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

## **Final report, part two: Evaluation framework**

November 2012

Department of Health and Ageing

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## 1. Introduction

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This document provides a framework for the evaluation of the National Bowel Cancer Screening Program (the NBCSP), encompassing the period from the commencement of the program with its pilot phase in 2002 through Phase One and Phase Two of the program to 2014.

The framework forms part two of the final report of the review of the NBCCSP, Phase Two, undertaken by KPMG between December 2011 and June 2012. The framework has been developed on the basis of the review findings, as well as feedback from the Department of Health and Ageing and from the Program Advisory Group for the National Bowel Cancer Screening Program.

The framework provides a guide for the future program evaluation. It identifies the key questions and information requirements, suggests suitable data collection methods, and highlights the likely gaps, challenges and limitations for data collection. The detailed approaches to be used in the evaluation, as well as any strategies to address the identified gaps and limitations, will need to be considered during the evaluation design process

The framework is set out as follows:

- Section 2 provides an overview of the program (page 2); this section includes a suggested results logic for the program at page 6 – the logic should be reviewed and validated during the evaluation design process
- Section 3 sets out the objectives of the evaluation (page 7)
- Section 4 sets out the key evaluation questions and components within each question (page 11)
- Section 5 suggests an approach and methods for collecting the information needed to answer the evaluation questions (page 15)
- The appendix table provides a summary of the evaluation questions and components, information requirements, available information sources, and likely gaps or challenges in the data collection process (page 19).

## 2. Overview of the NBCSP

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The National Bowel Cancer Screening Program (NBCSP) provides a screening service to cohorts selected from the Australian population who have a higher risk of bowel cancer, and provides referral and follow up services to support assessment, diagnosis and treatment.

### 2.1 Goal of the program

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.<sup>17</sup>

### 2.2 Objectives of the program

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
- 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.

### 2.3 Operation of the program

The Department of Health and Ageing is responsible for NBCSP management and governance, policy development and funding, however the program is implemented cooperatively with a number of government and private sector partners, outlined under section 1.4.

The NBCSP is structured in accordance with the Australian Population Based Screening Pathway<sup>1</sup>; incorporating the five steps of recruitment, screening, assessment, diagnosis and outcome.

The key activities undertaken by the program at each step are outlined below.

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<sup>1</sup> AHMAC Australian Population Health Development Principal Committee, Screening Subcommittee (2008) *Population based screening framework*, Commonwealth of Australia: Canberra

- **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 a 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.
- **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 national bowel cancer morbidity and mortality rates are included within the NBCSP monitoring framework.

The NBCSP is administered by the Department of Health and Ageing to the point of FOBT result on the screening pathway. The Department funds the states and territories to perform the Participant Follow-Up Function (PFUF) with those participants who have received a positive FOBT result but who have not been recorded as having seen a health practitioner. 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 (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 services provider for the provision of the FOBT kits and pathology.

States and territories have an advisory role for the NBCSP through the AHMAC Screening Subcommittee, as well as the NBCSP Program Managers' Group and the NBCSP Program Advisory Group. Clinicians are also represented on the Program Advisory Group (PAG).

## 2.4 Eligibility to participate in the program

The program was established as a pilot targeting 57,000 people aged between 50-74 years over 2002 – 2004. The program has continued in two phases: phase one (2006 – 2008), and phase two (initially 2008 – 2010, and extended to 2014).

Eligibility to participate in the program has been gradually expanding since its commencement.

In addition to the age cohort expansions, biennial screening of all people aged between 50 and 74 years is being progressively phased in, commencing in 2017-18 and starting with people aged 72 years.

Biennial screening of people aged between 50 and 74 years is in line with current medical evidence on efficacious bowel cancer screening intervals, and the current National Health and Medical Research Council guidelines for bowel cancer screening.

*Table 1: NBCSP timelines showing progressive expansion of age cohorts and screening interval*

Phase	Dates	Description
Pilot phase	Nov 2002 – Jan 2004	Approx. 57,000 people aged 50-74 invited to participate in the pilot
Phase One	Aug 2006 – Jun 2008	Approx 1 million people aged 55 and 65 years, plus those involved in the pilot, invited to participate
Phase 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.
Phase Two (resumed)	2 November 2009	Program resumed with new iFOBT kits, Affected participants invited to re-screen.
Phase Two (continued)	1 July 2011	Invitations commenced for people turning 50, 55 or 65 from 1 January 2011.
Phase 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 2012-13 Budget papers*

## 2.5 Program partners

Table 2: Roles of NBCSP program partners

Partner	Role
Department of Health and Ageing	Program and policy manager, responsible for quality oversight of Recruitment and Screening on the pathway
State/Territory Governments	Jurisdiction managers, responsible for quality oversight of Assessment and Diagnosis on the pathway and for Participant Follow Up Function
Department of Human Services	Responsible for maintenance of the Register, operation of the Helpline and mail house function.
FOBT provider	Provision of FOBT kits and pathology services
Medical service providers	General Practitioners (GPs) and other primary health care providers, pathologists, colonoscopists, histopathologists (public and private)
Participants	Cohorts recruited to take part in the screening pathway

Source: Department of Health and Ageing

## 2.6 Results Logic for the Program

A suggested results logic model for the NBCSP is shown on the following page. This should be validated as part of the evaluation design.





### 3. Evaluation of the NBCSP

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An evaluation of the program is expected with the completion of stage two in 2014. The evaluation will consider performance of the program over the pilot phase, phase one and two, covering a period of twelve years (2002 – 2014).

The framework established in this document outlines the objectives, main considerations, questions, information requirements and suggested data collection methods for the evaluation.

#### 3.1 Objectives of the evaluation

The objectives of the evaluation are to:

- Evaluate the extent to which the program goal and objectives have been achieved
  - This encompasses the entire period of the program (phase one and phase two, to 2014)
- Evaluate the effectiveness of the service delivery model
  - This includes effectiveness of the program registry and mail house; program monitoring and reporting processes; recruitment processes; screening mechanisms; and model of care for assessment, diagnosis and treatment
- Assess the cost effectiveness and efficiency of the program
- Assess the ongoing appropriateness of the program
  - This includes alignment with government policy and contemporary good practice approaches for bowel cancer screening, as well as ongoing appropriateness of the program goal and objectives
- Identify any opportunities for improvement
  - This includes identification of barriers and enablers for achievement of program objectives, and identification of unintended consequences (positive and negative).

#### 3.2 Key aspects to consider in the evaluation

A review of the program undertaken by KPMG in May 2012 identified the following key considerations to be addressed in the evaluation:

- *Participation rates and trends over time, by cohort and location.* This information is collected as part of ongoing program monitoring, however the evaluation will provide an opportunity to compare longitudinal data and investigate the reasons behind changes in participation trends. Refer to Appendix 1, *Summary of the Evaluation Framework* sections 1.2 and 4.1 to 4.4 for further details on evaluating participation trends.
- *Reasons for higher participation rates in inner regional and outer regional areas than in major cities.* In addition to longitudinal information on participation trends discussed above, the evaluation framework includes interviews of people who declined to participate in order to determine the most significant reasons for non-participation. Targeting of the sample group for these interviews to include sufficient numbers of non-participants from city areas, as well as any other groups with high non-participation rates, will enable a useful analysis to

be made. Refer to Appendix 1, *Summary of the Evaluation Framework* section 4.1 for further details on evaluating reasons for low participation.

- *Comparison to participation rates and benchmarks, if available, in other cancer screening programs (Australian and international).* Refer to Appendix 1, *Summary of the Evaluation Framework* section 1.2 for further details on evaluating participation rates, including benchmarking against comparable programs.
- *Accessibility to screening and follow-up services for 'hard to reach' groups, including the impact and effectiveness of alternative pathways for these groups.* The evaluation framework includes interviews with program participants and service providers to assess the effectiveness of each point on the screening pathway. In addition, reporting from pilot alternative service delivery pathways will be assessed, and follow up interviews with the relevant partners included if required to determine effectiveness. Refer to Appendix 1, *Summary of the Evaluation Framework*, sections 4.1 to 4.4 and section 6 for further details on evaluating service delivery for 'hard to reach' groups.
- *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).* The evaluation framework incorporates surveys of both participants and non-participants which can be used to assess awareness of bowel cancer and screening. In addition, interviews with service providers and in particular GPs are proposed to assess the effectiveness of promotion. Refer to Appendix 1, *Summary of the Evaluation Framework* section 4.1 for further details on evaluating the effectiveness of promotion.
- *Comparison to international benchmarks for timeliness and quality of colonoscopy.* Refer to Appendix 1, *Summary of the Evaluation Framework*, section 4.2 for further details on evaluating the quality and timeliness of assessment colonoscopy, including benchmarking against international best practice.
- *Effectiveness of the program data collection and monitoring framework, including comparisons to other Australian cancer screening programs and international bowel cancer screening benchmarks.* The evaluation framework provides for review of the effectiveness of data collection, monitoring, reporting and evaluation through combination of document review and feedback from key partners, as well as benchmarking with comparable programs. Refer to Appendix 1, *Summary of the Evaluation Framework* key evaluation question 5 for further details on this aspect of the evaluation.
- *Comparison of different service delivery approaches in the jurisdictions; specifically, comparison of the effectiveness and efficiency of a dedicated resources approach.* The evaluation framework plans for a comparison in the effectiveness of different approaches in the *assessment* component of the screening pathway, including assessment colonoscopy and histopathology services, as the quality of these services is central to the program's fourth objective. Analysis will also draw on participation and outcomes data disaggregated by jurisdiction in order to link information on approach to information on outcomes achieved. Refer to Appendix 1, *Summary of the Evaluation Framework* section 4.3 for further details on the effectiveness of different approaches to assessment between jurisdictions.

### 3.3 Limitations and issues impacting on the evaluation

There are a number of limitations and issues which will impact on the evaluation. Many of these relate to the availability of data to measure progress against program objectives, or to the difficulty in attributing change to the program. The following limitations and issues have been identified:

- *Lack of agreed key performance indicators.* As it is currently configured, the program does not have any targets for participation rates or any key performance indicators. Some short-term and longer-term indicators may be generally inferred from the World Health Organization's benchmarks for evaluation of national cancer control programs (that is, 30 per cent of cancers detected on examination or tests within 5 years, a 30 per cent reduction in targeted advanced cancers within 10 years, and a 15 per cent reduction in mortality for targeted cancers within 15-20 years)<sup>2</sup>, but the lack of specific indicators for the NBCSP will limit the robustness of the evaluation in determining the program's actual and projected impact over time.
- *Lack of data in relation to reasons for non-participation, GP consultations, colonoscopy referrals and outcomes, and histopathology outcomes.* Current rates of data returns at several points of the screening pathway are not optimal. Whilst actions are being taken to simplify and increase reporting, the limitations of the existing data set may limit the robustness of trend analysis and projections modelling that the evaluation is able to conduct.
- *Lack of treatment outcomes data for program participants.* Currently, it is not possible to track the outcomes of program participants who have been diagnosed with bowel cancer. This information is important in terms of measuring impact of the program on mortality.
- *Lack of agreed national standards for colonoscopy timeliness.* Objective three relates to the delivery of colonoscopy services which are timely, acceptable and appropriate. Currently, there is no nationally agreed standard on timeliness of assessment colonoscopy following a positive iFOBT result. This presents a significant challenge to the evaluation.
- *Lack of a quality management strategy for the program.* The national population-based screening framework requires that population-based screening programs have a quality management strategy<sup>3</sup>. In addition to this need for an overall quality management approach, program objectives three and five relate specifically to quality assurance and quality management within certain aspects of the program. At the time of writing, there is no quality management strategy for the program. The lack of a quality management strategy (or any other form of nationally agreed and measured quality standards) presents a challenge to the evaluation, both in terms of assessing progress against those specific objectives, and also in terms of objectively assessing overall program quality assurance and quality management. In addition, the lack of reliable adverse events data for colonoscopies presents a further challenge to the evaluation in terms of assessing quality across the screening pathway.

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<sup>2</sup> World Health Organization (2002) *National cancer control programs: Policies and managerial guidelines*, 2<sup>nd</sup> edition, WHO: Geneva

<sup>3</sup> AHMAC Australian Population Health Development Principal Committee, Screening Subcommittee (2008) *Population based screening framework*, Commonwealth of Australia: Canberra

- *Implementation of agreed national colonoscopy quality standards and data.* Objective three relates to the delivery of colonoscopy services in accordance with national professional standards. Whilst colonoscopy quality standards for both services and colonoscopists have been developed and endorsed by AHMAC, at the time of writing there is a lack of evidence that these standards have been fully adopted by jurisdictions. Accreditation and data reporting against the standards is expected to be limited. This means that there will be little information available to the evaluation against which this objective can be measured. A related issue is the appropriateness of objective three as it is currently worded – given that assessment colonoscopy is delivered through a usual care model, and the program has no direct influence or control over the quality of those services. Appropriateness of the objectives will be a consideration for the evaluation.

These limitations and issues will need to be considered during the evaluation design process. Some of the limitations and issues could be addressed, or at least minimised, through additional data collection processes; others will simply need to be acknowledged as limitations.

## 4. Evaluation questions

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This section outlines the key evaluation questions addressed in this evaluation framework. These are grouped into questions which consider the program outcomes, key processes, and cost effectiveness and efficiency. The main considerations for each evaluation question are also summarised.

These considerations are summarised discussed in more detail in Appendix 1, *Summary of the Evaluation Framework*.

### 4.1 Outcomes evaluation

#### *Purpose of the outcomes evaluation*

- To evaluate the extent to which the program goal and objectives have been achieved to date
- To identify key barriers and enablers for achievement of the program objectives
- To identify any areas for improvement to enhance program outcomes

#### *Key questions for the outcomes evaluation*

##### **1. To what extent have the program goal and objectives been met?**

Key components to consider within this question include: outcomes for participants, service providers and government; any differences in access, participation and outcomes across participant demographic cohorts and locations; and overall participation and outcome trends over time.

##### **2. What are the barriers and enablers for achievement of the program goal and objectives?**

Key components to consider within this question include: the strength and completeness of the overall program results logic in the context of program data and other information about the program's performance (including internal and external factors identified by program stakeholders as affecting performance).

##### **3. Have there been any unintended consequences (positive or negative)?**

Key components to consider within this question include: consequences for participants, service providers and government which fall outside of the scope of the program results logic, such as:

- An indirect influence on the way other health services are provided or the extent to which they are accessed;
- An increase in public awareness of bowel cancer either reinforcing or 'crowding out' other health messages;
- The burden of implementing the program redirecting efforts previously invested in other activities;
- Any learning drawn from this program being applied in other areas by the participants.

## 4.2 Process evaluation

### *Purpose of the process evaluation*

- To evaluate the effectiveness of the service delivery processes
- To assess the ongoing appropriateness of the program

### *Key questions for the process evaluation*

#### **4. How effective is the service delivery model?**

Key components to consider within this question include effectiveness along each point of the screening pathway:

- *Recruitment:* Effectiveness of program communications and promotion, effectiveness of program invitation methods (including alternative entry pathways); effectiveness and appropriateness of the participant follow-up function (PFUF)
- *Screening:* Effectiveness of the screening test, taking into account positive predictive value; numbers of cancers of advanced adenomas detected per 1,000 people screened; perceived benefits and drawbacks by participants; and emerging technology.
- *Assessment:* Effectiveness and ongoing appropriateness of the of the testing technology (including positive predictive value of the screening test; alternative testing options based on emerging technology; alignment of the testing method with contemporary international good practice for bowel cancer screening); effectiveness of and differences between assessment and diagnosis service delivery models in (a) the public and private health system, and (b) public system approaches in different jurisdictions.
- *Diagnosis and treatment:* This element of the screening pathway falls within the usual care model and will therefore not be evaluated directly as a component of the program. However the program's ability to effectively monitor diagnosis and treatment services will be assessed under key evaluation question 5, and the morbidity and mortality outcomes are assessed under key evaluation question 1. In addition, the ongoing effectiveness and appropriateness of the usual care model – particularly in light of projected increases in program participation over time – will also be considered under key evaluation questions 6 and 7.

#### **5. How effective are the program registry, mail house, monitoring and reporting processes?**

Key components to consider within this question include: effectiveness and appropriateness of the registry, mail house, data collection, data monitoring/reporting, and program review processes; extent to which these inputs have resulted in program improvement.

#### **6. Is the program appropriate?**

Key components to consider within this question include: ongoing need for the program; appropriateness and effectiveness of the program goal and objectives; appropriateness of program delivery for the target populations, in particular 'hard to reach' groups; appropriateness of the usual care model of assessment and diagnosis service delivery; continued alignment of the program with contemporary good practice for cancer screening programs; and continued alignment of the program with government policy.

### 4.3 Cost effectiveness and efficiency

#### *Purpose of the cost effectiveness and efficiency analysis*

- To evaluate the cost effectiveness of the program relative to a base case (no screening program)
- To evaluate the efficiency of program delivery, including the relative efficiency of various program delivery arrangements that may exist in different States and Territories

#### *Key questions for the cost effectiveness analysis*

##### **7. Is the program efficient?**

Key components to consider within this question include:

- The cost of administering and delivering the program (incurred by the Australian and State/Territory governments), taking into account cost of administering the program by the Australian Government, and the costs of different program delivery arrangements that may exist in States and Territories
- The relative efficiency of the program overall (for example, as compared with other, similar screening programs), and relative efficiency of different program delivery arrangements in place in States and Territories
- Modifications to program administration or delivery to improve the efficiency of the program

##### **8. Is the program cost effective?**

Key components to consider within this question include:

- *The cost of bowel cancer screening relative to the benefits realised.* The costs of the program include direct costs associated with administrative and delivery components of the program, and other costs incurred by individuals (and their families), government or the community or economy as a result of the program.
  - The benefits of the program include both costs avoided from early detection (for example, costs associated with bowel cancer treatment, income and productivity impacts of bowel cancer on individuals affected and their families – in effect the costs of bowel cancer), as well as the benefits associated with people living longer and with a better quality of life as a result of earlier detection – in terms of years of life saved and years of life lived without disability.<sup>4</sup>
  - Benefits will be separately identified and quantified for individuals who are in the target group for screening (and at higher risk of bowel cancer), their families, governments, and the community or economy.

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<sup>4</sup> Utilising disability adjusted life years (DALYs) as the primary measure. DALYs incorporate years of life lost (saved) and years of life lived with (without) disability.



- *The value of the screening program relative to the base case (no screening program).* The value represents the net benefits realised from the screening program, taking into account all the costs of the program (both direct and indirect) as the benefits of the program, expressed in dollar (net present value) terms.

The cost-effectiveness of the program will be examined relative to a base case – that is, if there were no screening program in place – and will consider costs and benefits over the short-term (up to 5 years) and longer-term (more than 15 years)

The cost effectiveness component will consider the relative cost-effectiveness of different scenarios or sub-components, including the cost effectiveness of different testing regimes, different age groups who are currently in the target group for the program as well as in adjacent age groups, and taking onto account the variation in screening participation rates.

## 5. Information requirements and collection

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The following section outlines the key information requirements for the evaluation, grouped against the outcomes, process, and cost effectiveness evaluation questions. The suggested information or data collection methods are also outlined, and anticipated gaps in the available data identified.

### 5.1 Outcomes evaluation

#### *Key information required:*

- Participation rates for demographic cohorts and locations
- Morbidity and mortality outcomes for program participants and the broader population
- The number of cancers and advanced adenomas detected per 1,000 people screened
- Validated program results logic model
- Views of program managers, partners and participants on the program's impact, barriers and enablers for its success, and any unintended consequences.

#### *Available information sources:*

AIHW Monitoring Reports, data in the Register, data in the Australian Cancer Database, reporting from pilot alternative service delivery models

#### *Gaps in the available information:*

Data on morbidity and mortality outcomes for program participants diagnosed with cancer over the life of the program is not currently available, and benchmarks have not been set for these outcomes. Without a counterfactual, attribution of outcomes to the program is also a challenge. The Register does not hold complete data for participation throughout the screening pathway. The views of program managers, partners and participants regarding program outcomes will need to be systematically collected.

#### *Suggested approaches to address the gaps:*

- Collect morbidity and mortality outcomes for a statistically significant sample of program participants, and compare this both to national outcomes (exclusive of program participants if possible), and benchmarks for comparable programs (see section 2.3 for more detail).
- Consult with program managers, participants and partners to capture their views regarding the outcomes of the program, including unintended consequences. Use a contribution analysis approach to evaluate what role the program has played in achieving outcomes.
- Data gaps in the Register cannot be fully resolved, but should be considered in the analysis of outcome data and recognised as a limitation in the evaluation report.

#### *Suggested data collection methods:*

- The evaluation could seek to undertake data analysis from the Register to identify an appropriate sample (representative of each jurisdiction and age/gender cohort), and follow up survey of GPs to confirm morbidity and mortality outcomes – however, this would likely

be a time-consuming and involved task. It might also be difficult to model an appropriate sample size.

- A second alternative could be to examine frame shifts in tumour stage of individuals who have been screened, compared to those who have not screened as a surrogate marker for mortality – if data are available to do this.
- Use a combination of semi-structured interviews or focus groups based around key evaluation questions and sub-questions. Follow up data collection may be required to verify the themes identified through consultation.

## 5.2 Process evaluation questions

### *Key information required*

- Information on alternative service delivery pathways and other initiatives to increase participation
- Information on different approaches to assessment services across jurisdictions
- Information on the benefits and positive predictive value of the screening test and assessment colonoscopy compared to alternatives
- Timeliness of assessment colonoscopy and comparable international data
- Current information on good practice and benchmarks internationally for cancer screening programs and relevant Australian government policy
- Views of program participants, non-participants and partners on the effectiveness of the screening pathway and program operation.

Data gathered under the outcomes evaluation questions will also be used to link evaluation of process with observed outcomes.

### *Available information sources:*

AIHW Monitoring Reports, data in the Register, program management documentation held by the Department of Health and Ageing, the program logic model included in this framework, data from the AIHW Australian Cancer Database<sup>5</sup> AND/OR THE Bi-National Colorectal Cancer Audit<sup>6</sup>, reporting from pilot alternative service delivery models, international health literature, reporting from comparable programs.

### *Gaps in the available information:*

Data on the quality and timeliness of assessment colonoscopy and the outcomes of colonoscopy and histopathology are not readily available. This, along with data gaps in the Register and difficulty in finding comparable programs, limits analysis on effectiveness of the overall screening

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<sup>5</sup> The AIHW Australian Cancer Database is a data collection of all primary, malignant cancers diagnosed in Australia between 1982 and 2008: <http://www.aihw.gov.au/australian-cancer-database/>

<sup>6</sup> See <http://www.surgeons.org/for-health-professionals/audits-and-surgical-research/morbidity-audits/bcca/>

pathway. The views of program managers, partners and participants regarding program operation also need to be systematically collected.

*Suggested approaches to address the gaps:*

- Conduct a literature/desk review to identify new developments in technology and good practice internationally in order to assess ongoing appropriateness of the program.
- Use the time between assessment colonoscopy referral and reported service date as a proxy indicator for the availability and timeliness of colonoscopy services
- Use a combination of semi-structured interviews or focus groups based around key evaluation questions and sub-questions. Follow up data collection may be required to verify the themes identified through consultation.

Use qualitative information sourced through consultation with participants and service providers to identify potential issues with access to and quality of assessment services.

Collect targeted additional information to verify the themes identified through consultation (for example, waiting list data).

*Suggested data collection methods:*

- Analysis of data in the Register regarding referral and service dates
- Combination of semi-structured interviews or focus groups based around key evaluation questions and sub-questions.

### **5.3 Cost effectiveness**

*Key information required*

A range of different data should be utilised in the efficiency and cost effectiveness component – including (but not limited to):

- Number and characteristics of people in the target group for the NBCSP and the number and characteristics of people screened under the NBCSP (by year)
- Expenditure information, including costs of administering the program and costs of program delivery (by year, by State/Territory, by expenditure category and sub-category)
- Bowel cancer incidence and prevalence; bowel cancer mortality
- Bowel cancer treatment costs
- Range of publicly available data (e.g. from ABS, AIHW) to estimate productivity losses, income and other tax losses, costs to families/carers resulting from bowel cancer
- Burden of disease data

*Suggested approach and methods for the cost effectiveness analysis*

Much of the data required for the efficiency and cost effectiveness analysis will be able to be readily provided by the Department and jurisdictions (e.g. program expenditure information to

the point of screening and follow up services, number and characteristics of people screened), or will be available publicly from data sets held by agencies such as the AIHW.<sup>7</sup>

It is unlikely that expenditure data for assessment and diagnosis services related to program participants and performed in the private health sector will be readily available. This will be a limitation of the evaluation, unless arrangements can be agreed with private health providers to access this information.

The cost effectiveness analysis will utilise recognised techniques including cost-utility analysis and cost-benefit analysis.

### *Limitations of the approach*

Cost-utility analysis and cost-benefit analysis both rely on measures of benefit (and cost-benefit analysis on attaching a monetary value to these benefits), which may be difficult to establish. There are recognised methods of calculating benefits utilising these techniques, though they rely on the quality of underlying data. Cost-benefit analysis of health interventions or programs, while a recognised technique, does involve putting a value on years of life gained (or lost), and years of life lived with (or without) disability – using ‘willingness to pay’ methods. These can be seen as somewhat subjective, and a number of people have philosophical objections to valuing ‘life’.

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<sup>7</sup> It is noted that most jurisdictions will not be able to provide detailed expenditure data for assessment and diagnosis services *specific* to NBCSP participants, due to the difficulties in reliably ‘tracking’ program participants through the system, but it is expected that general expenditure data for assessment colonoscopy and diagnosis services will be available from all jurisdictions.

## Appendix 1: Summary of the Evaluation Framework

### Key Question 1: To what extent have the program goals and objectives been met?

Components	Information Required	Information sources	Collection methods	Gaps or challenges
1.1 To what extent has the program goal been met?				
<p>Have overall bowel cancer morbidity and mortality rates been reduced as a result of the program?</p> <p>Have bowel cancer morbidity and mortality rates been reduced for program participants?</p>	<p>Program participation and outcomes data</p> <p>International benchmarks for reductions in cancer incidence and mortality resulting from cancer control programs over time</p> <p>Specific morbidity and mortality outcomes for program participants, and comparative data for the national population</p>	<p>WHO policy and managerial guidelines for national cancer control programs</p> <p>AIHW program monitoring reports</p> <p>AIHW Australian Cancer Database</p> <p>RACS Bi-National Colorectal Cancer Audit (if data available)</p>	<p>Secondary analysis of program data</p> <p>Modelling of projections for future morbidity and mortality outcomes (based on trends and future expansion of age cohorts and screening intervals)</p>	<p>Data on morbidity and mortality outcomes for program participants diagnosed with cancer over the life of the program is not available.</p> <p>This could be remedied by selecting a representative sample of participants from cohorts and jurisdictions, analysing existing records and conducting a follow up survey to identify medical outcomes.</p> <p>If differences in outcomes for each participant cohorts are to be assessed, the sample will need to be large enough to provide statistically significant results for each cohort.</p>
<p>What other significant outcomes has the program contributed to?</p>	<p>Views of program partners on other outcomes achieved, and any supporting information</p>	<p>Feedback from program partners</p> <p>Journal articles</p>	<p>Interviews with program partners</p> <p>Literature review</p>	<p>Information may need to be tested and verified by additional data collection in order to strengthen findings. Alternatively, this could be tested and validated with an expert reference group.</p>

Components	Information Required	Information sources	Collection methods	Gaps or challenges
1.2 To what extent have program objectives been met?				
<i>(Objective 1):</i> To what extent is use of the screening pathway resulting in earlier detection of bowel cancer?	Stage of cancer when first detected for program participants, and comparative data for the national population	NBCSP Register for stage of cancer when first detected  Australian Cancer Database for comparative data for the population  Journal articles and papers	Secondary analysis of program data  Secondary analysis of data in the Australian Cancer Database  Review of journal articles, papers and other reviews	Program participants' data is expected to be included in the Australian Cancer Database.  If, at the time of the evaluation, it is possible to identify and remove program participants from the comparative national data, this should be done in order to improve the accuracy of the comparison.  However, if this cannot be done, it should be recognised as a limitation of the evaluation.
<i>(Objective 2):</i> How have program participation trends changed over time for different target groups?  How do participation rates compare with those of comparable cancer screening programs in Australia and overseas?	Participation rates across the screening pathway over the pilot period, phase one and phase two (2002 to 2014) disaggregated by: <ul style="list-style-type: none"> <li>• Age and gender</li> <li>• Jurisdiction</li> <li>• Locality</li> <li>• Indigenous status</li> <li>• CALD background</li> <li>• Disability</li> </ul>	AIHW monitoring reports  Reporting from pilot alternative service delivery models  Scan of health literature / data from reporting of comparable programs	Secondary analysis of program data  Literature scan / desk research	The NBCSP Register data cannot be expected to hold completely accurate information for items which are self reported (such as indigenous identity). This limitation should be recognised in the evaluation report.  Identification of 'comparable cancer screening programs' will need to be carefully considered during the evaluation design.

Components	Information Required	Information sources	Collection methods	Gaps or challenges
(Objective 3): Has the program contributed to improving the quality of colonoscopy?	<p>Time series data on colonoscopy quality</p> <p>Views of service providers regarding the impact of the program on their services</p> <p>Evidence to verify any reported changes in service delivery</p>	<p>Adverse event data reported through program monitoring</p> <p>Proxy data from data sets such as the Victorian Surgical Outcomes Initiative and similar (i.e data on colonoscopy complications, perforations, bleeding)</p> <p>Feedback from program partners</p>	<p>Review of colonoscopy quality data (if available)</p> <p>Interviews with program partners</p>	<p>There are several limitations to this question, which will need to be recognised in the evaluation design.</p> <ul style="list-style-type: none"> <li>• Firstly, the program-specific adverse event data is unreliable.</li> <li>• Secondly, there is a limited national approach to colonoscopy quality reporting and measurement.</li> <li>• Thirdly, there is unlikely to be sufficient global time series data on colonoscopy quality; even if global data are available, it would be difficult to attribute any changes in quality to the program (ideally, quality measures would include caecal intubation rates, polypectomy rates and perforation rates).</li> </ul> <p>This means the evaluation will be largely reliant on qualitative information provided by stakeholders.</p>

Source: KPMG



## **NOTES ABOUT QUESTION 1**

Objective 4 is addressed separately under key evaluation question 4, section 4.2

Objective 5 is addressed separately under key evaluation questions 4 and 5

Objective 6 is addressed separately under key evaluation question 7

**Key Question 2: What are the barriers and enablers for achievement of the program goal and objectives?**

Components	Information Required	Information Source	Collection Methods	Gaps or Challenges
2.1 What are the barriers and enablers for achievement of the program goal and objectives?				
<p>To what extent can progress against objectives be attributed to the program?</p> <p>Has the program worked as expected (i.e. as represented in the results logic model)?</p> <ul style="list-style-type: none"> <li>• What parts of the model are not supported by evidence</li> <li>• Has the program worked differently in practice?</li> </ul> <p>What other factors have influenced progress against objectives?</p>	<p>Mapping of data collected in response to Key Evaluation Questions against the results logic model</p> <p>Identification of any parts of the model which are not supported by the data, or which appear to have worked differently in practice</p> <p>Views of program managers, key partners and participants regarding the influence of external factors on progress against objectives</p> <p>Evidence to verify the reported external factors</p>	<p>Feedback from program participants and partners</p> <p>Results Logic Model included in this framework</p> <p>Data collected against key evaluation questions</p> <p>Contribution analysis undertaken by the evaluator</p>	<p>Interviews with program participants and partners</p> <p>Secondary analysis of evaluation data collected against the results logic</p>	<p>Without the existence of a counterfactual, it is not possible to attribute outcomes clearly to the program itself.</p> <p>Contribution analysis, however, can be undertaken utilising the data and program logic model in order to:</p> <ul style="list-style-type: none"> <li>• Assess the plausibility and probable extent of the contribution made by different parts of the program to observed outcomes, and</li> <li>• Identify and assess the role played by factors external to the program as it is represented by the logic model.</li> </ul>

Source: KPMG

**Key Question 3: Have there been any unintended consequences (positive or negative)?**

Components	Information Required	Information sources	Collection Methods	Gaps or Challenges
3.1 Have there been any unintended consequences (positive or negative)?				
<p>What unintended consequences have:</p> <ul style="list-style-type: none"> <li>• participants</li> <li>• partners and</li> <li>• government</li> </ul> <p>Experienced as a result of the program?</p>	<p>Views of participants, partners and government on what unintended consequences have been realised.</p> <p>Questions may focus on whether the program has:</p> <ul style="list-style-type: none"> <li>• Influenced the way other health services are provided, or accessed</li> <li>• Reinforced or competed with other health promotion messages</li> <li>• Redirected efforts of key partners</li> </ul>	<p>Feedback from program participants and partners</p> <p>Evidence to verify any reported unintended consequences</p> <p>Morbidity data from dedicated screening centres (where available)</p>	<p>Interviews with program participants and partners</p>	<p>Information provided through interview may need to be tested and verified by additional data collection in order to strengthen findings.</p> <p>It may be useful to interview representatives from organisations which are not program partners, if there are indications that the program may have impacted on their activities.</p> <p><i>(Note that the information sought here may duplicate responses to the question under 1.1 about other significant outcomes).</i></p>

Source: KPMG

**Key Question 4: How effective is the service delivery model?**

Components	Information Required	Information sources	Collection Methods	Gaps or Challenges
4.1 How effective has recruitment been?				
<p>How effective have approaches to recruitment been?</p> <p>How effectively has the program promoted key messages to the target cohorts?</p>	<p>Views of program participants, <i>non-participants</i> and partners on effectiveness of promotion and recruitment considering:</p> <ul style="list-style-type: none"> <li>• Invitation letters</li> <li>• Promotion, including through GPs</li> <li>• Pilot alternative entry pathways</li> </ul> <p>Participation trends for target cohorts before and after any adjustments to recruitment (such as pre-invitation letter)</p> <p>Data on participation trends for target cohorts through alternative entry pathways, and views of service providers on their effectiveness</p>	<p>Feedback from program partners, in particular GPs</p> <p>Feedback from program participants</p> <p>Feedback from non-participants of the program</p> <p>AIHW program monitoring reports</p> <p>Reporting from pilot alternative service delivery models</p>	<p>Interviews with program partners, in particular GPs</p> <p>Interviews, focus groups or surveys of program participants</p> <p>Interviews, focus groups or surveys of non-participants</p> <p>Secondary analysis of program data</p>	<p>Non-participants can be selected as a representative sample (to provide an overview of reasons for non-participation), or a purposively selected sample (to answer specific questions about why some people have lower participation rates).</p> <p>For example, the sample might exclude people who are recorded as not participating because of a recent FoBT test completed outside of the program. It may instead target representatives from city areas, culturally and linguistically diverse groups, or any other group with low participation rates.</p> <p><i>Note that the relevant information from AIHW Monitoring reports and alternative service delivery models is also collected under question 1.2, for Objective 2</i></p>

Components	Information Required	Information sources	Collection Methods	Gaps or Challenges
4.2 How effective has screening been?				
<p>How effective is the FOBT screening technology, considering emerging technology?</p> <p>To what extent have benefits been maximised and harms minimised?</p>	<p>Positive predictive value of the screening test</p> <p>Positive predictive value of alternative testing options</p> <p>Number of cancers and advanced adenomas detected per 1,000 people screened</p> <p>International evidence on best practice screening tests</p> <p>International evidence of benefits maximisation/harm minimisation in cancer screening</p> <p>Views of program participants, <i>non-participants</i> and partners on effectiveness on perceived benefits and harms</p>	<p>Data on number of cancers and advanced adenomas detected</p> <p>International medical literature</p> <p>Feedback from program partners</p> <p>Feedback from program participants</p> <p>Feedback from non-participants of the program</p>	<p>Secondary analysis of program data</p> <p>Literature scan / desk research</p> <p>Interviews with screening partners</p> <p>Interviews, focus groups or surveys of program participants</p> <p>Interviews, focus groups or surveys of non-participants</p>	<p>Non-participants can be selected as a representative sample (to provide an overview of reasons for non-participation), or a purposively selected sample (to answer specific questions about why some people have lower participation rates).</p> <p>For example, the sample might exclude people who are recorded as not participating because of a recent FoBT test completed outside of the program. It may instead target representatives from city areas, culturally and linguistically diverse groups, or any other group with low participation rates.</p>

Components	Information Required	Information sources	Collection Methods	Gaps or Challenges
4.3 How effective has assessment been?				
What have been the benefits and drawbacks of assessment colonoscopy for participants?	Data indicating the length of time between referral and access to assessment colonoscopy services  Comparable international data for the timeliness of assessment colonoscopy  Views of participants and medical practitioners	Data from the Register  International literature/ reporting of comparable programs  Feedback from participants and partners	Secondary analysis of program data  Literature scan / desk research  Interviews with program participants and partners	The lack of an agreed standard for colonoscopy timeliness presents a challenge in answering this question.  Lack of comparable public/private sector data
Are there significant differences in the effectiveness of assessment between:  (a) The public and private health system, and	Information on the model for provision of assessment colonoscopy and histopathology in each jurisdiction and the private sector  Participation trends following	AIHW Monitoring report / jurisdiction reporting  <i>Participation data collected against question 1.2</i>  Feedback from	Secondary analysis of program data  Interviews with program partners	Information provided through interview may need to be tested and verified by additional data collection in order to strengthen findings.  Alternatively, this information could be tested and validated with an expert reference group.  <i>Refer to question 1.2 (Objective 2) for details on the collection of participation rates by jurisdiction</i>

Components	Information Required	Information sources	Collection Methods	Gaps or Challenges
(b) Public system approaches in different jurisdictions?	initial referral in the screening pathway for each jurisdiction Views of program partners	program partners		

Source: KPMG

**NOTES ABOUT QUESTION 4:**

Key Question 6 addresses the appropriateness of the screening pathway and alignment with international good practice, and the effectiveness of monitoring across the pathway. Information collected in this section will relate strongly to that collected in response to Question 6.

**Key Question 5: How effective are the program registry, mail house, monitoring and reporting processes?**

Components	Information Required	Information sources	Collection Methods	Gaps or Challenges
5.1: How effective are the program registry, mail house, monitoring and reporting processes?				
<p>How effective have program monitoring and reporting been?</p> <p>How effectively has the register been used to collect accurate and complete data?</p> <p>How effective has the mail house been as a communication mechanism?</p> <p>To what extent have monitoring data been used for program improvement?</p>	<p>Views of program managers and partners on the effectiveness of:</p> <ul style="list-style-type: none"> <li>• The Register</li> <li>• Mail house function</li> <li>• Monitoring reports</li> <li>• Evaluations</li> </ul> <p>Overview of the data content of the register, and evidence of data quality</p> <p>Evidence of adjustments to the program operations based on findings of monitoring and evaluation reports</p> <p>Information on the effectiveness of arrangements for other comparable cancer screening programs</p>	<p>Feedback from program managers and partners</p> <p>Analysis of data in the Register</p> <p>Program management documents</p>	<p>Interviews with program managers and partners</p> <p>Secondary analysis of program data</p>	<p>Information provided through interview may need to be tested and verified by additional data collection in order to strengthen findings.</p> <p>Alternatively, this information could be tested and validated with an expert reference group.</p> <p>Identification of ‘comparable cancer screening programs’ will need to be carefully considered during the evaluation design.</p>

Source: KPMG



**Key Question 6: Is the program appropriate?**

Components	Information Required	Information sources	Collection Methods	Gaps or Challenges
6.1 Is the program appropriate?				
<p>Does the program, and the issues it addresses, remain a high priority?</p> <p>Do the program’s goals and objectives remain appropriate?</p> <p>Are the program’s goals and objectives measurable?</p>	<p>Prevalence of bowel cancer and burden of disease relative to other health challenges</p> <p>Feedback from managers and partners</p>	<p>International literature</p> <p>Interviews with program managers and partners</p>	<p>Literature scan / desk research</p> <p>Interviews with program managers and partners</p>	None anticipated.
<p>Does the program align with good practice for cancer screening programs?</p>	<p>Current information on good practice in cancer screening pathways</p>	<p>International literature/ reporting of comparable programs</p>	<p>Literature scan / desk research</p>	<p>Refer to section 2.3 in the text for discussion on limitations in comparable programs</p>

Components	Information Required	Information sources	Collection Methods	Gaps or Challenges
Is the program delivered in an appropriate way, particularly for 'hard to reach' groups?	Views of participants who have used alternative service delivery approaches  Views of non-participants	Pilot alternative service delivery reporting  Feedback from non-participants	Secondary analysis of program data  <i>Refer to section 4.1 for interviews of non-participants</i>	Pilot alternative service delivery reporting should provide feedback from the target groups, but if this is not sufficient additional interviews may be necessary  <i>Refer to section 4.1</i>
Is the usual care model an appropriate mechanism for delivery of assessment and diagnosis services?	Participation rates (trend data and projections)  Information on the effectiveness of arrangements for other comparable cancer screening programs  Current information on good practice in cancer screening  Views of program managers and partners	Analysis of data in the Register  International literature/ reporting of comparable programs  Interviews with program managers and partners	Secondary analysis of program data  Interviews with program managers and partners  Modelling of projections for future morbidity and mortality outcomes	Identification of 'comparable cancer screening programs' will need to be carefully considered during the evaluation design.
To what extent is the program aligned with current government policy and priorities?	Federal and state government priorities and budgets in the health sector, and views of key staff and representatives	Feedback from program managers and partners	Interviews with program managers and partners	None anticipated.

Source: KPMG

**Key Question 7: Is the program efficient and cost effective?**

Components	Information Required	Information sources	Collection methods	Gaps or challenges
<b>7.1: Is the program efficient?</b>				
<p>What is the cost of the program?</p> <p>How do costs (and unit costs) vary between different program delivery arrangements?</p> <p>How do unit costs compare with other, similar screening programs?</p> <p>How can the efficiency of the program be improved?</p>	<p>Expenditure (by year, by State/Territory, by expenditure category)</p> <p>Number of people screened (by characteristic such as age, location, by year)</p> <p>Unit costs of other screening programs (publicly available data/evaluations, data held by the Department)</p>	<p>Data to be provided by the Department and States/Territories (if not held by Department)</p> <p>Publicly available data</p>	<p>Secondary analysis of program data</p>	<p>Identification of the comparable cancer screening programs will need to be carefully considered and agreed during the evaluation design. Once the comparator programs have been agreed, it may be a challenge to obtain unit cost information for those programs.</p> <p>Identifying opportunities for efficiency improvements is also likely to be a challenge.</p> <p>Lack of comparable public/private sector data</p>

Components	Information Required	Information sources	Collection methods	Gaps or challenges
<b>7.2: Is the program cost-effective?</b>				
<p>What are the costs of the program, including direct and indirect costs?</p> <p>What are the benefits (costs avoided) as a result of early detection of bowel cancer (that is, as a result of the NBCSP)?</p> <p>What are the benefits, in terms of reduced mortality and morbidity, as a result of early detection of bowel cancer (that is, as a result of the NBCSP)?</p> <p>What is the value of the screening program, considering all of the costs and benefits, in net-present-value terms?</p>	<p>Number and characteristics of eligible people in target cohorts</p> <p>Bowel cancer prevalence, incidence and mortality data</p> <p>Bowel cancer treatment costs</p> <p>Number of people screened under the program (by characteristic)</p> <p>Direct program expenditure (by year, by State/Territory, by expenditure category)</p> <p>Indirect expenditure resulting from the program (individuals, families/carers, health system/government)</p> <p>Range of publicly available data to estimate productivity losses, income and other tax losses, costs to families/carers of bowel cancer</p> <p>Burden of disease data</p>	<p>Program monitoring data</p> <p>Other data held by AIHW, WHO (burden of disease, costs of bowel cancer treatment)</p>	<p>Secondary analysis of program data</p> <p>Access to relevant AIHW/WHO data sets and tables</p>	<p>A key challenge will be obtaining robust data on benefits – either costs avoided or improvements in mortality and morbidity – as a result of early detection</p> <p>Lack of comparable public/private sector data</p>

Source: KPMG