

- *Gender:* women were more likely than men to participate in the program (41.2 per cent versus 36 per cent)[42]
- *Age:* participation increased with age, with participation rates of 46.9 per cent for 65 year olds, 38.8 per cent for 55 year olds and 34 per cent for 50 year olds – this is similar to the experience in the UK
- *Location:* participants living in inner regional (41.1 per cent) and outer regional (39.9 per cent) areas were more likely to participate in the program than those in Major Cities, rural, remote or very remote areas. Participation also varied by state / territory, with the Northern Territory (27.7 per cent), New South Wales (36.4 per cent) and Queensland (37.4 per cent) all being lower than other jurisdictions
- *Socioeconomic status:* participation by invitees from within the lowest socioeconomic area was statistically significantly lower (36.4) than for those living in all other socioeconomic areas
- *Indigenous status:* participants who identified as being Aboriginal and Torres Strait Islander were less likely to participate in the program[43]
- *Culturally and linguistically diverse:* no reliable data relating to this was collected.

Follow-up with primary health care practitioners: Of the participants who had a positive FOBT, 54.6 per cent were recorded as having a follow up visit with a primary health care practitioner within one year of their screening result (these visits appear to be under-reported). 92.1 per cent of those recorded as attending a follow-up primary health care visit were referred for colonoscopy; recorded reasons for non-referral included ‘Recent colonoscopy’ (39.4 per cent), ‘Patient declined colonoscopy’ (37 per cent) and ‘Other medical condition(s)’ (27.8 per cent). Specifically, with regard to:

- *Gender:* Women (55.2 per cent) were more likely than men (51.9 per cent) to follow up with a primary health care practitioner. However, women had a slightly higher rate of reported symptoms (16.9 per cent for women and 14.7 per cent for men), and a slightly lower rate of referral for colonoscopy (94.2 per cent for women and 94.7 per cent for men). The higher percentage of women (37 per cent) declining colonoscopy than men (30.5 per cent) was identified as a possible explanation for this discrepancy

---

[42] Research suggests that previous contact with cancer screening (such as cervical or breast cancer screening) predicts an improved likelihood of bowel cancer screening (Gregory et al. 2011); this may influence gender specific differences in participation

[43] An invitees’ status is not known at the time of invitation—these details are only collected if a person becomes a participant in the NBCSP and completes the relevant section of their participant details form.

- *Age:* Primary health care practitioner follow-up rates increased with age
- *Location:* Participants in inner regional (57 per cent) and outer regional areas (56.8 per cent) had statistically significant higher rates of primary health care practitioner consultations than other areas (this may reflect under-reporting of follow-ups by primary health care practitioners in major cities)
- *Socioeconomic status:* Although primary health care practitioner follow-up was highest for participants living in areas with the lowest socioeconomic status and lowest for participants living in areas with the highest socioeconomic status, this difference was not statistically significant
- *Indigenous status:* Although Aboriginal and Torres Strait Islander participants accessed primary health care practitioner follow-up services at lower rates than other Australians, caution is required in drawing conclusions due to the low numbers provided
- *Culturally and linguistically diverse status*: There was no statistically significant difference in the rate of primary health care practitioner follow-up between culturally and linguistically diverse and non-culturally and linguistically diverse participants.

Follow-up with colonoscopies: 74 per cent of participants with a positive FOBT were recorded as attending a follow-up colonoscopy. Specifically, with regard to:

- *Gender:* There was no statistically significant difference in the rate of colonoscopy follow-up between women and men
- *Age:* The rate of colonoscopy follow-up for people aged 65 (72.3 per cent) was statistically significantly higher than for those aged 50 and 55 (both, interestingly, 70.9 per cent)
- *Location:* Participants living in major cities (73.7 per cent) had statistically significant higher rates of colonoscopy consultations than other areas, which correlates with reports by stakeholders to this review of generally poorer access to colonoscopy (public or private) outside of those areas. Participants in South Australia (79.7 per cent), Queensland (77.8 per cent), the Australian Capital Territory (76.1 per cent) and Tasmania (74.2 per cent) accessed colonoscopy services at statistically significant higher rates than other jurisdictions.
- *Socioeconomic status:* Participants living within the lowest socioeconomic areas had the lowest colonoscopy follow-up rates. This is interesting given the evidence that the majority of colonoscopies are performed in the private sector, and the jurisdictions with the highest rates of public colonoscopies were also those with the highest rates of (recorded) colonoscopy follow-up. Stakeholders interviewed for this review suggested that cost was perceived as a barrier to colonoscopy by many participants (private colonoscopy costs, prior to any health insurance refunds, is around $1,500 to $2,000). This information does suggest colonoscopy access is an actual or perceived barrier. This is an area that could be explored in more detail in the evaluation.
- *Indigenous status:* although Aboriginal and Torres Strait Islander participants accessed colonoscopy follow-up services at lower rates than other Australians, caution is required in drawing conclusions due to the low numbers provided

- *Culturally and linguistically diverse status:* non-culturally and linguistically diverse participants (71.9 per cent) had a statistically significant higher rate of colonoscopy follow-up than culturally and linguistically diverse participants (67.5 per cent)

Qualitative information on access

Qualitative research undertaken by the Ipsos-Eureka Social Research Institute ('Ipsos') [44] did not directly test participants' perceptions of accessibility of the NBCSP and its components, but participants' views can be inferred from a range of statements which indicate that, in general, NBCSP participants found the program to be accessible.

Participants consulted by Ipsos generally agreed that the NBCSP was 'an excellent initiative' that was 'well organised and currently operating smoothly'. Ipsos also reported that provision of free FOBTs sent to participants' home 'was particularly well received'.

Feedback from participants around the accessibility of the program components and resources also support this view. For example, Ipsos reported the following participant feedback:

- The *participant invitation letter* 'communicated all necessary information, and that the tone of the letter was appropriate'
- The *FOBT kit* was generally well received 'with most reporting that they were pleased or relieved, and keen to participate as soon as possible'. Other reactions reported included that it was 'user friendly' or 'simple and less 'hands on' than expected' and those with initial concerns found that 'the instructions were easy to read, helpful, straight forward, and assuaged many of their initial concerns. The inclusion of diagrams was particularly well received'.
- Some participants reported the kit as 'overwhelming and scary', 'overly complicated' or containing a 'daunting amount of information', with those experiencing difficulties tending to be from non-English speaking backgrounds or having lower literacy levels. To put this in context, 90 per cent of surveyed participants described completion of the FOBT as 'not at all difficult'[45]
- The *information booklet*, while not read by all participants, was 'very informative' for many. However, again those with lower literacy levels experienced difficult, perceiving the booklet as 'being quite intimidating in terms of the quantity and depth of information'
- The *Helpline* was accessed by few participants interviewed but was still 'appreciated' as an option for those experiencing difficulty with the instructions
- Access to *primary health care practitioner follow-up* was usually prompt and 'participants generally reported that they were swift in following up a positive result with their GP, who most often referred them on for a colonoscopy'

---

[44] Ipsos-Eureka Social Research Institute (2011a) *National Bowel Cancer Screening Program: Perspectives and Experiences, (unpublished)*.

[45] Ipsos-Eureka Social Research Institute (2011b) *National Bowel Cancer Screening Program: Perspectives and Experiences. Report on the quantitative research phase*, (unpublished).

- Access to *colonoscopy services* was ‘generally perceived to be appropriate, or even better than anticipated’. It is notable that the overwhelming proportion of colonoscopies are performed by private providers.

Barriers to participation cited by participants interviewed by Ipsos included participation in alternative screening methods (e.g. FOBT or colonoscopy outside of the NBCSP), fear of a positive result, discomfort in collecting stool samples, doubts about the accuracy of the test, a preference for alternative testing methods (e.g. blood test), the perceived complexity of the kit, and doubts about their ability to correctly complete the test.

With regard to Aboriginal and Torres Strait Islander participants, Ipsos reported that some aspects of the NBCSP were well received, particularly the fact that the test is free, but there was a need for more specific targeting of Indigenous people; suggestions included having a dedicated screening team visit remote communities and a preference for a more visual representation of instructions and simpler language.

3.2.3 Appropriateness, timeliness and quality of assessment colonoscopy

Appropriateness: It was difficult for the review to gather relevant information regarding appropriateness of colonoscopy; this is an aspect which may need to be more clearly defined in the program objectives. The NHMRC guidelines recommend that colonoscopy is the appropriate form of assessment after a positive FOBT result, and the data indicates that most people with a positive FOBT (whose follow-up actions are recorded) undergo a colonoscopy. Several stakeholders did raise concerns about the apparent widespread use of colonoscopy as an inappropriate form of screening, but this related to colonoscopies outside of the NBCSP.

Timeliness: During Phase Two, there were no time related targets or performance indicators for the provision of follow-up colonoscopy services. In the absence of any agreed program benchmark, it is instructive for the review to consider stakeholder perceptions in relation to the acceptability of the time taken to access colonoscopy services.

The AIHW reported that, of those participants with a positive FOBT, 71.4 per cent has a follow-up colonoscopy. Of those who received this service, an estimated 69.4 per cent had a colonoscopy within 26 weeks of notification of their positive result, and an estimated 74.0 per cent had a colonoscopy within 52 weeks of notification of their positive result.[46] Residents of the Northern Territory (48.4 per cent), New South Wales (62.2 per cent) and Western Australia (63.8 per cent) were least likely to have received a colonoscopy by 26 weeks.[47]

Ipsos reported that participant complaints relating to public colonoscopy waiting times were ‘quite common’ and were experienced by those without private health insurance, those living in

---

[46] This may be an underestimate given the lag time between booking and undergoing a colonoscopy, the delay experienced in returning Colonoscopy Report forms, and the failure of some colonoscopists to return Colonoscopy Report forms.

[47] As indicated above, these data relate to the time taken from *notification* of a positive FOBT result, to when the colonoscopy *procedure is reported as having occurred*. It is not immediately clear from the data how long it takes from the date of primary health care practitioner referral to the date of the procedure, or the time between when a procedure is booked and when it is performed.

rural and remote areas or those living in the Northern Territory. When asked about satisfaction with waiting times, 51 per cent of participants were very satisfied, 27 per cent were somewhat satisfied and 15 per cent were either somewhat or very dissatisfied.

Ipsos also reported 'some concern among GPs about the speed at which patients with a positive result receive colonoscopy', with many noting 'a significant waiting list, causing a great deal of anxiety among their patients'. GP concerns that 'patients with positive FOBTs are forced to wait a substantial length of time before receiving a colonoscopy' were also reported.

Access to colonoscopy services, and the timeliness with which they are provided, varied by State and Territory, with the Northern Territory experiencing significant issues while New South Wales and Western Australian residents were also less likely to have received a colonoscopy by 26 weeks than other jurisdictions.

NBCSP quality: As noted above, the program does not currently have a quality management plan or quality assurance framework at a national level (Queensland has a program-specific quality management plan). The program monitoring does collect and report some adverse event data, but this information is not reliable. The review suggests that thorough collection and reporting of global (rather than program-specific) quality and adverse event data (including caecal intubation rates, polypectomy rates, and perforation rates) would be more useful than the current, self-reported, voluntary adverse event data specific to program participants.

The issue of colonoscopy quality – and the extent to which the NBCSP can or should influence this – was the single most polarising issue discussed with stakeholders. Most readily agreed that colonoscopy quality is an area that needs more attention in Australia, and many felt that nationally-consistent, standards-based accreditation and credentialing, supported by more extensive data collection and monitoring linked to accreditation, and preferably based on benchmark systems such as those used in the UK or in Queensland, would be the most effective methods for achieving that. Where stakeholders disagreed was in terms of whether leadership for that work should rest with the NBCSCP, or whether it was seen as a responsibility for jurisdictions and medical colleges.

3.2.4 Maximise benefits and minimise harm

In terms of benefits, the Ipsos data showed that 98 per cent of participants reported positive views of the program (90 per cent very positive and 8 per cent somewhat positive) and 94 per cent expecting to participate in the program in the future (88 per cent very likely and 6 per cent said somewhat likely). Reasons for the positive views included:

- Detection of cancer that would otherwise have not been detected, with several stating that the program had 'saved their life'
- Free FOBT kit sent directly and discreetly to participants, requiring minimal effort to complete
- Directly and indirectly contributed to raising bowel cancer awareness, including through participants becoming advocates for the program and for bowel cancer screening more generally.

Many participants also commented on the approach undertaken by the NBCSP and components, with most commenting that the delivery and level of information provided was appropriate.

Similar responses were recorded for health professionals, who generally reported positive impressions of the program, with 83 per cent of GPs and 62 per cent of colonoscopists surveyed having recommended participation in the NBCSP to patients. Those interviewed were 'quick to acknowledge that the program probably led to an earlier diagnosis, and therefore better prognosis, in a number of participants'. Health professionals also reported that the program had raised community awareness about bowel cancer. Indirect benefits of the program were also identified, with positive FOBT results seen to 'sometimes motivate those who rarely visit their GP to do so' and workload of GPs reduced as there was less need to refer patients for a FOBT.

Stakeholders interviewed for the review supported these findings, with some also indicating that clinicians' awareness and understanding of bowel cancer screening was increasing due to their involvement with early detection of cancers with NBCSP participants.

In terms of harms, AIHW data reported that less than 1 per cent of recorded colonoscopies undergone by NBCSP participants resulted in an adverse event, but the data quality is considered to be poor.

Very little was reported in the Ipsos data in relation to perceived harms. While a small minority of participants reported concerns with how the program was implemented (e.g. overly complex information, distasteful nature of the tests), these aspects were not expressed as harmful outcomes of the program. Some concerns were also expressed regarding the 'seemingly 'arbitrary' targeting of certain ages' and the fact that it is not offered to all at risk. Some anxiety as a result of receiving a positive FOBT result was reported, with Ipsos stating that despite clear communication about results, 'a positive result was still a considerable shock for most'.

Health professionals appeared to have been less positive about the program, with many reporting 'that they do not see the NBCSP as a 'screening' program at all, as it fails to comply with NHMRC standards'. The major issue here was the frequency of the screening given it is not in line with NHMRC guidelines. This issue has now been addressed with the changes announced in the 2012-13 Budget, but it will be important to communicate these changes – and the progressive phasing-in timelines – to health professionals.

Many GPs also reported, with significant waiting lists for colonoscopy, 'a great deal of anxiety among their patients' was observed. The raises the issue of potential psychosocial harm to participants, which was also raised by a number of stakeholders during the review.

3.2.5 Achieve high standards of program management

In terms of managing the *service delivery components* of the program, the review concluded that the distribution of kits, operation of the information line, analysis and reporting of results, and the mail house functions are all working effectively. The Register also appears, overall, to be functioning effectively – although the review notes the reliance on manual data handling and processing and manual processes for matching incomplete data samples with invitations could be more efficient; over time, this may be significantly addressed through the proposed Data Hub.

In terms of *monitoring and evaluation and accountability,* the review concludes that, notwithstanding the scope to improve data collection identified elsewhere in this report, the program monitoring mechanisms are of a high standard through the regular AIHW reports. Although monitoring at the regional level (that is, 'drilled down' from the jurisdiction level) has not been optimal – several jurisdictions reported that they had found the process of accessing region-level data time-consuming and cumbersome – the review notes that jurisdictions now receive regular data extracts from the Register via the Department. The development of a state/territory portal should address these issues.

3.2.6 Cost effective and reduces morbidity and mortality

Cost effectiveness: This review did not specifically consider cost-effectiveness of the NBCSP, on the basis that the program was subjected to detailed cost effectiveness analyses during the pilot and Phase One, and both of these found that the program was cost effective. It is notable that the Phase One analysis also found that the program would be most cost effective if implemented with biennial screening for all people aged 50-74, especially with an optimal participation rate of 60 per cent in the first round of screening[48]; recent modelling research has suggested that a full biennial screening program for all people aged 50-74 would have gross costs of $150 million per annum and reduce bowel cancer mortality by 15 to 25 per cent[49]. These analyses do suggest that, on balance, a full biennial screening program across the full target population may be more cost effective than the current approach of five to ten year screening intervals across three age cohorts within the target population; however, as noted earlier in this report, the rationale for that approach is the phasing in of the program over time (as has occurred in the UK and Ireland) and to monitor impact on assessment and diagnosis services.

The most recent study in relation to NBCSP cost effectiveness, published in 2011, found that, as currently structured and delivered, the program implementation and delivery cost per Life Year Saved (LYS) through earlier detection of bowel cancer, modelled from actual participation data, was $38,216 per LYS, which is below the Australian benchmark of $50,000 for health intervention cost effectiveness [50]

It appears that, overall, the program continues to be implemented in a way that is cost effective, taking into account the policy decision to phase in the program over a number of years (i.e. the program meets this objective).

Detailed consideration of overall program cost effectiveness should be included in the future program evaluation.

Reduction of morbidity and mortality: Impact of screening programs on cancer morbidity and mortality are long-term outcomes. In the initial years, screening would be expected to generate an increase in incidence (number of newly diagnosed cancers) and morbidity (total number of people in a population with a diagnosed cancer) would be expected to increase. Over a longer period, screening should result in an overall reduction in mortality (deaths by the targeted cancer).The NBCSP has not yet been operating long enough to see significant increases in incidence or decreases in mortality. The World Health Organization suggests that target

---

[48] Access Economics (2007) *National Bowel Cancer Screening Program economic evaluation*, for the Department of Health and Ageing (unpublished)

[49] Pignone, MP et al (2011) 'Costs and cost-effectiveness of full implementation of a biennial faecal occult blood test screening program for bowel cancer in Australia', *Medical Journal of Australia*, 194(4), 180:185.

[50] Tran, B et al (2011) 'A preliminary analysis of the cost-effectiveness of the National Bowel Cancer Screening Program: Demonstrating the potential value of comprehensive real world data'*, Internal Medicine Journal*, September 2011.

outcomes timeframes for cancer screening would be a 30 per cent reduction in incidence of targeted advanced cancers within 10 years and a 15 per cent reduction in mortality within 20 years.[51]

The AIHW monitoring framework for the program includes reporting of incidence and mortality of bowel cancer. In 2008 (the most recent available data), bowel cancer accounted for 12.7 per cent of all invasive cancers, making it the second most commonly diagnosed cancer in Australia. The number of new cases for males more than doubled between 1982 and 2008 (122 per cent increase), with a smaller increase for women (85 per cent). Population ageing is a factor in the increased incidence, since bowel cancer mostly affects older people.

In 2007, bowel cancer accounted for 10.1 per cent of all deaths from invasive cancers in Australia, second only to lung cancer. Bowel cancer was responsible for 50,818 potential years of life lost by the age of 85.

The AIHW has suggested that it would be helpful to link NBCSP participant data (including outcomes after cancer diagnosis, which is not currently recorded) to the national cancer database. The review notes advice from the Department that this work is planned to occur in the near future. The review supports this work, as it will improve the ability to track and measure the NBCSP impact on incidence and mortality, and aid greater comparison to the general population, over time.

---

[51] World Health Organization (2002) *National cancer control programs: Policies and managerial guidelines,* 2nd edition, WHO: Geneva.

3.3 Key points: Performance against program objectives

Main findings

- ***Maximise early detection:*** The program is successful in aiding early detection of bowel cancer. The extent to which this is 'maximised' is difficult to judge at the program's current stage of maturity.
- ***Equitable access:*** The program is universally available within the eligible age cohorts but participation in screening and recorded follow-up of positive results is lower for traditionally 'hard-to-reach' groups (Aboriginal and Torres Strait Islander background, culturally and linguistically diverse background, low socioeconomic background). Pilot projects have shown variable but promising results for alternative pathways into the program for Aboriginal and Torres Strait Islander peoples, which could be explored further.
- Program participation data suggest that accessibility issues may also be experienced by men, people aged 50 years, people living in rural and remote areas, people living in the Northern Territory, New South Wales and Queensland, and people living in the areas with the lowest socioeconomic status. Correlation against qualitative feedback obtained through the Ipsos interviews indicate that, whilst the majority of program participants find the NBCSP accessible, those who have low literacy levels or are Indigenous or of a culturally and linguistically diverse background experience accessibility issues.
- There also may be accessibility issue in relation to colonoscopy services, with access inequitably favouring those with private health insurance or the ability to pay for privately delivered care.
- ***Assessment colonoscopy timeliness:*** 69.4 per cent of participants recorded as undergoing a colonoscopy received that service within 26 weeks of notification of their positive result, although there is no program benchmark or performance indicator against which to assess that period as a measure of timeliness (given that bowel cancer usually develops slowly, this may well be an appropriate timeframe, but it is difficult to assess in the absence of a benchmark); it is also not clear how long the waiting time is between primary health care practitioner referral and actual conduct of the colonoscopy (as opposed to time between notification of the positive FOBT and reported conduct of the colonoscopy).
- ***Assessment colonoscopy quality:*** The data are unclear on the extent to which *quality* assessment colonoscopy is delivered.
- ***Maximise benefits and minimise harm:*** Early detection of cancers for participants is evidence that the program is maximising benefits, but there may be a potential harm of participants being re-assured by a negative FOBT if they do not also understand the need to undergo re-screening after two years. More evidence of participant behaviour in this regard is needed (that is, whether participants take the initiative to re-screen after two years if they are not prompted to do so).
- There is little evidence in relation to adverse events for NBCSP participants in order to make an assessment in relation to actual harms posed by colonoscopy.

3.4 Applying the findings: Performance against program objectives

Opportunities for improvement

Within current program parameters:

- Develop a strategy for full implementation of the program in line with the 2012-13 Budget announcement.
- Develop KPIs and targets for participation and outcomes to enhance program monitoring and continuous improvement. The review notes that this work is already planned.
- Address the gap in the data relating to outcomes for participants after cancer diagnosis/resection. The review notes that this work is already planned.
- The alternative pathways work for remote Aboriginal and Torres Strait Islander participants should be reviewed with consideration given to a wider rollout of alternative program entry points for this group and other 'hard to reach' groups.

Beyond current program parameters:

- Link program performance and outcomes data to the national cancer database to assist in measuring program impact on morbidity and mortality over time.
- Consider regular collection of information on consumer experiences and perceptions, including information from people that choose not to participate.
- In terms of accessibility, possible areas of future focus for targeted recruitment may include men, those of Aboriginal or Torres Strait Islander background, those from culturally and linguistically diverse backgrounds and those from lower socioeconomic areas.

Considerations for the program evaluation

- Effectiveness of the program data collection and monitoring framework, including comparisons to other cancer screening programs
- Accessibility to screening and follow-up services (primary health care practitioner assessment and colonoscopy) for 'hard to reach' groups, including the impact and effectiveness of alternative pathways for these groups.
- Reasons for higher participation rates in inner regional and outer regional areas than in major cities.
- Comparison to international benchmarks for timeliness and quality of colonoscopy.
- Cost effectiveness.

4. Opportunities to improve the program

This chapter discusses opportunities to improve the operation of the NBCSP, either within or beyond the current program parameters. It draws primarily on the stakeholder interviews and has been supplemented by a literature scan of best practice and good practice approaches to management and delivery of screening programs. It considers in more detail some of the issues that have been touched on in the previous two chapters, specifically alignment of the program with the policy framework, alignment with 'best practice' for screening program management, and opportunities to improve governance and management, service delivery and data collection and monitoring. The chapter concludes with a summary of key points and issues to consider in developing the evaluation framework.

4.1 Alignment with policy framework

The NBCSP in its current configuration does not fully align with the overarching policy outlined in the national population based screening framework. Table 3 below provides an assessment of the program against the nationally agreed, AHMAC-endorsed criteria for a population based screening program.

Table 3: Assessment of NBCSP against agreed national screening program criteria

Screening program criteria[52] *The screening program must:*	**NBCSP alignment with criteria (at time of review)**
Response to a recognised need	Aligns
Have a clear definition of the objectives of the program and the expected health benefits	Aligns
Have scientific evidence of screening program effectiveness	Aligns
Identify the target population which stands to benefit from screening	Partially aligns
Clearly define the screening pathway and interval	Partially aligns
Ensure availability of the organisation, infrastructure, facilities and workforce needed to deliver the screening program	Aligns (at current participation levels)

---

[52] AHMAC Australian Population Health Development Principal Committee, Screening Subcommittee (2008) *Population based screening framew*ork, Commonwealth of Australia: Canberra.

Screening program criteria[52] *The screening program must:*	**NBCSP alignment with criteria (at time of review)**
Have measures available that have been demonstrated to be cost effective to encourage high coverage	Aligns
Have adequate facilities available for having tests and interpreting them	Aligns
Have an organised quality control program across the screening pathway to minimise potential risks of screening	Does not align
Have a referral system for management of any abnormalities found and for providing information about normal screening tests	Aligns
Have adequate facilities for follow-up assessment, diagnosis, management and treatment	Unclear
Have evidence based guidelines and policies for assessment, diagnosis, and support for people with a positive test result	Aligns
Have adequate resources available to set up and maintain a database of health information collected for the program	Aligns
Integrate education, testing, clinical services and program management	Unclear
Have a database capable of providing a population register for people screened that can issue invitations for initial screening, recall individuals for repeat screening, follow those with identified abnormalities, correlate with morbidity and mortality results and monitor and evaluate the program and its impact	Aligns
Plan evaluation from the outset to ensure that program data are maintained so that evaluation and monitoring of the program can be performed regularly	Aligns
Be cost effective	Aligns
Ensure informed choice, confidentiality and respect for autonomy	Aligns
Promote equity and access to screening for the entire target population	Partially aligns
Ensure the overall benefits of screening outweigh the harm	Aligns

Source: KPMG analysis

Aspects where the review suggests that the NBCSP either does not currently align or only partially aligns with the policy framework area:

- *Identification of the target population* – the program does clearly identify and recruit its eligible population – which currently consists of three age cohorts within a wider population for whom biennial screening is recommended under the NHMRC guidelines – and so technically the program has clearly identified the target population that stands to benefit. The difficulty here is around the lack of clarity in terms of the messages communicated to the target population: biennial testing is recommended to the population, but it is not currently available through the program. The review notes that the 2012-13 Budget announcement will progressively phase-in a biennial screening program over time, but there is still an issue about how to communicate a biennial screening recommendation to the target population in the meantime.
- *Clearly define the screening interval* – again, the issue here is around screening interval, and how to communicate the recommended biennial screening interval to current program participants given that it will take a number of years for the full biennial screening program to be rolled out. Current program letters to participants with negative results advise that biennial screening is recommended in the clinical guidelines, but do not explicitly state that biennial screening is not currently offered under the program and that participants will need to make their own arrangements for screening until they next become eligible for a free test under the program.
- *Availability of infrastructure and workforce to deliver the program* – at current rates of participation, this criterion is met, but it is not clear whether there are sufficient processes in place to measure colonoscopy capacity and distribution to ensure the program remains sustainable as participation increases. There are already indicators or apparent accessibility issues to timely colonoscopy based on rurality or cost for some participants.
- *Organised quality control program across the screening pathway* – there is no program-wide quality control program covering assessment and diagnosis.
- *Adequate facilities for follow-up assessment and diagnosis* – it is unclear whether the waiting times for colonoscopy in some areas aligns to this criterion; the review understands that there is no evidence that waiting times for colonoscopy are associated with poorer clinical outcomes or later-stage cancer detection[53]. However, there may be psychosocial impacts for participants experiencing long waiting times for assessment colonoscopy following a positive FOBT.
- The main rationale for the phased approach to implementation of the program (that is, the restricted age cohorts and the five to 10 year interval) is to monitor the impact of the program on assessment and diagnosis capacity, especially colonoscopy services. However, it is not clear whether there are sufficient processes in place to accurately measure colonoscopy capacity and access for program participants – as discussed in previous

---

[53] Viaalia, CH et al (2007) 'Waiting times for colonoscopy and colorectal cancer diagnosis', *Medical Journal of Australia*, 186 (6), 282:285.

chapters, the majority of participants requiring a colonoscopy received one within 26 weeks, but the clinical appropriateness of this time period is unclear; there is also evidence of (actual or perceived) accessibility issues based on location and cost for some program participants. The issue of monitoring colonoscopy access, as well as colonoscopy workforce capacity and distribution, in order to make decisions about future expansions of eligible age cohorts and/or screening intervals should be considered.

- *Promote equity and access for the entire eligible population* – the program is universally accessible, but participation statistics and consumer feedback research suggests that specific measures may be needed to promote access for hard-to-reach groups.

Table 4 below provides an assessment of the program against the nationally agreed, AHMAC-endorsed principles for implementation and management of a screening program.

Table 4: Assessment of NBCSP against agreed national implementation & management principles

Principles for implementation and management[54]	**NBCSP alignment with principles**
There must be agreement by the Commonwealth, state and territory governments that a population based screening program should be implemented	Aligns
There should be stakeholder agreement and acceptance of the decision to introduce the program	Aligns
A national policy framework should be agreed which defines the goals and objectives of the program	Aligns
An agreed quality management plan should be in place to ensure ongoing management of quality and a continuous quality improvement framework	Does not align
Sufficient funding should be agreed and allocated to ensure the screening program is able to achieve its targets and objectives	Not assessed

Source: KPMG analysis

The national screening framework requires a quality management plan including: evidence-based systems and process for quality management and monitoring, including standards, a data dictionary, quality assurance processes applicable to all program elements, accreditation processes as required, a risk management plan, ensure physical and psychosocial safety for participants, ensure ongoing workforce professional development and training, ensure realistic funding and ensure equity and consistency of service regardless of geographical location. The NBCSP does not currently have an approved quality management plan and there are few processes in place to consistently manage these matters at a national level within the program,

---

[54] AHMAC Australian Population Health Development Principal Committee, Screening Subcommittee (2008) *Population based screening framework*, Commonwealth of Australia: Canberra.

although the review notes advice from the Department that the AIHW has recently been tasked with developing KPIs and a data dictionary for the program.

Development of a quality management plan should therefore be a priority for the program to ensure its alignment with the national policy framework. The form in which such a plan could take, however, seems relatively open, so long as it addresses the required aspects. For example, given that assessment and diagnosis is provided under usual care in the NBCSP, it may be appropriate for each state and territory to have their own quality management plan, so long as they are relatively consistent in form and content.

4.2 Alignment with best practice

The NBCSP program design and service delivery approach is largely consistent with common international practice for bowel cancer screening, including: recruitment methods; screening modality (FOBT); use of colonoscopy for follow-up assessment/investigation; and monitoring and evaluation frameworks[55]. The key area where the NBCSP did not mirror common international practice at the time of the review was the screening interval (which is generally biennial or in some cases annual in other programs); however, the 2012-13 Budget announcement provides for the progressive phasing-in of biennial screening. Some examples of other programs are provided in the table below.

Table 5: Comparison of screening intervals and age eligibility in bowel cancer screening programs

Country	Age group	Screening interval	Screening method
Canada (Ontario)	50-79	Once	gFOBT[56]
Czech Republic	50+	Biennial	gFOBT
Denmark	45-75	Biennial	gFOBT
France (national pilot)	50-74	Biennial	gFOBT
Israel	50-74	Annual	gFOBT
Italy	50-69	Biennial	iFOBT[57]
Japan	40+	Annual	iFOBT
Taiwan	50-79	Annual	iFOBT
United Kingdom	50-69	Biennial	gFOBT

Source: Benson (2007)[58]

---

[55] Benson VS et al (2007) ‘Colorectal cancer screening: A comparison of 35 initiatives in 17 countries’, *International Journal of Cancer*, 122, 1357-1367.

[56] Refers to the *guaiac Faecal-Occult Blood Test*, which is considered to be less sensitive and more cumbersome for participants than the alternative iFOBT test used under the NBCSP, as it requires dietary restrictions prior to collection of samples and it also needs more comparison samples for testing. In Australia, the Roatray BowelScan program uses gFOBT kits.

[57] Refers to the immunochemical Faecal Occult Blood Test (iFOBT), which is used in the NBCSP. It is also used by Bowel Screen Australia.

This review attempted to identify evidence in relation to the benefits of a usual care model of assessment and treatment for bowel cancer as opposed to the dedicated resources model preferred by many stakeholders. The Queensland and English models incorporate specific quality assurance (including accreditation) measures. However, whilst both of those specific models have been evaluated[59] [60], this review was unable to identify any *comparative evidence* in relation to the benefits of a dedicated resources versus a usual care service model for bowel cancer screening, or indeed any other form of cancer screening).

Whilst participation rates in the English program are notably higher than the Australian program (participation in the third pilot round was about 57 per cent; that program has only published data from its three pilot periods, covering 2006 to 2010, and has yet to publish any regular program data since becoming a regular NHS program in 2010)[61], Queensland participation rates are generally on par with other Australian jurisdictions, and lower than Western Australia, South Australia, Tasmania and the ACT; Queensland rates of reported primary health care practitioner follow-up and colonoscopy follow-up for people returning a positive FOBT were both higher than the Australian average rate, but not higher than all other jurisdictions. Therefore, there are no obvious inferences to be drawn about the effectiveness of a dedicated resources model as opposed to a usual care model in the current Australian context at this time – this may be an area for further consideration and analysis in the future evaluation.

During the stakeholder interviews for this review, the NBCSP was frequently compared to the English/Welsh NHS Bowel Cancer Screening Program, with that program cited as a 'gold standard' model for the Australian NBCSP (although several stakeholders acknowledged that a number of the English/Welsh program components relating to quality assurance, notably staff credentialing and facility accreditation, were not directly transferable to the Federated government context of Australia).

The Queensland approach to assessment and diagnosis is comparable to the UK model, including the use of authorised providers and the employment of gastrointestinal nurse coordinators to assist and guide patients through the public system. That model exists because Queensland chose to dedicate additional resources to the program, but other jurisdictions have chosen not to follow this approach (although, as previously noted, Victoria does have a designated provider system for NBCSP colonoscopy referrals).

---

[58] Benson VS et al (2007) 'Colorectal cancer screening: A comparison of 35 initiatives in 17 countries', *International Journal of Cancer*, 122, 1357-1367.

[59] Queensland Health (2009) *Queensland Bowel Cancer Screening Program: Phase 1 Evaluation, 7 August 2006 – 30 June 2008*, Queensland Government: Brisbane.

[60] Weller, D et al (2009) *Evaluation of the third round of the English bowel cancer pilot: Report to the NHS Cancer Screening Programmes,* December 2009, University of Edinburgh.

[61] It should also be noted that recruitment methods for the NHS programs significantly differ from the Australian program, in that the UK approach involves the participants' registered general practitioner in the recruitment.

4.3 Management and governance

> Governance is about ensuring the success of an activity…There should be clarity of roles within the governance arrangements to ensure that efforts are directed towards success and that responsibilities are performed in an efficient manner (Uhrig, 2003: 24-25).

The Department of Health and Ageing, which funds the NBCSP, is an FMA Act agency: its Secretary is accountable to the Minister and the Parliament for the expenditure of public funds within the programs it administers on behalf of the Australian Government. Governing boards or executive committees with some form of decision-making power or binding authority (the type of NBCSP governance model advocated by some stakeholders) is neither possible nor appropriate for this program.[62]

However, advisory boards or committees can form an important, non-executive part of effective program management by providing a forum for representation of stakeholder views, without those stakeholders being involved in the program governance. Advisory boards or committees can provide access to skills and expertise, including stakeholder or community representation, but program management responsibility rests with the Department. Their main role should be to contribute expert perspectives to improve the implementation of government policies[63].

The current NBCSP committee structures are intended to operate in exactly this manner – provision of expertise and advice to the Department – but it is apparent from the stakeholder interviews undertaken for this review that some stakeholders either do not understand or are dissatisfied with this role, with many wanting a more influential role for the PAG or the Program Managers' Group in directing the program. This suggests a lack of clarity about roles and responsibilities within the current NBCSP governance and advisory structures. Ensuring clarity of individual roles, responsibilities and relationships is critical to effective governance[64]. Established best practice protocols for ensuring clarity of roles and effectiveness of committees include:

- Ensuring committees are strategically focussed with clear terms of reference, including clear responsibilities and accountability
- Selecting appropriate committee members – are members invited to be representative, or related to required expertise?
- Provision of necessary resources and support, including secretariat and record-keeping
- Regular review of committee performance, appropriateness and 'fit-for-purpose'
- Clearly determine and articulate whether a committee is time-limited or ongoing[65].

---

[62] Department of Finance and Administration (2005) 'Chapter 4: Factors influencing governance arrangements', in *Governance arrangements for Australian Government bodies: Financial management reference material no.2*, Commonwealth of Australia: Canberra.

[63] Uhrig, J (2003) 'Chapter 2: Governance', in *Review of the corporate governance of statutory authorities and office holders*, Commonwealth of Australia: Canberra.

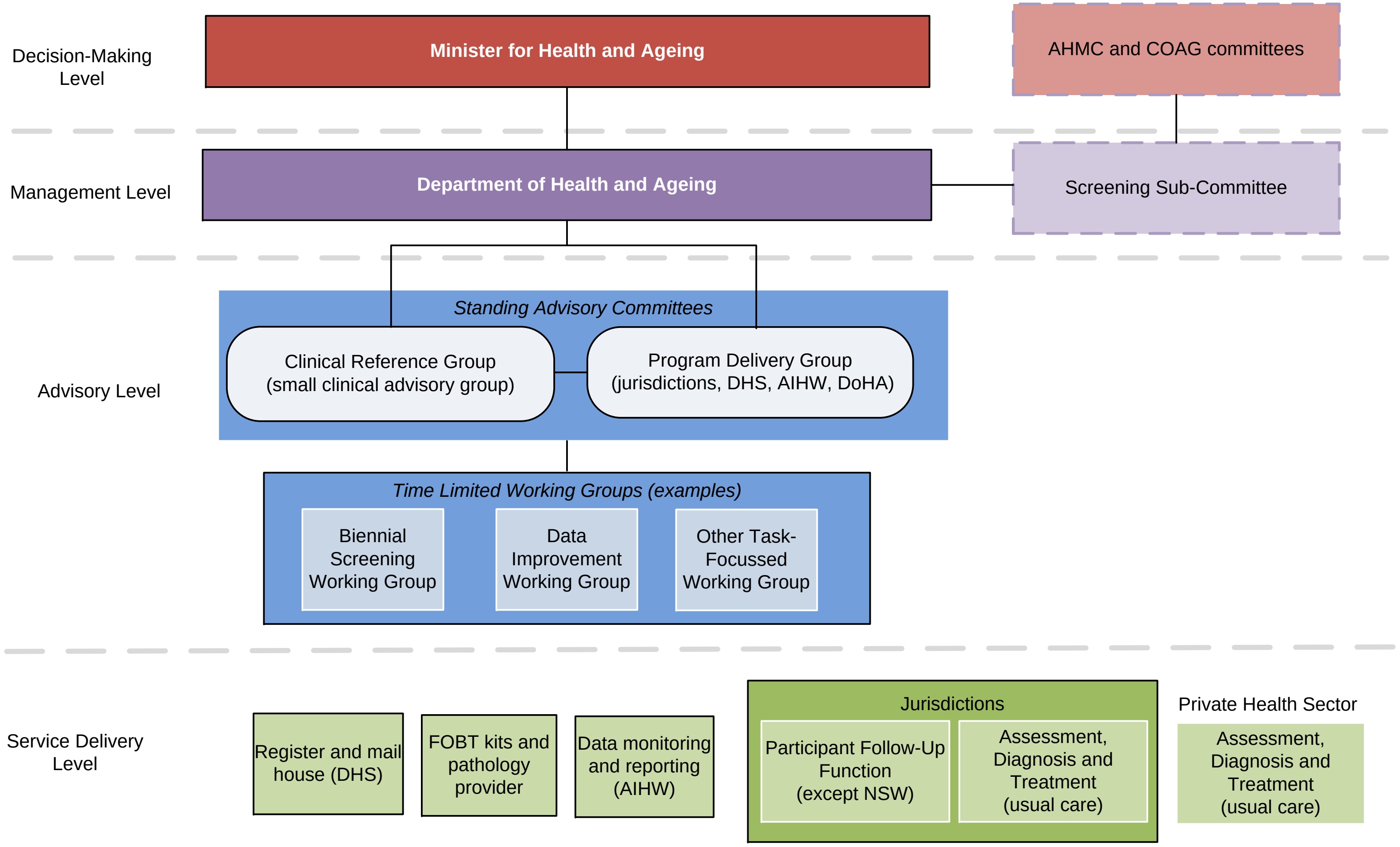
[64] Ibid

[65] Australian Public Service Commission (2008) *Building better governance*, Commonwealth of Australia: Canberra.

The review suggests that it would be appropriate to refine the NBCSP governance and management structure, to ensure it is in line with best practice and that it meets the needs of the program into the future, noting that it is now an established, ongoing program.

Figure 6 below depicts a suggested refined structure that might better serve the management and governance needs of the program.

Figure 6: Proposed refined governance model for NBCSP



Source: KPMG

The diagrammatic depiction of decision-making, management, advisory and service delivery levels of the program makes the roles and responsibilities of each committee clear. It shows the Minister for Health and Ageing as the ultimate level of decision-making authority, with the Department responsible for program management.

Under this proposal, the current Program Advisory Group and a Program Delivery Group would be replaced by two standing advisory committees: a Clinical Reference Group and a Program Delivery Group. Terms of reference would be clearly separated between clinical advice and oversight, and service delivery/operations.

The Clinical Reference Group would:

- Be comprised of small, core group of clinicians, based on their expertise in screening and assessment, as well as a consumer representative and a state/territory representative.
- Be chaired by the Department
- Have revised Terms of Reference focussed on the provision of clinical advice, clinical quality assurance, provision of clinical expertise and clinical input to program policy
- Meet in person at least once a year, with teleconference meetings and email interaction as needed

The Service Delivery Committee would:

- Be comprised of all jurisdictions, the AIHW, DHS, a consumer representative and a clinician representative (about 12 members) – it could also include a private colonoscopy provider representative and/or private hospital or day surgery representation
- Be chaired by the Department
- Have revised Terms of Reference focussed on program implementation and review, monitoring, information sharing, data development, and overarching program quality assurance
- Meet one-two times a year (including videoconference, teleconference), and email interaction as needed

Sitting beneath these two advisory committees would be time-limited working groups, reporting to the Department through either or both committees, working on various aspects of the program. Ideally their membership would be drawn from the advisory committees and more widely, to ensure the appropriate levels of expertise needed.

This structure is not radically different from the current structure, but it does aim to remove duplicated representation, refine the terms of reference and allow for the provision of additional advisory expertise. It also allows a clarification of committee roles and the decision-making lines for the program.

4.4 Service delivery

The review identified no tangible options to improve service delivery within current program parameters, with the exception of improving data capture along the pathway and, possibly, looking at opportunities to expand the PFUF role.

4.5 Data collection and monitoring

There are many challenges with the current, manual data collection processes: they rely on GPs, colonoscopists and histopathologists first being aware of the program reporting requirements, secondly being able to identify a patient as a program participant, and thirdly making the effort to send voluntary, program-specific forms to the Register.

Stakeholders generally did not feel that the information payment provided a sufficient incentive for reporting – not because of the amount ($6.60 per report), but because incentives generally were not seen to be effective. Many stakeholders suggested that clinicians would value some form of data report or benchmarking report being given to them rather than a cash incentive to report. As outlined in the previous chapter, work has commenced on electronic data collection processes, and this work is supported by stakeholders. The review suggests that this move to electronic reporting is the most likely method for improving data capture, along with effective communication to practitioners about how, when and why to report to the register.

A number of stakeholders pointed to the mandatory reporting requirements of other cancer screening programs as an example for the NBCSP, but others pointed out that this would not address the problem of practitioners being able to identify a program participant in the first place (currently dependent on GPs and colonoscopists noting the patient’s NBCSP participation status in the referral). There is also the challenge for GPs of the relatively low volume of participants they see each year, making it difficult to remember the required processes. The review suggests that mandatory reporting would not, on its own, be an effective means of improving data capture at this time, unless steps were also taken to address these other issues.

Some stakeholders considered that there were too many data collection points along the pathway and suggested that, with a move to electronic reporting, there was also potential to collapse some of those data collection points: colonoscopy and histopathology, for example, could be reported back to the Register through the primary health care practitioner and/or colonoscopist, preferably electronically, once they received the results. Easier still would be for all participants to be electronically flagged so that colonoscopists and histopathologists could simply copy their reports to the Register which could match them to the participant; this approach may be possible in the future with a unique patient identifier.

As noted in the previous chapter, there are some gaps in the current data collection, including lack of information on outcomes for program participants after they have a diagnosed bowel cancer. Another area where there is a lack of data relates to the level of FOBT testing occurring in the community, amongst the target population, through non government programs (which distribute FOBT testing kits through pharmacies and other channels). This information would be helpful in analysing program participation rates, and also in developing and targeting communication messages. The review suggests that steps be taken to explore whether it is possible to access some of this data.

4.6 Key points: Improving the program

Main findings

- ***Alignment with policy framework:*** The program does not currently meet the requirement of the national screening policy to have a quality management plan in place.

- ***Alignment with best practice:*** The program is comparable to identifiable common practice and good practice approaches for organised bowel cancer screening.

- ***Management and governance:*** Current governance structures could be improved. There is a lack of clarity amongst stakeholders about the role and purpose of the committees. There is some duplication of work across the committees. The committees are also quite large.

- ***Service delivery:*** There are no tangible opportunities to improve service delivery within current program parameters.

- ***Data collection and monitoring:*** Improving data capture along the screening pathway should be a priority. Move to electronic reporting should assist in this goal.

- Key gaps in the current data collection include (a) data around the levels of non- NBCSP related FOBT testing undertaken by the target population (i.e through Rotary or Bowel Screen Australia), and (b) outcomes for program participants diagnosed with bowel cancer. Information on the level of off-program screening.

- The process for ***measuring program impact on services*** including colonoscopy capacity, distribution and accessibility is unclear.

4.7 Applying the findings: Improving the program

Opportunities for improvement:

Within current program parameters:

- Revise the current governance and advisory structures.

- Develop a strategy for full implementation of the program, against which committee terms of reference and work plans or agendas can be developed and reviewed

- Develop a quality management plan.

- Develop KPIs and targets for participation and outcomes.

- Address the gap in the data relating to outcomes for participants after cancer diagnosis.

- Work with non government screening programs to capture information about the level of non-NBCSP screening taking place in the community amongst the target population.

- Continue progressing moves to electronic data capture.

Considerations for the program evaluation

- Colonoscopy capacity, distribution and accessibility.
- Comparison of different service delivery approaches in the jurisdictions; specifically, comparison of the effectiveness and efficiency of a dedicated resources approach (i.e. Queensland), partly dedicated resources approach (Victoria) and usual care approach to assessment and diagnosis.

5. Opportunities to increase participation rates

This chapter discusses opportunities to increase participation rates, either within or beyond the current program parameters. It draws primarily on the literature scan and stakeholder interviews. The chapter concludes with a summary of key points and issues to consider in developing the evaluation framework.

5.1 Interpreting current participation rates

The overall participation rate during the pilot phase was 45.4 per cent. Participation was higher amongst women (47.4 per cent) than men (43.4 per cent) – the NBCSP was the first organised cancer screening program in Australia targeting men. Nine per cent of participants returned a positive FOBT result. During Phase One the overall participation rate was 38.7 per cent, and in Phase Two it was 38.4 per cent.[66]

By way of comparison, uptake in the first round of the English bowel cancer screening pilot was 61.8 per cent. It reduced to 57 per cent in the second round, and then increased to 58.7 per cent in the third and final pilot round – although as previously noted, the recruitment method in the English pilots differed from the Australian approach in that it involved participants' registered NHS general practitioners (and recommendation from a trusted health provider is a key predictor of participation). In the English pilots, people from culturally and linguistically diverse and low SES backgrounds were less likely to participate – and this was consistent across the three rounds[67]. Uptake was lower in men, but this difference decreased over time.[68] Of those diagnosed with cancer, the majority (70 per cent) were early stage cancers.[69]

There was considerable variation in the way stakeholders interpreted the participation rates. A number of stakeholders consider 38 per cent to be a positive participation rate, especially given that rates have increased from Phase One for the older (and at higher risk) cohorts, and also given lack of promotion for the program and generally low levels of bowel cancer awareness in the community. Others feel that participation rates are disappointing and should be closer to 50 or 60 per cent, based on the English experience and the Australian BreastScreen and cervical cancer screening rates. However, others maintained that NBCSP participation was excellent given its level of

---

[66] It should be noted that participants in the pilot phase were older (aged 55-75), which is likely to be one of the reasons for the significantly higher overall participation in the pilot compared to subsequent rounds; in the subsequent rounds, the older age cohorts have continued to have the highest participation rates.

[67] Von Wagner, C et al (2011) 'Inequalities in participation in an organized national colorectal cancer screening programme: Results from the first 2.6 million invitations in England', *International Journal of Epidemiology*, 40 (3), 712:718.

[68] Moss, SM et al (2011) 'Performance measures in three rounds of the English bowel cancer screening pilot', *Gut*, published online 10 May at www.gut.bmj.com/content/early/2011/05/10/gut.2010.236430.full.html#ref-list-1

[69] Logan, RL et al (2011) 'Outcomes of the Bowel Cancer Screening Program (BCSP) in England after the first 1 million tests', *Gut*, published online 7 December at www.gut.bmj.com/content/early/201111/22gutjnl-2011-300843.full.html#ref-lisr-1

maturity, and they noted that, by comparison, Australian breast and cervical cancer screening rates at the same level of maturity were lower than that achieved by the NBCSP.

The review has concluded that, although comparisons to other screening programs can provide a useful (if qualified) guide to interpreting participation rates, it is very difficult to interpret the 'success' of participation rates in the absence of agreed, published program target participation rates.

It is also noted again that the level of screening occurring in the community outside of the NBCSP, is not currently well-known. This information is highly relevant to understanding NBCSP participation rates.

5.2 Awareness by the target population

There is limited literature on general public perceptions and awareness of the NBCSP, but the available literature indicates that awareness is fairly low. A survey conducted in Victoria in 2008 found that 40 per cent of participants had heard of the program, although awareness was higher among those in the program, target group.[70]

Research commissioned by the NBCSP and conducted by Ipsos-Eureka during Phase Two found that the cancers for which there is the highest awareness are prostate cancer for men and breast cancer for women; although bowel cancer is the second most common form of cancer afflicting both men and women, there is higher awareness of this fact in relation to men (45per cent of participants, 48per cent of non-participants and 50per cent of non-invitees were aware) than in relation to women (25per cent of participants, 24per cent of non-participants and 21per cent of non-invitees were aware)[71]. Very few people stated that bowel cancer was symptomless, with 76 per cent of NBCSP participants and 72 per cent of non-participants identifying bleeding from the bowel as a symptom. Four in five participants (82per cent) and non-participants (79per cent) nominated bowel cancer as one of the screening programs they were aware of. There was lower awareness amongst non-invitees (66per cent), and male non-invitees were less likely to be aware of bowel cancer screening programs than female non-invitees (60per cent, compared with 72per cent). Seven in ten non-invitees (70per cent) had heard of the NBCSP and 71per cent of participants and non-participants recalled having heard of the NBCSP prior to being invited to participate.

The broader literature on bowel cancer screening demonstrates that in addition to lack of awareness of programs, there are also a number of common misconceptions about bowel cancer screening and FOBT which may limit participation rates or the perceived relevance, and social acceptability, of screening. Several studies have found that a considerable proportion of those in the target group believe that testing by FOBT is only necessary for those who display symptoms of bowel cancer.[72] [73] [74] [75] [76] [77] Further, a belief that testing only has to be conducted once appears to

---

[70] The Social Research Centre (2009) *A Survey of Bowel Cancer Knowledge, Perceptions and Screening Behavior in the Victorian Community*. The Cancer Council of Victoria: Melbourne.

[71] Ipsos-Eureka (2010) *National Bowel Cancer Screening Program: Pespectives and experiences: Report based on the quantitative research phase*, prepared for the Department of Health and Ageing (unpublished)

[72] Weitzman, E. R., J. Zapka, et al. (2001) 'Risk and Reluctance: Understanding Impediments to Colorectal Cancer Screening.' *Preventive Medicine,* 32, 502:513

[73] Department of Health and Ageing (2004) *Bowel Cancer Knowledge, Perceptions and Screening Behaviours: Knowledge, Attitudes & Practices Pre- and Post-Intervention Surveys*, Commonwealth of Australia: Canberra

be commonly held,[78] as is the perception that a negative test result indicates a low risk of bowel-cancer and negates the need for future testing or the importance of maintaining a healthy lifestyle.[79]

The literature also indicates that negative associations with screening for other types of cancer, such as breast or prostate screening, may lead to the misconception that the FOBT test will be painful, embarrassing or uncomfortable.[80] As Worthley and colleagues[81] demonstrate, there will always be people who decide not to participate without reading the instructions, which suggests a need for education campaigns which demystify bowel cancer screening and address the many misconceptions that surround it. This may improve the acceptability of the NBCSP and the chance that members of the target audience do not immediately reject the concept of screening when the FOBT kit arrives.

There are indications, however, that awareness is improving. A study conducted by Jalleh and colleagues[82] in 2010 suggests that the NBCSP has increased knowledge and awareness of bowel cancer among members of the NBCSP target group from levels identified in 2000 and 2004. The first phase of the NBCSP took place in WA between 29 January 2007 and 30 June 2008. The study surveyed 1005 persons aged 55-74 years in Western Australia in April 2007, and again in June 2008, in order to measure changes in knowledge, awareness, and beliefs about bowel cancer as the screening program continued.

The researchers found an increase in the proportion of those who believed that bowel cancer was preventable, from 80 per cent in 2007 to 85 per cent in 2008 ($p=0.02$).

It was not clear how many believed that early detection and treatment of bowel cancer was important, or understood the role of screening. Canadian research has shown that, despite high levels of population awareness about bowel cancer and the screening process (over 80 per cent of

---

[74] Clavarino, A. M., M. Janda, et al. (2004) 'The view from two sides: a qualitative study of community and medical perspectives on screening for colorectal cancer using FOBT.' *Preventive Medicine,* 39, 482:490

[75] Tong, S., K. Hughes, et al. (2006) 'Colorectal Cancer Screening with Faecal Occult Blood Testing: Community Intention, Knowledge, Beliefs and Behavior.' *Asian Pacific Journal of Public Health* 18(1), 16:23

[76] Worthley, D. L. et al. (2006) 'Screening for colorectal cancer by faecal occult blood test: why people choose to refuse.' *Internal Medicine Journal* ,36, 607:610

[77] Javanparast, S., P. Ward, et al. (2010). 'How equitable are colorectal cancer screening programs which include FOBTs? A review of qualitative and quantitative studies, *Preventive Medicine*

[78] Weitzman, E. R., J. Zapka, et al. (2001). 'Risk and Reluctance: Understanding Impediments to Colorectal Cancer Screening.', *Preventive Medicine* 32: 502-513.

[79] Rosenfeld, E. L. and A. E. Duggan (2008). 'Colorectal cancer screening: ensuring benefits outweigh the risks.' *Medical Journal of Australia* 188(4): 196-197.

[80] Paddison, J. S. and M. J. Yip (2010). 'Exploratory study examining barriers to participation in colorrectal cancer screening.' *Australian Journal of Rural Health* 18: 11-15.

[81] Worthley, D. L., S. R. Cole, et al. (2006). 'Screening for colorectal cancer by faecal occult blood test: why people choose to refuse.' *Internal Medicine Journal* 36: 607-610.

[82] Jalleh, G., R. J. Donovan, et al. (2010). 'Beliefs about bowel cancer among the target group for the National Bowel Cancer Screening Program in Australia.' *Australian and New Zealand Journal of Public Health* 84(2): 187-192.

people surveyed), most of those people failed to understand that screening occurs before symptoms have developed[83].

5.3 Communication with the target population

As discussed earlier, it appears that accessibility or uptake issues in relation to the NBCSP may be experienced by men (especially those who are single and/or childless, noting information in the Ipsos research indicated that many men who did participate did so after 'nagging' or encouragement from their partners or children), people in the 50 year old cohort, people living in the Northern Territory, people living in the areas with the lowest socioeconomic status, Indigenous people and people from a culturally and linguistically diverse background. It would seem appropriate, therefore, to target awareness-raising and engagement strategies to these specific groups.

General potential improvements to increase participation identified by participants in the Ipsos research included:

- For the invitation letter:
    - Provide additional information on bowel cancer and emphasise the importance of early detection (for example, 'tell people how we do change lives by picking up precancerous lesions and removing them by simple polypectomy and not surgery')
    - Provide information suited to people from non-English speaking backgrounds or with lower literacy levels
    - Make more use of bullet points and visual representation
    - Provide more information about the testing process
    - Provide more information about bowel cancer symptoms
    - Give prominence to the helpline phone number in the letter (when asked about the NBCSP Information Line and FOBT Helpline, 92 per cent of participants and 88 per cent of non-participants interviewed had not contacted either line)
- For the FOBT kit:
    - Provide information suited to people from non-English speaking backgrounds or with lower literacy levels
- For the information booklet:
    - Provide this to participants with the first invitation letter, rather than with the test kit. 30 per cent of participants thought this approach would be more useful, and a further 38 per cent thought this would make no difference, suggesting the former group could be satisfied without impacting the latter

Access issues relating to colonoscopy services in particular have been identified, which are more significant in rural and remote areas, and in particular in the Northern Territory. Accessibility issues

---

[83] Sewitch, MJ et al (2008) 'Colorectal cancer screening in Canada: Results of a national survey', *Chronic Diseases in Canada*, 29 (1), 9:21

were also experienced by those without private health insurance or the ability to pay for privately delivered care. GPs interviewed as part of the Ipsos research also suggested that there may be some a lack of understanding in the profession as to what level of priority should be allocated to patients who present with a positive FOBT result. Future communications with GPs about the program could therefore include a recommendation about categorisation of such participants.

When health professionals were asked by Ipsos whether they believed the NBCSP was operating efficiently, 54 per cent of GPs and 59 per cent of colonoscopists agreed or strongly agreed with this statement. Of those that disagreed (consisting of 55 GPs, 10 colonoscopists and 2 histopathologists), reasons cited included lack of promotion or public awareness of the program, inaccurate FOBT results and the burden of reporting. When asked what could improve the program, the most common responses were increasing awareness about the program (35 per cent of GPs, 28 per cent of colonoscopists and 23 per cent of histopathologists) and expanding the availability of the kit to a larger population (21 per cent of GPs, 26 per cent of colonoscopists and 19 per cent of histopathologists).

Stakeholders interviewed for this review suggested a number of approaches to increasing participation, including:

- *Within current program parameters*
    - Continue the alternative pathways work for Indigenous Australians
    - Targeted 'small media' campaigns (new brochures and information packs to GPs, brochures to community health centres and other community centres, partnerships with business and other community 'champions' to promote bowel cancer and screening awareness)
    - Improved and more engaging information on the website with links from the invitation letter (seen as particularly useful for the 50 year old cohort)
- *Beyond current program parameters*
    - Make kits available to the eligible age cohorts through GPs as an alternative to the mail invitation (with a mechanism for GPs to record this on the Register)
    - Expand the alternative pathways work to provide additional entry points to the program, particularly targeted to culturally and linguistically diverse and low SES participants)
    - Make kits available to the eligible age cohorts through community pharmacies
    - Make kits available to people outside of the eligible age cohorts (i.e. those aged 56-59, 61-64, and those aged over 66), on request, to encourage greater participation by promoting 'joint' screening by people within the same household[84]

---

[84] The review notes that in the English/Welsh program, participants above the eligible age population are able to access FOBT testing on request; there is also evidence from the Japanese program – which is older than the Australian program but has far lower participation rates, of around 18 per cent – that uptake significantly increased where two members of the same household were both invited to participate at the same time: see Jepson, R et al (2000) 'The determinants of screening uptake and interventions for increasing uptake', *Health Technology Assessments*, 4 (14).

- Targeted workplace-based campaigns to raise awareness[85], which may be particularly effective for 50 year olds
- Mass media campaigns

5.3.1 Mass media

Many stakeholders lamented the overall lack of promotion for the program and suggested that a mass media campaign was needed to raise awareness of bowel cancer and the importance of increase participation rates. They pointed to mass media campaigns having successfully raised awareness of breast and cervical cancer screening, as well as a host of other health promotion activities.

The evidence does not support mass media campaigns, on their own, as an intervention to increase participation in cancer screening; they can raise awareness of cancers and of screening availability, but even their level of impact and effectiveness in this regard is not entirely clear.[86] Mass media campaigns can raise general bowel cancer awareness, but, on their own, are less effective in reaching low SES and culturally and linguistically diverse groups[87], although such campaigns may be more successful in targeting low SES when combined with other, targeted awareness raising strategies[88].

For culturally and linguistically diverse people, a mix of opportunistic and organised screening approaches can be effective in increasing participation – the evidence suggests that neither an opportunistic, GP-based screening system nor an organised, call/recall system alone will effectively target hard-to-reach populations, but a combined approach can do this[89]. In South Australia, employment of a CALD Project Officer responsible for coordination of a CALD-recruitment program for breast cancer screening using forums such as community education, ethnic radio, attendance at community festivals led to a significant increase in CALD participation in breast cancer screening.[90] The Indigenous alternative pathways pilots suggest that such a 'mixed' approach can be effective for the NBCSP.

---

[85] The review notes very high uptake in a Taiwanese workplace-based FOBT testing campaign (although there are cultural factors around workplace authority and conformity that may not translate from an Asian setting): see Hou, SI (2004) 'Home-administered faecal occult blood testing for colorectal cancer screening among worksites in Taiwan', *Preventive Medicine*, 38, 78:84

[86] Day, S et al (2010) *Improving participation in cancer screening programs: A review of social cognitive models, factors affecting participation and strategies to improve participation*, Victorian Cytology Service: Carlton South

[87] Schroy, PC et al (2008) 'Has the recent surge in media attention increased public awareness about colorectal cancer and screening?', *Journal of Community Health*, 33 (1), 1:9.

[88] Anderson, JO *et al*. (2009) 'Mass media campaign improves cervical screening across all socio-economic groups', *Health Education Research*, 24 (5), 867:-875

[89] Grunfeld, E (1997) 'Cervical cancer: Screening hard-to-reach groups', *Canadian Medical Association Journal*, 157 (5), 543:545.

[90] Aldridge, M (2011) 'Can we increase screening participation for women from culturally and linguistically diverse backgrounds in South Australia – YES we can!', *Paper to the BreastScreen Australia Conference*, 28-30 October, Melbourne.

5.3.2 ‘Small media’ and web-based strategies

A mix of client reminders and targeted ‘small media’ (videos, brochures, pamphlets, websites) appears effective in increasing participation across all cancer screening programs[91].

Fleisher (2011) found that users aged 50-59 years more likely than other age cohorts to access a website for bowel cancer screening information[92], suggesting a potentially useful method of reaching younger age groups.

The current NBCSP website is under-developed as a tool to communicate with participants and to promote participation. In comparison to websites operated by other bowel cancer charities and organisations promoting screening in Australia, and the UK bowel cancer screening website, the NBCSP website is not very consumer-friendly. It is somewhat static, highly text-based, and does not contain interesting graphics, testimonials, case studies or articles, nor any animated instructions or other visual aids that may be of interest to consumers. There is significant potential to invigorate this website.

5.3.3 Awareness raising and consistency of messages to the community

There are a number of organisations in Australia which promote bowel cancer awareness and encourage participation in FOBT screening; some of these organisations also provide their own FOBT programs.

What is particularly notable here is the fragmented messages being delivered by a number of different organisations, particularly around age groups most at risk, age to commence screening and optimal screening interval. It is also notable that many of these organisations have internet presences that are more accessible and engaging than the official NBCSP website.

The review finds that there is a potential risk arising from these fragmented messages that are being delivered around bowel cancer and screening. This could potentially impact on overall population understanding and willingness to participate in screening, although the degree to which such an impact is likely is difficult to estimate. There is a lack of ‘quality control’ or consistency around bowel cancer messages

A small number of stakeholders suggested that the branding of the NBCSP was not as eye-catching as some of the non-government initiatives pointing to the prominent ‘pink’ branding of BreastScreen Australia as an appropriate ‘branding’ benchmark. The review does not have any evidence to make any findings in regard to this issue, but the review does note that the ‘branding’ of the NBCSP appears to be generally consistent with international programs such as the English/Welsh, Scottish and Irish programs – although those programs do tend to have more interactive and eye-catching websites than the NBCSP. This is a matter which could be considered as part of the future communications strategy work.

---

[91] Brouwers, MC (2011) ‘What implementation interventions increase cancer screening rtaes? A systematic review’, *Implementation Science*, 6 (111).

[92] Fleisher, L *et al*. (2011) ‘Build it, and will they come? Unexpected findings from a study on a web-based intervention to improve colorectal cancer screening’, *Journal of Health Communications: International Perspectives*, 17(1), p41 -53

5.4 Communication with health professionals

Despite considerable international evidence that GP recommendation is the single greatest predictor of participation in screening, it is notable that very few program participants discussed participation with their GP prior to completing the FOBT (11 per cent of participants interviewed by Ipsos). However, when asked if receiving NBCSP information through certain sources would make them more likely to participate, less likely to participate, or if it would not affect their likelihood to participate, 92 per cent of participants nominated their GP as the most influential source. By contrast, 88 per cent of participants indicated that information sent directly by the program would have a positive impact on their likelihood of participation. This indicates that although GP endorsement and encouragement may lead to an increased participation rate, current information sources already influence the majority of participants. Other sources that were identified as influences included information from other health professionals (77 per cent), information from family or friends (71 per cent), and advertising on television or radio (66 per cent).

Feedback from stakeholders suggested that some GPs were wary of the NBCSP as a result of scepticism about FOBT and/or lack of confidence due to the remediation experience. Others suggested that many GPs did not even realise the program was still operating. This suggests that targeted, refreshed communication and information packs for GPs might be timely.

5.5 Key points: Improving participation

Main findings

- The participation rates achieved during Phase Two, particularly the increasing participation of older cohorts, is a positive achievement. More meaningful interpretation of participation rates would be aided by having a published target participation rate for the program

- Currently, there are relatively low levels of community awareness around bowel cancer prevalence, risk and screening

- A combination of small media interventions, promoting GP endorsement of screening, and provision of patient navigation or coaching for participants, should be considered.

- Currently, there are a number of charities and community based organisations involved in raising awareness of bowel cancer and screening. The message is somewhat fragmented, with some of these organisations promoting screening for people aged 40 or even younger (which is not consistent with NHMRC guidelines).

5.6 Applying the findings: Improving participation

Opportunities for improvement:

Within current program parameters:

- Develop KPIs and targets for participation and outcomes to enhance program monitoring and continuous improvement (the review notes advice from the Department that this work is planned to occur in the near future)
- Work with charities and community groups promoting bowel cancer screening to develop a consistent, national message promoting bowel cancer and screening awareness
- Review and finalise the draft communications framework, including consideration of a number of small media interventions to promote participation such as:
  - Review and revise the NBCSP website
  - Review and revise program letters
  - Review and re-distribute information packages to primary health care practitioners

Beyond current program parameters:

- Expand alternative pathways pilots for Aboriginal and Torres Strait Islander peoples, potentially to include urban areas
- Pilot new alternative pathways models for culturally and linguistically diverse groups and people from low socioeconomic areas
- Consider/trial expansion of the PFUF role and/or wider adoption of the Queensland GE nurse coordinator role into a patient navigator to assist participants along the screening pathway
- Consider a collaborative media approaches to raise awareness of bowel cancer and screening as part of an integrated communications framework (preferably in partnership with other actors such as cancer charities and community groups involved in community-based FOBT testing to promote a consistent, national message)

Considerations for the program evaluation

- Participation trends over time and future projections
- Comparison to participation rates and benchmarks, if available, in other comparable cancer screening programs (Australian and international)
- Bowel cancer and screening awareness levels in the target population (comparison at time of evaluation to point in time information collected during the pilot and during Phase Two)

6. Conclusions

This chapter draws together the key findings from the review, and suggested approaches for applying those findings to improve the program and participation rates. It also includes a summary of the key considerations for the evaluation framework..

6.1 Phase Two: Achievements

Overall, the ***participation rates*** attained during Phase Two are an achievement of the program. Participation overall is close to 40 per cent in an environment where there is no direct promotion of the program, low levels of community understanding of bowel cancer risk and the purpose of bowel cancer screening, and variable levels of primary health care practitioner acceptance and support for FOBT testing as a screening method. Furthermore, participation rates are increasing amongst the older age cohorts who are most at risk of bowel cancer.

However, participation rates amongst hard to reach groups is low, and there is a need for targeted measures to address this, but this is also true of other cancer screening programs.

The review also suggests that, on balance, the management of ***remediation process*** was an achievement of Phase Two. It showed that there are sufficient clinical risk management processes in place to identify critical issues, and the problem was addressed in a timely manner.

The various ***quality projects*** and ***consumer projects*** which were undertaken (including the consumer experience research and the alternative pathways pilots) were also a notable achievement of Phase Two. Although some of the quality agenda remains unaddressed, with decisions needing to made about how much of that work should proceed and whether it should be driven through the NBCSP or elsewhere, the completion of the draft quality framework, the colonoscopy quality report, the accreditation pilot and the credentialing pilots were, in themselves, all achievements.

Some stakeholders also suggested that there were several other achievements during Phase Two: increased community awareness of bowel cancer, increased professional awareness and understanding of FOBT screening, more sharing of information across government, and collection of a useful data which is now being used for secondary research (such as the down-staging research). It is difficult to assess or quantify these achievements, but the review notes these views.

6.2 Phase Two: Issues and risks

The review suggests that a key risk for the program is its level of compliance with the overarching ***policy framework*** and best practice in terms of quality assurance, target population and screening interval. The risk arises because of the potential for stakeholder disengagement from the program, which may affect participation rates.

- The review proposes that one way to address this risk would be to have a clear strategy for the implementation of the program, in line with the 2012-13 Budget announcement.
- There is also a need to have a quality management plan to satisfy compliance with the policy framework.

Another risk for the program relates to ***governance and advisory structures***. There is a lack of clarity about the roles and influence of the various committees. There also appears to be duplication of representativeness across committees and some duplication of function. The review proposes a refreshed governance structure to address this.

The need for special measures to target ***hard-to-reach groups*** has already been mentioned. The alternative pathways pilots that have already been conducted point to a useful starting point for new initiatives.

There is currently a ***fragmented message*** about bowel cancer risk and screening promotion. In some part, this is due to a lack of communication strategy for the NBCSP, but it is also because of a lack of consistent, clear messages from other community organisations which have taken on a role in bowel cancer awareness. This presents a risk to community awareness and understanding, and, ultimately, a risk to participation. The review proposes that the communications work be revisited (this should include review of the program website), and that where possible other groups involved in bowel cancer awareness be engaged to partner with the program.

The final risk for the program relates to the need to ***improve data reporting***. Considerable work is underway to promote easy, electronic reporting, but this may take some time to roll out. It is also notable that many stakeholders are unaware of the current status of this work. There are also gaps in the data, including a lack of KPIs to report against, lack of information about screening taking place outside of the NBCSP, and lack of data on outcomes for participants after a cancer diagnosis.

6.3 Opportunities to improve the program and participation rates

The review has identified a number of opportunities to improve the program. *Within current program parameters*, the following could occur:

- Develop a strategy for full implementation of the program in line with the 2012-13 Budget announcement.

- Revise the current governance and advisory structures.

- Develop KPIs and targets for participation and outcomes to enhance program monitoring and continuous improvement.

- Develop a quality management plan.

- Address the gap in the data relating to outcomes for participants after cancer diagnosis / resection.

- Review and refine current data collection and reporting with a view to increased capture of outcomes for participants with a bowel cancer diagnosis.

- Work with non government organisations to capture information about the level of non-NBCSP screening taking place in the community amongst the target population and to develop a consistent, national message promoting bowel cancer and screening awareness.

- Continue progressing moves to electronic data capture.

- Review and finalise the draft communications framework, with a focus on small media interventions

- Work with charities and community groups promoting bowel cancer screening to develop a consistent, national message promoting bowel cancer and screening awareness

- The alternative pathways work for remote Aboriginal and Torres Strait Islander participants should be reviewed with consideration given to a wider rollout.

Beyond current program parameters, the following could be undertaken:

- Link program performance and outcomes data to the national cancer database to assist in measuring program impact on morbidity and mortality over time.

- Consider regular collection of information on consumer experiences and perceptions, including information from people that choose not to participate.

- Pilot new alternative pathways models for culturally and linguistically diverse groups and people from low socioeconomic areas

6.4 Key considerations for developing the evaluation framework

The review has identified a number of key considerations for the evaluation framework, specifically:

- Effectiveness of the program data collection and monitoring framework.
- Accessibility to screening and follow-up services for ‘hard to reach’ groups, including the impact and effectiveness of alternative pathways for these groups.
- Colonoscopy capacity, distribution and accessibility.
- Comparison to international benchmarks for timeliness and quality of colonoscopy.
- Comparison of different service delivery approaches in the jurisdictions.
- Participation trends over time and future projections
- Bowel cancer and screening awareness levels in the target population (comparison at time of evaluation to point in time information collected during the pilot and during Phase Two)
- Reasons for higher participation rates in inner regional and outer regional areas.
- Cost effectiveness.

7. Glossary

Adenoma: An adenoma (adenomatous polyp) is a benign tumour that arises from epithelial cells. All adenomas have malignant potential. Adenomas in the rectum or colon have a higher chance of developing into cancer (adenocarcinoma) than adenomas in most other organs.

AHMAC: Australian Health Ministers' Advisory Council.

Bowel Cancer: Comprises cancer of the colon and cancer of the rectum, collectively known as colorectal cancer.

Colonoscopy: Procedure to examine the bowel using a special scope (colonoscope) usually carried out in a hospital or day clinic.

Dedicated resource model: Queensland provides its own dedicated resources model for assessment, which involves the employment of regional gastroenterological nurses to guide public patients on the post-screening steps of the pathway, regional promotion officers, state-wide coordination and quality management plan, with an authorised provider system for public colonoscopy providers which incorporates an accreditation process. This is in contrast to the 'usual model of care.'

Downstaging: Refers to the shift in stage distribution of a cancer at the time that it is detected, from stage 4 (the cancer has spread from where it started to another part of the body) to stage 1 (the smallest cancer).

Histopathology: The microscopic study of the structure and composition of tissues and associated disease.

iFOBT: Immunochemical faecal occult blood test—a self-administered test to detect blood in stool (faeces), but not bowel cancer itself. The FOBT is analysed by a pathology laboratory, and results forwarded to the Register, participant and PHCP (if nominated). Pathologists categorise the returned FOBT into one of three groups: 1. correctly completed; 2. incorrectly completed; 3. unsatisfactory.

Participants are provided with specific instructions on how to complete the FOBT. Any tests not completed according to these instructions are classified as incorrectly completed. Unsatisfactory tests refer to those tests that could not be processed due to a problem with the kit (for example, an expired kit, kit samples that have been taken more than 2 weeks apart, or a kit that has taken more than 1 month in transit to arrive). Participants with FOBTs that are not correctly completed are requested to complete another FOBT.

Mainstream health services: Refers to follow-up diagnostic and treatment services (including primary health care consultation, assessment colonoscopy and cancer treatment) after a positive iFOBT result, all of which are provided in the public or private health systems.

NBCSP: National Bowel Cancer Screening Program.

Participant: An eligible person who has agreed to participate in the National Bowel Cancer Screening Program by returning a completed FOBT kit and Participant Details form.

Pathology: The branch of medicine dealing with changes in body tissues and organs that cause or are caused by disease.

Polyp: Colorectal polyps are small growths of colon tissue that protrude into the colonic or rectal lumen. They are usually asymptomatic, but sometimes cause visible rectal bleeding, and rarely, other symptoms. Polyps may occur individually but it is common for a person to have multiple polyps. They occur more commonly in later life, and hereditary and dietary (lifestyle) factors may play a part.

Primary health service practitioner/provider: Classified by Department of Human Services as a general practitioner or other primary health care provider. This may include remote health clinics or specialists providing general practitioner services.

Register: National Bowel Cancer Screening Program Register maintained by Department of Human Services.

Resection: Removal (cutting away) of cancerous tissue during an operation.

Screening pathway: The organised, progressive sequence through which an asymptomatic participant is recruited and screened for a disease. The NBCSP screening pathway aligns with the Australian Population Based Screening Framework and comprises five components: recruitment, screening, assessment, diagnosis and outcome.

Usual model of care: States and territories deliver follow-up assessment colonoscopy and treatment services in the public health system for those program participants returning a positive screening result and who, following a consultation with their nominated primary health care professional, choose to be treated through the public system. Participants can also receive assessment colonoscopy and treatment in the private health system.