

# 1

## Introduction

The Australian Government Department of Health and Ageing funded three pilot sites for the Bowel Cancer Screening Pilot Program (BCSPP). The aim of the pilot program was to assess the feasibility, acceptability and cost effectiveness of population based bowel cancer screening in the Australian context. In this pilot program men and women between the ages of 55 and 74 were screened using Faecal Occult Blood Tests (FOBT), which determine the presence of blood in faeces. There is international level one evidence that the use of FOBT can significantly reduce mortality from bowel cancer when used in a population based screening program.

The pilot sites are Mackay, Queensland and defined geographic areas of Adelaide and Melbourne<sup>1</sup>. As part of this pilot program the Australian Government funded Queensland Health to undertake surveys of households in the pilot sites of the three states to determine Knowledge, Attitudes and Practices (KAP) about bowel cancer and bowel cancer screening in the latter stages of the pilots. An earlier survey was undertaken prior to the commencement of the pilots and this data has provided a baseline from which to evaluate the pilots. All surveys were conducted by the Epidemiology Services Unit, Health Information Branch, and involved residents aged between 50 and 74 years. Surveys were conducted over the following periods:

Site	2002	2004
Mackay	7 October – 13 November	16 January – 3 March
Adelaide	31 October – 21 November	30 January – 10 March
Melbourne	20 November – 14 December	1 March – 8 April

The telephone surveys comprised questions on knowledge, attitudes and behaviours in relation to cancers, especially colorectal cancer and FOBT. Standard demographic questions were also asked. The post-intervention surveys also included questions directed towards people who reported that they had received an FOBT kit.

These questions were about the acceptability and practicality of population based bowel cancer screening using FOBT. This project involved carrying out statistical analysis of the survey results to assist in evaluation of the pilot program.

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<sup>1</sup> Mackay postcodes: 4740, 4741, 4750, 4751  
Adelaide postcodes: 5011, 5012, 5022, 5023, 5024, 5040, 5044, 5045, 5048  
Melbourne postcodes: 3070, 3071, 3078, 3079, 3081, 3083, 3084, 3085, 3087, 3088

# 2

## Methods

In 2002 a general population survey of people aged between 50 and 74 years was conducted in each site. In 2004 two surveys were conducted in each pilot site: a general population survey of people aged between 50 and 74 years, and a participants' survey of people who reported that they had completed and returned the FOBT kit that had been sent to them in the pilot program.

A simple random sample of households for each survey was selected by randomly choosing telephone numbers from editions of the electronic White Pages over the previous four years.

Interviews were conducted using the Health Information Branch computer-assisted telephone interviewing (CATI) system. Trained telephone interviewers and supervisors were employed to conduct the interviews.

A combination of daytime and evening interviewing sessions was utilised in order to give people, particularly shift workers, every opportunity to participate. Sessions were Monday to Friday (3:30pm - 8:30pm), Tuesday (9:30am - 1:30pm), Thursday (9:30 - 1:30pm) and Saturday (10:00am - 5:00pm), local times. If a respondent was contacted at an inconvenient time, an appointment was made for a more suitable time if possible.

### 2.1 General population surveys – 2002 and 2004

The target population was households in the selected postcode areas with at least one individual aged between 50 and 74 years. If there was more than one eligible individual in a household contacted, the person who had most recently celebrated their birthday was asked to participate.

The following individuals were excluded from selection:

- those under 50 or over 74 years of age;
- those unable to speak English sufficiently well for an interview to be conducted;
- those with a mental or physical disability which prevented them from being able to take part in a telephone interview;
- usual residents of the selected household who were absent from the household during the hours in which interviews were conducted during the survey period; and
- visitors to the selected household who did not usually live in that household.

### *Response Rate*

Tables 2.1.1 and 2.1.2 list the number of interviews completed and the response and contact rates for each city for 2002 and 2004.

**Table 2.1.1: Response and contact rates for the General Population Survey (2002)**

	<b>Interviews</b>	<b>Response Rate</b>	<b>Contact Rate</b>
	n	% of contacted in-scope people	% of telephone numbers attempted
<b>City</b>			
Mackay	848	86.8	87.3
Adelaide	963	87.3	88.6
Melbourne	978	84.2	84.9
Combined	2789	86.1	86.7

**Table 2.1.2: Response and contact rates for the General Population Survey (2004)**

	<b>Interviews</b>	<b>Response Rate</b>	<b>Contact Rate</b>
	n	% of contacted in-scope people	% of telephone numbers attempted
<b>City</b>			
Mackay	1000	81.2	87.3
Adelaide	1004	74.2	87.9
Melbourne	980	72.8	84.0
Combined	2984	75.9	86.2

## **2.2 Participants survey (2004)**

The target population was households in the selected postcode areas with at least one individual who reported receiving an FOBT kit as part of the pilot program, and who completed the test and returned it to the laboratory for testing. If there was more than one eligible individual in a household that was contacted, the person who had most recently celebrated their birthday was asked to participate.

The following individuals were excluded from selection:

- those who reported that they had not been sent an FOBT kit as part of the pilot program;
- those who reported that they had been sent an FOBT kit as part of the pilot program but had not completed the test and returned it to the laboratory for testing;
- those unable to speak English sufficiently well for an interview to be conducted;
- those with a mental or physical disability which prevented them from being able to take part in a telephone interview;
- usual residents of the selected household who were absent from the household during the hours in which interviews were conducted during the survey period; and
- visitors to the selected household who did not usually live in that household.

### *Response Rate*

The number of interviews achieved and the response and contact rates for each city and the combined sample are listed in table 2.2.1 below.

**Table 2.2.1: Response and contact rates for the Participants' Survey (2004)**

	<i>Interviews</i>	Response Rate	Contact Rate
	n	% of contacted in-scope people	% of telephone numbers attempted
City			
Mackay	117	83.6	87.3
Adelaide	111	85.1	88.0
Melbourne	119	79.9	84.8
Combined	347	82.7	86.3

## **2.3 Weighting procedures**

Weighting is the process of adjusting results from a sample survey to infer results for the total population. The aim of weighting is to minimise any bias in the data resulting from an over- or under-representation of a particular age group or sex and to adjust for the chance of the respondent being included in the survey. To do this, a 'weight' is allocated to each respondent.

The first step in calculating weights for the KAP surveys was to assign an initial weight. Initial weights were based on how many people in the respondent's household were eligible to respond to the survey. A person's initial weight was calculated as the inverse of the probability of being selected within their household. For example, if the respondent was the only eligible person in their household then they had a probability of 1 of being selected so they were assigned an initial weight of 1. If there were 2 eligible people in the household then the respondent had a probability of 1/2 of being selected so they were assigned an initial weight of 2.

The initial weights were adjusted to align with independent estimates of the population of interest, referred to as 'benchmarks', in designated sex by age categories. Weights adjusted against population benchmarks compensate for over- or under-enumeration of particular categories of persons and ensure that the survey estimates conform to the independently estimated distribution of the population by age and sex, rather than to the distribution within the sample itself.

The KAP surveys were benchmarked to population counts from the 2001 Census of Population and Housing (Australian Bureau of Statistics, 2001).

To combine the general population survey and participants' survey, the proportions of those who had received and completed an FOBT were firstly calculated for each sex by age category from the general population survey. The proportions were then used to calculate weights, which would represent the proportion of those who received and completed an FOBT. Weights were then adjusted to match the survey population sampled.

## **2.4 Analysis procedures**

A series of cross tabulations and chi-square tests were performed to allow comparisons of proportions. All analyses were performed using SAS Version 8 (SAS Institute Inc. Cary NC; 1999).

# 3

## Data Quality

As previously described, great care was taken to ensure the results of the survey were as accurate as possible. However, certain factors that cannot be compensated for may affect the results and are discussed below.

### 3.1 Sampling variability

All estimates in this survey are based on a sample of the population and therefore may differ from the figures which would have been obtained had the entire adult population been interviewed.

### 3.2 Non-sampling errors

Non-sampling error refers to errors that occur in any enumeration, whether it is a full count or a sample. Every effort is made to reduce non-sampling error to a minimum by careful design of questionnaires, intensive training and supervision of interviewers, and efficient operating procedures. The main types of non-sampling error are discussed below:

#### *Errors related to scope and coverage*

The KAP surveys were conducted by telephone therefore excluding:

- people living in households without a fixed telephone;
- people unable to speak English sufficiently well for an interview to be conducted;
- people with a mental or physical disability which prevented them from being able to take part in a telephone interview; and
- people who were usual residents of the selected household who were absent from the household during the hours in which interviews were conducted during the survey period.

#### *Response errors*

Response errors may have arisen in the survey as a result of deficiencies in the questionnaire design, imperfections in reporting by respondents and recording by interviewers, and errors made in coding and processing data. Where possible, attempts were made to minimise these potential sources of error.

In the 2004 surveys, privacy legislation prevented release of information about participant status to Queensland Health. As a result respondents were asked whether they had received the FOBT kit and whether they had returned it. The self-reported responses to these questions

were used to classify respondents (see Figure 4.1). Misclassification errors may have arisen where people who had been sent the kit at some time over the previous year but had discarded it, and did not recall having received it.

#### *Non-response bias*

There are two main types of non-response – when people cannot be contacted and when people refuse to participate. Non-response may bias the results to the extent that non-responders differ from respondents in the characteristics being measured. It was not possible to quantify these differences in this study but attempts were made to keep the non-response rate as low as possible.

For further details of the survey methodology, please contact:

Kerry Brady – phone (07) 3234 1587, e-mail [Kerry\\_Brady@health.qld.gov.au](mailto:Kerry_Brady@health.qld.gov.au)

Michael Findlay – phone (07) 3234 1880, e-mail [Michael\\_Findlay@health.qld.gov.au](mailto:Michael_Findlay@health.qld.gov.au)

# 4

## Results

### 4.1 Respondents - 2004

A total of 3331 individuals aged 50-74 years completed the Knowledge, Attitudes and Practices 2004 interview. Tables 4.1a and 4.1b present demographic characteristics of these respondents. Population counts of the sites surveyed were available from the 2001 Australian Bureau of Statistics (ABS) Census of Population and Housing for the demographic variables of age and sex. These are included in Table 4.1a.

Compared with the 2001 ABS Census, there was a slight under-representation of individuals aged 50-59 years and a slight over-representation of individuals aged 60-74 years in the 2004 survey. To adjust for these age and sex differences (so that results are representative of the population) the data has been weighted for all analyses.

**Table 4.1a: Sex and age characteristics of 2004 survey respondents (n=3331)**

<b>Characteristic</b>	<b>2004 Survey Sample</b>		<b>2001 ABS</b>
	n	%	%
<b>Sex</b>			
Male	1651	49.6 <sup>#</sup>	48.3
Female	1680	50.4 <sup>#</sup>	51.7
<b>Age category</b>			
50-59 years	1392	42.1	49.2
60-69 years	1318	39.9	34.4
70-74 years	596	18.0	16.4

<sup>#</sup> Sample stratified by sex hence approx. 50:50 male : female ratio

**Table 4.1b: Socio-demographic characteristics of survey respondents (n=3303)**

	<b>2004 Survey Sample*</b>	
	n	%
<b>Marital status</b>		
Married/ de-facto	2551	77.2
Single/ never married	337	10.2
Separated/ divorced	256	7.8
Widowed	159	4.8
<b>Highest Education Level</b>		
University/ college degree	705	21.3
Trade/ technical cert./ diploma	947	28.6
Senior high school	300	9.1
Junior high school/ Intermediate	824	24.9
Primary school or less	539	16.2
<b>Employment status</b>		
Full-time	959	29.1
Part-time/ casual	475	14.4
Home duties	395	12.0
Retired	1260	38.2
Unemployed/ unable to work/ other	212	6.4
<b>Household income</b>		
Less than \$20,000	837	25.1
\$20, 000 - \$60,000	1206	36.2
Over \$60, 000	789	23.7
Don't know/ No response	529	15.9

\*Excludes those diagnosed with bowel cancer during pilot

## 4.2 Determinants of FOBT participation - 2004

Of the 3331 people interviewed in 2004, a total of 1767 (53%) respondents aged 55-74 years<sup>2</sup> reported that they had received the FOBT kit. These respondents were asked additional questions relating to their pilot experiences. For analysis purposes respondents who reported that they had been sent an FOBT kit were divided into 3 groups:

“Participants”- People who reported returning the kit;

- people who reported that they had not returned the kit but intended to do so; and
- “Non-returners”- People who reported that they would not return the kit.

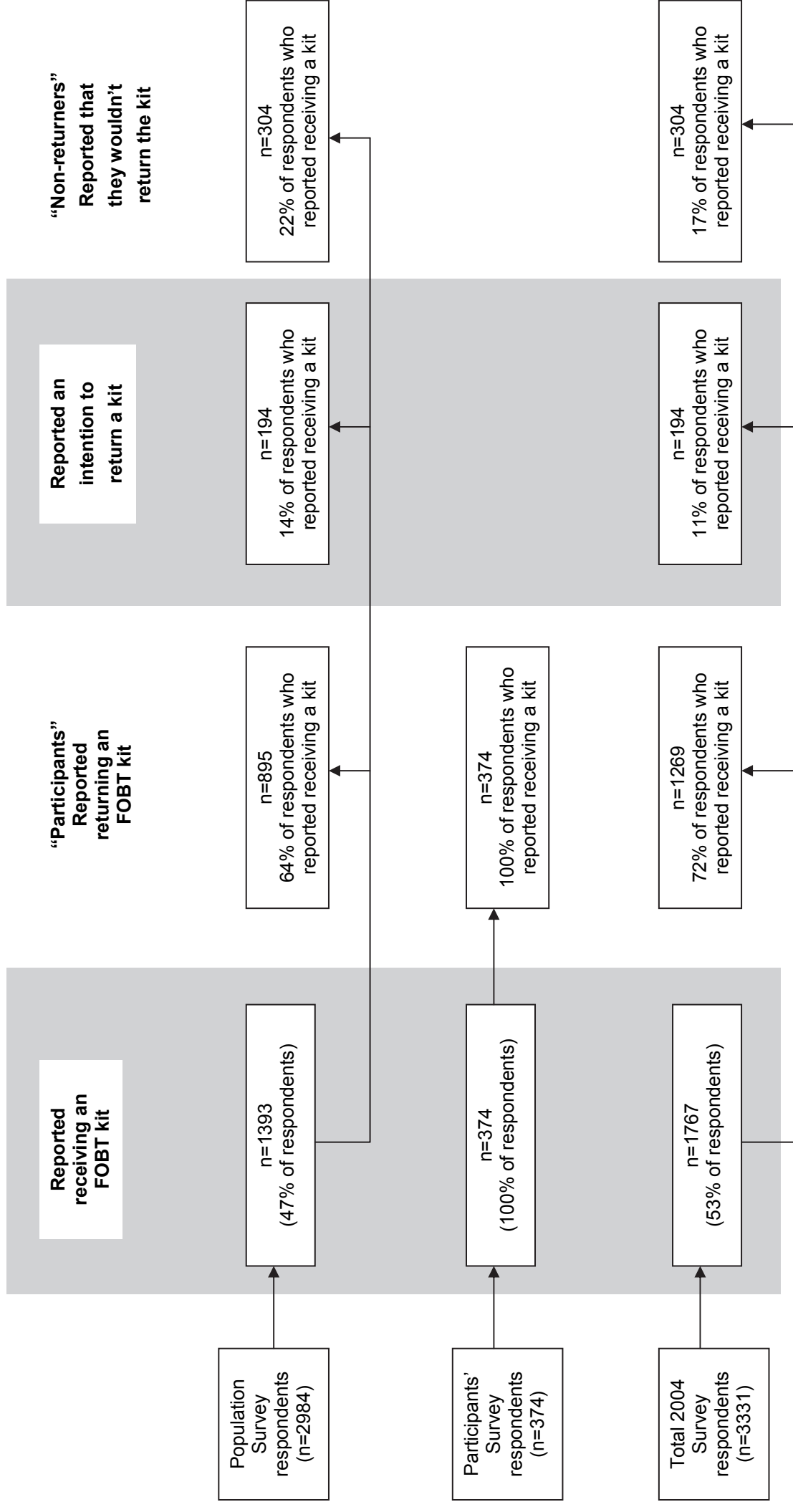
Figure 4.1 demonstrates the number of respondents from each of the 2004 post-intervention surveys who were classified into these groups.

Analysis was complicated by the fact that the FOBT mail-outs were still occurring at the time of the survey. Respondents who “intended to return” the FOBT kit were therefore excluded from the analysis as it was impossible to differentiate between respondents who had received the kit recently and would, in fact, return it and those who would probably never return it despite reported good intentions.

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<sup>2</sup> Eleven people (0.6%) with a reported age of 50-54 years indicated that they received a BCSPP FOBT kit and have been included in this data (with the 55-59 years age group). They comprise eight people who did not complete the kit and three who reported that they completed and returned the kit. Possible reasons for participants aged less than 55 years reporting that they received the kit may include: being aged 54 years turning 55 years that calendar year; having obtained a kit elsewhere; having completed a kit sent to someone else; or having been sent the kit in error. Analysis based on the 55-74 years age group (i.e. excluding these eleven respondents would be very similar to the results reported here.

Figure 4.1 Knowledge, Attitudes and Practices: 2004 Post-Intervention Surveys<sup>1</sup>



<sup>1</sup>Responses to questions relating to participation have been weighted against the 2001 ABS Census.

*Socio-demographic determinants*

Bi-variate (chi-square) analysis showed that people aged 55 to 59 years were slightly less likely than others to have returned the kit. However the proportion of people returning the kit did not differ significantly across different sex, marital status, education levels and employment status (Table 4.2.1a).

**Table 4.2.1a: Socio-demographic determinants of FOBT participation**

	Returned FOBT kit				p value
	Yes		No		
	n	%	n	%	
<b>Sex</b>					0.26
Male	602	79.5	155	20.5	
Female	667	81.7	149	18.3	
<b>Age category (years)</b>					0.05
55-59	263	76.9	79	23.1	
60-69	686	82.9	142	17.1	
70-74	309	79.2	81	20.8	
<b>Marital status</b>					0.35
Married/ de-facto	960	79.9	242	20.1	
Single/ never married	61	79.2	16	20.8	
Separated/ divorced/ widowed	245	84.2	46	15.8	
<b>Highest Education Level</b>					0.81
University/ college degree	250	81.4	57	18.6	
Trade/ technical cert./ diploma	335	80.1	83	19.9	
Senior high school	106	76.8	32	23.2	
Junior high school/ Intermediate	322	81.9	71	18.1	
Primary school or less	251	81.8	56	18.2	
<b>Employment status</b>					0.08
Full-time	215	75.2	71	24.8	
Part-time/ casual	138	78.9	37	21.1	
Home duties	170	80.6	41	19.4	
Retired	665	82.7	139	17.3	
Unemployed/ unable to work/ other	74	82.2	16	17.8	
<b>Household income</b>					0.10
Less than \$20,000	381	83.0	78	17.0	
\$20, 000 - \$60,000	490	81.5	111	18.5	
Over \$60, 000	206	78.0	58	22.0	
Don't know/ No response	192	77.1	57	22.9	

Table 4.2.1b shows significant differences in the percentage of kits returned between the different pilot sites. Mackay residents were more likely to have returned their kit than either Adelaide or Melbourne residents.

**Table 4.2.1b: FOBT participation by pilot site**

<b>Pilot site</b>	<b>Returned FOBT kit</b>				<b>p value</b>
	<b>Yes</b>		<b>No</b>		
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	
Mackay	425	86.4	67	13.6	0.0002
Adelaide	463	79.7	118	20.3	
Melbourne	381	76.2	119	23.8	

*Bowel cancer awareness and behaviours*

Table 4.2.2 demonstrates that people with a biological family history of bowel cancer were more likely than others were to have returned their kit. People who knew someone else with a history of bowel cancer and those who recalled having had symptoms they believed may have been associated with bowel cancer in the past were no more likely to have returned the kit. Having consulted a doctor for bowel cancer concerns or having had other bowel tests in the past had no effect on the proportion of respondents who had returned the kit.

**Table 4.2.2: Bowel cancer awareness and behaviours**

	<b>Returned FOBT kit</b>				p value
	<b>Yes</b>		<b>No</b>		
	n	%	n	%	
<b>Biological family history of bowel cancer</b>					0.02
Yes	311	85.4	53	14.6	
No	902	78.9	241	21.1	
Don't know	56	84.9	10	15.2	
<b>Knows others with a history of bowel cancer (e.g. partner, friend)</b>					0.44
Yes	797	81.4	182	18.6	
No	455	79.8	115	20.2	
<b>Had perceived symptoms of bowel cancer in past</b>					0.73
Yes	282	80.3	69	19.7	
No	955	81.1	222	18.9	
<b>Consulted doctor because of bowel cancer concerns</b>					0.93
Yes	302	80.7	73	19.3	
No	964	80.5	230	19.5	
<b>Had any previous bowel test other than FOBT</b>					0.92
Yes	512	80.9	121	19.1	
No	747	80.7	179	19.3	

### *Bowel cancer knowledge and attitudes*

Table 4.2.3 shows that people who had returned the kit were much more likely to be able to name or describe a sign or symptom of bowel cancer than non-returners. This is demonstrated by the lower percentage of participants who responded “don’t know/ not sure” when asked “What do you think are the signs or symptoms of bowel cancer?” (11% of returners, compared with 21% of non-returners). Participants were also more likely to correctly identify bleeding, blood and/ or mucus in bowel motions as a symptom of bowel cancer than those who wouldn’t return the kit. Other symptoms commonly identified by both participants and non-returners included changes in normal bowel patterns, pain in general and persistent cramping or abdominal pain.

The following differences in attitudes were observed between participants and non-returners:

- Twenty-two percent of participants reported that they perceived it was very likely or likely that they would develop bowel cancer in their lifetime compared to 19% of non-returners;
- Ninety-eight percent of participants reported that they strongly agreed or agreed with the statement “*It is important to check for bowel cancer even if I have no symptoms.*” compared with 73% of non-returners;
- Eighty-eight percent of participants strongly agreed with the statement “*Treating bowel cancer in the early stages increases a person’s chance of survival.*” compared with 70% of non-returners. However the proportion of respondents who did not report that they strongly agreed or agreed with this statement was the same for both participants and non-returners;
- Ninety-six percent of participants responded that they strongly agreed or agreed with the statement “*If bowel cancer is treated early a person may need less extensive treatment and may not need a colostomy bag.*” compared with 92% of non-returners; and
- Ninety-six percent of participants reported that they disagreed or strongly disagreed with the statement “*Having a test like FOBT seems like more trouble than it’s worth.*” compared with 67% of non-returners.

**Table 4.2.3: Bowel cancer knowledge and attitudes**

	<b>Returned FOBT kit</b>				<b>p value</b>
	<b>Yes</b>		<b>No</b>		
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	
<b>What do you think are the signs and symptoms of bowel cancer?*</b>					
Bleeding/ blood/ mucus from the bowel motion	1036	81.6	217	71.4	<0.0001
Diarrhoea or constipation (change in normal bowel patterns)	503	39.6	110	36.2	0.27
Pain in general	195	15.4	40	13.2	0.33
Persistent cramping or abdominal pain	141	11.1	39	12.8	0.40
Unexplained loss of weight	53	4.2	17	5.6	na
No symptoms	37	2.9	10	3.3	na
Lack of energy/ tired	29	2.3	6	2.0	na
Pain in bowels/ passing motions	19	1.5	3	1.0	na
Bloating/ flatulence	19	1.5	5	1.6	na
Polyps	10	0.8	1	0.3	na
Lack of appetite	7	0.6	4	1.3	na
Anaemia	7	0.6	1	0.3	na
Feeling of incomplete emptying of bowel	6	0.5	1	0.3	na
Don't know/ not sure	141	11.1	63	20.7	<0.0001
<b>How likely do you think it is that you would develop bowel cancer in your lifetime?</b>					
					0.03
Very likely	42	3.4	11	3.7	
Likely	232	18.7	46	15.5	
Unlikely	475	38.3	100	33.8	
Very unlikely	319	25.7	88	29.7	
Neither likely nor unlikely	17	1.4	0	0.0	
Not sure/ don't know/ it depends	155	12.5	51	17.2	
<b>It is important to check for bowel cancer even if I have no symptoms</b>					
					<0.0001
Strongly agree	977	77.8	102	34.7	
Agree	248	19.8	113	38.4	
Disagree	15	1.2	52	17.7	
Strongly disagree	10	0.8	18	6.1	
Neither agree nor disagree	5	0.4	9	3.1	
<b>Treating bowel cancer in the early stages increases a person's chance of survival</b>					
					<0.0001
Strongly agree	1111	87.8	214	70.4	
Agree	129	10.2	68	22.4	
Disagree	6	0.5	5	0.5	
Strongly disagree	2	0.2	2	0.2	
Neither agree nor disagree	4	0.3	2	0.3	

\* multiple responses were possible

na: test not applicable due to sample size

Table 4.2.3 continued

<b>If bowel cancer is treated early a person might need less extensive treatment and may not need colostomy bag</b>					<0.0001
Strongly agree	1037	82.0	197	64.8	
Agree	178	14.1	82	27.0	
Disagree	3	0.2	2	0.7	
Strongly disagree	2	0.2	3	1.0	
Neither agree nor disagree	5	0.4	0	0.0	
Unsure/ don't know	38	3.0	18	5.9	
<b>Having a test like FOBT seems like more trouble than it's worth</b>					<0.0001
Strongly agree	5	0.4	14	4.6	
Agree	20	1.6	55	18.1	
Disagree	305	24.1	115	37.8	
Strongly disagree	908	71.8	90	29.6	
Neither agree nor disagree	8	0.6	10	3.3	
Unsure/ don't know	15	1.2	19	6.3	

Table 4.2.4 shows that FOBT participants were more likely to know of tests to check for bowel cancer, be able to name or describe the FOBT without interviewer prompting, and identify that they had heard of FOBT after interviewer descriptions and prompting.

Table 4.2.4: Knowledge of bowel cancer screening (n=1565)

	<b>Returned FOBT kit*</b>				p value
	<b>Yes</b>		<b>No</b>		
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	
<b>Do you know of any tests that you or a doctor can do to check for bowel cancer?</b>					<0.0001
Yes	1165	92.1	245	80.6	
No	98	7.8	57	18.8	
<b>Can you tell me the name of the tests?*</b>					
FOBT	995	85.4	154	62.9	<0.0001
Colonoscopy	647	55.5	137	55.9	0.91
Blood test	81	7.0	14	5.7	na
Barium enema	53	4.6	13	5.3	na
X-ray/ CT scan	53	4.5	14	5.7	na
Digital rectal examination	50	4.3	13	5.3	na
Sigmoidoscopy	26	2.2	7	2.9	na
Ultrasound	14	1.2	3	1.2	na
Virtual colonoscopy	2	0.2	2	0.8	na
Other	50	4.3	15	6.1	na
Can't give name or describe	12	1.0	11	4.5	0.0001

Table 4.2.4 continued

<b>[Interviewer describes and names FOBT]</b>					
<b>Have you heard of such a test before?</b>					<0.0001
Yes	1265	99.7	280	93.0	
No	4	0.3	21	7.0	
<b>In the last 12 months has a doctor suggested you have this FOBT?</b>					0.14
Yes	105	8.4	16	5.7	
No	1153	91.6	263	94.3	

\* multiple responses were possible  
na: test not applicable due to sample size

### *Cancer awareness and past screening behaviour*

Cancer awareness and past screening behaviour was examined separately for males and females. Fifty-one per cent of males nominated bowel cancer as one of the two most prevalent cancers in men. These men were no more likely to have returned their kit than men who did not place bowel cancer among the two most common (Table 4.2.5). However men who had undergone a screening test for prostate cancer in the previous two years were more likely to have returned the kit.

**Table 4.2.5: Cancer awareness and screening behaviour amongst males**

	<b>Returned FOBT kit</b>				p value
	<b>Yes</b>		<b>No</b>		
	n	%	n	%	
<b>Identified bowel cancer as one of the two most prevalent cancers</b>					0.31
Yes	315	80.9	74	19.1	
No	287	78.0	81	22.0	
<b>In the past two years have you had a screening test for prostate cancer?</b>					0.0001
Yes	366	84.1	69	15.9	
No	229	72.7	86	27.3	

Twenty-eight per cent of females nominated bowel cancer as one of the two most prevalent cancers in women but these women were no more likely to have returned their kit than other women (Table 4.2.5). However women who had had a screening mammogram in the previous two years were more likely to have returned the kit.

Interestingly, 40 per cent of women nominated cervical cancer, which is relatively rare, as one of the two most prevalent cancers in women. This heightened awareness of cervical cancer may indicate the influence government interventions, such as screening programs, can have on people's perceptions.

**Table 4.2.6: Cancer awareness and screening behaviour amongst females**

	Returned FOBT kit				p value
	Yes		No		
	n	%	n	%	
<b>Identified bowel cancer as one of the two most prevalent cancers</b>					0.96
Yes	185	81.9	41	18.1	
No	482	81.7	108	18.3	
<b>In the past two years have you had a screening Pap smear test?</b>					0.10
Yes	380	84.1	72	15.9	
No	186	77.5	54	22.5	
Don't need to	95	81.9	21	18.1	
<b>In the past two years have you had a screening mammogram?</b>					<0.0001
Yes	586	84.7	106	15.3	
No	75	63.6	43	36.4	

### 4.3 Practical experiences of FOBT interventions – 2004

Analysis was carried out separately for people who reported they had returned the kit (participants), and those who stated that they would not be returning the kit (non-returners). For this section those who reported that they intended to return it were excluded.

Participants (n=1269)

#### *Reasons for participation*

The major reasons reported for taking part in the pilot were “precaution/ prevention/ early detection/ health check important” (48%) and “want to know whether had bowel cancer/ peace of mind” (36%) (Table 4.3.1).

**Table 4.3.1: Reasons for participating in FOBT pilot (n=1269)**

<i>Why did you decide to complete the test?*</i>	n	%
Precaution/ prevention/ early detection/ health check important	606	47.9
Want to know whether had bowel cancer/ peace of mind	449	35.5
Received in mail	312	24.7
Increasing age	185	14.6
Family history/ personal experience of CRC or other cancer	171	13.5
It was free	147	11.6
Simple test/ little inconvenience/ private/ non-invasive	100	7.9
Doctor/ government recommendation	88	7.0
Research/ to help/ participate	78	6.2
Encouragement from spouse/ partner	34	2.7
Good for society/ community	23	1.8
Media campaign	20	1.6
In a colorectal cancer prevalent/ risk group	8	0.6
Preferable to colonoscopy	2	0.2
Other	301	23.8

\* multiple responses were possible

### *Sources of information recalled by participants*

Participants in different pilot sites reported hearing about FOBT from different sources (Table 4.3.2). The results are consistent with the interventions used in each site. Participants from Mackay were much more likely to have heard of FOBT from television programmes than were participants from other sites, which correlates with local television coverage the pilot received by the pilot in this location. Likewise there was an intensive focus on GP involvement in Adelaide, which is reflected in participants from this site being much more likely to have heard about FOBT from their GP. Interestingly, participants from Mackay were less likely than others to recall or report having received information in their FOBT pilot kit.

**Table 4.3.2: Sources of information about FOBT recalled by those who participated in pilot (n=1261)**

Where have you heard or seen information about FOBT?*							
	Pilot Site						p value
	Mackay (n=424)		Adelaide (n=458)		Melbourne (n=379)		
	n	%	n	%	n	%	
FOBT government kit	344	81.3	416	90.8	341	89.9	<0.0001
TV programme	155	36.6	48	10.5	28	7.4	<0.0001
Newspaper	111	26.2	118	25.8	105	27.7	0.81
Doctor	42	9.9	116	25.3	44	11.6	<0.0001
Friends	42	9.9	54	11.8	29	7.7	0.14
Magazine	34	8.0	28	6.1	19	5.0	0.21
Radio	24	5.7	19	4.2	13	3.4	na
Other information in the mail	12	2.8	19	4.2	2	5.5	na
Community Health Centre	11	2.6	3	0.6	4	1.1	na
Rotary Club	10	2.4	3	0.6	1	0.3	na
Family	9	2.1	20	4.3	17	4.5	na
Chemist	6	1.4	32	7.0	2	0.5	na
Cancer Council	2	0.5	0	0	4	1.1	na
Other	48	11.3	57	12.5	49	12.9	0.77

\* multiple responses were possible.

na: test not applicable due to sample size

### *Ease of kit use*

Overall the majority of participants (94%) found the kits easy to use. The “brush” (Enterix) kit was found to be slightly easier to use than the “stick” (Bayer) kit (Table 4.3.3). More participants from Mackay found the kit easy to use than participants from Adelaide and Melbourne. Ease of kit use was not associated with age or sex.

**Table 4.3.3: Factors determining ease of kit use (n=1261)**

	<b>Did you find the test easy to use?</b>		
	<b>Yes</b>		
	n	%	p value
<b><i>Kit type used</i></b>			0.01
Brush (Enterix kit)	538	96.4	
Stick (Bayer kit)	626	92.5	
Not sure/ Can't remember	31	94.9	
<b>Sex</b>			0.52
Male	570	94.7	
Female	625	93.8	
<b>Age category (years)</b>			0.53
50-59	248	94.7	
60-69	643	93.7	
70-74	295	95.5	
<b>Pilot site</b>			0.007
Mackay	412	97.2	
Adelaide	430	92.9	
Melbourne	353	92.7	

The most common problem reported by people who did not find the kit easy to use was that the paper (which was part of the Bayer kit) became wet, sank or disintegrated (36%) (Table 4.3.4). The “stick” (Bayer) kit was used by 7 out of the 11 people who reported that the instructions were hard to understand.

**Table 4.3.4: Difficulties reported by those participants who did not find the test easy to use (n=73)**

<i>Problem with test*</i>	n	%
Paper became wet/ sank/ disintegrated	26	35.6
Instructions were hard to understand	11	15.1
Dealing with bowel motions was distasteful	7	9.6
Brush/ stick difficult to use	5	6.9
Vials/ test card difficult to use	5	6.9
Not confident/ too difficult	4	5.5
Instructions were hard to read	1	1.4
Barcodes/ stickers difficult to use	1	1.4
Couldn't provide two samples in the time required	1	1.4
Arthritis/ mobility problems	1	1.4
Other	34	46.6

\* multiple responses were possible

Feedback from interviewers indicated that participants were concerned that the FOBT kit was sent in a package with 'Bowel Cancer Test Kit' in large prominent lettering on the outside, and indicated their preference for a discrete appearance.

#### *Intention of Future Participation*

The majority of current participants (98%) stated that they would participate in FOBT screening in the future (Table 4.3.5). If FOBT screening was recommended by a doctor the proportion of respondents who replied that they would be **very** likely to take part was higher than with a Health Department recommendation. Likelihood of future participation if a FOBT kit was just mailed out was almost as high as with a doctor's recommendation.

**Table 4.3.5: Likelihood of future participation amongst current participants by method of approach**

	How likely are you to participate in bowel cancer screening in the future...							
	from time to time using FOBT?		with FOBT kit mail-out?		with Health Department recommendation?		with doctor's recommendation?	
	n	%	n	%	n	%	n	%
Very likely	921	72.8	1098	86.9	1055	83.4	1110	87.7
Likely	225	17.8	126	10.0	159	12.6	122	9.6
Unlikely	41	3.2	15	1.2	20	1.6	5	0.4
Very unlikely	23	1.8	11	0.9	10	0.8	4	0.3
Other responses*	55	4.3	14	1.1	21	1.7	24	1.9

\* Not sure/ don't know/ depends on something

### *Reasons for future participation*

The main reason given for future participation amongst current participants was “precaution/ prevention/ early detection/ health check important” (63%) (Table 4.3.6).

**Table 4.3.6: Reasons for participating in future FOBT screening amongst current participants (n=1233)**

Why do you think you would participate in the future?*	n	%
Precaution/ prevention/ early detection/ health check important, unli	781	63.3
Want to know whether have bowel cancer/ peace of mind	454	36.8
Doctor/ government recommendation	170	13.8
Family history/ personal experience of CRC or other cancer	135	10.9
Increasing age	126	10.2
Simple test/ little inconvenience/ private/ non-invasive	116	9.4
Research/ to help/ participate	54	4.4
If it was free	49	0.8
Personal medical history, not CRC or cancer	18	1.5
In a colorectal cancer prevalent/ risk group	12	0.4
Good for society/ community	11	0.9
Preferable to colonoscopy	7	0.6
Encouragement from spouse/ partner	4	0.3
If it was sent to me	3	0.2
Other	136	11.0

- multiple responses were possible

When all questions regarding future screening intention were examined only 27 (2%) current participants said they were unlikely or very unlikely to participate in FOBT screening in the future (Table 4.3.7). The most common reason given was having a lack of symptoms or “feeling well” (26%).

**Table 4.3.7: Reasons for not participating in future FOBT screening amongst current participants (n=27)**

<b>Why do you think you would/ might not participate in the future?*</b>	<b>n</b>	<b>%</b>
Lack of symptoms/ feeling well	7	25.9
Already have had other bowel tests	4	14.8
Costs/ not covered by Medicare	4	14.8
Lack of confidence in tests/ doctors	3	11.1
No reason in particular/ don't know	2	7.4
No family history	1	3.7
Embarrassment/ distaste with stool collection	1	3.7
Lack of time/ too busy	1	3.7
Don't care/ couldn't be bothered	1	3.7
Afraid won't collect samples correctly	0	0
Fear of results/ cancer/ further tests/ surgery	0	0
Don't know enough about the test	0	0
Other	12	44.4

\* multiple responses were possible

#### Non-Returners (n=304)

##### *Reasons for not participating*

The major reasons reported for not taking part in the pilot were having already had other bowel tests (24%) and having a lack of symptoms or “feeling well” (16%) (Table 4.3.8).

**Table 4.3.8: Reasons for not participating in FOBT pilot (n=304)**

<b>Why did you decide not to complete the test?*</b>	<b>n</b>	<b>%</b>
Already have had other bowel tests	72	23.7
Lack of symptoms/ feeling well	47	15.5
Embarrassment/ distaste with stool collection	32	10.5
No reason in particular/ don't know	26	8.6
Lack of time/ too busy	25	8.2
Fear of results/ cancer/ further tests/ surgery	20	6.6
Don't care/ couldn't be bothered	20	6.6
Blood present because of other condition/ haemorrhoids	10	3.3
No family history	7	2.3
Afraid won't collect sample correctly	4	1.3
Unwilling to answer	2	0.7
Don't know enough about the test	1	0.3
Lack of confidence in tests/ doctors	1	0.3
Other	129	42.4

\* multiple responses were possible

*Sources of information recalled by non-returners*

Overall, people who had returned the kit were more likely than non-returners to recall having seen or heard information about FOBT from the FOBT government kit (87% vs. 75%), a newspaper (26% vs. 16%), or a television programme (18% vs. 12%) (Tables 4.3.9 and 4.3.2, respectively).

The differences among sites for each source of information were also less marked, although recall of information having been received from doctors was still more prevalent among non-returners in Adelaide than those in Mackay or Melbourne.

**Table 4.3.9: Sources of information about FOBT recalled by those who declined to participate in pilot**

	Where have you heard or seen information about FOBT?*						
	Pilot site						p value
	Mackay (n=59)		Adelaide (n=111)		Melbourne (n=110)		
	n	%	n	%	n	%	
FOBT Government Kit	42	71.2	78	70.3	91	82.7	0.07
TV Programme	9	15.2	14	12.6	12	10.9	na
Newspaper	6	10.2	19	17.1	19	17.2	na
Friends	6	10.2	10	9.0	11	10.0	na
Doctor	5	8.5	27	24.3	10	9.1	na
Family	4	6.8	9	8.1	7	6.4	na
Magazine	3	5.1	9	8.1	7	6.4	na
Radio	3	5.1	7	6.3	2	1.8	na
Community Health Centre	3	5.1	1	0.9	0	0.0	na
Other information in the mail	1	1.7	4	3.6	9	8.2	na
Chemist	0	0.0	3	1.1	2	1.8	na
Rotary Club	0	0.0	1	0.9	1	0.0	na
Cancer Council	0	0.0	0	0.0	1	0.0	na
Other	6	10.2	12	10.8	11	10.0	na

\* multiple responses were possible

na: test not applicable due to sample size

*Intention of Future Participation*

Likelihood of future participation in FOBT screening increased dramatically if a doctor’s recommendation was mentioned compared to a screening program without any recommendation at all (58% vs. 20%) (Table 4.3.10). There were smaller increases in likelihood of participation with other approaches such as a FOBT mail-out or a Health Department recommendation.

**Table 4.3.10: Likelihood of future participation amongst non-returners by method of approach (n=304)**

	How likely are you to participate in bowel cancer screening in the future							
	from time to time using FOBT?		With FOBT kit mail-out?		With Health Department Recommendation?		With doctor recommendation?	
	n	%	n	%	n	%	n	%
Very likely	60	19.7	83	27.3	101	33.2	175	57.5
Likely	61	20.1	77	25.3	71	23.4	79	26.0
Unlikely	80	26.3	48	15.8	56	18.4	17	5.6
Very unlikely	79	26.0	68	22.4	49	16.1	15	4.9
Other responses*	24	7.9	28	9.2	27	8.8	18	5.9

\* Not sure/ don’t know/ depends on something

*Reasons for future participation*

The major reason given by non-returners for participating in FOBT screening in the future was receiving a “doctor/ government recommendation” (52%) (Table 4.3.11).

**Table 4.3.11: Reasons for participating in future FOBT screening amongst current non-returners (n=255)**

Why do you think you would participate?*	n	%
Doctor/ government recommendation	131	51.6
Precaution/ prevention/ early detection/ health check important	88	34.6
Want to know whether had bowel cancer/ peace of mind	37	14.6
Increasing age	25	9.9
Family history/ personal experience of CRC or other cancer	17	6.7
Simple test/ little inconvenience/ private/ non-invasive	7	2.8
Personal medical history, not CRC or cancer	3	1.2
Research/ to help/ participate	2	0.8
If it was free	2	4.0
Preferable to colonoscopy	2	0.8
In a colorectal cancer prevalent/ risk group	1	0.4
Encouragement from spouse/ partner	1	0.4
If it was sent to me	1	0.4
Other	27	10.6

multiple responses were possible

When all questions regarding future screening intention were examined 49 (16%) non-returned said they wouldn't participate in FOBT screening in the future. The most common reason given was having a "lack of symptoms" or "feeling well" (31%) (Table 4.3.12).

**Table 4.3.12: Reasons for not participating in future FOBT screening amongst current non-returned (n=49)**

<b>Why do you think you would/ might not participate in the future?*</b>	<b>n</b>	<b>%</b>
Lack of symptoms/ feeling well	15	30.6
Fear of results/ cancer/ further tests/ surgery	7	14.3
Already have had other bowel tests	6	12.2
Embarrassment/ distaste with stool collection	4	8.2
No family history	3	6.1
Don't care/ couldn't be bothered	3	6.1
Blood present because of other condition/ haemorrhoids	2	4.1
Lack of confidence in tests/ doctors	2	4.1
No reason in particular/ don't know	2	4.1
Afraid won't collect samples correctly	1	2.0
Costs/ not covered by Medicare	1	2.0
Lack of time/ too busy	0	0.0
Other	21	42.9

\* multiple responses were possible

## 4.4 Effects of screening interventions (2002 vs 2004)

### *Socio-demographic characteristics*

Table 4.4.1 shows that the age and income status of survey respondents was different in 2002 and 2004, with more older and slightly more higher income respondents in the 2004 survey.

**Table 4.4.1: Socio-demographic characteristics of survey respondents**

	<b>Year of Survey</b>				<b>p value</b>
	<b>2002</b>		<b>2004</b>		
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>	
<b>Sex</b>					0.83
Male	1390	49.8	1651	49.6	
Female	1399	50.1	1680	50.4	
<b>Age category (years)</b>					<0.0001
50-59	1338	49.6	1392	42.1	
60-69	1021	37.8	1318	39.9	
70-74	341	12.6	596	18.0	
<b>Marital status</b>					0.08
Married/ de-facto	2104	75.9	2551	77.2	
Single/ never married	308	11.1	337	10.2	
Separated/ divorced/ widowed	359	12.9	415	12.6	

Table 4.4.1 continued				
<b>Highest Education Level</b>				0.31
University/ college degree	529	19.1	705	21.3
Trade/ technical cert./ diploma	816	29.4	947	28.6
Senior high school	262	9.4	300	9.1
Junior high school/ Intermediate	699	25.2	824	24.9
Primary school or less	471	17.0	539	16.3
<b>Employment status</b>				0.05
Full-time	793	28.7	959	29.1
Part-time/ casual	401	14.5	475	14.4
Home duties	399	14.4	398	12.0
Retired	988	35.6	1266	38.2
Unemployed/ unable to work/ other	190	6.9	213	6.4
<b>Household income</b>				0.04
Less than \$20,000	747	26.8	837	25.1
\$20, 000 - \$60,000	1053	37.8	1206	36.2
Over \$60, 000	568	20.4	789	23.7
Don't know/ no response	421	15.1	529	15.9
<b>Pilot site</b>				0.03
Mackay	848	30.4	1117	33.5
Adelaide	963	34.5	1115	33.5
Melbourne	978	35.1	1099	33.0

*Bowel cancer awareness and behaviours*

Respondents in 2004 were more likely to report having a biological family history of bowel cancer (22.8%) or knowing someone else with a history of bowel cancer (61.0%) than were respondents in 2002 (Table 4.4.2). This may reflect an increase in awareness of, or interest in, bowel cancer. Respondents in 2004 were also more likely to have had bowel tests other than FOBT. The percentage of people who reported they had experienced symptoms that they thought may be bowel cancer was no different after the interventions (23%), and the percentage of respondents who had consulted a doctor for bowel cancer concerns also remained the same (23%).

**Table 4.4.2: Bowel cancer awareness and behaviours of survey respondents**

	Year of Survey				p value
	2002 (n=2752)		2004 (n=3272)		
	n	%	n	%	
<b>Biological family history of bowel cancer</b>					0.03
Yes	552	20.1	748	22.8	
No	2087	75.8	2396	73.2	
Don't know	113	4.1	128	3.9	
<b>Knows others with a history of bowel cancer (e.g. partner, friend)</b>					0.06
Yes	1612	58.6	1995	61.0	
No	1140	41.4	1277	39.0	
<b>Had any previous bowel test other than FOBT</b>					<0.0001
Yes	850	30.6	1197	36.2	
No	1929	69.4	2113	63.8	
<b>Had perceived possible bowel cancer symptoms in past</b>					0.99
Yes	615	22.5	734	22.5	
No	2117	77.5	2514	77.5	
<b>Consulted doctor because of bowel cancer concerns</b>					0.99
Yes	620	22.5	737	22.5	
No	2132	77.5	2535	77.5	

*Bowel cancer knowledge and attitudes*

Table 4.4.3 shows that after the pilot interventions respondents were more likely to identify bleeding/ blood/ mucus from bowel motions as a symptom of bowel cancer (75.6%). The percentage of respondents who didn't know any signs or symptoms of bowel cancer was significantly lower in 2004 (15.4%).

Attitudes towards bowel cancer were also significantly different in 2004 from those reported in 2002:

- Sixty percent of respondents in 2004 reported that they believed they were unlikely or very unlikely to develop bowel cancer in their lifetime compared with 58% in 2002.
- Eighty-nine percent of respondents in 2004 reported that they agreed or strongly agreed with the statement “It is important to check for bowel cancer even if I have no symptoms.” compared with 81% of respondents in 2002.
- Eighty-two percent of respondents in 2004 reported that they strongly agreed with the statement “Treating bowel cancer in the early stages increases a person’s chance of survival.” compared with 72% of respondents in 2002. Most of the shift appears to be from the agree category.
- Seventy-seven percent of respondents in 2004 reported that they strongly agreed with the statement “If bowel cancer is treated early a person might need less extensive treatment and may not need a colostomy bag.” compared with 65% of respondents in 2002. Most of the shift appears to be from the agree category.
- Fifty-eight percent of respondents in 2004 reported that they strongly disagreed with the statement “Having a test like FOBT seems like more trouble than it’s worth.” compared with 45% of respondents in 2002. Most of the shift appears to be from the disagree category.

**Table 4.4.3: Bowel cancer knowledge and attitudes**

	Year of Survey				
	2002		2004		p value
	n	%	n	%	
<b>What do you think are the signs and symptoms of bowel cancer?*</b>					
Bleeding/ blood/ mucus from the bowel motion	1853	66.5	2517	75.6	<0.0001
Diarrhoea or constipation (change in normal bowel patterns)	1059	38.0	1304	39.2	0.35
Pain in general	382	13.7	523	15.7	0.03
Persistent cramping or abdominal pain	359	12.9	408	12.3	0.46
Unexplained loss of weight	107	3.8	145	4.4	0.31
Bloating/ flatulence	57	2.0	62	1.9	na
No symptoms	49	1.8	84	2.5	na
Pain in bowels/ passing motions	46	1.7	54	1.6	na
Lack of energy/ tired	29	1.0	66	2.0	na
Feeling of incomplete emptying of bowel	24	0.9	22	0.7	na
Lack of appetite	23	0.8	23	0.7	na
Anaemia	15	0.5	16	0.5	na
Polyps	3	0.1	24	0.7	na
Don't know/ not sure	614	22.0	513	15.4	<0.0001

Table 4.4.3 continued

<b>How likely do you think it is that you would develop bowel cancer in your lifetime?</b>					<0.0001
Very likely	87	3.2	141	4.3	
Likely	558	20.3	671	20.5	
Unlikely	1128	41.0	1242	38.0	
Very unlikely	455	16.5	728	22.3	
Neither likely nor unlikely	39	1.4	48	1.5	
Not sure/ don't know/ it depends	485	17.6	438	13.4	
<b>It is important to check for bowel cancer even if I have no symptoms</b>					<0.0001
Strongly agree	1129	40.5	2052	61.7	
Agree	1133	40.6	915	27.5	
Disagree	311	11.2	209	6.3	
Strongly disagree	54	1.9	74	2.2	
Neither agree nor disagree	58	2.1	34	1.0	
Unsure/ don't know	100	3.6	38	1.1	
<b>Treating bowel cancer in the early stages increases a person's chance of survival</b>					<0.0001
Strongly agree	2012	72.1	2738	82.3	
Agree	674	24.2	461	13.9	
Disagree	24	0.9	28	0.8	
Strongly disagree	7	0.3	15	0.5	
Neither agree nor disagree	13	0.5	13	0.4	
Unsure/ don't know	58	2.1	70	2.1	
<b>If bowel cancer is treated early a person might need less extensive treatment and may not need colostomy bag</b>					<0.0001
Strongly agree	1819	65.2	2554	76.8	
Agree	784	28.1	584	17.6	
Disagree	19	0.7	23	0.7	
Strongly disagree	5	0.2	10	0.3	
Neither agree nor disagree	11	0.4	13	0.4	
Unsure/ don't know	148	5.3	136	4.1	
<b>Having a test like FOBT seems like more trouble than it's worth</b>					<0.0001
Strongly agree	45	1.6	56	1.7	
Agree	174	6.2	181	5.4	
Disagree	1157	41.5	1022	30.7	
Strongly disagree	1250	44.8	1935	58.2	
Neither agree nor disagree	36	1.3	33	1.0	
Unsure/ don't know	117	4.2	90	2.7	

\* multiple responses were possible

na: test not applicable due to sample size

*Knowledge of bowel cancer and screening tests*

After the interventions respondents were much more likely to be aware of tests to check for bowel cancer (Table 4.4.4). The percentage of respondents who named or described an FOBT without prompting from the interviewer increased significantly from 30% to 69%. The percentage of respondents who recognised FOBT after interviewer descriptions almost doubled between 2002 and 2004 (43% to 84%).

**Table 4.4.4: Knowledge of bowel cancer and screening tests**

	Year of Survey				p value
	2002		2004		
	n	%	n	%	
<b>Do you know of any tests that you or a doctor can do to check for bowel cancer?</b>					<0.0001
Yes	1660	60.0	2648	80.1	
No	1107	40.0	657	19.9	
<b>Can you tell me the name of the tests?*</b>					
Colonoscopy	962	58.0	1522	57.5	0.74
FOBT	493	29.7	1829	69.1	<0.0001
Barium enema	129	7.8	140	5.3	0.001
Sigmoidoscopy	57	3.4	74	2.8	0.23
Digital rectal examination	118	7.1	146	5.5	0.03
X-ray/ CT scan	61	3.7	150	5.7	0.003
Ultrasound	26	1.6	40	1.5	0.88
Other	66	4.0	147	5.6	0.02
Can't give name or describe	300	18.1	105	4.0	<0.0001
<b>[Interviewer describes and names FOBT]</b>					<0.0001
<b>Have you heard of such a test before?</b>					
Yes	1204	43.6	2809	84.8	
No	1555	56.4	505	15.2	

\* multiple responses were possible

*Bowel cancer awareness*

The percentage of men who named bowel cancer as one of the two most common male cancers increased from 42% to 50% between 2002 and 2004 (Table 4.4.5). Awareness was also elevated among women, with the percentage who named bowel cancer as one of the two most prevalent female cancers increasing from 20% in 2002 to 25% in 2004.

**Table 4.4.5: Bowel cancer awareness by sex**

		Year of Survey				p value
		2002		2004		
		n	%	n	%	
<b>Identified bowel cancer as one of the two most prevalent cancers</b>						
<b>Men</b>						<0.0001
Yes		590	42.4	820	49.7	
No		809	57.6	831	50.3	
<hr/>						
<b>Women</b>						0.0003
Yes		273	19.5	420	25.0	
No		1126	80.5	1260	75.0	

*GP awareness and behaviours*

Respondents were much more likely to report that their doctor knew or had asked them about any family history of bowel cancer after the intervention (41% vs. 31%) (Table 4.4.6). This increase was highly significant across all pilot sites.

Overall, respondents in 2004 were also more likely to report that their doctor had suggested that they have a test for bowel cancer or a bowel examination. However when the pilot sites were examined separately a significant change was only observed for Melbourne, which increased from 23% to 29%. However the percentage of respondents who reported that their doctor had suggested such a test was still higher for Adelaide than for Mackay or Melbourne.

It is uncertain to what extent the increase in Melbourne is due to an actual increase in GPs suggesting that people have bowel tests, and to what extent improved awareness of bowel tests and bowel cancer has led to increased recall of such recommendations.

**Table 4.4.6: Patient reported GP bowel cancer awareness and behaviours**

	Year of Survey				p value
	2002		2004		
	n	%	n	%	
<b>Does your doctor know or has your doctor ever asked you about any family history of bowel cancer?</b>					
Overall					<0.0001
Yes	868	31.1	1355	40.7	
No	1836	65.8	1900	57.0	
Don't know	84	3.0	76	2.3	
Mackay					<0.0001
Yes	245	28.9	473	42.4	
No	579	68.3	618	55.3	
Don't know	24	2.8	26	2.3	
Adelaide					<0.0001
Yes	321	33.3	475	42.6	
No	618	64.2	613	55.0	
Don't know	24	2.5	27	2.4	
Melbourne					0.003
Yes	302	30.9	407	37.0	
No	639	65.3	669	60.9	
Don't know	37	3.8	23	2.1	
<b>Has a doctor ever suggested you have a test to check for bowel cancer or to examine the functioning of your bowels?</b>					
Overall					0.01
Yes	763	27.4	1008	30.4	
No	2017	72.6	2303	69.6	
Mackay					0.36
Yes	222	26.2	312	28.1	
No	624	73.8	799	71.9	
Adelaide					0.35
Yes	315	32.8	384	34.8	
No	645	67.2	721	65.2	
Melbourne					0.006
Yes	226	23.2	312	28.5	
No	748	76.8	783	71.5	

*Likelihood of future participation*

A variable was created to combine a number of questions in order to clarify respondents' stated likelihood to participate in FOBT screening. Four categories were compiled as follows:

- **Very highly likely** - respondents who said they are very likely to participate in FOBT without any recommendation;
- **Highly likely** - respondents who said they are very likely/ likely (or it depended on cost) to participate in FOBT if recommended by a doctor and very likely/ likely (or if it depended on cost) if recommended by the health department;
- **Likely** - respondents who said they are very likely/ likely (or it depended on cost) to participate if recommended by one of a doctor or the Health Department, but who were **not** very likely/ likely to participate with the other recommendation; and
- **Unlikely** - respondents who said they would not participate at all.

Table 4.4.7 demonstrates that the overall likelihood of participation increased substantially between 2002 and 2004. Most of the shift appears to be from the “highly likely” category to the “very highly likely” category. The percentage of respondents who would be very highly likely to participate regardless of what approach was used more than doubled from 24% in 2002 to 56% in 2004. Highly significant increases were observed in each of the pilot sites.

**Table 4.4.7: Likelihood of future participation\***

	Year of Survey				
	2002		2004		p value
	n	%	n	%	
	(n=2789)		(n=3303)		
<b>Overall</b>					<0.0001
Very highly likely (regardless of approach)	668	24.0	1859	56.3	
Highly likely	1719	61.6	1063	32.2	
Likely	275	9.9	264	8.0	
Unlikely	127	4.6	117	3.5	
<b>Mackay</b>					<0.0001
Very highly likely (regardless of approach)	251	29.6	718	64.7	
Highly likely	485	57.2	311	28.0	
Likely	74	8.7	58	5.2	
Unlikely	38	4.5	22	2.0	

Table 4.4.7 continued

<b>Adelaide</b>					<0.0001
Very highly likely (regardless of approach)	207	21.5	604	54.7	
Highly likely	624	64.8	364	33.0	
Likely	91	9.5	102	9.2	
Unlikely	41	4.3	34	3.1	
<b>Melbourne</b>					<0.0001
Very highly likely (regardless of approach)	210	21.5	537	49.3	
Highly likely	610	62.4	388	35.6	
Likely	110	11.3	104	9.6	
Unlikely	48	4.9	61	5.6	

\*See definitions on page 40

*Motivators and barriers for future participation*

In 2002 the most common reason for future participation was receiving a recommendation from a doctor or the government (Table 4.4.8). Respondents in 2004 were more likely to report that they would participate in the future as a precaution or because they believed prevention, early detection or health checks were important ( $p < 0.0001$ ), suggesting an elevation in their awareness of the risk of bowel cancer and intention to screen.

**Table 4.4.8: Reasons for future participation in FOBT screening**

<b>Why do you think you would participate in the future?*</b>	<b>2002</b>		<b>2004</b>	
	<b>(n=2627)</b>		<b>(n=3136)</b>	
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
Doctor/ government recommendation	927	35.5	666	21.2
Family history/ personal experience of CRC or other cancer	286	10.9	386	12.3
Increasing age	186	7.1	331	10.5
Precaution/ prevention/ early detection/ health check important	84	3.2	1873	59.5
Personal medical history, not CRC or cancer	71	2.7	53	1.9
Want to know whether had bowel cancer/ peace of mind	62	2.4	991	31.5
Simple test/ little inconvenience/ private/ non-invasive	62	2.4	216	6.9
Research/ to help/ participate	50	1.9	91	2.9
In a colorectal cancer prevalent/ risk group	30	1.2	32	1.0
Preferable to colonoscopy	27	1.0	15	0.5
If it was free	0	0.0	76	2.4
Good for society/ community	0	0.0	16	0.5
If it was sent to me	0	0.0	11	0.4
Encouragement from spouse/ partner	0	0.0	11	0.4
Other	134	5.1	347	11.0

\* multiple responses were possible

In 2002 a major barrier to future participation was having a “lack of symptoms” or “feeling well” (39%) (Table 4.4.9). In 2004 the reasons for not participating in the future were more varied, with no particular reasons standing out.

**Table 4.4.9: Reasons for not participating in FOBT screening in the future**

Why do you think you would/ might not participate in the future?*	2002 (n=162)		2004 (n=167)	
	n	%	n	%
Lack of symptoms/ feeling well/ no family history	63	38.9	4	2.4
Embarrassment/ distaste with stool collection	17	10.5	9	5.4
Already have had other bowel tests	7	4.3	18	10.8
Lack of time/ too busy	6	3.7	3	1.8
Fear of results/ cancer/ further tests/ surgery	1	0.6	12	7.9
Lack of confidence in tests/ doctors	0	0.0	18	10.8
No reason in particular/ don't know	0	0.0	11	6.6
Don't care/ couldn't be bothered	0	0.0	7	4.2
Costs/ not covered by Medicare	0	0.0	7	4.2
Don't know enough about the test	0	0.0	2	1.2
Blood present because of other condition/ haemorrhoids	0	0.0	2	1.2
Afraid won't collect samples correctly	0	0.0	1	0.6
Other	69	42.6	72	43.1

\* multiple responses were possible

# 5

## Conclusion

This report provides a comparative analysis of data from the 2002 and 2004 Knowledge, Attitudes and Practices surveys of respondents living in the pilot sites of the Bowel Cancer Screening Pilot Program (BCSPP). The surveys were designed to evaluate the knowledge, attitudes and behaviours of respondents' pre- and post-pilot program implementation. The survey population is a sample of the general population; as such there are limitations to generalisations arising from the findings. However, the diverse demographic, socioeconomic and cultural characteristics of the pilot sites allow for some extrapolation to the broader Australian population.

The findings for the 2004 survey indicated that Mackay residents were significantly more likely to have returned the Faecal Occult Blood Test (FOBT) than were respondents in Adelaide or Melbourne. These results may reflect the variations in interventions of the pilot sites, resulting from the differences in pilot catchment areas. The Mackay pilot had a discrete area which allowed the use of a media campaign. The Melbourne and Adelaide pilots were less defined and comprised of a number of post codes. To contain the number of participants and minimise leakage outside the pilot area, the community mobilisation strategies were limited to those areas of the pilot. The Adelaide pilot implemented strategies focusing on General Practitioners whereas the Melbourne pilot implemented strategies targeting culturally and linguistically diverse populations as well as generic recruitment strategies.

Participants aged 55 to 59 years were slightly less likely to have returned the FOBT kit. However the proportion of people returning the kit did not differ significantly across different sex, marital status, education levels and employment status. It is probable that those who are 55 to 59 years and are employed have greater time constraints. The development of strategies for the potential national bowel cancer screening program should consider the time constraints on participants, in order to make screening as widely accessible as possible.

The findings reflected the impact of education strategies in organised screening programs. Women who had undergone a screening mammogram test in the previous 2 years were more likely to have returned the kit. However those who nominated bowel cancer as one of the two most prevalent female cancers were no more likely to have returned the kit. Men who had undergone a prostate screening test in the previous 2 years were more likely to have returned the kit. However those who nominated bowel cancer as one of the two most prevalent male cancers were no more likely than others to have returned the kit.

The FOBT was well accepted among participants. The majority of participants (94%) found the FOBT kits easy to use. The "brush" (Enterix) kit was found to be slightly easier to use than the "stick" (Bayer) kit. Ease of kit use was not associated with age or sex.

Among participants the major reasons given for participating were prevention/ early detection (48%) and want to know whether they had bowel cancer/ peace of mind (36%). However, about a quarter of respondents (24.7%) cited the reason for participating as receiving it in the mail. For participants the likelihood of future participation, if a FOBT kit was just mailed out, was almost as high as with a doctors' recommendation. In addition, the direct mail approach was well accepted by participants.

A minor proportion of the BCSPP participants (2%) indicated they would be unlikely or very unlikely to participate in FOBT screening in the future. The major reasons reported for not participating included having already had other bowel tests (24%) and having a lack of symptoms or "feeling well" (16%). The majority of non-returners (84%) reported that they would participate in FOBT screening in the future.

The 2004 survey results indicated an increase in knowledge of the signs and symptoms of bowel cancer, with respondents more likely to identify bleeding/ blood/ mucus from bowel motions as a symptom of bowel cancer. The percentage of respondents who didn't know any signs or symptoms of bowel cancer was significantly lower in 2004.

Attitudes towards bowel cancer were also significantly different in 2004 from those reported in 2002. After the interventions respondents were more likely to perceive that they thought it was 'very likely' or 'likely' that they would develop bowel cancer in their lifetime. After the intervention respondents were much more likely to be aware of tests to check for bowel cancer.

Bowel cancer awareness improved after the interventions. The percentage of men who named bowel cancer as one of the two most common male cancers increased from 42% to 50%, and the percentage of women who named bowel cancer as one of the two most prevalent female cancers increased from 20% to 25%.

Respondents in different pilot sites reported hearing about FOBT from different sources. The results are consistent with the interventions used in each site. The proportion of respondents who named or described FOBT without prompting from the interviewer increased significantly from 30% to 69%. The percentage of respondents who recalled having heard of FOBT after interviewer descriptions almost doubled between 2002 and 2004 (43% to 84%).

The overall likelihood of participation in future FOBT screening increased substantially between 2002 and 2004. The major shift was from the "highly likely" to "very highly likely" category. The likelihood of future participation if a FOBT kit was posted was comparable to participating with a doctor's recommendation. Likelihood of future participation in FOBT screening increased significantly if a doctor's recommendation was mentioned compared, to a screening program without promotion. The percentage of respondents who would be very highly likely to participate regardless of what approach was used more than doubled from 24% in 2002 to 56% in 2004.

In conclusion, the findings in this report indicate that the knowledge, attitudes and practices of respondents within the pilot sites have changed between the pre- and post-pilot program implementation. The knowledge of respondents had increased significantly and reflects the success of the community mobilisation strategies. The FOBT was accepted by respondents,

and a majority found this test easy to use. The intention of respondents to participate in a potential national bowel cancer screening program was high, the direct mail approach was well received and would complement a combined general practitioner and Health Department recommendation.

# 6

## Questionnaires

### 6.1 General population survey - 2002 Questionnaire

#### INTRODUCTION

##### Correct

**Hello, my name is ..... I'm calling from the Health Department.  
Can I check whether I have rung (read out phone no.)?**

*if number is non residential skip to Non residential log screen  
if number is residential skip to intro1*

##### intro1

**Thank-you. As I said, my name is .....**

**The Health Department is aiming to better understand people's knowledge and attitudes regarding cancer and screening for cancer. To achieve this we are currently conducting short interviews on this subject. We only need to interview a certain number of people from each area so firstly, can I ask what is the postcode for the house where we've rung you?**

(INTERVIEWER: If R hesitant, say: "At the moment we are interviewing in only certain postcodes in the Adelaide/Mackay/Melbourne vicinity. Can you tell me your postcode so I can see if you are in the area we're looking for?")

- 1 Gave postcode (INTERVIEWER: Type in postcode)
- 2 Don't know
- 3 Refused to answer

Adelaide postcode must = 5011, 5012, 5022, 5023, 5024, 5040, 5044, 5045 or 5048  
otherwise skip to household ineligible screen

Mackay postcode must = 4740, 4741, 4750 or 4751  
otherwise skip to household ineligible screen

Melbourne postcode must = 3070, 3071, 3078, 3079, 3081, 3083, 3084, 3085, 3087 or 3088  
otherwise skip to household ineligible screen

*if (ans = 2) skip to household ineligible screen  
if (ans = 3) skip to household ineligible screen*

**intro 1**

**The interviews are aimed at people aged 50 to 74 years. And it is important that we speak with equal numbers of men and women so for this particular interview I need to speak with a man/woman living in the house aged 50 to 74. Is there anyone living in the household who fits this description?**

- 1 Yes
- 2 No
- 3 Refused to answer

*if yes skip to number*  
*if 'no' skip to household ineligible screen*  
*if they refuse skip to refusal log screen*

**Number**

**Is there just the one male/female aged 50-74 years living in the household, or is there more than one?**

- 1 Just the one
- 2 More than one
- 3 No one fits description
- 4 Refusal - didn't establish if required person in household

*if 1 skip to One*  
*if more than 1 skip to More*  
*if no one fits description skip to household ineligible screen*  
*if they refuse skip to household ineligible screen*

**One**

**Would you be that person?**

- 1 Yes
- 2 No
- 3 Refusal

**More**

**Given that there is more than one man/woman who fits this criteria, I'd like to speak with the one who has most recently had a birthday. Would you be that person?**

- 1 Yes
- 2 No
- 3 Refusal

**Once have R on the line:**

**The interview is completely confidential and only takes about 10 minutes to complete.**

**Could you spare ten minutes to answer some questions for me please?**

(IF NECESSARY SAY: Your telephone number was randomly selected by computer and participation is completely confidential and voluntary. It is a very important project aimed to better understand knowledge and attitudes regarding bowel cancer. Are you sure you wouldn't be willing to take part?)

INTERVIEWER: If respondent says no, ask "Is that because the time is inconvenient? I would be happy to call you back at a suitable time"

- 1 Agreed to interview
- 2 Agreed to interview but suggested a call-back
- 3 No, refused interview

*if agreed to interview skip to good*

*if call back skip to appointment screen*

*if they refused skip to refusal screen*

**Good**

**Good, thank-you. Before we begin, I should stress the importance of answering the questions as accurately as possible. So please feel free to take as much time as you need before responding.**

**Also if there are any questions you would rather not answer, just say so.**

**Some calls are monitored by my supervisor for training and quality purposes.**

(INTERVIEWER: If R is concerned about someone 'listening in' on their conversation, tell them that "My supervisor sometimes listens to check that I am conducting the interview properly, and reading the questions correctly")

*if respondent male skip to q2am*

*if respondent female skip to q2af*

## **BODY OF QUESTIONNAIRE**

### **q2am**

**Which of the following cancers do you think is most common in men?**

**(INTERVIEWER: read highlighted options and mark response)**

- 1 Prostate cancer
- 2 Lung cancer
- 3 Melanoma
- 4 Bowel cancer
- 5 Don't know

### **q2am (second part of question)**

**And which do you think is the next most common in men?**

**(INTERVIEWER: read remaining highlighted options and mark response)**

- 1 Prostate cancer
- 2 Lung cancer
- 3 Melanoma
- 4 Bowel cancer
- 5 Don't know

**skip to q1a**

### **q2af**

**Which of the following cancers do you think is most common in women?**

**(INTERVIEWER: read highlighted options and mark response)**

- 1 Cancer of the cervix
- 2 Lung cancer
- 3 Melanoma
- 4 Breast cancer
- 5 Bowel cancer
- 6 Don't know

### **q2af (second part of question)**

**And which do you think is the next most common in women?**

**(INTERVIEWER: read remaining highlighted options and mark response)**

- 1 Cancer of the cervix
- 2 Lung cancer
- 3 Melanoma
- 4 Breast cancer
- 5 Bowel cancer
- 6 Don't know

**q1a**

**Now I'd like to ask whether you have had certain screening tests for cancer in the last 2 years. A screening test is a test you have when you DON'T HAVE ANY SYMPTOMS, just to check.**

**If respondent is male**

**So, in the last 2 years have you had a screening prostate cancer test?**

**If respondent is female**

**So, in the last 2 years have you had a screening Pap smear test?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response
- 5 Don't need to (hysterectomy / Dr says too old)

**if respondent is male skip to q1c**

**q1b**

**In the last 2 years have you had a screening mammogram?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response

**q1c**

**In the last 2 years have you had a screening skin cancer check?**

**(INTERVIEWER: if necessary, 'This is a check by a health professional')**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response

**q1d**

**And, have you had any other screening test for cancer in the last 2 years? And I still mean a test when you didn't have any symptoms.**

- 1 Yes (specify)
- 2 No
- 3 Don't know / can't remember
- 4 No response

**if (ans > 1) skip to q2c**

**q1e (Adelaide and Melbourne)**

**(INTERVIEWER: Did the person just describe an FOBT?)**

- 1 Yes
- 2 No

**q2c**

**Before we go any further, I'll just read you a brief description of bowel cancer:**

**In bowel cancer, cancers are found on the bowel wall. The bowel is the part of the body that removes solid waste (poo) from the body. Bowel cancer may also be called colon cancer, rectal cancer or cancer. Have you ever had bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**if (ans=1) skip to q2d**

**if (ans>1) skip to q3**

**q2d**

**The rest of the questions in this study relate to bowel cancer screening for people who have never experienced bowel cancer first hand. We're sure you appreciate the importance of this area of research. However, the rest of the questions are not relevant to people who have been diagnosed with bowel cancer.**

**THANK YOU FOR YOUR TIME!**

**(INTERVIEWER: press any key to exit interview)**

**q3**

**How likely is it, do you think, that you would develop bowel cancer in your lifetime?**

**Would you say it is likely or unlikely?**

**(INTERVIEWER: probe for VERY, or just UN/LIKELY)**

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Not sure / don't know/ depends
- 7 No response

**q8**

**Does your doctor KNOW, or has your doctor EVER ASKED YOU, about any family history of bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q4**

**Now I'd like you to think about your family, and family in this instance refers to persons who are biologically related to you, for example your parents, brothers & sisters, children, grandparents, aunts, uncles. Has a member of your family ever had bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**If (q4=1) skip to q5**

**If (q4>1) skip to q7a**

**q5**

**Thinking about natural or blood related relatives only, has a parent, brother or sister, or child of yours been diagnosed with bowel cancer BEFORE THEY REACHED THE AGE OF 55 YEARS?**

**(INTERVIEWER: prompt with 'Can I just check that this person is a blood relative?')**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q6a**

**The next question refers to ALL your blood relatives, including: parents, brothers, sisters, children, grandparents, aunts, and uncles. Do you have two or more relatives who have had bowel cancer at any age?**

**(INTERVIEWER: prompt with 'Can I check that these people are your blood relatives?')**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**If (q6a=1) skip to q6b**

**If (q6a>1) skip to q7a**

**q6b**

**Are at least two of these relatives on the same side of your family? That is, at least two from your mother's side of the family, or at least two from your father's side?**  
**(INTERVIEWER: a child or sibling of R counts on both sides of R's family)**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q7a**

**Has anyone else you know had bowel cancer?**

- 1 Yes
- 2 No
- 3 Not sure
- 4 No response

**if (ans > 1) skip to q9**

**q7b**

**What relationship is that person to you?**

**(INTERVIEWER: multiple responses possible prompt with 'Anyone else?')**

- 1 Husband/ wife/ partner
- 2 Half-sibling
- 3 In-laws / Partner's relatives / married-in relatives
- 4 Other relative (eg cousin)
- 5 Friend
- 6 Acquaintance eg neighbour / work colleague
- 7 No-one
- 8 Other (specify)
- 9 Don't know
- 10 No response

**q9**

**What do you think are the signs or symptoms of bowel cancer?  
(INTERVIEWER: Prompt with 'Anything else?')**

- 1 Bleeding / Blood/mucus from the bowel motion
- 2 Diarrhoea or constipation (change in normal bowel patterns)
- 3 Pain in general
- 4 Persistent cramping or abdominal pain
- 5 Unexplained loss of weight
- 6 Feeling of incomplete emptying of bowel
- 7 Other (specify)
- 8 No symptoms
- 9 Don't know / not sure
- 10 Unwilling to answer / no response

**q10**

**Have you ever had symptoms that you thought might be bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response

**q11**

**Have YOU ever consulted a doctor because YOU were concerned that you might have bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response

**q12a**

**Do you know of any tests that you or a doctor can do to check for bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**if (ans > 1) skip to q12d**

**q12b**

**Can you tell me the names of the tests?**

**(INTERVIEWER: multiple responses allowed, prompt with 'Any others?'**

**If R can't name the test ask 'Can you describe it to me?'**

- 1 Colonoscopy
- 2 FOBT (faecal occult blood test)
- 3 Barium enema
- 4 Sigmoidoscopy
- 5 Digital rectal examination
- 6 X-ray
- 7 Ultrasound
- 8 Other (specify)
- 9 Can't give name
- 10 Unwilling to answer / no response

**Mackay**  
**if FOBT named skip to q12c**

**Adelaide and Melbourne**  
**skip to q12d**

**q12d**

**Has a doctor ever suggested you have a test to check for bowel cancer or to examine the functioning of your bowels?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q13**

**One particular screening test for bowel cancer is the faecal occult blood test, or FOBT for short. This test can detect tiny amounts of blood in samples of your bowel motion. This is one of the signs of bowel cancer. The samples can be collected at home, usually by smearing small samples of 3 separate bowel motions on cards. And these are then sent to a laboratory for analysis. Have you heard of such a test before?**

- 1 Yes
- 2 No
- 3 Not sure / don't know
- 4 No response

**Mackay**  
**if (ans=1) skip to q14**  
**if (ans>1) skip to q18a**

**Adelaide and Melbourne**  
**if (q13 = 1) skip to q12c**  
**if (q13 = 4) skip to q18a**  
**if (q13 > 1)**  
**if (q1e=1) skip to q13a**  
**if (q12b=2) skip to q13a**  
**skip to q18a**

**q13a**

**(INTERVIEWER, this person has already named or described an FOBT in q1d or q12b. Remind them about this and explain that this is a type of FOBT. Then press PREVIOUS to go back and correct the previous question.)**

**(If they still insist that they haven't heard of FOBT, go back to q12b or q1d to clarify their response.)**

**skip to q18a**

**q12c**

**From now on I shall just refer to this test as 'FOBT'. Where have you heard or seen information about FOBT?**

**(INTERVIEWER: multiple responses allowed, prompt with 'Anywhere else?' If R can't name the test ask 'Can you describe it to me?')**

- 1 Rotary Club
- 2 Doctor
- 3 Friends
- 4 Family
- 5 TV Program
- 6 Radio
- 7 Newspaper
- 8 Magazine
- 9 Information in the MAIL
- 10 Chemist
- 11 SCOOP (Sthn Co-Otve Prgm for Prevn of Colorectal Cancer)
- 12 Other (specify)
- 13 Can't remember
- 14 No response

**Mackay  
skip to q12d**

**Adelaide and Melbourne  
skip to q14**

**q14**

**Has a doctor ever recommended that you have this FOBT?**

- 1 Yes
- 2 No
- 3 Not sure / can't remember
- 4 No response

**skip to q15**

**q15**

**Have you ever had this FOBT?**

- 1 Yes
- 2 No
- 3 Not sure
- 4 No response

**If (q15=1) skip to q16**

**If (q15>1) skip to q18a**

**q16**

**How long ago did you have the FOBT?**

**(INTERVIEWER: prompt with categories only if necessary If R has had more than 1 test put in an F2 note)**

- 1 Less than 1 year ago
- 2 1 to less than 2 years ago
- 3 2 to less than 5 years ago
- 4 5 years ago or more
- 5 Don't know / can't remember
- 6 No response

**q18a**

**From now on I shall just refer to this test as FOBT. How likely are you to participate in bowel cancer screening using the FOBT test for faecal blood/using FOBT again? Would you say you are likely or unlikely?**

**(INTERVIEWER: probe for VERY, or just UN/LIKELY)**

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 No response

**if (ans=1) skip to q20**

**if (ans=8) skip to q22b**

**q18b**

**If it was recommended that ALL people in your age group be checked for bowel cancer every 1 to 2 years using FOBT - would you say you'd be likely or unlikely to participate if the recommendation came from the HEALTH DEPARTMENT?**

**(INTERVIEWER: probe for VERY, or just UN/LIKELY)**

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 No response

**if (ans=8) skip to q22b**

**q18c**

**What if the recommendation came from YOUR DOCTOR – how likely would you be then to participate?**

**(INTERVIEWER: if necessary prompt: Would you say you'd be likely or unlikely to participate?)**

**(INTERVIEWER: probe for VERY, or just UN/LIKELY)**

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 Other (specify)
- 9 No response

**if (ans<3) skip to q20**

**if (ans=3) skip to q19**

**if (ans=4) skip to q19**

**if (ans=5) skip to q19**

**if (ans=6) skip to q19**

**if (ans=7) skip to q19**

**if (ans=9) skip to q22b**

**if (q18c=8) & if (q18b<3) skip to q20**

**if (q18c=8) & if (q18b>2) skip to q19**

**q19**

**Why do you think that you would/might NOT participate?**

**(INTERVIEWER: multiple responses allowed prompt with "Anything about the test itself?" and "Anything else?")**

- 1 Lack of symptoms / feeling well / no family history
- 2 Embarrassment / distaste with stool collection
- 3 Afraid won't collect samples correctly
- 4 Lack of time / too busy
- 5 Fear of positive results or cancer
- 6 Fear of further tests or surgery
- 7 Don't know enough about the test
- 8 Already have other bowel test/s
- 9 Other (specify)
- 10 No reason in particular
- 11 Don't know
- 12 Unwilling to answer / no response

**skip to q22a**

**q20**

**Why do you think you would participate?**

**(INTERVIEWER: multiple responses allowed prompt with "Anything about the test itself?" and Anything else?")**

- 1 Believe health checks are important
- 2 Peace of mind
- 3 Wanted to know if had bowel cancer/ that didn't have bowel cancer
- 4 Precaution/ prevention/ early detection
- 5 Doctor/ government recommendation
- 6 Family history/ personal experience of CRC or other cancer
- 7 Increasing age
- 8 Other (specify)
- 9 No reason in particular
- 10 Don't know
- 11 Unwilling to answer / no response

**q22a**

**If the government introduced a National Bowel Cancer Screening Program in the future and sent you an FOBT kit in the mail, would you say you are likely or unlikely to participate?**

**(INTERVIEWER: probe for VERY, or just UN/LIKELY)**

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 Other (specify)
- 9 No response

**q22b**

**Have you ever had any test, other than FOBT, to check for bowel cancer or any other bowel problem?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**if (ans=1) skip to q23**

**if (ans>1) skip to q24d**

**q23**

**What test was that?**

**(INTERVIEWER: multiple responses allowed, prompt with 'Any others?')**

**If R can't name the test ask 'Can you describe it to me?')**

- 1 Endoscopy
- 2 Colonoscopy
- 3 Sigmoidoscopy
- 4 Digital rectal examination
- 5 Barium enema
- 6 X-ray
- 7 Blood test
- 8 Ultrasound
- 9 Other (specify)
- 10 Not sure
- 11 Unwilling to answer / no response

**q24d**

**I am now going to read you some statements about health and bowel cancer in general. I would like you to tell me whether you agree or disagree with each of the statements. The first statement is: Having a test like FOBT seems like more trouble than it's worth. Do you agree or disagree?**

**(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)**

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

**q24a**

**The second statement is: It is important to check for bowel cancer even if I have no symptoms. Do you agree or disagree?**

**(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)**

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

**q24b**

**The third statement is: Treating bowel cancer in the early stages increases a person's chance of survival. Do you agree or disagree?**

**(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)**

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

**q24c**

**And the last statement is: If bowel cancer is treated early, it might need less extensive treatment, and that the person may not need to have a colostomy bag. Do you agree or disagree?**

**(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)**

**(INTERVIEWER: if necessary, "A colostomy bag is an external attached to the person's abdomen to collect solid waste. This may need to be used if the person's back passage has to be surgically closed after the removal of a cancer.")**

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

## **DEMOGRAPHICS**

**d1**

**Finally, I would like to ask you some background questions about yourself. Could you please tell me your date of birth?**

**(INTERVIEWER: If R is hesitant about answering this sort of question say: " Date of birth is asked as most people find it easier to remember their date of birth than their age.").**

- 1 Gave date of birth or age or age group
- 2 Refused to answer

**d2**

**Which of the following best describes your current employment status?**

**(INTERVIEWER: Read out highlighted options)**

- 1 Employed full-time
- 2 Employed part-time or casual
- 3 Home duties
- 4 Unemployed
- 5 Full-time student
- 6 Part-time student
- 7 Retired
- 8 Permanently ill/unable to work
- 9 Other (specify)
- 10 No response

**d3**

**What is your current marital status?**

**(INTERVIEWER: Read out highlighted options)**

- 1 Married
- 2 De facto
- 3 Separated
- 4 Divorced
- 5 Widowed
- 6 Single - never married
- 7 Unwilling to say / no response

**d4a**

**Now, could you think about the HIGHEST level of education you have COMPLETED? I'll now read out a list of education levels, please tell me one applies to you. You've COMPLETED a university or college degree.**

**(INTERVIEWER: this includes REGISTERED nurses [not enrolled])**

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

**if (ans <> 2) skip to d5**

**d4b**

**You've COMPLETED a trade or technical certificate or diploma.**

**(INTERVIEWER: this includes ENROLLED nurses [not registered])**

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

**if (ans <> 2) skip to d5**

**d4c**

**You've COMPLETED high school Leaving Honours (Adelaide).**

**You've COMPLETED senior high school (Mackay).**

**You've COMPLETED high school HSC or Matriculation (Melbourne).**

**(INTERVIEWER: Year 5, age 17-18 in SA)**

**(INTERVIEWER: Grade 12, age 17-18 in QLD)**

**(INTERVIEWER: Form 6, age 17-18 in Vic)**

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

**if (ans <> 2) skip to d5**

**d4d**

**You've COMPLETED high school to Leaving Certificate (Adelaide).**

**You've COMPLETED junior high school (Mackay).**

**You've COMPLETED high school to Leaving (Melbourne).**

**(INTERVIEWER: Year 4, age 16-17 in SA)**

**(INTERVIEWER: Grade 10, age 15-16 in QLD)**

**(INTERVIEWER: Form 5, age 16-17 in Vic)**

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

**if (ans <> 2) skip to d5**

**d4z**

**You've COMPLETED high school to Intermediate Certificate (Adelaide).**

**You've COMPLETED high school to Intermediate (Melbourne).**

**(INTERVIEWER: Year 3, age 15-16 in SA)**

**(INTERVIEWER: Form 4, age 15-16 in Vic)**

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

**if (ans <> 2) skip to d5**

**d4e**

**You've COMPLETED primary school.**

**(INTERVIEWER: Grade 7, age 11-12 in SA)**

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

**if (ans <> 2) skip to d5**

**d4f**

**You didn't complete primary school or you have no formal schooling.**

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

**if (ans <> 2) skip to d5**

**d4g**

**Can you describe your education level for me?**

- 1 Yes (specify)
- 2 Don't know
- 3 Refused

**d5**

**In total, how many men/women aged 50 to 74, INCLUDING YOURSELF, live in your household?**

**(INTERVIEWER: Type in the number of people.)**

**(INTERVIEWER: If respondent is unwilling to answer, skip to next question using F10)**

**d6**

**Which of the following categories does your total GROSS annual household income from ALL sources fall into? That is the total income from ALL members of your household before tax is deducted.**

(INTERVIEWER: Read out highlighted categories)

- 1 Less than \$20,000
- 2 \$20,001 - \$60,000
- 3 Over \$60,000
- 4 Don't know
- 5 No response

**d9**

**In your home do you usually speak a language other than English?**

- 1 Yes
- 2 No
- 3 No response

**if (ans > 1) skip to d7**

**d9a**

**What language do you usually speak at home?**

(INTERVIEWER: if more than one language (besides English), ask for the one spoken most often)

- 1 Italian
- 2 Greek
- 3 Arabic
- 4 Vietnamese
- 5 Cantonese
- 6 Mandarin
- 7 Croatian
- 8 Maltese
- 9 German
- 10 Other (specify)
- 11 No response

**skip to d7**

**d7**

**And finally, increasing numbers of people are seeking to have their phone numbers not listed in the White Pages. Can you tell me whether your number is listed or not?**

- 1 Yes - listed
- 2 No - not listed
- 3 Don't know
- 4 Unwilling to answer

**info1**

**If you are interested in further information about bowel cancer and FOBT I can give you a phone number to call. Would you like this number?**

- 1 Yes
- 2 No / Don't care

**if (ans=1) skip to info2**

**if (ans=2) skip to QAname**

**info2**

**For more information about bowel cancer or cancer in general you can call the Cancer Council South Australia 'Cancer Helpline' toll free on 13 11 20. If they cannot assist you with your query or if you want more information about FOBT we suggest you contact your local doctor.**

**(INTERVIEWER: Press any key to continue)**

**QA name**

**Well that's the end of the questionnaire. I just have one last thing to ask.**

**Occasionally my supervisor will call some people back to check I have conducted the interview properly. Would you be willing to give me your first name only in case she wishes to call you?**

- 1 Yes – (INTERVIEWER: Type R's name and phone number)
- 2 No

**Thanks**

**THANK-YOU VERY MUCH FOR ALL YOUR HELP. Once again, my name is \_\_\_\_\_ calling on behalf of the Health Department. GOOD-BYE!**

## 6.2 General population survey – 2004 Questionnaire

### INTRODUCTION

#### Correct

Hello, my name is .....I'm calling from the Commonwealth Department of Health and Ageing.

Can I check whether I have rung (read out phone no.)?

*if number is non residential skip to Non residential log screen*

*if number is residential skip to pcode*

#### pcode

Thank-you. As I said, my name is.....

The Department of Health and Ageing is aiming to better understand people's knowledge and attitudes regarding cancer and screening for cancer. To achieve this we are currently conducting short interviews on this subject.

We only need to interview a certain number of people from each area so, firstly, can I ask what is the postcode for the house where we've called?

*if number is not among pilot area postcodes skip to Household ineligible-not in study area log screen*

*if number is among pilot area postcodes skip to intro1*

#### intro 1

The interviews are aimed at people aged 50 to 74 years. And it is important that we speak with equal numbers of men and women so for this particular interview I need to speak with a [man/woman] living in the house aged 50 to 74. Is there anyone living in the household who fits this description?

- 1 Yes
- 2 No
- 3 Refused to answer

*if yes skip to number*

*if 'no' skip to household ineligible screen*

*if they refuse skip to refusal log screen*

#### Number

Is there just the one [man/woman] aged 50-74 years living in the household, or is there more than one?

- 1 Just the one
- 2 More than one
- 3 No one fits description
- 4 Refusal - didn't establish if req'd person in household

*if 1 skip to One*

*if more than 1 skip to More*

*if no one fits description skip to household ineligible screen*

*if they refuse skip to household ineligible screen*

**One**

**Would you be that person?**

- 1 Yes
- 2 No
- 3 Refusal

**More**

**Given that there is more than one man/woman who fits this criteria, I'd like to speak with the one who has most recently had a birthday. Would you be that person?**

- 1 Yes
- 2 No
- 3 Refusal

**Once have R on the line:**

**The interview is completely confidential and only takes about 15 minutes. Could you spare a little time to answer some questions for me please?**

(IF NECESSARY SAY: Your telephone number was randomly selected by computer and participation is completely confidential and voluntary. It is a very important project aimed to better understand knowledge and attitudes regarding bowel cancer. Are you sure you wouldn't be willing to take part?)

INTERVIEWER: If respondent says no, ask "Is that because the time is inconvenient? I would be happy to call you back at a suitable time"

- 1 Agreed to interview
- 2 Agreed to interview but suggested a call-back
- 3 No, refused interview

*if agreed to interview skip to good*

*if call back skip to appointment screen*

*if they refused skip to refusal screen*

**Good**

**Good, thank-you.**

**Before we begin, I should stress the importance of answering the questions as accurately as possible. So please feel free to take as much time as you need before responding. Also if there are any questions you would rather not answer, just say so. Some calls are monitored by my supervisor for training and quality purposes.**

(INTERVIEWER: If R is concerned about someone 'listening in' on their conversation, tell them that "My supervisor sometimes listens to check that I am conducting the interview properly, and reading the questions correctly")

*if respondent male skip to q2am*

*if respondent female skip to q2af*

## **BODY OF QUESTIONNAIRE**

### **q2am**

**Which of the following cancers do you think is most common in men?**

(INTERVIEWER: read highlighted options and mark response)

- 1 Prostate cancer
- 2 Lung cancer
- 3 Melanoma
- 4 Bowel cancer
- 5 Don't know

**q2am** (second part of question)

**And which do you think is the next most common in men?**

(INTERVIEWER: read remaining highlighted options and mark response)

- 1 Prostate cancer
- 2 Lung cancer
- 3 Melanoma
- 4 Bowel cancer
- 5 Don't know

*skip to q1a*

### **q2af**

**Which of the following cancers do you think is most common in women?**

(INTERVIEWER: read highlighted options and mark response)

- 1 Cancer of the cervix
- 2 Lung cancer
- 3 Melanoma
- 4 Breast cancer
- 5 Bowel cancer
- 6 Don't know

**q2af** (second part of question)

**And which do you think is the next most common in women?**

(INTERVIEWER: read remaining highlighted options and mark response)

- 1 Cancer of the cervix
- 2 Lung cancer
- 3 Melanoma
- 4 Breast cancer
- 5 Bowel cancer
- 6 Don't know

**q1a**

**Now I'd like to ask whether you have had certain screening tests for cancer in the last 2 years. A screening test is a test you have when you DON'T HAVE ANY SYMPTOMS, just to check.**

If respondent is male

**So, in the last 2 years have you had a screening prostate cancer test?**

*If respondent is female*

**So, in the last 2 years have you had a screening Pap smear test?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response
- 5 Don't need to (hysterectomy / Dr says too old)

*if respondent is male skip to q1d*

**q1b**

**In the last 2 years have you had a screening mammogram?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response

**q1d**

**And, have you had any other screening test for cancer in the last 2 years? And I still mean a test when you didn't have any symptoms.**

- 1 Yes (specify)
- 2 No
- 3 Don't know / can't remember
- 4 No response

*if (ans > 1) skip to q2c*

**q1e**

(INTERVIEWER: Did the person just describe an FOBT?)

- 1 Yes
- 2 No

**q2c**

**Before we go any further, I'll just read you a brief description of bowel cancer:  
In bowel cancer, cancers are found on the bowel wall. The bowel is the part of the  
body that removes solid waste matter, or faeces, from the body. Bowel cancer may  
also be called colon cancer, rectal cancer or colorectal cancer.  
Have you ever had bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

*if (ans=1) skip to q2pilot  
if (ans>1) skip to q3*

**q2pilot**

**I'm really sorry to hear that.**

**Was your bowel cancer diagnosed as a result of FOBT testing in  
the National Bowel Cancer Screening Pilot Program?**

(INTERVIEWER: if R needs clarification

The National Pilot Program mailed FOBT kits to people and invited  
them to complete and return their kit to a laboratory for testing.)

- 1 Yes
- 2 No
- 3 Not sure / don't know / can't remember
- 4 No response

*if (ans=1) skip to q8  
if (ans>1) skip to q2d*

**q2d**

**The rest of the questions in this study relate to bowel cancer screening for people who  
have never experienced bowel cancer first hand. We're sure you appreciate the  
importance of this area of research. However, the rest of the questions are not  
relevant to people who have been diagnosed with bowel cancer.**

**If you'd like any further information about the study I can give you a 1300 number to  
call the researchers. Would you like that number? 1300 366 205**

**THANK YOU FOR YOUR TIME!**

(INTERVIEWER: press any key to exit interview)

**q3**

**How likely is it, do you think, that you would develop bowel cancer in your lifetime?**

**Would you say it is likely or unlikely?**

(INTERVIEWER: probe for VERY, or just UN/LIKELY)

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Not sure / don't know/ depends
- 7 No response

**q8**

**Does your doctor KNOW, or has your doctor EVER ASKED YOU, about any family history of bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q4**

**Now I'd like you to think about your family, and family in this instance refers to persons who are biologically related to you, for example your parents, brothers & sisters, children, grandparents, aunts, uncles. Has a member of your family ever had bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

If (q4=1) skip to q5

If (q4>1) skip to q7a

**q5**

**Thinking about natural or blood related relatives only, has a parent, brother or sister, or child of yours been diagnosed with bowel cancer BEFORE THEY REACHED THE AGE OF 55 YEARS?**

(INTERVIEWER: prompt with 'Can I just check that this person is a blood relative?')

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q6a**

**The next question refers to ALL your blood relatives, including: parents, brothers, sisters, children, grandparents, aunts, and uncles. Do you have two or more relatives who have had bowel cancer at any age?**

(INTERVIEWER: prompt with 'Can I check that these people are your blood relatives?')

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

*If (q6a=1) skip to q6b*

*If (q6a>1) skip to q7a*

**q6b**

**Are at least two of these relatives on the same side of your family? That is, at least two from your mother's side of the family, or at least two from your father's side?**

(INTERVIEWER: a child or sibling of R counts on both sides of R's family)

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q7a**

**Has anyone else you know had bowel cancer?**

- 1 Yes
- 2 No
- 3 Not sure
- 4 No response

*if (ans > 1) skip to q9*

**q7b**

**What relationship is that person to you?**

(INTERVIEWER: multiple responses possible prompt with 'Anyone else?')

- 1 Husband/ wife/ partner
- 2 Half-sibling
- 3 In-laws / Partner's relatives / married-in relatives
- 4 Other relative (eg cousin)
- 5 Friend
- 6 Acquaintance (eg neighbour / work colleague)
- 7 No-one
- 8 Other (specify)
- 9 Don't know
- 10 No response

**q9**

**What do you think are the signs or symptoms of bowel cancer?**

(INTERVIEWER: Prompt with 'Anything else?')

- 1 Bleeding / Blood/mucus from the bowel motion
- 2 Diarrhoea or constipation (change in normal bowel patterns)
- 3 Pain in general
- 4 Persistent cramping or abdominal pain
- 5 Unexplained loss of weight
- 6 Feeling of incomplete emptying of bowel
- 7 No symptoms
- 8 Other (specify)
- 9 Don't know / not sure
- 10 Unwilling to answer / no response

**q10**

**Have you ever had symptoms that you thought might be bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response

**q11**

**Have YOU ever consulted a doctor because YOU were concerned that you might have bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response

*if (q2pilot = 1) skip to q15b*

**q12a**

**Do you know of any tests that you or a doctor can do to check for bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

*if (ans > 1) skip to q12d*

**q12b****Can you tell me the names of the tests?**

(INTERVIEWER: multiple responses allowed, prompt with 'Any others?')

If R can't name the test ask 'Can you describe it to me?' and select the test they describe if possible)

- 1 Colonoscopy
- 2 Virtual Colonoscopy
- 3 FOBT (faecal occult blood test)
- 4 Barium enema
- 5 Sigmoidoscopy
- 6 Digital rectal examination
- 7 X-ray / CT Scan
- 8 Whole-of-Body CT scan for cancer
- 9 Ultrasound
- 10 Other (specify)
- 11 Can't give name or describe
- 12 Unwilling to answer / no response

**q12d****Has a doctor ever suggested you have a test to check for bowel cancer or to examine the functioning of your bowels?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q13****One particular screening test for bowel cancer is the faecal occult blood test, or FOBT for short. This test can detect tiny amounts of blood in samples of your bowel motion. This could be one of the signs of bowel cancer. The samples can be collected at home, usually by taking small samples of bowel motions. These are then sent to a laboratory for analysis. Have you heard of such a test before?**

(INTERVIEWER: If R thinks you mean a blood test, say "This test doesn't involve collecting a sample of blood, it involves collecting samples from the bowel motions." Then read the last paragraph of the definition again.)

- 1 Yes
- 2 No
- 3 Not sure / don't know
- 4 No response

*if (q13 = 1) skip to q12c*

*if (q13 = 4) skip to q14a*

*if (q1e = 1 ) skip to q13a*

*if (q12b=2) skip to q13a*

*skip to q14a*

**q13a**

(INTERVIEWER: this person has already named or described an FOBT in q1d or q12b. Remind them about this and explain that this is a type of FOBT.

Then press PREVIOUS to go back and correct the previous question.)

(If they still insist that they haven't heard of FOBT, go back to q12b or q1d to clarify their response.)

*skip to q21a*

**q12c**

**From now on I shall just refer to this test as 'FOBT'. Where have you heard or seen information about FOBT?**

(INTERVIEWER: multiple responses allowed, prompt with 'Anywhere else?')

- 1 Gov't kit / Nat'l Bowel Cancer Screening info kit
- 2 Community Health Centre
- 3 Cancer Council
- 4 Rotary Club
- 5 Doctor
- 6 Friends
- 7 Family
- 8 TV Program
- 9 Radio
- 10 Newspaper
- 11 Magazine
- 12 Other information in the MAIL
- 13 Chemist
- 14 SCOOP (Sthn Co-Otve Prgm for Prevn of Colorectal Cancer)
- 15 Other (specify)
- 16 Can't remember
- 17 No response

**q14**

**In the last 12 months has a doctor recommended that you have this FOBT?**

- 1 Yes
- 2 No
- 3 Not sure / can't remember
- 4 No response

**q14a**

**The National Bowel Cancer Screening Pilot Program has been operating in your area over the past 12 months. This Program has mailed invitations, with an FOBT kit for people to complete and send back to a pathology laboratory for analysis.**

**Did you receive a kit in the mail?**

- 1 Yes
- 2 No
- 3 Not sure / can't remember
- 4 No response

*If (q14a = 1) skip to q15a*

*If (q14a > 1) skip to q21a*

**q15a**

**Did you complete and return the FOBT kit for testing?**

- 1 Yes
- 2 No
- 3 Not sure
- 4 No response

*If (q15a = 1) skip to q15b*

*If (q15a > 1) skip to q15d*

**q15b**

**Two different types of kit were trialled. Would you mind telling me whether you used a brush or a small stick like a toothpick to collect the sample?**

(INTERVIEWER: If R says they used something else, ask whether a brush or small stick device came with their kit)

- 1 Brush (Enterix kit)
- 2 Stick / Toothpick (Bayer kit)
- 3 Not sure / Can't remember
- 4 No response

**q15b2**

**Did you find the test easy to use?**

- 1 Yes
- 2 No
- 3 Can't remember
- 4 No response

*If (ans = 2) skip to q15b3*

*If (q2pilot = 1) skip to d1*

*skip to q15c*

**q15b3**

**What was the problem that you had with it?**

(INTERVIEWER: multiple responses allowed prompt with 'Anything else?')

- 1 Instructions were hard to READ
- 2 Instructions were hard to UNDERSTAND
- 3 Dealing with bowel motions was DISTASTEFUL
- 4 BRUSH / STICK-TOOTHPICK difficult to use
- 5 VIALS / TEST CARD difficult to use
- 6 Using the BARCODES / STICKERS was difficult
- 7 Couldn't provide 2 SAMPLES in the TIME required
- 8 ARTHRITIS or MOBILITY problems
- 9 Not CONFIDENT / too DIFFICULT
- 10 Other (specify)
- 11 Can't remember
- 12 No response / unwilling to answer

*if (Q2pilot = 1) skip to d1*

**q15c**

**If you have received your FOBT test result, can you tell me what the result was?**

(INTERVIEWER: if R says "Positive" or "Negative" confirm whether or not blood was found)

- 1 Blood found (Positive)
- 2 No blood found (Negative)
- 3 Have not yet received result
- 4 Can't remember
- 5 No response / unwilling to answer

*skip to q20a*

**q15d**

**Do you intend to complete the test in the next couple of weeks?**

- 1 Yes
- 2 No
- 3 Not sure
- 4 No response

*if (ans=1) skip to q20a*

*if (ans>1) skip to q19a*

**q20a****Why did you decide to complete the test?**

(INTERVIEWER: multiple responses allowed. Prompt with “Anything about the test itself?” and “Anything else?”)

- 1 Received in the mail
- 2 It was free
- 3 Media campaign
- 4 Pressure/encouragement from spouse/partner
- 5 Precaution/ prevention/ early detection/ health checks important
- 6 Wanted to know whether had bowel cancer/ peace of mind
- 7 Doctor/ government recommendation
- 8 Family history/ personal experience of CRC or other cancer
- 9 Increasing age
- 10 Other (specify)
- 11 Don't know / No reason in particular
- 12 Unwilling to answer / no response

*skip to q21a*

**q19a****Why did you decide not to [Are there any reasons why you might not] complete the test?**

(INTERVIEWER: multiple responses allowed. Prompt with "Anything about the test itself?" and "Anything else?")

- 1 Lack of symptoms / feeling well
- 2 No family history
- 3 Embarrassment/distaste with stool collection
- 4 Afraid won't collect samples correctly
- 5 Lack of time / too busy
- 6 Fear of results/ cancer/ further tests/ surgery
- 7 Don't know enough about the test
- 8 Already have other bowel test/s
- 9 Cost / not covered by Medicare
- 10 Lack of confidence in doctors / tests
- 11 Don't care / couldn't be bothered
- 12 Other (specify)
- 13 No reason in particular / don't know
- 14 Unwilling to answer / no response

*if (q19a=9) skip to q19acost*  
*skip to q21a*

**q19acost**

**What costs are you concerned about?**

(INTERVIEWER: multiple responses allowed. Prompt with "Any other costs?")

- 1 FOBT
- 2 Follow-up tests (eg colonoscopy, pathology, etc)
- 3 Treatment / hospital costs
- 4 Not sure
- 5 No response

*skip to q21a*

**q21a**

**[From now on I shall just refer to this test as FOBT.]**

**How likely are you to participate in bowel cancer screening from time to time using [FOBT / the FOBT test for faecal blood] in the future?**

**Would you say you are likely or unlikely to participate?**

(INTERVIEWER: probe for VERY, or just UN/LIKELY)

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 Other (specify)
- 9 No response

**q18b**

**If it was recommended that ALL people in your age group be checked for bowel cancer every 1 to 2 years using FOBT - would you say you'd be likely or unlikely to participate if the recommendation came from the HEALTH DEPARTMENT?**

(INTERVIEWER: probe for VERY, or just UN/LIKELY)

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 Other (specify)
- 9 No response

*if (ans=9) skip to q22b*

**q18c**

**What if the recommendation came from YOUR DOCTOR - how likely would you be then to participate?**

(INTERVIEWER: if necessary prompt: Would you say you'd be likely / unlikely to participate?)

(INTERVIEWER: probe for VERY, or just UN/LIKELY)

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 Other (specify)
- 9 No response

*if (ans<3) skip to q20*

*if (ans=3,4,5,6,7) skip to q19*

*if (ans=9) skip to q22b*

*if (q18b<3) skip to q20*

*if (q18b>2) skip to q19*

**q19**

**[You said earlier that you would be unlikely to participate.]**

**Why do you think that you [would / might] NOT participate?**

(INTERVIEWER: multiple responses allowed. Prompt with "Anything about the test itself?" & "Anything else?")

- 1 Lack of symptoms / feeling well
- 2 No family history
- 3 Embarrassment / distaste with stool collection
- 4 Afraid won't collect samples correctly
- 5 Lack of time / too busy
- 6 Fear of results/ cancer/ further tests/ surgery
- 7 Don't know enough about the test
- 8 Already have other bowel test/s
- 9 Cost / not covered by Medicare
- 10 Lack of confidence in doctors/tests
- 11 Don't care / couldn't be bothered
- 12 Other (specify)
- 13 No reason in particular / don't know
- 14 Unwilling to answer / no response

*if (q19=9) skip to q19cost*

*skip to q22a*

**q19cost**

**What costs are you concerned about?**

(INTERVIEWER: multiple responses allowed. Prompt with "Any other costs?")

- 1 FOBT
- 2 Follow-up tests (eg colonoscopy)
- 3 Treatment / hospital costs
- 4 Not sure
- 5 No response

*skip to q22a*

**q20**

**[You said earlier that you would be [very] likely to participate.]**

**Why do you think you would participate?**

(INTERVIEWER: multiple responses allowed

Prompt with "Anything about the test itself?" & "Anything else?")

- 1 It was free
- 2 Pressure/encouragement from spouse/partner
- 3 Precaution/ prevention/ early detection/ health checks important
- 4 Wanted to know whether had bowel cancer / Peace of mind
- 5 Doctor/government recommendation
- 6 Family history/ personal experience of CRC or other cancer
- 7 Increasing age
- 8 Other (specify)
- 9 Don't know / no reason in particular
- 10 Unwilling to answer / no response

**q22a**

**If the government introduced a National Bowel Cancer Screening Program in the future and sent you an FOBT kit in the mail, would you say you are likely or unlikely to participate?**

(INTERVIEWER: probe for VERY, or just UN/LIKELY)

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 Other (specify)
- 9 No response

**q22b**

**Have you ever had any test, other than FOBT, to check for bowel cancer or any other bowel problem?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

*if (ans=1) skip to q23*

*if (ans>1) skip to q24d*

**q23**

**What test was that?**

(INTERVIEWER: multiple responses allowed, prompt with 'Any others?'.  
If R can't name the test ask 'Can you describe it to me?')

- 1 Endoscopy
- 2 Colonoscopy
- 3 Virtual Colonoscopy
- 4 Sigmoidoscopy
- 5 Digital rectal examination
- 6 Barium enema
- 7 X-ray / CT Scan
- 8 Whole-of-Body CT scan for cancer
- 9 Blood test
- 10 Ultrasound
- 11 Other (specify)
- 12 Not sure
- 13 Unwilling to answer / no response

**q24d**

**I am now going to read you some statements about health and bowel cancer in general. I would like you to tell me whether you agree or disagree with each of the statements.**

**The first statement is: Having a test like FOBT seems like more trouble than it's worth.**

**Do you agree or disagree?**

(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

**q24a**

**The second statement is: It is important to check for bowel cancer even if I have no symptoms.**

**Do you agree or disagree?**

(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

**q24b**

**The third statement is: Treating bowel cancer in the early stages increases a person's chance of survival.**

**Do you agree or disagree?**

(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

**q24c**

**And the last statement is: If bowel cancer is treated early, it might need less extensive treatment, and that the person may not need to have a colostomy bag.**

**Do you agree or disagree?**

(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)

(INTERVIEWER: if necessary, "A colostomy bag is an external appliance attached to the person's abdomen to collect solid waste. This may need to be used if the person's back passage has to be surgically closed after the removal of a cancer.")

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

## DEMOGRAPHICS

### d1

**Finally, I would like to ask you some background questions about yourself. Could you please tell me your date of birth?**

(INTERVIEWER: If R is hesitant about answering this sort of question say: " Date of birth is asked as most people find it easier to remember their date of birth than their age.").

- 1 Gave date of birth or age or age group
- 2 Refused to answer

### d2

**Which of the following best describes your current employment status?**

(INTERVIEWER: Read out highlighted options)

(INTERVIEWER: Self employed = employed, probe for full/part time)

- 1 Employed full-time (incl. those on any type of leave)
- 2 Employed part-time or casual (incl. those on any type of leave)
- 3 Home duties
- 4 Unemployed
- 5 Full-time student
- 6 Part-time student
- 7 Retired
- 8 Permanently ill/unable to work
- 9 Other (specify)
- 10 No response

### d3

**What is your current marital status?**

(INTERVIEWER: Read out highlighted options)

- 1 Married
- 3 De facto
- 3 Separated
- 4 Divorced
- 5 Widowed
- 6 Single - never married
- 7 Unwilling to say / no response

**d4a**

**Now, could you think about the HIGHEST level of education you have COMPLETED? I'll now read out a list of education levels, please tell me one applies to you.**

**Have you COMPLETED a university or college degree?**

(INTERVIEWER: this includes REGISTERED nurses [not enrolled])

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4b**

**Have you COMPLETED a trade or technical certificate or diploma?**

(INTERVIEWER: this includes ENROLLED nurses [not registered])

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4c**

**Have you COMPLETED high school Leaving Honours? (Adelaide).**

(INTERVIEWER: Year 5, age 17-18 in SA).

**Have you COMPLETED senior high school? (Mackay).**

(INTERVIEWER: Grade 12, age 17-18 in QLD).

**Have you COMPLETED high school HSC or Matriculation? (Melbourne).**

(INTERVIEWER: Form 6, age 17-18 in Vic).

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4d**

**Have you COMPLETED high school to Leaving Certificate?** (Adelaide).

(INTERVIEWER: Year 4, age 16-17 in SA).

**Have you COMPLETED junior high school?** (Mackay).

(INTERVIEWER: Grade 10, age 15-16 in QLD).

**Have you COMPLETED high school to Leaving?** (Melbourne).

(INTERVIEWER: Form 5, age 16-17 in Vic).

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4z** (Adelaide and Melbourne only).

**Have you COMPLETED high school to Intermediate Certificate?** (Adelaide).

(INTERVIEWER: Year 3, age 15-16 in SA).

**Have you COMPLETED high school to Intermediate?** (Melbourne).

(INTERVIEWER: Form 4, age 15-16 in Vic).

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4e**

**Have you COMPLETED primary school?**

(INTERVIEWER: Grade 7, age 11-12 in SA).

(INTERVIEWER: Grade 7, age 12-13 in Qld)

(INTERVIEWER: Grade 6, age 11-12 in VIC).

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4f**

**Did you leave before completing primary school, or did you not do any formal schooling?**

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4g**

**Can you describe your education level for me?**

- 1 Yes (specify)
- 2 Don't know
- 3 Refused

**d5**

**In total, how many [men/women (*same sex as R*)] aged 50 to 74, INCLUDING YOURSELF, live in your household?**

(INTERVIEWER: If respondent is unwilling to answer, skip to next question)

**d6**

**Which of the following three broad categories does your total GROSS annual household income from ALL sources fall into? That is the total income from ALL members of your household before tax is deducted.**

(INTERVIEWER: Read out highlighted categories)

- 1 Less than \$20,000
- 2 \$20,001 - \$60,000
- 3 Over \$60,000
- 4 Don't know
- 5 No response

**d9**

**In your home do you usually speak a language other than English?**

- 1 Yes
- 2 No
- 3 No response

*if (ans > 1) skip to d7*

**d9a**

**What language do you usually speak at home?**

(INTERVIEWER: if more than one language (besides English), ask for the one spoken most often)

- 1 Italian
- 2 Greek
- 3 Arabic
- 4 Vietnamese
- 5 Cantonese
- 6 Mandarin
- 7 Croatian
- 8 Maltese
- 9 German
- 10 Other (specify)
- 11 No response

**q26**

**When the Government sent out invitations and kits, they obtained people's contact details from Medicare. Do you think it's alright for them to use this information to contact you?**

(INTERVIEWER: If R asks why we want to know this, say 'The Privacy Commissioner has asked us to let him know how people feel about their Medicare contact details being used for this purpose').

- 1 Yes
- 2 No
- 3 Don't care
- 4 Don't know
- 5 No response

*if (q26 = 2) skip to Q26a  
skip to d7*

**q26a**

**How strongly do you feel about this?**

**Would you say that you're concerned about it, or very concerned?**

(INTERVIEWER: If necessary suggest that they talk about their concerns with one of the people who organised this process:

(Screening Section Commonwealth Department of Health and Ageing)

- 1 Concerned
- 2 Very concerned
- 3 No response

**d7**

**And finally, increasing numbers of people are seeking to have their phone numbers not listed in the White Pages. Can you tell me whether your number is listed or not?**

- 1 Yes - listed
- 2 No - not listed
- 3 Don't know
- 4 Unwilling to answer

**info1**

**If you are interested in further information about bowel cancer and FOBT I can give you a phone number to call. Would you like this number?**

- 1 Yes
- 2 No / Don't care

*if (ans=1) skip to info2*  
*if (ans=2) skip to QA name*

**info2**

**For more information about bowel cancer or cancer in general you can call the Cancer Council 'Cancer Helpline' toll free on 13 11 20. If they cannot assist you with your query or if you want more information about FOBT we suggest you contact your local doctor.**

(INTERVIEWER: Press any key to continue)

**QA name**

**Well that's the end of the questionnaire. I just have one last thing to ask. Occasionally my supervisor will call some people back to check I have conducted the interview properly. Would you be willing to give me your first name only in case she wishes to call you?**

- 1 Yes – (INTERVIEWER: Type R's name and phone number)
- 2 No

**thanks**

**THANK-YOU VERY MUCH FOR ALL YOUR HELP.**

**Once again, my name is....., calling on behalf of the Commonwealth Department of Health and Ageing.**

**GOOD-BYE!**

**d8**

INTERVIEWER: What is the sex of the respondent?

(INTERVIEWER: Do not ask this question aloud)

- 1 Male
- 2 Female
- 3 Don't know

(INTERVIEWER: Press 1 to complete interview)

## 6.3 Participants' survey – 2004 Questionnaire

### INTRODUCTION

#### Correct

Hello, my name is.....I'm calling from the Commonwealth Department of Health and Ageing.

Can I check whether I have rung (read out phone no.)?

*if number is non residential skip to Non residential log screen*

*if number is residential skip to pcode*

#### pcode

Thank-you. As I said, my name is.....

The Department of Health and Ageing is aiming to better understand people's knowledge and attitudes regarding cancer and screening for cancer. To achieve this we are currently conducting short interviews on this subject.

We only need to interview a certain number of people from each area so, firstly, can I ask what is the postcode for the house where we've called?

*if number is not among pilot area postcodes skip to Household ineligible-not in study area log screen*

*if number is among pilot area postcodes skip to intro1*

#### intro 1

The Department of Health and Ageing is trying to evaluate how effective a recent bowel cancer screening program has been. This program was aimed at people aged 55 to 74 years.

Is there anyone in this age group living in the household?

- 1 Yes
- 2 No
- 3 Refused to answer

*if (ans = 1) skip to intro1a*

*if (ans = 2) skip to Household ineligible log screen*

*if (ans = 3) skip to Refusal log screen*

**intro 1a**

**The National Bowel Cancer Screening Pilot Program has been operating in your area over the past 12 months. This Program has mailed invitations, with an FOBT kit for people to complete and send back to a pathology laboratory for analysis.**

**Did anyone in the household receive a kit in the mail?**

(INTERVIEWER: If more detail about FOBT test kit needed:

The samples are collected at home by taking small samples of bowel motions. These are then sent to a laboratory for analysis).

(INTERVIEWER: If the person is uncertain, ask to speak with a person who would know).

- 1 Yes
- 2 No
- 3 Need to call back later to speak with someone else
- 4 Not sure / don't know / can't remember
- 5 No response

*if (ans = 1) skip to intro1b*

*if (ans = 2, 5) skip to Household ineligible log screen*

*if (ans = 3) skip to Appointment screen*

*if (ans = 5) skip to Refusal log screen*

**intro 1b**

**The interviews are aimed at people who have completed this test.**

**Did anyone in the household complete and return a kit for testing?.**

(INTERVIEWER: If the person is uncertain, ask to speak with a person who would know).

- 1 Yes
- 2 No
- 3 Intend to, but not done it yet
- 4 Need to call back later
- 5 Not sure / don't know / can't remember
- 6 No response

*if (ans = 1) skip to intro1c*

*if (ans = 2, 3, 5) skip to Household ineligible log screen*

*if (ans = 4) skip to Appointment screen*

*if (ans = 6) skip to Refusal log screen*

### **intro 1c**

(INTERVIEWERS NOTE: If the respondent has already said they are the only person in the household who has done the test DO NOT READ OUT THIS QUESTION - press '1' to continue)

**Is there just the one person living in the household WHO HAS COMPLETED THIS TEST, or is there more than one?**

- 1 Just the one
- 2 More than one
- 3 Refusal - didn't establish if required person in household

*if 1 skip to One*

*if more than 1 skip to More*

*if they refuse skip to household ineligible screen*

### **One**

**Would you be that person?**

- 1 Yes
- 2 No
- 3 Refusal

### **More**

**Given that there is more than one person who fits these criteria, I'd like to speak with the one who has most recently had a birthday. Would you be that person?**

- 1 Yes
- 2 No
- 3 Refusal

### **Once have R on the line:**

**The interview is completely confidential and only takes about 15 minutes. Could you spare a little time to answer some questions for me please?**

(IF NECESSARY SAY: Your telephone number was randomly selected by computer and participation is completely confidential and voluntary. It is a very important project aimed to better understand knowledge and attitudes regarding bowel cancer. Are you sure you wouldn't be willing to take part?)

INTERVIEWER: If respondent says no, ask "Is that because the time is inconvenient? I would be happy to call you back at a suitable time"

- 1 Agreed to interview
- 2 Agreed to interview but suggested a call-back
- 3 No, refused interview

*if agreed to interview skip to good*

*if call back skip to appointment screen*

*if they refused skip to refusal screen*

### **Good**

**Good, thank-you. Before we begin, I should stress the importance of answering the questions as accurately as possible. So please feel free to take as much time as you**

**need before responding. Also if there are any questions you would rather not answer, just say so.**

**Some calls are monitored by my supervisor for training and quality purposes.**

(INTERVIEWER: If R is concerned about someone 'listening in' on their conversation, tell them that "My supervisor sometimes listens to check that I am conducting the interview properly, and reading the questions correctly")

## **BODY OF QUESTIONNAIRE**

### **d8**

INTERVIEWER: What is the sex of the respondent?

(INTERVIEWER: Do not ask this question aloud)

- 1 Male
- 2 Female
- 3 Don't know

*if (ans = 1) skip to q2am*

*if (ans = 2) skip to q2af*

### **q2am**

**Which of the following cancers do you think is most common in men?**

(INTERVIEWER: read highlighted options and mark response)

- 1 Prostate cancer
- 2 Lung cancer
- 3 Melanoma
- 4 Bowel cancer
- 5 Don't know

**q2am** (second part of question)

**And which do you think is the next most common in men?**

(INTERVIEWER: read remaining highlighted options and mark response)

- 1 Prostate cancer
- 2 Lung cancer
- 3 Melanoma
- 4 Bowel cancer
- 5 Don't know

*skip to q1a*

### **q2af**

**Which of the following cancers do you think is most common in women?**

(INTERVIEWER: read highlighted options and mark response)

- 1 Cancer of the cervix
- 2 Lung cancer
- 3 Melanoma
- 4 Breast cancer
- 5 Bowel cancer
- 6 Don't know

**q2af** (second part of question)

**And which do you think is the next most common in women?**

(INTERVIEWER: read remaining highlighted options and mark response)

- 1 Cancer of the cervix
- 2 Lung cancer
- 3 Melanoma
- 4 Breast cancer
- 5 Bowel cancer
- 6 Don't know

**q1a**

**Now I'd like to ask whether you have had certain screening tests for cancer in the last 2 years. A screening test is a test you have when you DON'T HAVE ANY SYMPTOMS, just to check.**

If respondent is male

**So, in the last 2 years have you had a screening prostate cancer test?**

*If respondent is female*

**So, in the last 2 years have you had a screening Pap smear test?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response
- 5 Don't need to (hysterectomy / Dr says too old)

*if respondent is male skip to q1d*

**q1b**

**In the last 2 years have you had a screening mammogram?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response

**q1d**

**And, have you had any other screening test for cancer in the last 2 years? And I still mean a test when you didn't have any symptoms.**

- 1 Yes (specify)
- 2 No
- 3 Don't know / can't remember
- 4 No response

*if (ans > 1) skip to q2c*

**q1e**

(INTERVIEWER: Did the person just describe an FOBT?)

- 1 Yes
- 2 No

**q2c**

**Before we go any further, I'll just read you a brief description of bowel cancer:**

**In bowel cancer, cancers are found on the bowel wall. The bowel is the part of the body that removes solid waste matter, or faeces, from the body. Bowel cancer may also be called colon cancer, rectal cancer or colorectal cancer.**

**Have you ever had bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

*if (ans=1) skip to q2pilot*

*if (ans>1) skip to q3*

**q2pilot**

**I'm really sorry to hear that.**

**Was your bowel cancer diagnosed as a result of FOBT testing in the National Bowel Cancer Screening Pilot Program?**

(INTERVIEWER: if R needs clarification - The National Pilot Program mailed FOBT kits to people and invited them to complete and return their kit to a laboratory for testing).

- 1 Yes
- 2 No
- 3 Not sure / don't know / can't remember
- 4 No response

*if (ans=1) skip to q8*

*if (ans>1) skip to q2d*

**q2d**

**The rest of the questions in this study relate to bowel cancer screening for people who have never experienced bowel cancer first hand. We're sure you appreciate the importance of this area of research. However, the rest of the questions are not relevant to people who have been diagnosed with bowel cancer.**

**If you'd like any further information about the study I can give you a 1300 number to call the researchers. Would you like that number? 1300 366 205**

**THANK YOU FOR YOUR TIME!**

(INTERVIEWER: press any key to exit interview)

**q3**

**How likely is it, do you think, that you would develop bowel cancer in your lifetime?**

**Would you say it is likely or unlikely?**

(INTERVIEWER: probe for VERY, or just UN/LIKELY)

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Not sure / don't know/ depends
- 7 No response

**q8**

**Does your doctor KNOW, or has your doctor EVER ASKED YOU, about any family history of bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q4**

**Now I'd like you to think about your family, and family in this instance refers to persons who are biologically related to you, for example your parents, brothers & sisters, children, grandparents, aunts, uncles. Has a member of your family ever had bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

If (q4=1) skip to q5

If (q4>1) skip to q7a

**q5**

**Thinking about natural or blood related relatives only, has a parent, brother or sister, or child of yours been diagnosed with bowel cancer BEFORE THEY REACHED THE AGE OF 55 YEARS?**

(INTERVIEWER: prompt with 'Can I just check that this person is a blood relative?')

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q6a**

**The next question refers to ALL your blood relatives, including: parents, brothers, sisters, children, grandparents, aunts, and uncles. Do you have two or more relatives who have had bowel cancer at any age?**

(INTERVIEWER: prompt with 'Can I check that these people are your blood relatives?')

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

*If (q6a=1) skip to q6b*

*If (q6a>1) skip to q7a*

**q6b**

**Are at least two of these relatives on the same side of your family? That is, at least two from your mother's side of the family, or at least two from your father's side?**

(INTERVIEWER: a child or sibling of R counts on both sides of R's family)

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q7a**

**Has anyone else you know had bowel cancer?**

- 1 Yes
- 2 No
- 3 Not sure
- 4 No response

*if (ans > 1) skip to q9*

**q7b**

**What relationship is that person to you?**

(INTERVIEWER: multiple responses possible prompt with 'Anyone else?')

- 1 Husband/ wife/ partner
- 2 Half-sibling
- 3 In-laws / Partner's relatives / married-in relatives
- 4 Other relative (eg cousin)
- 5 Friend
- 6 Acquaintance (eg neighbour / work colleague)
- 7 No-one
- 8 Other (specify)
- 9 Don't know
- 10 No response

**q9**

**What do you think are the signs or symptoms of bowel cancer?**

(INTERVIEWER: Prompt with 'Anything else?')

- 1 Bleeding / Blood/mucus from the bowel motion
- 2 Diarrhoea or constipation (change in normal bowel patterns)
- 3 Pain in general
- 4 Persistent cramping or abdominal pain
- 5 Unexplained loss of weight
- 6 Feeling of incomplete emptying of bowel
- 7 No symptoms
- 8 Other (specify)
- 9 Don't know / not sure
- 10 Unwilling to answer / no response

**q10**

**Have you ever had symptoms that you thought might be bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response

**q11**

**Have YOU ever consulted a doctor because YOU were concerned that you might have bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 No response

*if (q2pilot = 1) skip to q15b*

**q12a**

**Do you know of any tests that you or a doctor can do to check for bowel cancer?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

*if (ans > 1) skip to q12d*

**q12b**

**Can you tell me the names of the tests?**

(INTERVIEWER: multiple responses allowed, prompt with 'Any others?' If R can't name the test ask 'Can you describe it to me?' and select the test they describe if possible).

- 1 Colonoscopy
- 2 Virtual Colonoscopy
- 3 FOBT (faecal occult blood test)
- 4 Barium enema
- 5 Sigmoidoscopy
- 6 Digital rectal examination
- 7 X-ray / CT Scan
- 8 Whole-of-Body CT scan for cancer
- 9 Ultrasound
- 10 Other (specify)
- 11 Can't give name or describe
- 12 Unwilling to answer / no response

**q12d**

**Has a doctor ever suggested you have a test to check for bowel cancer or to examine the functioning of your bowels?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

**q13**

**One particular screening test for bowel cancer is the faecal occult blood test, or FOBT for short. This test can detect tiny amounts of blood in samples of your bowel motion. This could be one of the signs of bowel cancer. The samples can be collected at home, usually by taking small samples of bowel motions. These are then sent to a laboratory for analysis. This was the type of test kit that I asked you about earlier, and you told me that you received one in the mail and you completed it and sent in to be analysed.**

(INTERVIEWER: Press "1" to continue.)

*skip to q12c*

**q13a**

(INTERVIEWER: this person has already named or described an FOBT in q1d or q12b. Remind them about this and explain that this is a type of FOBT.

Then press PREVIOUS to go back and correct the previous question.)

(If they still insist that they haven't heard of FOBT, go back to q12b or q1d to clarify their response.)

*skip to q21a*

**q12c**

**From now on I shall just refer to this test as 'FOBT'. Where have you heard or seen information about FOBT?**

(INTERVIEWER: multiple responses allowed, prompt with 'Anywhere else?')

- 1 Gov't kit / Nat'l Bowel Cancer Screening info kit
- 2 Community Health Centre
- 3 Cancer Council
- 4 Rotary Club
- 5 Doctor
- 6 Friends
- 7 Family
- 8 TV Program
- 9 Radio
- 10 Newspaper
- 11 Magazine
- 12 Other information in the MAIL
- 13 Chemist
- 14 SCOOP (Sthn Co-Otve Prgm for Prevn of Colorectal Cancer)
- 15 Other (specify)
- 16 Can't remember
- 17 No response

**q14**

**In the last 12 months has a doctor recommended that you have this FOBT?**

- 1 Yes
- 2 No
- 3 Not sure / can't remember
- 4 No response

**q15b**

**In the National Bowel Cancer Screening Pilot Program two different types of kit were trialled. Would you mind telling me whether you used a brush or a small stick like a toothpick to collect the sample?**

(INTERVIEWER: If R says they used something else, ask whether a brush or small stick device came with their kit).

- 1 Brush (Enterix kit)
- 2 Stick / Toothpick (Bayer kit)
- 3 Not sure / Can't remember
- 4 No response

**q15b2**

Did you find the test easy to use?

- 1 Yes
- 2 No
- 3 Can't remember
- 4 No response

*If (ans = 2) skip to q15b3*

*If (q2pilot = 1) skip to d1*

*skip to q15c*

**q15b3**

**What was the problem that you had with it?**

(INTERVIEWER: multiple responses allowed prompt with 'Anything else?')

- 1 Instructions were hard to READ
- 2 Instructions were hard to UNDERSTAND
- 3 Dealing with bowel motions was DISTASTEFUL
- 4 BRUSH / STICK-TOOTHPICK difficult to use
- 5 VIALS / TEST CARD difficult to use
- 6 Using the BARCODES / STICKERS was difficult
- 7 Couldn't provide 2 SAMPLES in the TIME required
- 8 ARTHRITIS or MOBILITY problems
- 9 Not CONFIDENT / too DIFFICULT
- 10 Other (specify)
- 11 Can't remember
- 12 No response / unwilling to answer

*if (Q2pilot = 1) skip to d1*

**q15c**

**If you have received your FOBT test result, can you tell me what the result was?**

(INTERVIEWER: if R says "Positive" or "Negative" confirm whether or not blood was found).

- 1 Blood found (Positive)
- 2 No blood found (Negative)
- 3 Have not yet received result
- 4 Can't remember
- 5 No response / unwilling to answer

**q20a**

**Why did you decide to complete the test?**

(INTERVIEWER: multiple responses allowed. Prompt with “Anything about the test itself?” and “Anything else?”)

- 1 Received in the mail
- 2 It was free
- 3 Media campaign
- 4 Pressure/encouragement from spouse/partner
- 5 Precaution/ prevention/ early detection/ health checks important
- 6 Wanted to know whether had bowel cancer/ peace of mind
- 7 Doctor/ government recommendation
- 8 Family history/ personal experience of CRC or other cancer
- 9 Increasing age
- 10 Other (specify)
- 11 Don't know / No reason in particular
- 12 Unwilling to answer / no response

**q21a**

**How likely are you to participate in bowel cancer screening from time to time using FOBT in the future?**

**Would you say you are likely or unlikely to participate?**

(INTERVIEWER: probe for VERY, or just UN/LIKELY)

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 Other (specify)
- 9 No response

**q18b**

**If it was recommended that ALL people in your age group be checked for bowel cancer every 1 to 2 years using FOBT - would you say you'd be likely or unlikely to participate if the recommendation came from the HEALTH DEPARTMENT?**

(INTERVIEWER: probe for VERY, or just UN/LIKELY)

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 Other (specify)
- 9 No response

*if (ans=9) skip to q22b*

**q18c**

**What if the recommendation came from YOUR DOCTOR - how likely would you be then to participate?**

(INTERVIEWER: if necessary prompt:

Would you say you'd be likely or unlikely to participate?)

(INTERVIEWER: probe for VERY, or just UN/LIKELY)

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 Other (specify)
- 9 No response

*if (ans<3) skip to q20*

*if (ans=3,4,5,6,7) skip to q19*

*if (ans=9) skip to q22b*

*if (q18b<3) skip to q20*

*if (q18b>2) skip to q19*

**q19**

**[You said earlier that you would be unlikely to participate.]**

**Why do you think that you [would / might] NOT participate?**

(INTERVIEWER: multiple responses allowed.

Prompt with "Anything about the test itself?" & "Anything else?")

- 1 Lack of symptoms / feeling well
- 2 No family history
- 3 Embarrassment / distaste with stool collection
- 4 Afraid won't collect samples correctly
- 5 Lack of time / too busy
- 6 Fear of results/ cancer/ further tests/ surgery
- 7 Don't know enough about the test
- 8 Already have other bowel test/s
- 9 Cost / not covered by Medicare
- 10 Lack of confidence in doctors/tests
- 11 Don't care / couldn't be bothered
- 12 Other (specify)
- 13 No reason in particular / don't know
- 14 Unwilling to answer / no response

*if (q19=9) skip to q19cost*

*skip to q22a*

**q19cost**

**What costs are you concerned about?**

(INTERVIEWER: multiple responses allowed. Prompt with "Any other costs?")

- 1 FOBT
- 2 Follow-up tests (eg colonoscopy)
- 3 Treatment / hospital costs
- 4 Not sure
- 5 No response

*skip to q22a*

**q20**

**Why do you think you would participate?**

(INTERVIEWER: multiple responses allowed

Prompt with "Anything about the test itself?" & "Anything else?")

- 1 It was free
- 2 Pressure/encouragement from spouse/partner
- 3 Precaution/ prevention/ early detection/ health checks important
- 4 Wanted to know whether had bowel cancer / Peace of mind
- 5 Doctor/government recommendation
- 6 Family history/ personal experience of CRC or other cancer
- 7 Increasing age
- 8 Other (specify)
- 9 Don't know / no reason in particular
- 10 Unwilling to answer / no response

**q22a**

**If the government introduced a National Bowel Cancer Screening Program in the future and sent you an FOBT kit in the mail, would you say you are likely or unlikely to participate?**

(INTERVIEWER: probe for VERY, or just UN/LIKELY)

- 1 Very likely
- 2 Likely
- 3 Unlikely
- 4 Very unlikely
- 5 Neither likely nor unlikely
- 6 Depends on cost
- 7 Not sure / don't know/ depends on something else
- 8 Other (specify)
- 9 No response

**q22b**

**Have you ever had any test, other than FOBT, to check for bowel cancer or any other bowel problem?**

- 1 Yes
- 2 No
- 3 Don't know
- 4 No response

*if (ans=1) skip to q23*

*if (ans>1) skip to q24d*

**q23**

**What test was that?**

(INTERVIEWER: multiple responses allowed, prompt with 'Any others?')

If R can't name the test ask 'Can you describe it to me?')

- 1 Endoscopy
- 2 Colonoscopy
- 3 Virtual Colonoscopy
- 4 Sigmoidoscopy
- 5 Digital rectal examination
- 6 Barium enema
- 7 X-ray / CT Scan
- 8 Whole-of-Body CT scan for cancer
- 9 Blood test
- 10 Ultrasound
- 11 Other (specify)
- 12 Not sure
- 13 Unwilling to answer / no response

**q24d**

**I am now going to read you some statements about health and bowel cancer in general. I would like you to tell me whether you agree or disagree with each of the statements.**

**The first statement is: Having a test like FOBT seems like more trouble than it's worth.**

**Do you agree or disagree?**

(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

**q24a**

**The second statement is:**

**It is important to check for bowel cancer even if I have no symptoms. Do you agree or disagree?**

(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

**q24b**

**The third statement is:**

**Treating bowel cancer in the early stages increases a person's chance of survival. Do you agree or disagree?**

(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

**q24c**

**And the last statement is:**

**If bowel cancer is treated early, it might need less extensive treatment, and that the person may not need to have a colostomy bag. Do you agree or disagree?**

(INTERVIEWER: probe for STRONGLY, or just DIS/AGREE)

(INTERVIEWER: if necessary, "A colostomy bag is an external appliance attached to the person's abdomen to collect solid waste. This may need to be used if the person's back passage has to be surgically closed after the removal of a cancer.")

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree
- 5 Neither agree nor disagree
- 6 Unsure / don't know
- 7 No response / unwilling to answer

## DEMOGRAPHICS

### d1

**Finally, I would like to ask you some background questions about yourself. Could you please tell me your date of birth?**

(INTERVIEWER: If R is hesitant about answering this sort of question say: " Date of birth is asked as most people find it easier to remember their date of birth than their age.").

- 1 Gave date of birth or age or age group
- 2 Refused to answer

### d2

**Which of the following best describes your current employment status?**

(INTERVIEWER: Read out highlighted options)

(INTERVIEWER: Self employed = employed, probe for full/part time)

- 1 Employed full-time (incl. those on any type of leave)
- 2 Employed part-time or casual (incl. those on any type of leave)
- 3 Home duties
- 4 Unemployed
- 5 Full-time student
- 6 Part-time student
- 7 Retired
- 8 Permanently ill/unable to work
- 9 Other (specify)
- 10 No response

### d3

**What is your current marital status?**

(INTERVIEWER: Read out highlighted options)

- 1 Married
- 2 De facto
- 3 Separated
- 4 Divorced
- 5 Widowed
- 6 Single - never married
- 7 Unwilling to say / no response

**d4a**

**Now, could you think about the HIGHEST level of education you have COMPLETED? I'll now read out a list of education levels, please tell me one applies to you**

**Have you COMPLETED a university or college degree?**

(INTERVIEWER: this includes REGISTERED nurses [not enrolled])

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4b**

**Have you COMPLETED a trade or technical certificate or diploma?**

(INTERVIEWER: this includes ENROLLED nurses [not registered])

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4c**

**Have you COMPLETED high school Leaving Honours? (Adelaide)**

(INTERVIEWER: Year 5, age 17-18 in SA)

**Have you COMPLETED senior high school? (Mackay)**

(INTERVIEWER: Grade 12, age 17-18 in QLD)

**Have you COMPLETED high school HSC or Matriculation? (Melbourne)**

(INTERVIEWER: Form 6, age 17-18 in Vic)

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4d**

**Have you COMPLETED high school to Leaving Certificate? (Adelaide)**

*(INTERVIEWER: Year 4, age 16-17 in SA)*

**Have you COMPLETED junior high school? (Mackay)**

*(INTERVIEWER: Grade 10, age 15-16 in QLD)*

**Have you COMPLETED high school to Leaving? (Melbourne)**

*(INTERVIEWER: Form 5, age 16-17 in Vic)*

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4z (Adelaide and Melbourne only)**

**Have you COMPLETED high school to Intermediate Certificate? (Adelaide)**

*(INTERVIEWER: Year 3, age 15-16 in SA)*

**Have you COMPLETED high school to Intermediate? (Melbourne)**

*(INTERVIEWER: Form 4, age 15-16 in Vic)*

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4e**

**Have you COMPLETED primary school?**

**(INTERVIEWER: Grade 7, age 11-12 in SA)**

**(INTERVIEWER: Grade 7, age 12-13 in Qld)**

**(INTERVIEWER: Grade 6, age 11-12 in VIC)**

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4f**

**Did you leave before completing primary school, or did you not do any formal schooling?**

- 1 Yes
- 2 No
- 3 Other (specify)
- 4 Don't know
- 5 Refused

*if (ans <> 2) skip to d5*

**d4g**

**Can you describe your education level for me?**

- 1 Yes (specify)
- 2 Don't know
- 3 Refused

**d5**

**In total, how many [men/women (same sex as R)] aged 50 to 74, INCLUDING YOURSELF, live in your household?**

(INTERVIEWER: If respondent is unwilling to answer, skip to next question)

**d6**

**Which of the following three broad categories does your total GROSS annual household income from ALL sources fall into? That is the total income from ALL members of your household before tax is deducted.**

(INTERVIEWER: Read out highlighted categories)

- 1 Less than \$20,000
- 2 \$20,001 - \$60,000
- 3 Over \$60,000
- 4 Don't know
- 5 No response

**d9**

**In your home do you usually speak a language other than English?**

- 1 Yes
- 2 No
- 3 No response

*if (ans > 1) skip to d7*

**d9a**

**What language do you usually speak at home?**

(INTERVIEWER: if more than one language (besides English), ask for the one spoken most often)

- 1 Italian
- 2 Greek
- 3 Arabic
- 4 Vietnamese
- 5 Cantonese
- 6 Mandarin
- 7 Croatian
- 8 Maltese
- 9 German
- 10 Other (specify)
- 11 No response

**q26**

**When the Government sent out invitations and kits, they obtained people's contact details from Medicare. Do you think it's alright for them to use this information to contact you?**

(INTERVIEWER: If R asks why we want to know this, say 'The Privacy Commissioner has asked us to let him know how people feel about their Medicare contact details being used for this purpose'.)

- 1 Yes
- 2 No
- 3 Don't care
- 4 Don't know
- 5 No response

*if (q26 = 2) skip to Q26a  
skip to d7*

**q26a**

**How strongly do you feel about this?**

**Would you say that you're concerned about it, or very concerned?**

(INTERVIEWER: If necessary suggest that they talk about their concerns with one of the people who organised this process:

Screening Section

Commonwealth Department of Health and Ageing

- 1 Concerned
- 2 Very concerned
- 3 No response

d7

**And finally, increasing numbers of people are seeking to have their phone numbers not listed in the White Pages. Can you tell me whether your number is listed or not?**

- 1 Yes - listed
- 2 No - not listed
- 3 Don't know
- 4 Unwilling to answer

**Info 1**

**If you are interested in further information about bowel cancer and FOBT I can give you a phone number to call. Would you like this number?**

- 1 Yes
- 2 No / Don't care

*if (ans=1) skip to info2*  
*if (ans=2) skip to QAname*

**info 2**

**For more information about bowel cancer or cancer in general you can call the Cancer Council 'Cancer Helpline' toll free on 13 11 20. If they cannot assist you with your query or if you want more information about FOBT we suggest you contact your local doctor.**

(INTERVIEWER: Press any key to continue)

**QA name**

**Well that's the end of the questionnaire. I just have one last thing to ask. Occasionally my supervisor will call some people back to check I have conducted the interview properly. Would you be willing to give me your first name only in case she wishes to call you?**

- 1 Yes – (INTERVIEWER: Type R's name and phone number)
- 2 No

**thanks**

**THANK-YOU VERY MUCH FOR ALL YOUR HELP.**

**Once again, my name is ..... calling on behalf of the Commonwealth Department of Health and Ageing.**

**GOOD-BYE!**

(INTERVIEWER: Press 1 to complete interview)