Appendix A: The screening pathway

The participant's screening pathway for the first phase of the program (Figure A.1) has been taken from the Australian Government Department of Health and Ageing website. The screening pathway and other information about the NBCSP and Pilot Program can be found at <www.cancerscreening.gov.au>.

The total number of people invited to participate in the NBCSP and their progression through the screening pathway is given in Figure A.2.

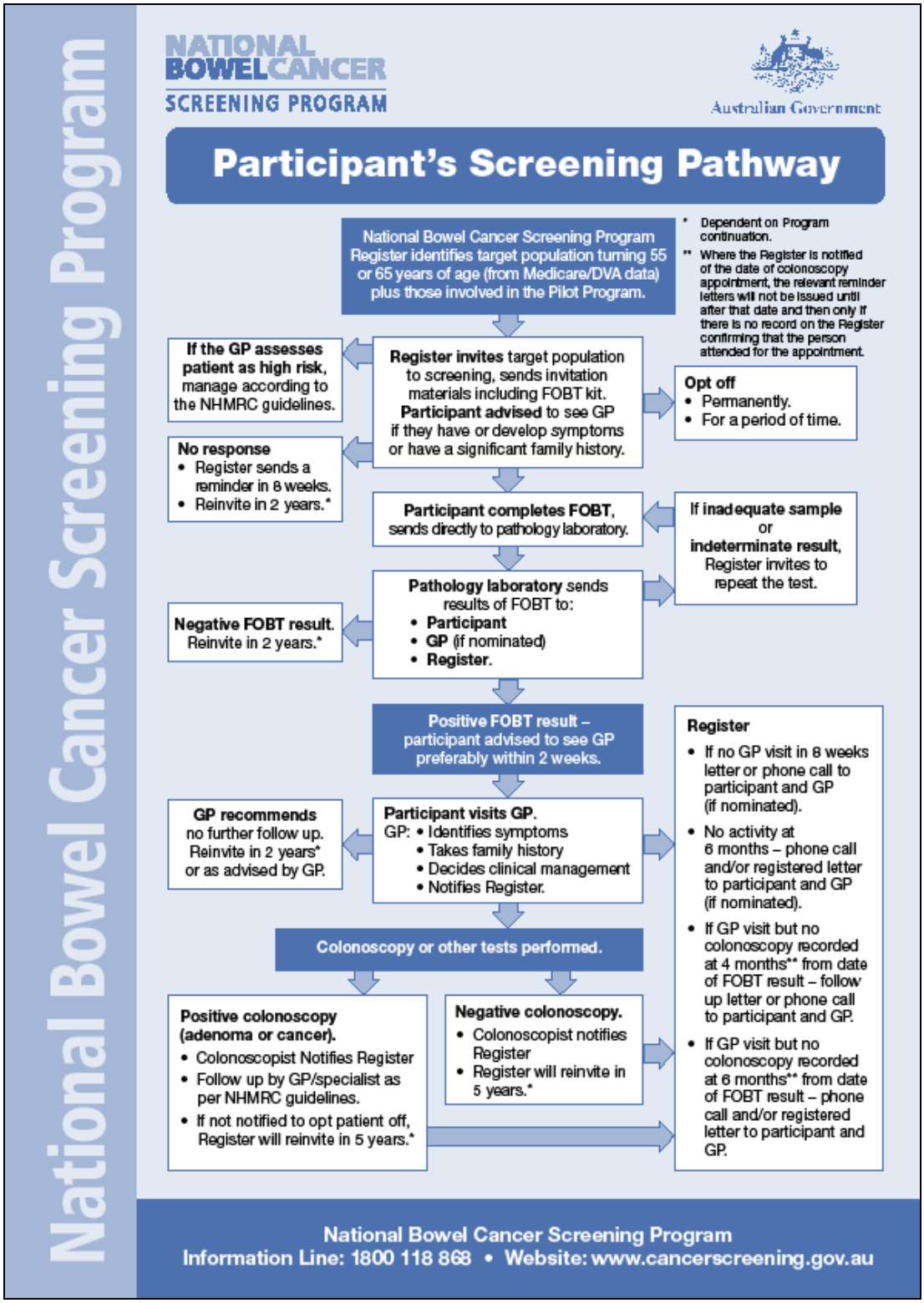
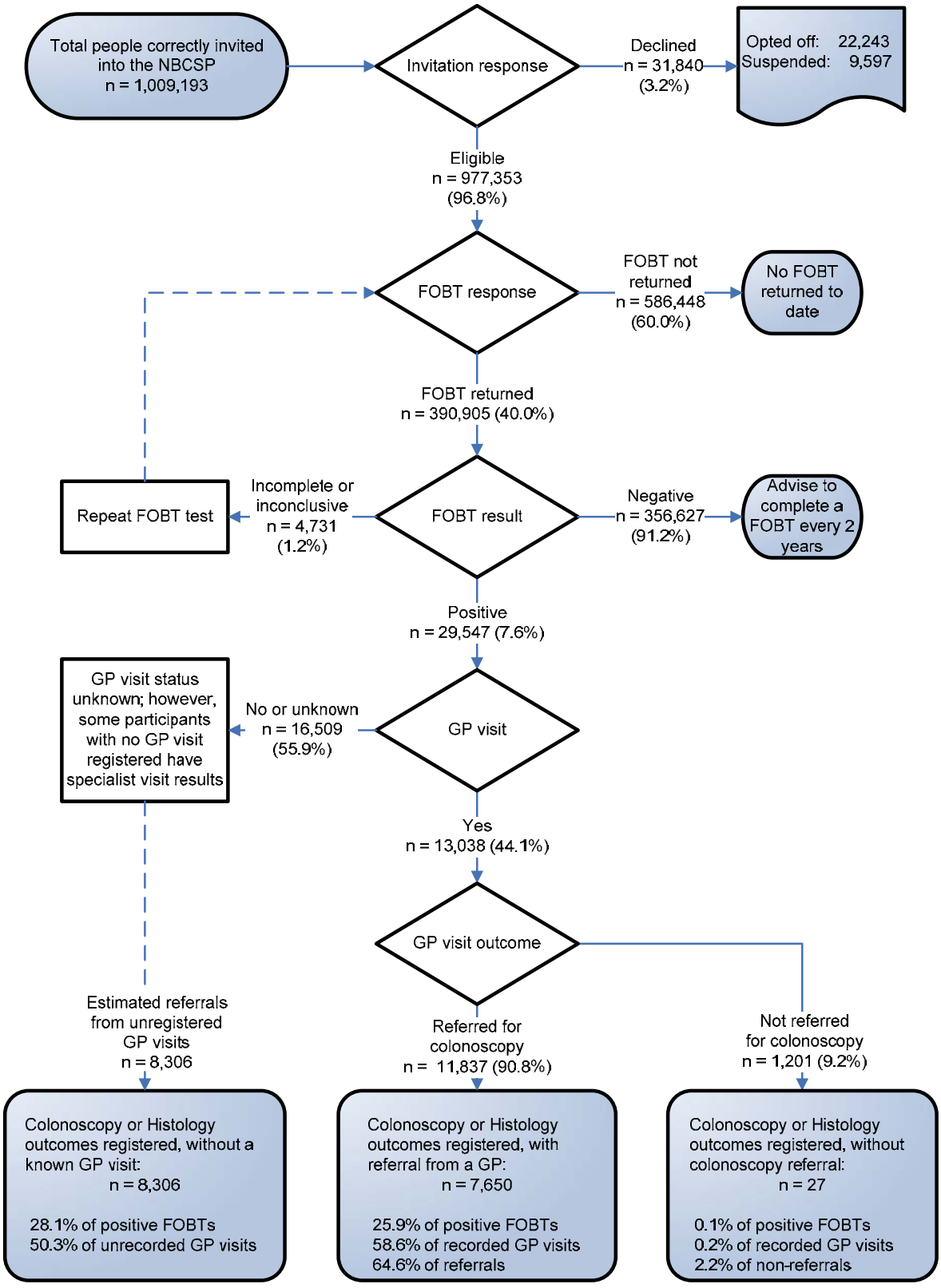


Figure A.1: Participant's screening pathway



Source: National Bowel Cancer Screening Program Register.

Figure A.2: Total number of people invited to participate in the NBCSP at key pathway points, 7 August 2006 to 30 June 2008

Appendix B: Definitions

Target population

Phase one of the NBCSP defines the eligible population as:

- Australians turning 55 or 65 years of age between 1 May 2006 and 30 June 2008; and
- those who were invited to participate in the Bowel Cancer Screening Pilot Program regardless of whether or not they participated in the Pilot Program.

Eligible population

National Program invitees who turned 55 or 65 years before 1 May 2006 or after 30 June 2008 or Pilot Program participants and invitees who were outside the ages of 55–74 years as at 1 January 2003 are ineligible to participate and are excluded from the analyses.

In addition, a person may choose to opt off or suspend participation in the NBCSP, or their GP may recommend they opt off or suspend participation in the NBCSP (for example, because of a recent colonoscopy or previous diagnosis of bowel cancer). A person can opt off or suspend participation at various points along the screening pathway, for example, before completing an FOBT, or when following up a FOBT result with their doctor. People choosing to opt off or suspend participation are classified as ineligible and excluded from further analysis.

Geographic location classifications

Geographic location was classified according to the Australian Bureau of Statistics (ABS) Australian Standard Geographical Classification (ASGC) Remoteness Structure, which groups geographic areas into six categories. These categories, called Remoteness Areas (RAs), are based on Census Collection Districts (CDs) and defined using the Accessibility/Remoteness Index for Australia (ARIA). ARIA is a measure of the remoteness of a location from the services provided by large towns or cities. Accessibility is judged purely on distance to one of the metropolitan centres. A higher ARIA score denotes a more remote location. The six RAs of the ASGC Remoteness Structure are listed in Table B.1; the sixth 'Migratory' area is not used in this publication.

Residential address postcodes of participants were mapped to Census Collection Districts (CDs) in 2006 and then classified to the five main RAs, ranging from Major cities to Very remote areas. As some postcodes can span different RAs, a weighting for each RA is attributed to the postcode.

Table B.1: Remoteness areas for the ASGC

Region	Collection districts within region
Major cities of Australia	CDs with an average ARIA index value of 0 to 0.2
Inner regional Australia	CDs with an average ARIA index value greater than 0.2 and less than or equal to 2.4
Outer regional Australia	CDs with an average ARIA index value greater than 2.4 and less than or equal to 5.92
Remote Australia	CDs with an average ARIA index value greater than 5.92 and less than or equal to 10.53
Very remote Australia	CDs with an average ARIA index value greater than 10.53
Migratory	Areas composed of off-shore, shipping and migratory CDs (not included in this report)

Socioeconomic classifications

Socioeconomic classifications are based on the ABS Index of Relative Socioeconomic Disadvantage (IRSD). Geographic areas are assigned a score based on attributes such as low income, low educational attainment, high unemployment and jobs in relatively unskilled occupations. It does not refer to the socioeconomic situation of a particular individual but instead refers to the area in which a person lives. A low score means an area has many low income families, people with little training and high unemployment, and may be considered disadvantaged relative to other areas. Areas with high index scores may be considered less disadvantaged relative to other areas. Geographic areas may be excluded where no score is determined due to low populations or high levels of non-response in the underlying census. In the 2006 Socio-Economic Index for Areas (SEIFA) 36 Postal Areas have been excluded.

In this report, a participant's socioeconomic status is classified using the participant's residential postcode according to the IRSD for 2006. Quintiles based on the level of the index are used for analysis where quintile 1 represents the least disadvantaged fifth of the population and quintile 5 the most disadvantaged fifth.

Aboriginal and Torres Strait Islander status

Identification of an individual as Aboriginal and Torres Strait Islander is based on self-identification to Medicare Australia through this or other programs. The denominator for initial participation rates for Aboriginal and Torres Strait Islander people is estimated from the 2006 Census. See Appendix C for a description of the method of estimation.

Preferred correspondence language

Identification of an individual as preferring to correspond in a language other than English is based on self-identification to Medicare Australia through this or other programs. However, if no preference was indicated by an individual, English is assumed. The denominator for initial participation rates stratified by preferred correspondence language is estimated from the 2006 Census. See Appendix C for a description of the method of estimation.

Disability status

A severe of profound disability status refers to those people who returned a completed FOBT kit and identified a need for assistance due to a disability in questions 6–9 in the Participant Details form. These questions relate to need for assistance with self-care, movement and communication and are directly comparable to questions on need for assistance due to a disability from the 2006 Census. The denominator for initial participation rates stratified by disability level is estimated from the 2006 Census. See Appendix C for a description of the method of estimation.

Polyps

Colorectal polyps are small growths of colon tissue that protrude into the colonic or rectal lumen. They are usually asymptomatic, but sometimes cause rectal bleeding, and rarely, other symptoms. Polyps may occur individually but it is not uncommon for a person to have multiple polyps. They occur more commonly in later life, and hereditary and dietary (lifestyle) factors are also implicated in their occurrence. Polyps may become cancerous and are generally defined as two main types:

- Hyperplastic: A type of polyp that has a low risk, if any, of developing into a cancer. However, people with multiple hyperplastic polyps are associated with an increased risk of bowel cancer.
- Adenoma (Adenomatous): A polyp that has a higher chance of becoming cancerous as they contain molecular characteristics that are common with adenocarcinoma. See Adenoma classifications (below).

Polyp number, size and microscopic features may also predict the likelihood of the polyp becoming cancerous, with larger and flatter (non-stalked) polyps having the higher risk. During a colonoscopy polyps are removed, thus lowering the risk of bowel cancer developing in the person.

Adenoma classifications

An adenoma (adenomatous polyp) is a benign tumour that arises from epithelial cells that line the inside surface of an organ. 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.

Although nearly all cancers in the colon (adenocarcinoma) arise from adenomas, only a small minority of adenomas (1 in 20 or less) actually progress to cancer (Ahnen & Macrae 2008). While most small tubular adenomas have a low risk of progressing to cancer, the risk is much higher in advanced adenomas.

Adenoma classifications are derived from information reported by colonoscopists and pathologists and are classified as listed below from highest risk (advanced) to lowest risk (diminutive). Where a person has multiple adenomas, he or she is classified according to the adenoma having the highest risk.

Advanced adenoma

If any of the indicators of higher risk listed below are present, the adenoma is classified as advanced.

Indicators of higher risk

- Adenoma multiplicity—three or more adenomas present at examination, regardless of histopathology or size.
- Adenoma size—a size of 10 mm or greater. The measurement of size is subject to certain problems with accuracy. Where colonoscopy and pathology reports differ in their recording of size, the larger size has been used.
- High-grade dysplasia.
- Significant villous change or serrated—adenomas recorded as serrated, tubulovillous or villous on pathology reports.

Small adenoma

A tubular or mixed adenoma between 5 mm and 9 mm in size.

Diminutive adenoma

A tubular or mixed adenoma smaller than 5 mm.

Appendix C: Data and statistical methods

Data sources

Multiple data sources were analysed to produce this report. These are summarised in Table C.1. All data used in this report are based on calendar years.

Table C.1: Sources for data presented in this report

Description	Data source
Participation	National Bowel Cancer Screening Program Register
Cancer detection	National Bowel Cancer Screening Program Register
Population data	Australian 2001 standard population and 2006 census, ABS
Incidence (ICD-10 C18–20)	National Cancer Statistics Clearing House, AIHW
Mortality (ICD-9 153, 154.0–154.1, ICD-10 C18–20)	National Mortality Database, AIHW

NBCSP data

As data items are collected from a variety of sources, not all data items may be recorded in the Register in sequence. GP, colonoscopy and histopathology forms are received from different sources and there are both time lags in submitting forms, and failure of clinicians to complete and submit forms to the Register. Hence there are data for colonoscopies without an associated GP Assessment form, and histopathology results without a completed Colonoscopy Report form. The effect of this under-reporting and lags in reporting is that the data on the actions resulting from a positive FOBT are significantly underestimated. Hence the data on colonoscopies undertaken and conditions found should be interpreted with great caution.

In those states using geographic rollout, Outer regional, Remote and Very remote locations may be relatively more under-reported than Major cities and Inner regional areas. Hence, the tables in this report by geographic location and socioeconomic status should be interpreted with caution.

Population data

National Program participation denominators for Aboriginal and Torres Strait Islander status (Table 2.1.4), preferred correspondence language (Table 2.1.5) and disability level (Table 2.1.6), were estimated from the proportion of people in these groups in the 2006 Census.

ABS Australian 2001 standard population data were used to calculate age-standardised rates for the Pilot program, and bowel cancer incidence and mortality.

Incidence data

Incidence data in this report came from the National Cancer Statistics Clearing House (NCSCH), a national collection of cancer statistics held and operated by the AIHW. The NCSCH receives data from individual state and territory cancer registries on cancers diagnosed in residents of Australia, and produces reports on national incidence.

Incidence of bowel cancer in this report is given for 1991–2005, the latest year for which national incidence data is available.

Mortality data

Data for this measure came from the AIHW's National Mortality Database. The National Mortality Database is a national collection of de-identified information for all deaths in Australia and is maintained by the AIHW. Information on the characteristics and causes of death of the deceased is provided by the Registrars of Births, Deaths and Marriages and coded nationally by the ABS. Information on the cause of death is supplied by the medical practitioner certifying the death, or by a coroner. The data are updated each calendar year.

Mortality data in this report are given for 1992–2006. During this time, changes have been made to the coding and processing of mortality data that affect comparability of the data. Data for holdings for 1987–1996 were manually coded using the ninth revision of the International Classification of Diseases (ICD-9). Data holdings for 1997 onwards were coded using ICD-10, using an automated system with slightly different coding rules.

The change to the coding and processing of mortality data introduced a break in the data time series. The ABS has developed comparability factors, which are applied to pre-1997 data, so that a single time series may still be derived (ABS 2006). For bowel cancer, the comparability factor is close to 1 (0.98).

Data were analysed using the year of occurrence of death for the period 1992–2005 and year of registration of death for 2006. This is because mortality data by year of occurrence of death is a more accurate reflection of mortality during a particular year than year of registration data; however, year of occurrence data for 2006 are still incomplete owing to late registrations.

All states and territories have provision for the identification of Indigenous deaths on their death registration forms. However, the coverage of deaths identified as Indigenous varies across states and territories and over time. While the identification of Indigenous deaths is incomplete in all state and territory registration systems, four jurisdictions (Queensland, Western Australia, South Australia and the Northern Territory) have been assessed by the ABS and the AIHW as having adequate identification. These four jurisdictions represent approximately 60% of the Indigenous population of Australia.

Data for Indigenous deaths, state and territory and geographic location have been combined for the 5-year period 2002–06 due to the small number of deaths from bowel cancer in each year.

Geographic classification

The approach taken in this report to classify participants as belonging to a specific geographic location is based upon the postcode of the participant's residential address. Postcodes do not map directly to the ARIA classification system (see Appendix B for explanation of the ARIA system). ARIA classifications for postal areas (similar to postcodes)

are determined by amalgamating component Collection Districts (CDs). Where postal areas have component CDs belonging to more than one remoteness area, the ARIA classification is apportioned. Participants with a postcode that spans ARIA classifications must be likewise apportioned. This results in non-integer counts for remoteness classifications. For example, the Northern Territory postal area 0822 is classified as 70.54% Very remote, 6.64% Remote and 22.82% Outer regional. Participants with postcode 0822 have their counts apportioned accordingly.

Tables in this report based on geographical location are rounded to integer values. Where figures are rounded, discrepancies may occur between totals and sums of the component items.

Comparisons and tests of statistical significance

This report includes statistical tests of the significance of comparisons of rates between population groups. Any statistical comparison applied to one variable must take account of any other potentially relevant variables. For example, any comparison of participation by state must also take account of differences in the distribution of age and sex between the states. These other variables are known as 'confounding' variables.

Crude rates

A crude rate is defined as the number of events over a specified period of time divided by the total population. The crude rate (for participation, attendance and follow-up) is the proportion of people who have proceeded to a key point on the screening pathway (at the date of the data download) out of those eligible to proceed to that point. For example, the crude FOBT participation is the proportion of the eligible people who return a completed FOBT kit by 30 June 2008. The crude colonoscopy follow-up is the proportion of people with a positive FOBT result who proceeded to colonoscopy by 30 June 2008.

The crude proportions will generally underestimate the true proportions of the population who participated in the NBCSP. This is because at any point in time there are members of the population who are eligible to proceed to the next point on the screening pathway but who have not yet had time to do so. For example, a person who has just received an invitation to screen may intend to participate in screening but may not have had time to do so. They will be counted in the denominator of the crude FOBT participation but not in the numerator. Similarly, there is a time lag between when a person with a positive FOBT result is referred for colonoscopy and when they can actually have the colonoscopy. A colonoscopy follow-up calculated during this lag includes them in the denominator but not in the numerator.

Kaplan-Meier estimates of participation and follow-up

The Bowel Cancer Screening Pilot Program employed the use of Kaplan-Meier estimates of participation, attendance and follow-up. This statistical method calculates a modelled rate based on the time it takes each individual invited for screening to move between points on the screening pathway. For example, FOBT participation is calculated by following each invited person and, for those who respond, recording the time it takes them to respond. This allows the calculation of a response rate over time from the date of invitation. Kaplan-Meier methods are standard methods used to model the time to an event and the changes in the rates of an event over time. In this case, the event is a person's response (by returning a completed FOBT kit) and the time to the event is measured in weeks from the date the

invitation was sent. These Kaplan-Meier estimates represent valid estimates of the true FOBT participation. The use of Kaplan-Meier estimates in the NBCSP was endorsed by the Implementation Advisory Group and allows direct comparison of participation, attendance and follow-up rates with the Bowel Cancer Screening Pilot Program.

In principle, the Kaplan-Meier estimate only gives a result at a specific point in time. The estimate is likely to grow for later points in time. However, inspection of these estimates shows that they reach a plateau after which they have only a negligible increase. Kaplan-Meier estimates in this report were calculated for participation at 38 weeks and colonoscopy follow-up at 52 weeks. Further, preliminary analyses based on modelling the survival time with both a Weibull and an exponential distribution shows that the latest observed Kaplan-Meier estimate differs from the long-term modelled estimate by less than 1 percentage point. Hence the latest Kaplan-Meier estimate can be taken as an approximate estimate of the overall rate.

The Kaplan-Meier estimates require that classifying variables be known for the population. Hence they can be calculated for FOBT participation classified by age, sex and state. However, they cannot be used for FOBT participation classified by Aboriginal and Torres Strait Islander status or language group which are not known for all the invited population. These variables are only known for those participants who identify themselves as a member of these groups on their returned Participant Details form. In these cases, a crude participation can be calculated by using known population counts (from the Australian Bureau of Statistics Census data) in the denominator. However, the Kaplan-Meier estimates cannot be applied in this situation. In these cases, all analyses will be based solely on the crude participation. Therefore, the FOBT participation presented in this report for Aboriginal and Torres Strait Islander people, people with a disability and people with a language other than English may represent underestimates of the true proportions.

Aboriginal and Torres Strait Islander and disability status and language group will be known for all people completing FOBT kits (at least to the extent that people self-identify as members of these groups). Hence in principle Kaplan-Meier estimates can be calculated for these groups for participation at subsequent points on the screening pathway. In practice, these calculations depend on sufficient numbers of people self-identifying as group members to allow the calculation of reliable estimates.

Age-specific rates

Age-specific rates are calculated by dividing the number of cases occurring in each specified age group by the corresponding population in the same age group, expressed as per 100,000 persons.

Age-standardised rates (ASRs)

Rates are adjusted for age to facilitate comparisons between populations that have different age structures, for example, between youthful and ageing communities. There are two different methods commonly used to adjust for age. In this publication direct standardisation is used, in which age-specific rates are multiplied against a constant population (the Australian 2001 population). This effectively removes the influence of age structure on the summary rate and is described as the age-standardised rate.

The method used for this calculation comprises three steps:

- Calculate the age-specific rate for each age group.
- Calculate the expected number of cases in each 5-year age group by multiplying the age-specific rates by the corresponding standard population and dividing by 100,000, giving you the expected number of cases.
- To give the age-standardised rate, sum the expected number of cases in each age group. Divide this sum by the total of the standard population used in the calculation and multiply by 100,000.

Confidence intervals (CI)

The crude rates in the National program and the age-standardised rates presented in the Pilot program also show 95% confidence intervals. These confidence intervals indicate the variation that might be expected in such estimates purely by chance. The confidence intervals for age-standardised rates in the Pilot program and Incidence and Mortality chapter are calculated using the methods presented by Holman et al. (1987).

A relatively simple approximation of the confidence intervals that readers might use when examining age-standardised rates is:

$$95\%\ \text{CI approximation} = \text{AS rate} \pm 1.96 \times \frac{\text{AS rate}}{\sqrt{\text{Number of cases}}}$$

Confidence intervals for crude proportions (p) were calculated using the basic confidence interval formula for binomial proportions:

$$95\%\ \text{CI for proportions} = p \pm 1.96 \times \sqrt{\frac{p \times (1-p)}{\text{Number of cases}}}$$

Glossary

Age-standardised rate: see Appendix C for definition.

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

Confidence interval: see Appendix C for definition.

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

Colonoscopy depth of insertion: abbreviations for depth of insertion of colonoscope are:

TI	terminal ileum
CAEC	caecum
ASC	ascending colon
HEP	hepatic flexure
TRAN	transverse colon
SPLN	splenic flexure
DESC	descending colon
SIG	sigmoid colon
RECT	rectum

Colonoscopy follow-up rate: the proportion of people with a positive FOBT who subsequently had a colonoscopy.

Dysplasia: Abnormal growth of cells or organs. For example, the abnormal growth of colon cells with colon cancer.

Eligible population: Australians turning 55 and 65 years of age between 1 May 2006 and 30 June 2008, and those invited to participate in the Bowel Cancer Screening Pilot Program who have not opted off or suspended participation in the Program.

FOBT: immunochemical faecal occult blood test—a self-administered test to detect blood in bowel motions, but not bowel cancer itself. The FOBT is analysed by a pathology laboratory and results forwarded to the Register, participant and primary health care practitioner (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 two weeks apart, or a kit that has taken over one month in transit to arrive). Participants with FOBTs that are not correctly completed are requested to complete a subsequent FOBT. See Appendix A for details of the participant screening pathway.

FOBT result: FOBT results are classified by pathologists as either:

1. Positive (blood is detected in at least one of two samples)
2. Negative (blood is not detected)
3. Inconclusive (the participant is asked to complete another kit).

GP attendance rate: the proportion of people who were sent a positive FOBT result and who subsequently visit a GP.

Invitee: a person who has been invited to participate in the National Bowel Cancer Screening Program.

National Program: participants in the NBCSP aged 55 or 65 years. Excludes participants and invitees from the Pilot Program.

NBCSP: National Bowel Cancer Screening Program, including both National Program participants and Pilot Program participants and invitees.

Opt off: invitees who do not wish to participate in the National Bowel Cancer Screening Program now or in the future. Invitees will not be contacted again. Invitees may elect to opt back on at a later date.

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

Pilot Invitee: invitees from the Pilot Program who did not participate in the Pilot Program but were re-invited to participate in the NBCSP.

Pilot Participant: participants from the Pilot Program who were re-invited to participate in the NBCSP.

Pilot Program: participants and invitees from the Bowel Cancer Screening Pilot Program (a study by the Australian Government from November 2002 to June 2004 in Mackay, Adelaide and Melbourne to assess the effectiveness of a National Bowel Cancer Screening Program) re-invited to participate in the NBCSP.

Positivity rate: number of positive FOBT results as a percentage of the total number of valid FOBT results.

Primary health care practitioner: classified by Medicare Australia as a general practitioner (GP) or other primary health care provider. This may include remote health clinics or other specialists providing GP services.

Register: National Bowel Cancer Screening Program Register maintained by Medicare Australia.

Rescreening: the repeated performance of screening tests on eligible people at regular intervals.

Screening: the performance of tests on apparently well people in order to detect a medical condition at an earlier stage than would otherwise be the case.

Socioeconomic status: see Appendix B for details.

Suspend: invitees who would like to participate in the National Bowel Cancer Screening Program but are unable to do so at this time. Invitees will be contacted once the nominated suspension period has elapsed.

Target population: Australians turning 55 and 65 years of age between 1 May 2006 and 30 June 2008, and those invited to participate in the Bowel Cancer Screening Pilot Program.

Valid results: only FOBT results that are either positive or negative are classified as valid results. Inconclusive results are excluded.

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List of tables

List of figures