Evaluation of the Bowel Screening Pilot – Baseline Population Survey Findings

Ministry of Health
Manatū Hauora

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Preface

This report has been prepared for the Ministry of Health by Michele Grigg and Ingrid McDuff from Litmus Limited. We acknowledge Reid Research Services Limited (for conducting the telephone surveys), Kaipuke Consultants Limited (for the qualitative interviews with Māori) and Integrity Professionals (for the qualitative interviews with Pacific peoples). We also sincerely thank James Reilly from Statistical Insights Limited for his work in preparing the survey data for analysis.

We acknowledge and thank all those who participated in the surveys (including the pretesting) and the qualitative interviews. We also thank:

- Professor Scott Ramsey for his expert review of the Bowel Screening Pilot Evaluation Plan prepared by Litmus Limited and Sapere Research Group
- Members of the Ministry of Health’s Bowel Screening Evaluation Advisory Group for their expert review comments on the Bowel Screening Pilot Evaluation Plan and draft survey questionnaires
- Litmus’ Governance Group members for their specialist screening evaluation advice and for their comments on this report: Associate Professor Barry Borman, Dr Deborah Read, Dr Debbie Ryan, Lisa Davies and James Reilly
- Staff in the Bowel Screening Pilot teams at the Ministry of Health and the Waitemata District Health Board for supporting the Bowel Screening Pilot Evaluation.

Please contact Michele Grigg (michele@litmus.co.nz) or Liz Smith (liz@litmus.co.nz) if you have any questions about this report.
1. Executive summary

1.1 Background

The Ministry of Health (MoH) has funded Waitemata District Health Board (WDHB) to run a Bowel Screening Pilot (BSP) over four years from 2012–16. An evaluation of the BSP is being undertaken by Litmus and Sapere Research Group, the results of which will contribute to a decision on whether or not to roll out a national bowel screening programme. The goal of the evaluation is to determine whether organised bowel screening could be introduced in New Zealand in a way that is effective, safe and acceptable for participants, equitable and economically efficient.

A set of telephone population surveys forms one of the planned evaluation activities. The surveys aim to measure awareness, knowledge and attitudes towards bowel cancer and the BSP. This report presents findings from two baseline population surveys undertaken among 50–74 year olds (ie, the eligible screening population) – one within WDHB and one outside of WDHB (referred to as the ‘National’ survey). Also presented is information obtained from a small number of qualitative interviews undertaken with Māori and Pacific peoples living in WDHB. The purpose of these interviews was to determine if face-to-face data collection resulted in information different from that collected in the surveys, and also to seek more explanatory information of responses to the surveys. A follow-up telephone survey within WDHB will be undertaken in 2013, which will enable changes in awareness, attitudes and knowledge to be tracked over time.

1.2 Methodology

The baseline surveys were conducted before promotions of the BSP became widespread. Questionnaires were developed incorporating advice from a range of experts. These were also pretested and piloted with members of the public (living outside WDHB).

The surveys were administered using computer-assisted telephone interviewing over a three-week period in November–December 2011. Randomised samples of 500 eligible respondents, plus booster samples of 100 Māori and 100 Pacific eligible respondents, were interviewed in each of the two surveys. Survey weights were applied to the data to ensure population sub-groups are represented in the correct proportions in the survey results.

1.3 Key findings

Findings from the two surveys provide indicative and useful information in an area where little is currently known about New Zealanders’ attitudes towards, and awareness of, bowel cancer and bowel cancer screening. Key findings from the baseline surveys are as follows.

- There is a moderate level of knowledge of bowel cancer prevalence in New Zealand, especially for cancers affecting men. Cervical cancer is perceived to be the second most diagnosed cancer among women in New Zealand (rather than bowel cancer). There is no significant variation by ethnicity, age or gender within WDHB.

- There is variable awareness of bowel cancer risk factors, with awareness being highest of the influence of fibre and family history on bowel cancer and lowest about the impact of moderate exercise and eating fruit and vegetables. Māori and Pacific peoples in WDHB have particularly low awareness of the influence of exercise, fibre and a diet high in fruit and vegetables on a person’s chance of developing bowel
cancer. Pacific peoples, however, have a high awareness of the impact of being overweight on bowel cancer.

- There is variable awareness of bowel cancer symptoms and relatively low confidence in being able to recognise a symptom (although confidence is higher among women). The majority are aware that blood in the bowel motion is a symptom of bowel cancer. Men, Pacific peoples, low-income household residents and those with no family history of bowel cancer are more likely than their counterparts not to know of any bowel cancer symptoms.

- People are more aware of colonoscopies than of faecal occult blood tests (FOBTs). Women and those in the Other ethnic group (ie, not Māori, Pacific or Asian) are more likely than their counterparts to name colonoscopies (unprompted and prompted). Levels of awareness are also significantly higher among those who have previous experience of a bowel screening test. Awareness of the BSP is low and there is minimal awareness of other test kits available at pharmacies.

- Unprompted mention of having done a bowel screening test is low (one in 10 people). Just over one in five have a family history of bowel cancer. This group is more likely than those with no family history to have had a doctor suggest they do a test to check for bowel cancer. Māori and Pacific respondents are the least likely to have a doctor suggest this. WDHB respondents are significantly more likely than National respondents to have done an FOBT, while experience of colonoscopy was similar in both surveys.

- Perceived risk of developing bowel cancer is low (one in 10), although this is higher among Pacific respondents in WDHB than in other ethnic groups and higher among those with a family history.

- Perceptions of FOBTs and colonoscopies vary. Half of respondents are either unsure or don’t know if the FOBT is inaccurate or messy. The colonoscopy is less likely to be seen as inaccurate but more likely to be viewed as painful, embarrassing and inconvenient.

- Around three-quarters of respondents indicate they are very or quite likely to participate in a bowel screening programme. There were no significant differences between key demographic groups, such as ethnicity and gender.

- Recognition of the importance of bowel screening is high overall, although there are some differences between ethnic groups. Pacific respondents in WDHB are significantly less likely than those from the Other ethnic group to agree that early treatment of bowel cancer increases a person’s odds of survival, but are significantly more likely to agree that it is important to check for bowel cancer even if symptoms are not present. Pacific and Māori respondents from WDHB are significantly less likely than the Other ethnic group to disagree that at-home FOBTs are more trouble than they are worth.

- At the time of the survey, one person in WDHB had received an invitation letter from the BSP. None had received an FOBT kit. An additional 16 people commented that someone else in their household had received a letter or kit.

### 1.4 Implications for the Bowel Screening Pilot

Results from the surveys provide indicative information to inform ongoing development of the BSP. The following implications have been identified for early BSP operations.
Knowledge of bowel cancer prevalence is not high and neither is awareness of the full range of bowel cancer risk factors and symptoms. Increasing awareness of risk factors among Māori and Pacific residents within WDHB will be important, along with increasing knowledge of bowel cancer symptoms among men, Pacific peoples and low-income households. This presents a health promotion opportunity for the BSP.

Low baseline awareness of the BSP and the FOBT indicates that promotions of the BSP and the test will be important for the duration of the first screening round. Health promotion materials will need to clearly articulate what is required of participants when undertaking the FOBT, including reassurances about the accuracy of the test and how to do the test without creating a mess.

Aside from these factors, there appears to be a positive predisposition towards doing the at-home FOBT test as part of a bowel screening programme. It is unclear, however, the extent to which this will convert to action. Uptake rates will require close monitoring.

1.5 Implications for the Bowel Screening Pilot Evaluation

The baseline population surveys provide a snapshot measure of awareness, knowledge and attitudes towards bowel cancer and the BSP. They are unable to provide any depth of information, however, about the reasons behind people’s responses. The set of qualitative activities, as outlined in the BSP Evaluation Plan, will be important for helping to explain reasons behind uptake of the BSP (or non-participation) and the drivers for these.

A repeat survey is planned for 2013, which will measure changes in awareness, knowledge and attitudes over time within the WDHB. Should budget become available in intervening years, it remains a recommendation that a national follow-up survey be conducted at that time to assist with projecting possible uptake of a national bowel screening programme.

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2. Introduction

2.1 Background

The Ministry of Health (MoH) has funded Waitemata District Health Board (WDHB) to run a Bowel Screening Pilot (BSP) over four years from 2012–16.\(^2\) The BSP began with a ‘soft launch’ in late 2011, with full operation of the pilot starting in January 2012. Litmus and Sapere Research Group have been funded by the MoH to undertake an evaluation of the BSP, including a cost-effectiveness analysis. The evaluation will contribute to a decision on whether or not to roll out a national bowel screening programme.

The overall goal and underlying objectives of the BSP and its evaluation are the same and have been defined by the MoH. The overall goal of both is to determine:

*Whether organised bowel screening could be introduced in New Zealand in a way that is effective, safe and acceptable for participants; equitable and economically efficient.*

The goal comprises four key aims.

1. **Effectiveness:** Is a national bowel screening programme likely to achieve the mortality reduction from bowel cancer for all population groups seen in international randomised controlled trials?

2. **Safety and acceptability:** Can a national bowel screening programme be delivered in a manner that is safe and acceptable?

3. **Equity:** Can a national bowel screening programme be delivered in a manner that eliminates (or does not increase) current inequalities between population groups?

4. **Economic efficiency:** Can a national bowel screening programme be delivered in an economically efficient manner?

Several activities are planned for the evaluation of the BSP.\(^3\) Included in these are a set of telephone population surveys. The population surveys inform a number of the evaluation questions.\(^4\) This report presents findings from two baseline population surveys undertaken among 50–74 year olds (ie, the eligible screening population): one within WDHB and one outside of WDHB (hereafter referred to as the ‘National’ survey). A follow-up survey within WDHB will be undertaken in 2013.

The New Zealand Health and Disability Multi-region Ethics Committee granted ethical approval for the suite of BSP evaluation activities (reference MEC/11/EXP/119).

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\(^3\) Refer to the Evaluation Plan for the Bowel Screening Pilot 2011–2016 (Litmus, 2011) for details of evaluation activities.

\(^4\) Refer to Section 2.4 of the Evaluation Plan for the Bowel Screening Pilot 2011–2016 (Litmus, 2011) for the full list of evaluation questions.
2.2 Survey purpose

The purpose of the surveys is to measure the eligible population’s awareness, knowledge and attitudes towards bowel cancer and the BSP, both within the WDHB and nationally. Information from the WDHB survey is to be used as a baseline measure for the follow-up WDHB survey planned for 2013. The follow-up survey will enable changes in awareness, attitudes and knowledge to be tracked over time within the BSP area, following commencement of the BSP.

The surveys also play an important role in informing projections for a possible national roll-out of a bowel screening programme. Record linkage of survey data with the BSP Programme Register will enable the investigation of correlations between screening uptake and outcomes, and participants' attitudes and self-reported risk factors. This, in turn, will enhance the accuracy of the national projections.\(^5\)

As the surveys measure awareness and knowledge of bowel cancer and the BSP, it was preferable for the first survey to be conducted before promotions of the BSP became widespread, so baseline data could be collected. Pre- and post-survey measures of the WDHB eligible population enable the exploration of the hypotheses that increased awareness, knowledge and positive perceptions will impact on completion of the immunochemical faecal occult blood test (iFOBT). For the National population survey, only a baseline measure will be taken. Section 2.6 of the BSP Evaluation Plan\(^6\) and Section 3.8 of this report document the implications of not conducting a follow-up National population survey.

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5 Ethical approval was also granted to this record-linking activity (reference MEC/11/EXP/119).
3. Survey methodology

This section outlines the:

- process used to design and test the two questionnaires
- sample design and sampling approach
- survey weighting processes
- survey response rates and representativeness
- sample description
- supplementary qualitative interviews with Māori and Pacific participants
- analysis notes
- methodological limitations.

3.1 Questionnaire design, pretesting and piloting

The content of the questionnaires was developed following review of overseas literature reporting on surveys for bowel screening programmes and assessments of bowel cancer screening. The WDHB and National surveys were developed to ensure similarities across the two, to enable cross-survey comparisons. Draft questionnaire content was reviewed by the evaluation team’s Governance Group, an independent expert reviewer, bowel screening experts from Australia and the United Kingdom, and the MoH’s Bowel Screening Evaluation Advisory Group. Changes were made accordingly.

Following this, pretesting for interpretation and understanding, and to gauge survey length, was undertaken with a total of eight participants (based outside of WDHB). Pretesting was undertaken face to face. A mix of Māori (n=3), Pacific (n=2) and other ethnicities (n=3) (sought through community networks) accepted the invitation to participate. Informed consent was sought, and participants were thanked for their time with a koha (see Appendices 8.1 and 8.2 for pretesting information sheet and consent form).

Modifications were subsequently made to the questionnaires to ensure:

- they met the required length
- questions were easy to understand
- terms and language used were appropriate and suitable for the New Zealand context
- the survey could be easily administered over the telephone.

Following modification, further pretesting was undertaken with three participants (one Pacific and two Pākehā) over the telephone. As with the face-to-face participants, informed

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consent was sought, and participants were thanked with a koha (Appendices 8.1 and 8.2). Final minor adjustments to the questionnaire were made reflecting feedback from these participants.

The survey was required to be no more than 20 minutes in length and to contain only closed questions. Future qualitative research with the eligible population (proposed in the BSP Evaluation Plan)\(^\text{11}\) will provide a depth of understanding about the responses received.

Both the WDHB and National surveys were conducted by Reid Research Services Limited on behalf of Litmus. Litmus attended the interviewer briefing session, where the study was outlined, all interviewers were taken through the questionnaires question by question, and role-play interviews were conducted. Piloting of the questionnaires was undertaken by Reid Research Services Limited during the first few days of the telephone surveying. Small modifications were made to the questionnaire as a result of the piloting.

Interviews were conducted by Reid Research Services-trained interviewers (many of whom are of Māori and/or Pacific ethnicity) over a three-week period from mid-November to mid-December 2011 using computer-assisted telephone interviewing (CATI) technology. The average interview duration was 19.5 minutes for the WDHB survey and 17.4 minutes for the National survey.\(^\text{12}\)

Final questionnaires are contained in Appendices 8.3 and 8.4.

### 3.2 Sample design and sampling approach

The final survey and sample design was determined after discussion with the MoH about a number of options for the best possible way of collecting the data, while ensuring survey objectives were met. Scoping was undertaken to identify whether there was an existing and accessible eligible population database with contact details to enable a more cost-effective randomised phone sampling survey method. The options considered, and their limitations, were noted in the Evaluation Plan.\(^\text{13}\) These included the following.

- **Sampling from the BSP Population Register or the National Health Index** – both databases contain names and addresses but no phone numbers. Door-to-door interviewing was discarded as an option due to cost. Consideration was given to whether names and/or addresses from these databases could be phone matched. As address–phone matching significantly under-represents Māori and Pacific peoples this option was discarded.

- **Accessing eligible population contact details from Primary Health Organisations** – feedback indicated that Primary Health Organisations would be unlikely to release this data, citing privacy concerns. Further, the logistics of seeking lists of patients from Primary Health Organisations across New Zealand was considered time-consuming and unrealistic.

- **Door-to-door interviewing using Statistics New Zealand meshblocks to identify clusters of the eligible population using age and ethnicity criteria** – this approach was discarded due to cost.

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\(^\text{12}\) Note the national survey contained fewer questions than the WDHB survey (as it did not ask questions about the WDHB BSP).

The CATI survey method was used, with the sample being selected by random digit dialling (ie, computer-generated telephone numbers). Respondents were screened to ensure they fit the criteria for the eligible population, specifically: age (50–74 years) and New Zealand residency. People who had previously been diagnosed with bowel cancer were asked a limited number of questions only. Respondents participating in the WDHB survey were required to be living within the WDHB region.

**Waitemata District Health Board survey sample**

A randomised sample of 500 eligible respondents aged 50–74 years who live in the WDHB region was interviewed, plus two booster samples of 100 Māori and 100 Pacific eligible respondents to ensure adequate numbers of Māori and Pacific in the resulting overall sample.

No quotas were applied (eg, by age, gender and ethnicity) due to the significant costs of finding these sub-populations using randomised digit dialling. Weighting was applied on completion of the survey (see below for further details). The maximum margin of error for weighted percentages on the combined sample of 700 eligible respondents in the WDHB region was ±4.6%, based on a design effect of 1.55.\(^{14,15}\)

The WDHB main survey sample (n=500) was selected through random digit dialling and included only telephone prefixes falling within the WDHB area (ie, old Waitakere City, old North Shore City and Rodney Regional Council areas).

**Table 1: Total numbers called and interviews completed, Waitemata District Health Board survey, 2011**

<table>
<thead>
<tr>
<th>District Health Board</th>
<th>Numbers called (includes disconnects)(^{16})</th>
<th>Completed interviews</th>
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<tbody>
<tr>
<td>Waitemata</td>
<td>7,536</td>
<td>500</td>
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Source: Reid Research Services Limited, 2012

The telephone prefixes within the WDHB area boundaries were clearly defined and identifiable. Respondents were asked to name the DHB area they lived in and, if unknown, their suburb was checked to enable accurate recording of DHB area. Checks of postcodes and telephone prefixes were made at the completion of each survey to further ensure accuracy. In some instances, follow-up telephone calls were made to double-check details. The majority of respondents were aware that they lived within the WDHB area.

There was one case identified in the National sample where a respondent who had previously lived outside the WDHB area had taken their telephone number with them when they moved into the WDHB area. This respondent was called back to participate in the WDHB main survey. There were no cases of respondents from the WDHB sample living in Auckland or Counties Manukau DHB areas. An assumption from this, therefore, is that there is a low incidence of incorrect sampling for non-respondents.

\(^{14}\) The net effect of a survey design can be measured by the ‘design effect’. The design effect is the ratio of the variance (a measure of precision) of an estimate achieved by a complex design relative to the variance of the same estimate that would be achieved by a simple random sample of the same size. The closer the design effect is to 1, the closer the design is to simple random sampling.

\(^{15}\) The design effect here allows for the selection of one person per household, booster sampling and weighting by age, gender and ethnicity. The true design effect varies between analyses; the value of 1.55 used is fairly conservative, being the 80th percentile of design effects calculated for each item gathered in the survey.

\(^{16}\) This is the unique number of individual telephone numbers called. It is not the total number of calls made (including multiple call backs to each unique telephone number).
Sample was generated and imported as one location in the WDHB questionnaire. Sample was then scattered by the Surveycraft program to ensure further randomisation.

For the sample that recorded as ‘no contact’, automated call backs were set to a maximum of 15 calls over a period of four days, before the number was filed as dead. The Surveycraft program prioritised the return of ‘no contact’ sample, before issuing any new ‘virgin’ sample. For example, a ‘no contact’ was delayed by three hours and then reissued to the next available interviewer, an engaged number was retried after 30 minutes for three cycles and then was retried every 1.5 hours. Priority was given to set appointments. This ensured that the minimum amount of sample was available to be distributed at any time and any live numbers were called a maximum of 15 times before being filed as dead.

As required, all respondents were offered the opportunity to arrange an appointment to complete the survey at a more convenient time.

If more than one person in a household was eligible, the person with the most recent birthday was interviewed.

**WDHB booster samples**

The WDHB booster sample (n=200) was selected through targeting surnames and known telephone prefixes based on areas with high Māori–Pacific populations within the WDHB area. Sample was manually selected from local directories, ensuring a spread of telephone prefixes. The manual selection methodology incorporated further randomisation by selecting a certain entry on a certain page of the directory. The selection methodology was dependent upon the number of entries, the number of pages in the telephone book to select from and the required sample volume. The generated numbers were stored in an Excel file, which was randomised. The Surveycraft program further randomised this sample when it was imported for calling. Further top-up sample was generated using telephone prefixes based on census data for high Māori–Pacific populations.

Five surveys (identifiable within the survey data) were completed using a database of known Pacific respondents who live within the WDHB area. These respondents belong to a Reid Research Services Limited panel of 48,036 people who self-register online or agree to participate in future market research studies following completion of a telephone interview.

Sample was generated and imported into one location in the WDHB booster questionnaire. Sample was then scattered by the Surveycraft program to ensure further randomisation.

As with the WDHB main survey, respondents were asked to name the DHB area they lived in and, if unknown, their suburb was checked to enable accurate recording of the DHB area. Checks of postcodes and telephone prefixes were made at the completion of each survey to further ensure accuracy. In some instances, follow-up telephone calls were made to double-check details.

Ethnicity screening was conducted to ensure that respondents identified themselves as being Māori or Pacific, to enable the n=100 Māori and n=100 Pacific quotas to be reached. If respondents identified as both Māori and Pacific, for the purpose of the quota, Māori was given priority over Pacific. Once the Māori quota was reached, any respondent who identified as both ethnicities was then counted as Pacific. This event did not occur within the WDHB booster file.

The same approach was used as for the WDHB main sample for setting call backs before filing a number as ‘dead’ and for offering alternative interview times. If more than one person in a household was eligible, the person with the most recent birthday was interviewed.
All respondents from the baseline WDHB survey (main and booster samples) were also asked for their consent to be recontacted with the intention that a portion will be invited to participate in the follow-up 2013 survey. This will enable collection of longitudinal data and an examination of changing attitudes and behaviours over time. Information from this sub-sample will assist with determining possible effectiveness of local-level communication activities about the BSP. The sample for the follow-up WDHB survey will be composed of this sample of previous respondents and a fresh sample from the eligible population.

**National survey sample**

A randomised sample of 500 eligible respondents aged 50–74 years, plus two booster samples of 100 Māori and 100 Pacific eligible respondents who live outside the WDHB region was achieved. Representation was sought across DHB location (without the use of quotas).

The National main sample (n=500) was selected regionally, through random digit dialling. The volume of numbers generated for each region was based on the proportionate population within each of the 19 DHBs (Table 2). The sample excluded any numbers falling into the WDHB area.

**Table 2: Total numbers called and interviews completed by District Health Boards, National survey, 2011**

<table>
<thead>
<tr>
<th>Regional ‘log in’ name</th>
<th>Corresponding District Health Boards</th>
<th>Numbers called (includes disconnects)(^{17})</th>
<th>Completed interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northland</td>
<td>Northland</td>
<td>566</td>
<td>25</td>
</tr>
<tr>
<td>Auckland</td>
<td>Auckland Counties Manukau</td>
<td>1,197</td>
<td>32</td>
</tr>
<tr>
<td>Waikato</td>
<td>Waikato</td>
<td>578</td>
<td>31</td>
</tr>
<tr>
<td>Bay of Plenty</td>
<td>Bay of Plenty Lakes</td>
<td>1,114</td>
<td>29</td>
</tr>
<tr>
<td>Gisborne</td>
<td>Tairawhiti</td>
<td>266</td>
<td>16</td>
</tr>
<tr>
<td>Hawke’s Bay</td>
<td>Hawke’s Bay</td>
<td>295</td>
<td>25</td>
</tr>
<tr>
<td>Taranaki</td>
<td>Taranaki</td>
<td>415</td>
<td>25</td>
</tr>
<tr>
<td>Manawatu-Whanganui</td>
<td>MidCentral Wairarapa Whanganui</td>
<td>2,049</td>
<td>25</td>
</tr>
<tr>
<td>Wellington</td>
<td>Capital and Coast Hutt Valley</td>
<td>1,349</td>
<td>29</td>
</tr>
<tr>
<td>Tasman Nelson Marlborough</td>
<td>Nelson Marlborough</td>
<td>524</td>
<td>25</td>
</tr>
<tr>
<td>West Coast</td>
<td>West Coast</td>
<td>283</td>
<td>15</td>
</tr>
<tr>
<td>Canterbury</td>
<td>Canterbury South Canterbury</td>
<td>1,481</td>
<td>34</td>
</tr>
<tr>
<td>Otago and Southland</td>
<td>Southern</td>
<td>1,033</td>
<td>52</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>11,150</strong></td>
<td><strong>500</strong></td>
</tr>
</tbody>
</table>

Source: Reid Research Services Limited, 2012

\(^{17}\) This is the unique number of individual telephone numbers called. It is not the total number of calls made (including multiple call backs to each unique telephone number).
Telephone prefixes were clearly defined and identifiable. In addition, respondents throughout the country were generally aware of what DHB they lived in. When uncertain of their DHB, the postcode, telephone prefix and address (if required) was checked and the respondent proceeded with the interview within the correct DHB category.

Sample was generated and imported into the 13 regional locations for the National survey. Sample was then scattered by the Surveycraft program to ensure further randomisation.

For sample that recorded as ‘no contact’, automated call backs were set to a maximum of 15 calls over a period of four days, before the number was filed as dead. The Surveycraft program prioritised the return of ‘no contact’ sample, before issuing any new ‘virgin’ sample. For example, a ‘no contact’ was delayed by three hours and then reissued to the next available interviewer, an engaged number was retried after 30 minutes for three cycles and then was retried every 1.5 hours. Priority was given to set appointments. This ensured that the minimum amount of sample was available to be distributed at any time and any live numbers were called a maximum of 15 times before being filed as dead.

As required, all respondents were offered the opportunity to arrange an appointment to complete the survey at a more convenient time. If more than one person in a household was eligible, the person with the most recent birthday was interviewed.

**National booster samples**

The National booster sample (n=200) was selected regionally through targeting surnames and known telephone prefixes based on high Māori–Pacific population areas. Sample was manually selected from local directories, ensuring a spread of telephone prefixes. The manual selection methodology incorporated further randomisation by selecting a certain entry on a certain page of the directory. The selection methodology was dependent upon the number of entries, the number of pages in the telephone book to select from and the required sample volume. The generated numbers were stored in an Excel file, which was then randomised. The Surveycraft program further randomised this sample when it was imported for calling. Further top-up sample was generated using telephone prefixes based on census data for areas with high Māori–Pacific populations.

The volume of numbers generated for each region was based on census data targets. The sample excluded any numbers falling into the WDHB area (Table 3). There were no set regional quotas.

As with the main sample, the booster sample was generated and imported into 13 regional locations. Sample was then scattered by the Surveycraft program to ensure further randomisation.

Respondents were asked to name the DHB area they lived in and, if unknown, their suburb was checked to enable accurate recording of DHB area. Checks of postcodes and telephone prefixes were made at the completion of each survey to further ensure accuracy. In some instances, follow-up telephone calls were made to double-check details.

Ethnicity screening was conducted to ensure that respondents identified themselves as being Māori or Pacific, to enable the quotas of n=100 Māori and n=100 Pacific to be reached. If respondents identified as both Māori and Pacific, Māori was given priority over Pacific for the purpose of allocating to a quota. Once the Māori quota was reached, any respondent who identified as both ethnicities was then counted in the Pacific quota. This occurred with two National booster survey respondents.
Table 3: Calculated target numbers by region for Māori and Pacific booster samples, National survey, 2011

<table>
<thead>
<tr>
<th>Regional ‘log in’ name</th>
<th>Total numbers called (includes disconnects)(^1)</th>
<th>Māori population</th>
<th>% Māori target</th>
<th>Pacific population</th>
<th>% Pacific target</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northland</td>
<td>366</td>
<td>43,527</td>
<td>8%</td>
<td>3,702</td>
<td>1%</td>
</tr>
<tr>
<td>Auckland</td>
<td>5,425</td>
<td>137,133</td>
<td>24%</td>
<td>177,936</td>
<td>66%</td>
</tr>
<tr>
<td>Waikato</td>
<td>996</td>
<td>76,572</td>
<td>14%</td>
<td>11,796</td>
<td>4%</td>
</tr>
<tr>
<td>Bay of Plenty</td>
<td>399</td>
<td>67,662</td>
<td>12%</td>
<td>6,465</td>
<td>2%</td>
</tr>
<tr>
<td>Gisborne</td>
<td>686</td>
<td>19,758</td>
<td>3%</td>
<td>1,299</td>
<td>1%</td>
</tr>
<tr>
<td>Hawke’s Bay</td>
<td>390</td>
<td>33,555</td>
<td>6%</td>
<td>5,265</td>
<td>2%</td>
</tr>
<tr>
<td>Taranaki</td>
<td>194</td>
<td>15,798</td>
<td>3%</td>
<td>1,368</td>
<td>1%</td>
</tr>
<tr>
<td>Manawatu-Wanganui</td>
<td>491</td>
<td>42,288</td>
<td>7%</td>
<td>5,892</td>
<td>2%</td>
</tr>
<tr>
<td>Wellington</td>
<td>1,278</td>
<td>55,434</td>
<td>10%</td>
<td>34,752</td>
<td>13%</td>
</tr>
<tr>
<td>Tasman Nelson Marlborough</td>
<td>220</td>
<td>10,953</td>
<td>2%</td>
<td>1,689</td>
<td>1%</td>
</tr>
<tr>
<td>West Coast</td>
<td>120</td>
<td>2,916</td>
<td>1%</td>
<td>282</td>
<td>1%</td>
</tr>
<tr>
<td>Canterbury</td>
<td>667</td>
<td>36,669</td>
<td>6%</td>
<td>10,926</td>
<td>4%</td>
</tr>
<tr>
<td>Otago</td>
<td>94</td>
<td>12,273</td>
<td>2%</td>
<td>3,141</td>
<td>1%</td>
</tr>
<tr>
<td>Southland</td>
<td>10,422</td>
<td>12,273</td>
<td>2%</td>
<td>1,461</td>
<td>1%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>11,326</strong></td>
<td><strong>564,960</strong></td>
<td><strong>100%</strong></td>
<td><strong>265,974</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

Source: Reid Research Services Limited, 2012

The same approach was used as for the National main sample for setting call backs before filing a number as ‘dead’ and for offering alternative interview times. If more than one person in a household was eligible, the person with the most recent birthday was interviewed.

Weighting was applied to the combined sample on completion of the survey (see below for further details). The maximum margin of error for weighted percentages on the combined sample of 700 eligible respondents outside the WDHB region was ±5.2%, based on a design effect of 2.0.\(^{19}\)

### 3.3 Weighting

On completion of the surveys, survey weights were calculated to adjust for the sample design and to align the sample with known population profiles. These weights ensure that population sub-groups are represented in the correct proportions in the survey results. This means that individual respondents in over-sampled groups, such as Māori and Pacific, generally need to receive lower weights than respondents in under-sampled groups.

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\(^{18}\) This is the unique number of individual telephone numbers called. It is not the total number of calls made (including multiple call backs to each unique telephone number).

\(^{19}\) The design effect here allows for the selection of one person per household, regional targets, booster sampling and weighting by age, gender and ethnicity. The true design effect varies between analyses; the value of 2.0 used is fairly conservative, being the 80th percentile of design effects calculated for each item gathered in the survey.
Inverse probability weights were applied to adjust for the selection of one eligible person from each household and for the regional sample targets used in the main National sample. Booster samples were combined, with the main samples using Wells’ method.20

After allowing for the sample design, weights were further adjusted using post-stratification to align the sample’s proportions with 2006 Census of Population and Dwelling figures for the eligible population, broken down by age, gender and prioritised ethnicity.21

3.4 Response rates and representativeness

Participation in the two surveys was voluntary, and informed consent was obtained before participation. Response rates for each survey are shown in Table 4.

Table 4: Achieved response rates, Waitemata District Health Board and National main and booster samples, 2011

<table>
<thead>
<tr>
<th>Survey</th>
<th>Main sample (%)</th>
<th>Booster sample (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waitemata District Health Board</td>
<td>22.4</td>
<td>6.6</td>
</tr>
<tr>
<td>National</td>
<td>17.8</td>
<td>7.6</td>
</tr>
</tbody>
</table>

These response rates were calculated following the Standard Definitions published by the American Association for Public Opinion Research.22 The calculation involves assigning outcomes to one of six components:

- complete interviews (I)
- refusals (R)
- non-contact (NC)
- unknown residential status (UH)
- residential households of unknown eligibility (UO)
- other (O).

The response rate is then calculated from the outcome counts for each component as follows:

\[
\text{Response rate} = \frac{I}{I + (R + NC + O) + e1*UO + e2*UH}
\]

where e1 and e2 are the estimated eligibility rates for each of the components of unknown eligibility. Not all telephone numbers are eligible, and to calculate the response rate it is necessary to estimate what proportion of them could be eligible. For residential households of unknown eligibility, the relevant eligibility rate e1 is estimated as the proportion of eligible households (ie, those with at least one eligible resident) among those households whose eligibility could be determined. For telephone numbers of unknown residential status, the relevant eligibility rate is estimated as the other eligibility rate e1 multiplied by the proportion

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20 For details, see Wells (1998).
of residential telephone numbers among numbers whose residential status could be
determined. The components used to calculate the response rates are listed in Table 5.

Table 5: Components of the response rate, National and Waitemata District Health Board
main and booster samples, 2011

<table>
<thead>
<tr>
<th>Response rate component</th>
<th>National</th>
<th>Waitemata District Health Board</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Main sample</td>
<td>Booster</td>
</tr>
<tr>
<td>I = Complete interviews</td>
<td>500</td>
<td>200</td>
</tr>
<tr>
<td>R = Refusals</td>
<td>1,001</td>
<td>997</td>
</tr>
<tr>
<td>NC = Non-contact</td>
<td>287</td>
<td>280</td>
</tr>
<tr>
<td>O = Other</td>
<td>82</td>
<td>323</td>
</tr>
<tr>
<td>UH = Unknown if household</td>
<td>881</td>
<td>1,130</td>
</tr>
<tr>
<td>UO = Unknown other</td>
<td>1,574</td>
<td>1,854</td>
</tr>
<tr>
<td>E1 – UO estimated eligibility</td>
<td>0.448</td>
<td>0.307</td>
</tr>
<tr>
<td>E2 – UH estimated eligibility</td>
<td>0.274</td>
<td>0.235</td>
</tr>
</tbody>
</table>

| Response rate                               | 17.8%    | 7.6%   | 22.4%       | 6.6%    |

These response rates are an estimate of the proportion of eligible people who would have responded. Some call outcomes, such as answering machines, could not be assigned definitively to one of the components listed above. They have been assigned to the component that would decrease the response rate the most, meaning that the response rates calculated here are conservative.

Feedback from Reid Research Services Limited is that there are perhaps several contributing factors influencing the final response rates for these surveys.23 While the age group that was interviewed is normally very agreeable to participating in surveys and usually easier to interview than other age groups, the following factors were identified as potentially offsetting these benefits in relation to the response rates.

- Interviewing in the weeks leading up to Christmas has a tendency to increase refusal rates – this was considered to be the main contributing factor to reduced response. Note that the interviewing timeframe was the only period available between agreement of the Evaluation Plan and launch of the BSP (planned for late 2011/early 2012).
- Asking people about cancer and screening for cancer is not something they would necessarily expect, be used to and/or be comfortable with discussing over the telephone.
- Even with the pretesting and piloting of the surveys, some questions required a level of understanding that sometimes proved difficult for those with English as a second language.

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23 Reid Research Services Limited, personal communication, 21 February 2012.
Similarly, there were some issues with those who had insufficient English being unable to assist with identifying an eligible person in the household.

The longer survey duration had an impact on lower uptake. Anything over 10 minutes is now seen to be too long by some people.

The feedback from those who did complete the survey was generally positive, and taking part in the survey was viewed as an enjoyable experience.24

Response rates are one indicator of survey quality. Their importance derives from the possibility that non-respondents may be different on average from respondents, and in significant ways. If non-respondents and respondents are similar on average, even a low response rate need not be of concern. The difficulty here is that, since we have not collected data from non-respondents, it is hard to know whether or not they are similar to respondents.

Some limited information about non-participation can be gleaned from sample skews relative to population benchmarks after the inverse probability weights have been taken into account. In both surveys, there were noticeable shortfalls among the younger cohort eligible to be interviewed (e.g., 43% aged 50–59 years old in Waitemata DHB, versus 54% in the Census). Māori were also somewhat under-represented, especially in the National (outside-WDHB) survey (5.6% versus 8.2% in the Census). There were also shortfalls among Pacific peoples and males, although these were much smaller. All these skews were removed from the final results by post-stratification of the weights, but they provide some indication of the extent of underlying non-response skews. Post-stratification will have helped reduce such skews on other variables as well, to the extent these are correlated with gender, age and ethnicity.

### 3.5 Sample description

Table 6 shows the weighted sample for each of the two surveys by key demographic variables. Note that the profile for WDHB differs from the National profile for ethnicity and household income. There are proportionately fewer Māori aged 50–74 within the DHB. In addition, a higher proportion of the DHB population aged 50–74 lives in a household with an income of more than $100,000. It could be expected that a portion of those who did not provide an income level are living in high-income households.

**Table 6: Weighted sample by key demographic variables, WDHB and National surveys, 2011**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Waitemata District Health Board survey</th>
<th>National survey</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%25</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>339</td>
<td>48.5</td>
</tr>
<tr>
<td>Female</td>
<td>361</td>
<td>51.5</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50–54</td>
<td>196</td>
<td>27.9</td>
</tr>
<tr>
<td>55–59</td>
<td>179</td>
<td>25.6</td>
</tr>
</tbody>
</table>

---

24 Partly reflected in the proportion of WDHB respondents who agreed to be recontacted for the follow-up survey (90%).

25 Percentages may not add to 100% due to rounding.

26 Percentages may not add to 100% due to rounding.
### Evaluation of the Bowel Screening Pilot – Baseline Population Survey Findings

#### 3.6 Supplementary qualitative interviews

It was identified during the evaluation planning stage that the research approach proposed for the quantitative surveys could prove to be less inclusive for Māori and Pacific. Booster samples were used in the surveys to ensure minimum sample sizes were achieved for these two groups. A small number of qualitative interviews with eligible Māori and Pacific peoples living in WDHB was undertaken at the same time that the telephone surveys were conducted. The purpose of these interviews was to first identify whether face-to-face data collection resulted in differing responses from the surveys and, second, seek more explanatory information of responses from the surveys.

Twenty people were interviewed face to face (n=10 Māori and n=10 Pacific) to understand their awareness, knowledge and attitudes towards bowel cancer and the BSP (Table 7). The sample was purposively designed to reflect a mix of ages and genders.

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27 Prioritised ethnicity.

28 Defined as one or more members of the respondent’s immediate family (‘immediate’ was defined as ‘people who are related to you’) having had bowel cancer (ever).

29 Note, bases are less than n=700 for family history of bowel cancer, as n=5 in WDHB and n=19 nationally who have previously been diagnosed with bowel cancer weren’t asked this question.

30 All Pacific participants were Samoan.
Table 7: Sample for supplementary qualitative interviews with eligible Māori and Pacific aged 50–74 living in Waitemata District Health Board, 2011

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Māori</th>
<th>Pacific</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Females</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>10</td>
</tr>
</tbody>
</table>

Participants were recruited through community connectors. Interviews were held in safe, private and convenient locations and were undertaken by Māori and Pacific researchers. The telephone survey questionnaire was used as the basis for the interviews and participants were encouraged to expand on and fully discuss their responses. See Appendices 8.5 and 8.6 for the information sheet and consent form used for the qualitative interviews.

3.7 Analysis

The following points explain the analytical approaches used in this report.

- ‘National’ refers to ‘non-WDHB’.
- A comparison of results from the WDHB and National surveys is presented. Differences between percentages were tested at the 95% confidence level using a t-test, adjusted using a conservative design effect for each survey. Differences between the two surveys that are statistically significant are noted as such in the text and are denoted on the graphs by an asterisk (*).
- The achieved sample sizes provide adequate power to identify substantial differences when comparing large sample sub-groups, including how results for Māori and Pacific peoples differ from the rest of the population. However, moderate differences may be obscured by random sampling variation.
- Information is reported in the text for key sub-groups (ie, ethnicity, age group, gender and family history of bowel cancer) where differences within groups are statistically significant.
- All data presented is weighted (see earlier).
- Figures quoted in the text have been rounded to whole numbers. One decimal place is used in the graphs (and tables where relevant).
- Relevant bases are indicated below each graph. Complex branching was used in parts of the questionnaires (refer to the questionnaires in Appendices 8.3 and 8.4 for details). The bases shown below the graphs are the actual numbers of people interviewed (ie, unweighted numbers) while all the percentages are based on weighted data.
- Respondents’ ethnicity was collected as per Statistics New Zealand’s protocol. In this report, prioritised ethnicity is used to report ethnic comparisons for the following ethnic groups: Māori, Pacific, Asian and Other (which comprises mainly New Zealand

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32 The design effects used were 1.55 for the WDHB survey and 2.0 for the National survey. These allow for the selection of one person per household, regional targets, booster sampling and weighting by age, gender and ethnicity. The true design effect varies between analyses; the values used here are the 80th percentile of design effects calculated for each item gathered in the survey.
European and Other European but excludes Māori, Pacific and Asian). Prioritisation was conducted using Statistics New Zealand’s classification for ethnicity output.\(^{33}\)

- Thematic analysis of the supplementary face-to-face interviews with Māori and Pacific peoples was undertaken to identify awareness, knowledge and attitudes towards bowel cancer, bowel cancer screening and the BSP. Information from these interviews is used to supplement and offer greater depth of understanding and interpretation of the quantitative survey data. It is referred to, where relevant, in the Findings (Section 4), and to add context to the discussion points (Section 5).

### 3.8 Methodological limitations

In the absence of any other population-level data on awareness and knowledge around bowel cancer and bowel screening, the telephone surveys conducted as part of the BSP evaluation provide useful information. They enable a baseline measurement of knowledge, awareness and attitudes before the launch of the BSP in early 2012. The planned follow-up survey in WDHB, in 2013, will allow tracking of any shifts in these attributes over time.

Population surveys, however, have their limitations. During the evaluation planning stage, the decision was made between the MoH and Litmus that generalisable results could be drawn at the completion of the evaluation from the three surveys (two at baseline, reported here, and the follow-up WDHB survey) provided the potential limitations of these were clearly noted. It is recognised that having just the baseline survey for the eligible national population is a limitation that has been agreed with the MoH. Ideally, a second National survey would be conducted in 2015 to assess the extent to which awareness, attitudes and behaviours may affect potential uptake of bowel screening if the programme is rolled out nationally.

Sample sizes for the surveys were agreed with the MoH and the MoH’s Bowel Screening Evaluation Advisory Group, with 500 determined for the general samples and booster samples of 100 Māori and 100 Pacific. While the survey results have a key role in informing the evaluation, the small sample sizes limit the possibility of extensive sub-group analysis and the reliability of comparisons over time.

While the general samples were selected using random digit dialling, the booster samples targeted telephone number prefixes with high Māori–Pacific incidence, along with relevant surnames. This may have led people who were less easily identifiable as Māori or Pacific to be less well represented in these samples, relative to those who were more easily identifiable as Māori or Pacific.

Non-respondents may have differed from respondents in unknown ways, which would affect the survey results. While this is an ever-present concern in any survey, the response rates heighten the issue’s relevance here. Weighting will have helped to mitigate the problem.

High response rates in telephone surveys are difficult to achieve for a number of reasons. The response rates achieved for the two main surveys (using a conservative measure) were reasonable, but not exceptional.

Survey length was restricted and only closed questions used. While the small set of qualitative interviews with potential Māori and Pacific BSP participants adds some explanation to the survey findings, the qualitative information should be interpreted with caution given the small numbers involved. In addition, only those identifying as Samoan

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\(^{33}\) Statistics New Zealand (2009).
participated in the Pacific interviews. Planned future in-depth qualitative evaluation activities with the eligible population will provide important information to ensure more detailed understanding about the responses received from these surveys and the small set of qualitative interviews.

We have no evidence to indicate the surveys provide biased estimates. Findings from the two surveys thereby provide indicative and useful information in an area where little is currently known about New Zealanders’ attitudes towards and awareness of bowel cancer and bowel cancer screening.

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34 It is likely that different Pacific ethnic groups have different levels of education, health literacy, patterns of engagement with health services and health outcomes. Education levels were not sought in the surveys due to survey length constraints, but an analysis by area of deprivation will be conducted on completion of the follow-up survey.

35 See Litmus Limited (2011) for the full set of planned evaluation activities.
4. Findings

This section presents findings from the two population telephone surveys:

- knowledge of bowel cancer rates in New Zealand, bowel cancer risk factors and the symptoms of bowel cancer
- awareness of bowel screening tests and kits, and for those living in WDHB, awareness of the BSP in particular
- previous experience with cancer screening, bowel cancer and bowel screening tests
- perceived personal risk of developing bowel cancer, along with views and attitudes about bowel screening generally and bowel screening tests
- very early (self-reported) levels of participation in WDHB’s BSP.

Key summary points are presented in boxes throughout this section.

In addition, differences between the two surveys that are statistically significant are noted as such in the text and are denoted on the graphs with an asterisk (*).

Information for key sub-groups in the WDHB is only reported in the text where differences within these groups are statistically significant.

The ‘Other ethnic group’ referred to in the text and graphs includes those people not identifying as Māori, Pacific or Asian.

‘National’ refers to ‘non-WDHB’.

4.1 Knowledge

Respondents were asked a series of questions about their understanding of the diagnosis of bowel cancer in New Zealand, the symptoms of bowel cancer and the risk factors for bowel cancer. Note that responses to these questions were unprompted – survey respondents were informed at the outset of their interview that the survey was about cancer and cancer screening. They were not informed that it was about bowel cancer specifically.

Most commonly diagnosed cancers

Bowel cancer is the second most commonly diagnosed cancer overall for both men and women in New Zealand, following prostate cancer for men and breast cancer for women.36 Among Māori, however, bowel cancer is the third most diagnosed cancer, with lung cancer being the second most diagnosed.37 Among Pacific peoples, bowel cancer is the fourth most diagnosed.38

In the survey, prostate cancer is perceived to be the most commonly diagnosed cancer for men in New Zealand (indicted by 58% of WDHB respondents and 60% of National

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37 Ibid.
38 Ibid.
Bowel cancer is thought to be the most commonly diagnosed cancer among men by 13% of WDHB respondents and 16% of National respondents. WDHB respondents who indicate they have a family history of bowel cancer are statistically significantly more likely (24%) than those with no family history (10%) to say bowel cancer is the most commonly diagnosed cancer among men.\textsuperscript{39}

Figure 1: Perception of the most commonly diagnosed cancer among New Zealand men, Waitemata District Health Board and National, 2011

The second most commonly diagnosed cancer among men is primarily thought to be bowel cancer (40% in WDHB and 37% nationally), followed by prostate cancer (Figure 2).

\textsuperscript{39} Differences between the two surveys are not statistically significant unless denoted by an asterisk on the graphs and referred to as ‘significant’ or ‘statistically significant’ in the text.

\textsuperscript{40} Differences within sub-groups are statistically significant when referred to as ‘significant’ or ‘statistically significant’ in the text (and are sometimes also presented graphically using the asterisk to denote a significant difference).
For women, the majority of respondents consider breast cancer to be the most commonly diagnosed cancer (78% among WDHB respondents and 76% nationally) (Figure 3). Cervical cancer is perceived to be the second most commonly diagnosed cancer among women however, ranked as such by 42% of WDHB respondents and 43% of respondents nationally (Figure 4).

Bowel cancer is not considered to be a commonly diagnosed cancer among women for many respondents (3% in WDHB and 5% nationally perceive it to be the most common cancer). The proportions viewing it as the second most commonly diagnosed cancer among women are also low (13% in WDHB and 14% nationally).

Despite the actual ethnic differences in cancer rates, there were no significant differences in perceptions of the most commonly diagnosed cancers within the WDHB survey by ethnicity (or any other sub-group).
Figure 3: Perception of the most commonly diagnosed cancer among New Zealand women, Waitemata District Health Board and National, 2011

![Bar chart showing perceived most common cancer diagnoses among New Zealand women.]

Base: All respondents  
Source: BSP Evaluation telephone surveys, 2011

Figure 4: Perception of the second most commonly diagnosed cancer among New Zealand women, Waitemata District Health Board and National, 2011

![Bar chart showing perceived second most common cancer diagnoses among New Zealand women.]

Base: All respondents  
Source: BSP Evaluation telephone surveys, 2011

**Summary:** There is a moderate level of knowledge of bowel cancer prevalence in New Zealand, especially for cancers affecting men. Cervical cancer is perceived to be the second most diagnosed cancer among women in New Zealand (rather than bowel cancer). There is no significant variation by ethnicity, age or gender within WDHB.
**Bowel cancer risk factors**

Survey respondents were asked how strongly they agree or disagree with the following six bowel cancer risk factor statements (Figures 5–10).

- Eating red or processed meat once a day or more can increase a person’s chance of developing bowel cancer.
- Eating fewer than five servings of fruit and vegetables a day can increase a person’s chance of developing bowel cancer.
- Having a diet low in fibre can increase a person’s chance of developing bowel cancer.
- Doing less than 30 minutes of moderate activity five times a week can increase a person’s chance of developing bowel cancer.
- Being overweight can increase a person’s chance of developing bowel cancer.
- Having a close relative who has had bowel cancer can increase a person’s chance of developing bowel cancer.

Levels of agreement are highest in both surveys for having a diet low in fibre (70% strongly agree or somewhat agree in WDHB, 68% nationally) (Figure 7) and having a close relative who had bowel cancer (64% in WDHB and 69% nationally) (Figure 10) as risk factors for increasing the odds of bowel cancer.

Levels of agreement are lowest, again in both surveys, for doing moderate exercise five days a week (33% either strongly or somewhat disagree in WDHB and 36% nationally) (Figure 8) or eating fewer than five servings of fruit and vegetables a day (33% disagree in WDHB and 37% nationally) (Figure 6).

Respondents are most likely to indicate they neither agree nor disagree with the statements about eating meat (28% in WDHB and 24% nationally) (Figure 5), doing exercise (26% in WDHB and 22% nationally) (Figure 8) and being overweight (21% in WDHB and 22% nationally) (Figure 9).
Figure 5: Agreement with the statement ‘eating red or processed meat once a day or more can increase a person’s chance of developing bowel cancer’, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

Figure 6: Agreement with the statement ‘eating fewer than five servings of fruit and vegetables a day can increase a person’s chance of developing bowel cancer’, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011
Figure 7: Agreement with the statement ‘having a diet low in fibre can increase a person’s chance of developing bowel cancer’, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

Figure 8: Agreement with the statement ‘doing less than 30 minutes of moderate activity five times a week can increase a person’s chance of developing bowel cancer’, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011
Figure 9: Agreement with the statement ‘being overweight can increase a person’s chance of developing bowel cancer’, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011
There are a number of statistically significant differences among sub-groups in WDHB for levels of agreement, or otherwise, with the risk factor statements.

- Māori and Pacific respondents are significantly more likely (14% and 17%, respectively) than those from the Other ethnic group (ie, not Māori, Pacific or Asian) (6%) to strongly disagree that eating red or processed meat once a day or more can increase a person’s chance of developing bowel cancer.

- Māori and Pacific respondents are also significantly more likely (46% and 45%, respectively) than those from the Other ethnic group (31%) to either somewhat or strongly disagree that eating fewer than five servings of fruit and vegetables a day can increase a person’s chance of developing bowel cancer (Figure 11).

- A similar pattern was the case for a low fibre diet and doing less than 30 minutes of moderate activity five times a week. Māori and Pacific respondents are significantly more likely (27% and 34%, respectively) than those from the Other ethnic group (12%) to either somewhat or strongly disagree with the statement that having a diet low in fibre can increase a person’s chance of developing bowel cancer. They are also significantly more likely (46% of Māori WDHB respondents and 50% of Pacific) than those in the Other ethnic group (31%) to somewhat or strongly disagree that doing less than 30 minutes of moderate activity five times a week can increase a person’s chance of developing bowel cancer (Figure 11).

- Being overweight is more likely to be considered a risk factor for developing bowel cancer by Pacific respondents in WDHB (77% somewhat or strongly agree) than by those in the Other ethnic group (55%) (Figure 11).

- WDHB respondents who are significantly more likely to agree (somewhat or strongly) that ‘having a close relative who has had bowel cancer can increase a person’s chance of developing bowel cancer’ include women (70%, compared to 59% of men) and those from the Other ethnic group (67%, compared to Māori, 47% and Pacific, 38%).
Those with a family history of bowel cancer are significantly more likely than those with no history to somewhat or strongly agree with the statements about fibre (80% with a family history, 67% without) and exercise (47% and 29%, respectively).

Respondents living in a household with a low household income (less than $25,000) were significantly more likely (43%) than those in a household with a high income (more than $100,000, 27%) to disagree that eating fewer than five servings of fruit and vegetables a day can increase a person’s chance of developing bowel cancer (Figure 12).

People living in low-income households were significantly more likely (23%) than those living in households with an income of $40,000–$60,000 (6%) to disagree that having a low fibre diet can increase a person’s chance of developing bowel cancer (Figure 12).

The supplementary qualitative interviews with Māori and Pacific participants also identified that these groups appear less confident about the risk factors for bowel cancer. In the Pacific interviews, there was a high awareness, however (as in the telephone surveys), that being overweight could cause bowel cancer.

**Figure 11: Significant differences in understanding of bowel cancer risk factors by ethnicity, Waitemata District Health Board, 2011**

Base: Respondents who have never had bowel cancer

Source: BSP Evaluation telephone surveys, 2011
Figure 12: Significant differences in understanding of bowel cancer risk factors by household income, Waitemata District Health Board, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

Summary: There is variable awareness of bowel cancer risk factors, with awareness being highest of the influence of fibre and family history on bowel cancer and lowest about the impact of moderate exercise and eating fruit and vegetables. Māori and Pacific peoples in WDHB have particularly low awareness of the influence of exercise, fibre and a diet high in fruit and vegetables on a person’s chance of developing bowel cancer. Pacific peoples, however, have a high awareness of the impact of being overweight on bowel cancer.

Recognising bowel cancer symptoms

Around one in five respondents indicate they are very confident in being able to recognise a symptom as a warning sign for bowel cancer (19% in WDHB and 23% nationally) (Figure 13). Conversely, a quarter are either not at all or not confident in noticing a symptom (26% in WDHB and nationally).

Within WDHB, women are significantly more likely to be very confident in recognising a bowel cancer symptom (23%) than men (16%). Younger respondents (aged 50–64 years) are significantly less likely (41%) than the older cohort (65–74 years) (55%) to be either confident or very confident in recognising symptoms.
Unprompted awareness of specific bowel cancer symptoms is highest for blood in the bowel motion, both within WDHB (72%) and nationally (66%) (Figure 14). A change in toileting patterns is mentioned second most frequently (46% of WDHB respondents and 44% of National respondents). A feeling that the bowel does not completely empty is mentioned by fewer people (10% in WDHB and 5% nationally).

Up to one in five respondents don’t know of any bowel cancer symptoms (16% in WDHB and 21% nationally).
Within WDHB, women are significantly more likely (57%) than men (35%) to mention a change in toileting patterns as a symptom of bowel cancer. People living in households earning more than $100,000 are significantly more likely (78%) than those living in households earning less than $25,000 (53%) to mention blood in the bowel motion.

Men are significantly more likely (20%) than women (12%), Pacific are significantly more likely (55%) than the Other ethnic group (12%), and those living in households with a low income (less than $25,000) are significantly more likely (30%) than those living in households earning more than $100,000 (13%) not to know of any bowel cancer symptoms. Similarly, those without a family history of bowel cancer are also significantly more likely (18%) than those with a family history (8%) not to know of any bowel cancer symptoms.

It was identified in the qualitative interviews that Māori and Pacific (particularly Pacific men) interviewees had low levels of awareness of bowel cancer symptoms.

Prompted levels of awareness of bowel cancer symptoms were also measured amongst those respondents who had not spontaneously mentioned one or more bowel cancer symptoms (Figure 15). Blood in the bowel motions is the most recognised symptom (88% in WDHB and 82% nationally) followed by a change in normal toileting patterns (68% in WDHB and 71% nationally). There are low levels of awareness about the symptom of the bowel not emptying completely (54% in WDHB and 53% nationally). The remaining respondents either believe it isn’t a symptom (25% in both WDHB and nationally) or are unsure (22% in each survey).

Figure 15: Awareness (prompted) of specific bowel cancer symptoms, Waitemata District Health Board and National, 2011

Among WDHB respondents, those with a family history, when prompted about symptoms, are significantly more likely to agree that a change in toileting patterns is a symptom of bowel cancer (79%), compared to those without a family history (66%). Similarly, those living in a household with an income of $25,000–$40,000 are more likely (78%) to agree that a change in toileting habits is a symptom of bowel cancer, when prompted, than those in a household earning over $100,000 (58%).
Pacific respondents are significantly less likely (70%) than those from the Other ethnic group (91%) to agree that blood in the bowel motion is a symptom of bowel cancer but are significantly more likely (20%) than the Other ethnic group (4%) to say that blood in the bowel motion is not a symptom.

**Summary:** There is variable awareness of bowel cancer symptoms and relatively low confidence in being able to recognise a symptom (although confidence is higher among women). The majority are aware that blood in the bowel motion is a symptom of bowel cancer. Men, Pacific peoples, low-income household residents and those with no family history of bowel cancer are more likely than their counterparts not to know of any bowel cancer symptoms.

### 4.2 Awareness

Survey respondents were asked a number of questions to gauge awareness of bowel screening tests and kits, and to determine levels of awareness of the BSP among WDHB residents.

**Awareness of bowel screening tests**

Levels of awareness of bowel cancer screening tests are consistent across the two surveys. Forty-one percent of respondents in WDHB and 42% nationally indicate they know of tests they can do, or a doctor can request, to check for bowel cancer. Women respondents from WDHB are significantly more likely (51%) than men (29%) to indicate they know of bowel cancer screening tests. WDHB respondents from the Other ethnic group are also significantly more likely (42%) than Pacific (19%) respondents to know of tests.

When asked to name a test, unprompted, around three-quarters of those 41–42% of respondents who stated they know of bowel screening tests mention colonoscopies, including a CT colonography (72% in WDHB and 76% nationally) (Figure 16). Among WDHB respondents, women are significantly more likely (78%) than men (64%) to name the colonoscopy (Figure 17). Those living in homes earning a household income between $60,000 and $100,000 and more than $100,000 are more likely (82% and 74%, respectively) than those living in a low-income household (earning less than $25,000, 53%) to name the colonoscopy (Figure 18).

Similarly, respondents from the Other ethnic group are significantly more likely (75%) than Māori (55%) or Pacific (32%) respondents to name the colonoscopy as a bowel screening test. Awareness of bowel screening tests was also very low among those Māori and Pacific interviewed face to face as part of the supplementary qualitative interviews.

Unprompted mention of the FOBT was 19% in WDHB and 16% nationally (Figure 16). Few mentioned the BowelScreen Aotearoa test kit that can be purchased from a pharmacy (1% in WDHB and 2% nationally). Four WDHB respondents (1%) mentioned the BSP.

Just over one in 10 respondents are unable to name a test for bowel cancer (14% in WDHB and 12% nationally).
Figure 16: Awareness (unprompted) of specific bowel cancer screening tests, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer AND were aware of tests in previous question
Source: BSP Evaluation telephone surveys, 2011
Note: FOBT = faecal occult blood test; WDHB = Waitemata District Health Board; OTC = over the counter; BS = BowelScreen.

Figure 17: Awareness (unprompted) of colonoscopies by ethnicity and gender, Waitemata District Health Board, 2011

Base: Respondents who have never had bowel cancer AND were aware of tests in previous question
Source: BSP Evaluation telephone surveys, 2011
Note: NZ Euro = New Zealand European
Figure 18: Awareness (unprompted) of colonoscopies by household income, Waitemata District Health Board, 2011

Base: Respondents who have never had bowel cancer AND were aware of tests in previous question
Source: BSP Evaluation telephone surveys, 2011

Those who didn’t mention one or more of the bowel screening tests (unprompted) were provided with an explanation of the FOBT\(^{41}\) and a colonoscopy\(^{42}\) and were asked if they had ever heard of either test before having the tests described to them. Taking responses to this question, together with unprompted responses to the earlier question about knowing of any tests for bowel cancer, almost half of respondents who have had bowel cancer said they have heard of the FOBT (49% in WDHB and 44% nationally) (Figure 19). Note this is total response (unprompted and prompted). Among WDHB respondents, those who are aware of the BSP were significantly more likely (75%) than those not aware (42%) to say they have heard of the FOBT.

A higher proportion of respondents (nine out of every 10) have heard of colonoscopies (90% in WDHB and 91% nationally). Among WDHB respondents, women are significantly more likely (94%) than men (87%) to have heard of a colonoscopy, and the Other ethnic group is significantly more likely (94%) than both Māori (79%) and Pacific (53%) to have heard of colonoscopies. As mentioned earlier, awareness of bowel screening tests was also very low among those Māori and Pacific who participated in the supplementary qualitative interviews.

People were also asked a prompted question about the take-home bowel screening test that can be purchased from a pharmacy (the BowelScreen Aotearoa kit) to determine prompted levels of awareness of the kit, which was launched in New Zealand in April 2011.\(^{43, 44}\) In total (unprompted and prompted), one in five WDHB respondents indicate they

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\(^{41}\) The explanation provided was: “One screening test for bowel cancer is the faecal occult blood test, or FOBT for short. This test can detect tiny amounts of blood in your poo. Samples can be collected at home, usually by smearing a small amount of poo or bowel motion into a small container that is then sent to a laboratory for testing.”

\(^{42}\) The explanation provided was: “The colonoscopy is another test for bowel cancer. This test examines the colon (the longest part of the large intestine) using a narrow, lighted tube that is inserted in the bottom. Beforehand, you need to drink a special mixture to clear out the bowel. The colonoscopy is done in hospital or a clinic and you’d usually be given medicine to make you sleepy.”


\(^{44}\) Interviewers took care to ensure respondents weren’t referring to bowel cleansing or detox kits.
are aware of the kit (20%), compared to 17% nationally (Figure 19). Among WDHB residents, those from the Other ethnic group are significantly more likely (22%) than Māori (9%) or Pacific (7%) to have heard of the BowelScreen Aotearoa kit.

Figure 19: Total awareness (prompted and unprompted) of bowel cancer screening tests, Waitemata District Health Board and National, 2011

![Figure 19: Total awareness (prompted and unprompted) of bowel cancer screening tests, Waitemata District Health Board and National, 2011](image)

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011
Note: FOBT = faecal occult blood test

**Awareness of the Waitemata District Health Board Bowel Screening Programme**

Those WDHB respondents who had not previously mentioned the BSP specifically (only four had mentioned it) were prompted with a question asking if they had seen or heard any information about a bowel screening programme being run in their area by the DHB. After prompting, 20% indicate they have seen or heard about the BSP (79% said they have not, and 1% cannot recall).

Women are significantly more likely (25%) than men (15%) to have heard of the BSP in WDHB. Just one of the Māori and Pacific participants in the qualitative interviews had heard of the BSP in their area, however, there are no significant differences between ethnic groups in the telephone surveys.

**Summary:** People are more aware of colonoscopies than of FOBT. Women and those in the Other ethnic group are more likely than their counterparts to name colonoscopies (unprompted and prompted). Levels of awareness are also significantly higher among those who have previous experience of a bowel screening test. Awareness of the BSP is low and there is minimal awareness of the BowelScreen Aotearoa test kit.
4.3 Previous bowel cancer experience

This section outlines respondents’ previous experience with cancer screening, bowel cancer and bowel screening tests.

Previous cancer screening, including bowel cancer

Self-reported uptake of specific cancer screening tests shows no significant difference between the two surveys (Figure 20):

- breast screen in previous two years\(^{45}\) (85% of WDHB women and 83% nationally)\(^{46}\)
- cervical screen in previous three years\(^{47}\) (65% of WDHB women and 70% nationally)\(^{48}\)
- prostate screen in previous two years (70% of WDHB men and 64% nationally)
- skin cancer check in previous two years (41% in WDHB and 38% nationally).

Figure 20: Self-reported uptake (prompted) of cancer screening tests, Waitemata District Health Board and National, 2011

<table>
<thead>
<tr>
<th>Test</th>
<th>Waitemata</th>
<th>National</th>
</tr>
</thead>
<tbody>
<tr>
<td>(n=403) Women only Breast screening</td>
<td>85.0%</td>
<td>83.4%</td>
</tr>
<tr>
<td>(n=403) Women only Cervical screening</td>
<td>65.4%</td>
<td>70.2%</td>
</tr>
<tr>
<td>(n=297) Man only Prostate screening</td>
<td>70.0%</td>
<td>64.3%</td>
</tr>
<tr>
<td>(n=700) All Skin cancer screening</td>
<td>40.5%</td>
<td>38.3%</td>
</tr>
</tbody>
</table>

Base: All respondents
Source: BSP Evaluation telephone surveys, 2011

All respondents were also asked if they had had any other screening test for cancer in the previous two years where they had no signs or symptoms. One in 10 WDHB respondents

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(10%) has previously had some sort of bowel screening test (Figure 21). This compares to 12% nationally. Tests mentioned included FOBTs and/or colonoscopies. A slightly lower (but not significant) proportion mentioned another (one or more) cancer screening test (8% in WDHB and 9% nationally).

Figure 21: Unprompted mention of bowel cancer screening test and other cancer screening test (not already mentioned) in previous two years, Waitemata District Health Board and National, 2011

Base: All respondents
Source: BSP Evaluation telephone surveys, 2011

Diagnosis of bowel cancer

Respondents were asked to indicate if they had ever been diagnosed with bowel cancer. Small numbers say that they have – five in WDHB (1%) and 19 nationally (3%). These respondents were subsequently asked the demographic questions, thanked for their time and agreement to participate, and were asked no further questions.

Family history of bowel cancer

Amongst the remaining respondents, self-reported history of bowel cancer among immediate family members (defined for respondents as ‘people who are related to you’) is very similar in the two surveys (Figure 22). Twenty-three percent of both WDHB and National survey respondents report that they have history of bowel cancer in their family. About 1% in each survey doesn’t know whether they have history of bowel cancer in their family.

Note that none of these had been diagnosed through the BSP.
Pacific respondents living in WDHB are significantly less likely (8%) than respondents of Other ethnicity (ie, not Māori, Pacific or Asian) (24%) to report that someone in their immediate family has had bowel cancer (Figure 23).50

Testing for bowel cancer

The reporting of previous experience of symptoms or signs that respondents thought might be bowel cancer is similar in both surveys (21% in WDHB and 23% nationally) (Figure 24). Respondents of Other ethnicity living in WDHB are significantly more likely (22%) than Māori (8%) and Pacific (10%) WDHB respondents to report they had previously experienced symptoms or signs they thought might be bowel cancer (Figure 25). Similarly, those living in high-income households (more than $100,000) were significantly more likely (26%) than those living in households with an income of $25,000–$40,000 (7%) to say they have previously experienced bowel cancer symptoms.

In WDHB, 26% state that a doctor has suggested in the past that they do a test to check for bowel cancer or the functioning of their bowels, compared to 27% nationally (Figure 24). WDHB respondents aged 65–74 years are significantly more likely (33%) to have had a doctor suggest a test for bowel cancer than respondents aged 50–64 (23%). Similarly, those with a family history of bowel cancer are also significantly more likely (37%) to have had a bowel cancer test suggested by a doctor than those with no family history (23%).

In addition, Māori and Pacific respondents living within WDHB are significantly less likely (14% each) to have had a doctor suggest a test to check for bowel cancer, compared to those from the Other ethnic group (28%) (Figure 25). This was also identified in the qualitative interviews with Māori and Pacific respondents.

Figure 24: Previous experience of bowel cancer symptoms and suggestion by doctor to do a bowel cancer test, Waitemata District Health Board and National, 2011

<table>
<thead>
<tr>
<th></th>
<th>Waitemata (n=691)</th>
<th>National (n=680)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of possible bowel cancer symptoms</td>
<td>20.5%</td>
<td>23.0%</td>
</tr>
<tr>
<td>Dr suggestion of bowel/ bowel cancer test</td>
<td>26.0%</td>
<td>27.1%</td>
</tr>
</tbody>
</table>

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011
Note: Dr = doctor
The proportion of people who have ever done an FOBT (of any type) is significantly different between WDHB and nationally. Just over one in three (35%) of WDHB respondents have previously done an FOBT, compared to 21% nationally (Figure 26). Among WDHB respondents, men are significantly more likely (41%) to have done an FOBT than women (29%), as are those aged 65–74 years (45%, compared to 30% of 50–64 year olds).

An inverse pattern is evident for colonoscopies, with 24% of WDHB respondents having ever had a colonoscopy, compared to 29% nationally (Figure 26). This is not a significant difference, however.
Figure 26: Previous experience of faecal occult blood test (FOBT) and previous experience of colonoscopy, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer AND have heard of FOBT or colonoscopy
Source: BSP Evaluation telephone surveys, 2011

Among those who had ever done an FOBT, the most common frequency of doing such a test during the previous five years is once (53% in WDHB and 41% nationally, a statistically significant difference). This is followed by a number of respondents who have done two or three FOBTs (22% in WDHB and 18% nationally) (Figure 27). National respondents who have ever done an FOBT are significantly more likely not to have done such a test during the previous five years (25%, compared to 18% in WDHB).

Figure 27: Number of faecal occult blood test in previous five years, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer AND have ever done an FOBT
Source: BSP Evaluation telephone surveys, 2011

Recalculating on the WDHB survey base of n=691, 14% of WDHB respondents, who have never had bowel cancer, have done an FOBT in the past five years.
Among those who have ever had a colonoscopy, the most common frequency over the previous five years is one (47% in WDHB and 49% nationally) (Figure 28), with about a third (nearly 33%) of respondents who have ever had a colonoscopy indicating they have not had the procedure within the past five years.  

**Summary:** Unprompted mention of having done a bowel screening test is low (one in 10 people). Just over one in five have a family history of bowel cancer. This group is more likely than those with no family history to have had a doctor suggest they do a test to check for bowel cancer. Māori and Pacific are the least likely to have a doctor suggest this. WDHB respondents are significantly more likely than National respondents to have done an FOBT, while experience of colonoscopy was similar in both surveys.

### 4.4 Attitudes

Survey respondents were asked a series of questions about their views of FOBTs, colonoscopies and bowel screening generally. They were also asked to indicate their own perceived risk of developing bowel cancer.

**Perceived risk of bowel cancer**

Respondents were asked to indicate their views on how likely or unlikely it is that they will develop bowel cancer in their lifetime. One in 10 (11% in WDHB and nationally) feel they would be either quite or very likely to develop bowel cancer (Figure 29). Among WDHB respondents who have never had bowel cancer and have ever had a colonoscopy in the past five years, 16% have had a colonoscopy in the past five years.  

Recalculating on the WDHB survey base of n=691, 16% of WDHB respondents, who have never had bowel cancer, have had a colonoscopy in the past five years.
respondents, Pacific are significantly more likely (23%) to consider they are likely to develop bowel cancer than Māori (9%) or those from the Other ethnic group (11%), as are those who have a family history of bowel cancer (19%, compared to those who don’t 8%).

A third are not sure either way (31% in WDHB and 35% nationally). About a half feel they are unlikely to develop bowel cancer (53% in WDHB and 49% nationally), with the majority of these stating they are quite, rather than very, unlikely. Older WDHB respondents (65–74 years) are significantly more likely (60%) than the younger group (50–64 years, 50%) to feel they are unlikely to develop bowel cancer.

Figure 29: Perceived likelihood of developing bowel cancer within lifetime, Waitemata District Health Board and National, 2011

![Figure 29: Perceived likelihood of developing bowel cancer within lifetime, Waitemata District Health Board and National, 2011](image)

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

Faecal occult blood tests

Views were sought on the FOBT, in particular, whether or not it is perceived as being embarrassing, painful, messy, inconvenient and/or inaccurate (Figures 30–34).

Respondents appear reasonably sure that the FOBT is neither embarrassing nor painful. Just over half (57% in WDHB and 52% nationally) strongly disagree it could be embarrassing (Figure 30) and almost 70% of WDHB respondents strongly disagree that the test could be painful (66% nationally) (Figure 31). They are less confident that it could be inconvenient (39% strongly disagree in WDHB and 42% nationally) (Figure 33). Respondents living in households with a household income of more than $100,000 are significantly more likely (94%) than those living in a household earning less than $25,000 (77%) to disagree that the FOBT could be painful.

Respondents appear particularly unsure about whether or not the test could be messy or inaccurate (Figures 34 and 32). When asked to rate if the test could be inaccurate, 23% of WDHB respondents and 20% of National respondents are unable to provide a rating (ie.

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they didn’t know). An additional 28% in WDHB and 23% nationally neither agree nor disagree (ie, they remain neutral).

WDHB Pacific respondents are significantly more likely (39%) than those from Māori (16%) and the Other ethnic group (15%) to agree that the FOBT could be inaccurate. This was also identified in the qualitative face-to-face interviews with Pacific peoples living in WDHB.

Of all the statements about FOBTs, levels of agreement are highest, both in WDHB and nationally, that the test could be messy (30% strongly or somewhat agree in WDHB and 33% nationally).

**Figure 30: Agreement that the faecal occult blood test could be embarrassing, Waitemata District Health Board and National, 2011**

![Bar chart showing agreement levels for the faecal occult blood test]
Figure 31: Agreement that the faecal occult blood test could be painful, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

Figure 32: Agreement that the faecal occult blood test could be messy, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011
Figure 33: Agreement that the faecal occult blood test could be inconvenient, Waitemata District Health Board and National, 2011

![Bar chart showing agreement levels for the faecal occult blood test being inconvenient.]

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

Figure 34: Agreement that the faecal occult blood test could be inaccurate, Waitemata District Health Board and National, 2011

![Bar chart showing agreement levels for the faecal occult blood test being inaccurate.]

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

**Colonoscopies**

Respondent views were also sought about colonoscopies, again for whether or not they are perceived as being embarrassing, painful, messy, inconvenient and/or inaccurate (Figures 35–39). Views on colonoscopies differ from those of FOBT. In particular, respondents are
less likely to consider colonoscopies to be inaccurate, but more likely to view them as embarrassing, painful and inconvenient. In addition, respondents are more likely to have a view, either positive or negative, about all aspects of colonoscopies, than they are for some aspects of FOBTs, where many remain unsure or neutral in their views.

While there are reasonably high levels of respondents strongly disagreeing that colonoscopies could be embarrassing or messy (Figures 35 and 37), views are more evenly spread for perceived levels of pain or inconvenience (Figures 35 and 38). As mentioned, levels of disagreement are highest for colonoscopies being inaccurate (66% strongly or somewhat disagree in WDHB and 68% nationally) (Figure 39).

Those living in households with a lower household income (less than $25,000 and $25,000–$40,000) are significantly more likely (52% and 58%, respectively) than those in high-income households (more than $100,000, 30%) to disagree that colonoscopies could be inconvenient.

**Figure 35: Agreement that colonoscopies could be embarrassing, Waitemata District Health Board and National, 2011**

![Bar chart showing agreement levels](image)

*Base: Respondents who have never had bowel cancer*

*Source: BSP Evaluation telephone surveys, 2011*
Figure 36: Agreement that colonoscopies could be painful, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

Figure 37: Agreement that colonoscopies could be messy, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011
Figure 38: Agreement that colonoscopies could be inconvenient, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

Figure 39: Agreement that colonoscopies could be inaccurate, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011
Summary: Perceived risk of developing bowel cancer is low (one in 10), although is higher among Pacific respondents in WDHB than in other ethnic groups and higher among those with a family history. Perceptions of FOBTs and colonoscopies vary. Half of respondents are either unsure or don’t know if the FOBT is inaccurate or messy. The colonoscopy is less likely to be seen as inaccurate but more likely to be viewed as painful, embarrassing and inconvenient.

Participating in a bowel screening programme with an at-home FOBT kit

Respondents were asked how likely or unlikely they would be to participate in a bowel cancer screening programme if they received an invitation letter (stating their doctor’s support) in the mail, followed by an FOBT kit that they would need to complete before sending to a laboratory.

Self-reported levels of likelihood in participating in such a programme are high in both surveys (Figure 40). Over half said they would be very likely to participate in such a programme and, again, this is consistent in both surveys (59% in both WDHB and nationally). An additional number said they would be quite likely to participate, bringing total potential participation to 73% in WDHB and 76% nationally.

Figure 40: Likelihood of participating in a bowel screening programme involving an at-home faecal occult blood test kit, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

Those respondents who said they would be likely to participate in a bowel screening programme involving the FOBT kit were asked to give their reasons for this. Answers were
The following are the main reasons respondents provide for participating (Figure 41):

- health checks are important (45% in WDHB, 36% nationally)
- want to know bowel cancer status (28% in WDHB, 21% nationally)
- as a precaution and/or prevention measure (27% in WDHB, 30% nationally)
- for peace of mind and/or reassurance (20% in WDHB, 20% nationally)
- can do the test at home and/or convenience (8% in WDHB, 9% nationally).

Figure 41: Main reasons for participating in a bowel screening programme involving an at-home faecal occult blood test kit, Waitemata District Health Board and National, 2011

The small proportion of respondents who indicate they wouldn’t take part (Figure 42):

- not concerned (33% in WDHB, 29% nationally)
- would prefer to see doctor (23% in WDHB, 28% nationally).

Small numbers of respondents provide a number of other reasons (fewer than 20 respondents per reason).

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54 The list of reasons was identified during pretesting of the questionnaires.
55 Multiple response was allowed.
56 Multiple response was allowed.
Views about bowel cancer and bowel cancer screening

Respondents were asked a number of attitudinal questions about at-home FOBTs, screening for bowel cancer, and their views on the importance of both. Specifically, they were asked to indicate how much they agree or disagree with the following statements (Figures 43–47):

- ‘Having a test like the at-home poo test seems like more trouble than it’s worth’
- ‘It is important to check for bowel cancer even if you don’t have symptoms’
- ‘Treating bowel cancer in the early stages increases a person’s chance of survival’
- ‘At-home poo tests are necessary even if there is no family history of bowel cancer’

Views on early treatment of bowel cancer to increase the odds of survival are particularly positive – 94% of WDHB respondents and 95% nationally either strongly or somewhat agree with this statement (Figure 45). WDHB Pacific respondents are significantly less likely (85%) than those from the Other ethnic group (95%) to agree with this statement (Figure 47).

There is also strong agreement with the importance of checking for bowel cancer without the presence of symptoms (Figure 44) and reasonably strong agreement (but with a higher percentage remaining neutral) that at-home FOBTs are necessary even without a family history of bowel cancer (Figure 46).

Pacific WDHB respondents are significantly more likely (88%) than those from the Other ethnic group (76%) to agree that it is important to check for bowel cancer even if symptoms are not present.

Over half of respondents disagree with the statement that at-home FOBTs are more trouble than they are worth (74% somewhat or strongly disagree in WDHB and 72% nationally).
WDHB Māori and Pacific respondents are significantly less likely to disagree with this statement, however (64% of Māori and 47% of Pacific), than those from the Other ethnic group (77%).

Figure 43: Level of agreement with the statement ‘having a test like the at-home poo test seems like more trouble than it’s worth’, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

Figure 44: Level of agreement with the statement ‘it is important to check for bowel cancer even if you don’t have symptoms’, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011
Figure 45: Level of agreement with the statement ‘treating bowel cancer in the early stages increases a person’s chance of survival’, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011

Figure 46: Level of agreement with the statement ‘at-home poo tests are necessary even if there is no family history of bowel cancer’, Waitemata District Health Board and National, 2011

Base: Respondents who have never had bowel cancer
Source: BSP Evaluation telephone surveys, 2011
4.5 Participation in the Waitemata District Health Board bowel screening pilot

A number of questions were included in the WDHB survey asking if people had recently received a letter of invitation and/or FOBT kit in the mail. Subsequent questions asked if people had completed, or intended to complete, the kit, if enough information was received and whether or not they had been notified of their results.

One person had received the invitation letter at the time of the survey. None had received a kit. An additional 16 people commented that, while they themselves hadn’t received a letter or kit, someone else in their household had. One person didn’t know if they had received a letter or a kit.

The person who had received the invitation letter indicated that the information in the letter was easy to understand and they intend to complete and return the at-home kit for testing, once it arrived.

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57 A ‘soft launch’ of the BSP was undertaken in November–December 2011, whereby 500 letters and kits were mailed to eligible potential participants registered with two practices within WDHB.

58 In addition, none of the qualitative interviewees had received a letter or kit from the BSP at the time of their interview.
5. Discussion

This report provides a benchmark measure of the eligible population’s awareness, knowledge and attitudes towards bowel cancer and bowel cancer screening, both within WDHB and nationally. There are high levels of consistency in the views expressed by respondents in each of the surveys. This indicates that information about the BSP may have had minimal impact on the views and attitudes about bowel cancer and bowel cancer screening held by WDHB residents, which is important for ensuring a ‘clean’ baseline measure.

The following key points have been identified from the analysis of the survey data.

High level of previous FOBT experience: There is one statistically significant difference between the two surveys – 35% of WDHB respondents have ever done an FOBT, compared to 21% nationally. Most of the WDHB respondents have done one FOBT in the past five years (again this is a significant difference). This difference could reflect one of a number of factors. The population profile of WDHB differs from the National (outside-WDHB) profile. It is known that there are proportionately fewer Māori aged 50–74 within the DHB (4.3%, compared with 7.7% nationally).59 In addition, WDHB is dominated by large urban areas and includes a larger proportion of residents living in households with higher incomes.60 These factors combined mean that WDHB residents may be more likely, and have more opportunity, to access health services and perhaps influence discussions with their doctor about the availability of bowel screening tests. Conversely, the higher rates of FOBT experience in WDHB could indicate a heightened awareness among health providers of the BSP starting in the WDHB area (announced in 2010), thereby perhaps influencing their own behaviour in suggesting that patients do an FOBT.

Moderate level knowledge of bowel cancer prevalence: While there appears to be good knowledge about the bowel cancer burden for men, ‘high profile’ female cancers (ie, breast and cervical cancer) dominate the perceived burden of cancer among women, for both male and female respondents. This may reflect the visibility of breast and cervical screening promotions in New Zealand, along with associated breast cancer fundraising and other awareness-raising programmes. Raising the profile of bowel cancer, including its relative impact on New Zealanders, will be an important component of a bowel screening programme.

Variable awareness of bowel cancer symptoms and risk factors: The perceived risk of getting bowel cancer is low. There is a low reported level of confidence in recognition of the symptoms of bowel cancer. Less than a quarter of respondents are confident that they would recognise a symptom, this is also supported by the Māori and Pacific qualitative interviews.61 Awareness is particularly low for recognising that changes in toilet patterns or the bowel not completely emptying are symptoms of bowel cancer.

While there is reasonably high awareness (although not exceptionally so) of a low fibre diet and family history of bowel cancer being risk factors for bowel cancer, there is low awareness of the influence of exercise and a diet containing sufficient fruit and vegetables.

60 Thirty-seven percent of WDHB residents live in households with a total household of income of more than $70,000, compared to 28% in the rest of New Zealand. Specifically, 22% in WDHB live in households earning more than $100,000, compared to 15% in the rest of New Zealand. An additional 16% in both WDHB and the rest of New Zealand do not state their household income (Statistics New Zealand, 2006).
61 However, as noted earlier, caution is required in the interpretation of the qualitative interviews, firstly due to the small numbers and, secondly, because only those identifying as Samoan participated in the Pacific qualitative interviews.
Awareness of these latter two risk factors is significantly low among Māori and Pacific respondents. In addition, there are reasonable levels of uncertainty amongst many about the other main risk factors (eating red or processed meat and being overweight). There is an opportunity for improving people’s understanding of the known risk factors for bowel cancer and symptoms of the disease.

Of interest, Pacific peoples are more likely than others to consider being overweight is a risk factor for bowel cancer. The qualitative fieldwork suggests that this is perhaps because the impact of obesity on health outcomes is particularly salient among Pacific peoples and that this understanding may have been translated to the impact of being overweight on bowel cancer.

**Higher awareness of colonoscopies than FOBT:** Levels of awareness and knowledge about different bowel screening tests varies. As would be expected, those who have previously experienced bowel screening tests (eg, through having a family history of bowel cancer) have significantly higher levels of knowledge. Levels of awareness about the colonoscopy are highest. FOBTs are not as widely known about, even after prompting. Clear information about FOBTs – including what they are and how they work – will be a critical component of a bowel screening programme. There is minimal awareness of bowel screening test kits available for purchase over the counter in chemists.

**Some uncertainty about FOBTs and colonoscopies:** Perceptions of the FOBT and colonoscopies vary. Around half of respondents are either unsure or don’t know if the FOBT is inaccurate or messy. Inaccuracy of the test is of particular concern to Pacific peoples, a perception that was also identified in the qualitative research with Pacific participants.

While Māori survey respondents are no more or less likely than others to express negative views about the FOBT, the qualitative fieldwork identified a number of potential cultural sensitivities with bowel screening and the FOBT, in particular, specifically around tūtae/tiko (faeces), whakamā (embarrassment) and kanohi-ki-ti-kanohi (face-to-face) engagement. While both Māori men and women raised these issues, they were more strongly raised by men.

Messaging, information and engagement about a bowel screening programme need to be cognisant of concerns with the FOBT, including cultural issues (especially of those held by Māori men).

Views on colonoscopies are also varied. This screening test is less likely to be seen as inaccurate but more likely to be viewed as embarrassing, painful and inconvenient, indicating areas of special focus in materials explaining colonoscopies for those who have a positive FOBT.

**Low awareness of the BSP but reasonable intentions of participating:** WDHB respondents have limited awareness of the BSP, rising to one in five after prompting. Low levels of awareness were also identified in the qualitative fieldwork with Māori and Pacific participants. Nevertheless, intended likelihood of participating in the pilot is reasonable, and this was the same nationally (in the event that a national programme is rolled out). Over half (59%) state they are very likely to participate in a bowel screening programme, with an additional 13% to 17% saying they are quite likely. Analysis of actual uptake rates from the BSP Register will indicate the extent to which these intentions translate into action in WDHB.

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62 This low awareness among Pacific respondents of the impact of diet on bowel cancer differs considerably from their reasonably high levels of awareness around the importance of diet as a risk factor for diabetes, for example (Phoenix Research, 2010). This could reflect the lower incidence of bowel cancer (compared to other cancers) among Pacific peoples.
While indications are that all groups appear to have reasonably similar intentions to participate in a bowel screening programme, the qualitative interviews identify a few factors that may require investigation in future planned evaluation activities (and depending on actual uptake rates). Pacific participants in the qualitative study indicate they would feel a sense of shame in undertaking the FOBT. On the one hand, they see the benefit of conducting the test in the privacy of their own home but contrasting this is the view that it would be preferable to have a hospital-based test in the event that clinical input, support and advice is needed. Thus, even though respondents said they would do the FOBT, it appears there is a preference for doing an FOBT in the hospital setting. The hospital is seen to be clean and convenient, where you have a set appointment and ‘properly trained’ doctors and nurses on site.

Similarly, the Māori qualitative interviews identified a preference by people to do the FOBT in the doctors’ rooms where they would have the opportunity to engage face to face with the doctor to talk about the test. This qualitative information needs to be interpreted with caution, however, due to the small number of interviews conducted.

**Recognised importance of bowel screening:** Responses to attitudinal questions about bowel screening indicate a clear recognition of the importance of checking for bowel cancer (even when there are no symptoms) and that early treatment of bowel cancer is important to increase chances of survival. The qualitative fieldwork identified that, among Māori, whānau experiences (of cancer) play a very strong role in increasing willingness to participate in cancer screening programmes such as the BSP. However, Māori men indicate they may be less amenable to participating in the screening programme than Māori women. Involvement of significant others in conveying key messages to encourage Māori (and perhaps also Pacific) men to participate will be important.

Among Pacific, there appears to be some hesitancy in the effectiveness of early cancer treatment. Comments in the Pacific qualitative interviews indicate a belief that Pacific peoples who get diagnosed with cancer usually have a short life span after diagnosis.

**Early participation in the BSP:** The telephone surveys were conducted during an initial ‘soft launch’ of the BSP in late 2011, which involved eligible people from two WDHB practices being invited (via letter) to participate in the pilot. At the time of the survey, one person had received the BSP invitation letter (but not the kit at that stage). This provides reassurance that the views given in the WDHB survey have not been overly influenced by promotion of the BSP, thereby leading to possible heightened awareness.

**Variation amongst population groups:** A number of key sub-group distinctions (all statistically significant) are evident within WDHB.

- **A history of bowel cancer in the family** plays an important role in increasing awareness of the risk factors of bowel cancer and knowledge of symptoms. Likelihood of having undertaken an FOBT and/or colonoscopy is also higher in this group.

- **Women** are more likely than men to recognise bowel cancer symptoms, to know specific bowel cancer symptoms, to know of specific bowel screening tests and to have heard of the BSP.

- **Māori and Pacific peoples** (compared to the Other ethnic group) have lower awareness of bowel cancer symptoms, lower knowledge of risk factors and bowel screening tests, and little previous experience of bowel screening tests. They are also less likely to have discussions with their doctor about doing a bowel screening test. Pacific peoples

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63 Caution must be used in interpreting this information due to the small numbers and Samoan-only interviews. However, this has been a key finding in other health research undertaken with Pacific peoples by Litmus, for example, [http://www.health.govt.nz/publication/immunisation-audience-research](http://www.health.govt.nz/publication/immunisation-audience-research) Accessed 22 February 2012.
in particular consider themselves more likely to develop bowel cancer in their lifetime. For Māori, these patterns could be a reflection of the lower levels of health literacy amongst this group.64 This is also likely to be the case for Pacific. Differences between specific Pacific ethnicities, however, cannot be determined from the survey and qualitative interviews.

- There are minimal differences between the younger and older cohorts within the 50–74 age group.

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6. References


7. Glossary

**Ninety-five percent confidence interval:** A range of values for a prevalence rate, constructed to reflect random sampling variation so that 95% of such intervals would include the true value of the prevalence.

**Other ethnic group:** In this report, defined as non-Māori, non-Pacific and non-Asian. Mainly includes those who identified as New Zealand European or Other European.

**P-value:** A numerical indication of the likelihood that the difference observed could have occurred by chance. In this report, if the p-value is less than 0.05 (5%), the difference between two prevalence values is said to be statistically significant.

**Prioritised response ethnicity:** This involves each person being allocated to one ethnic group, regardless of how many ethnic groups they identified in response to the ethnicity question. This results in percentages totalling to 100%.

**Statistically significant:** Differences between estimates are said to be statistically significant when the 95% confidence interval for the difference does not include zero. Statistical significance means that a finding is unlikely to merely reflect random sampling variation. However, it does not mean that the result is necessarily important or of any practical significance.

**Weights:** Survey weights are applied to data to allow for the sample design and align the sample with population benchmarks. They ensure that population sub-groups are represented in the survey results in their correct proportions.
8. Appendices

Appendix 8.1: Pretesting – information sheet
Appendix 8.2: Pretesting – consent form
Appendix 8.3: Questionnaire – Waitemata District Health Board
Appendix 8.4: Questionnaire – non-Waitemata District Health Board (National)
Appendix 8.5: Qualitative interviews with Māori and Pacific – information sheet
Appendix 8.6: Qualitative interviews with Māori and Pacific – consent form
Appendix 8.1: Pretesting – information sheet

Survey Pretesting – Bowel Screening Pilot Evaluation
Information Sheet

Thank you for your interest in this project. Your information will assist with finalising a survey to be used for evaluating the Bowel Screening Pilot, being rolled out in Auckland. Please read this information before deciding whether or not to take part. If you decide to take part, we thank you. If you decide not to take part, we thank you for your time taken to consider our request.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the purpose of the project?</td>
<td>Litmus (a research company) has been asked by the Ministry of Health to find out how the Bowel Screening Pilot is working in Auckland. As part of that we will be surveying people over the phone. The purpose of the project is <strong>to determine if organised bowel screening could be introduced to all of New Zealand</strong> in a way that is effective, safe and acceptable.</td>
</tr>
<tr>
<td>What will I be asked to do?</td>
<td>We are talking with people from outside of Auckland to <strong>pretest</strong> the telephone survey, face-to-face. This will help us find out if there are any issues with the survey questions. The pretesting will take <strong>about 30-45 minutes</strong>. There are no right or wrong answers.</td>
</tr>
<tr>
<td>What types of questions will you ask me?</td>
<td>We will be asking you questions that we have developed for the survey and will then ask about <strong>your perceptions</strong> about the questions. We are especially interested in your feedback on the survey questions – are they easy to understand or difficult to answer? You do not have to answer any questions that you feel uncomfortable with.</td>
</tr>
<tr>
<td>Why have you asked me to participate?</td>
<td>We are speaking with people who potentially could be invited to participate in a bowel screening programme if it was available nationally – so that’s <strong>people aged 50-74 years</strong>.</td>
</tr>
<tr>
<td>How will the researchers ensure my personal information is confidential?</td>
<td>Litmus will ensure <strong>your contribution is kept confidential</strong>. What you say in the pretesting will be written down, and with your permission, audio taped. Audio recordings and notes will be kept securely at the Litmus Office or in secure storage for up to 2 years, and then securely destroyed. Your name and address and any other identifying information will not be used in any reporting.</td>
</tr>
<tr>
<td>Can I change my mind and withdraw from the project?</td>
<td><strong>You may stop the pretesting at any time.</strong> You do not need to give a reason and there will be no disadvantage to you of any kind.</td>
</tr>
<tr>
<td>Who will be doing the pretesting?</td>
<td>The pretesting is being done by Litmus, a research and evaluation company. For more information about Litmus go to <a href="http://www.litmus.co.nz">www.litmus.co.nz</a>.</td>
</tr>
<tr>
<td>What if I have any questions?</td>
<td>If you have any questions about this project, please contact: <strong>Michele Grigg</strong>, Principal Consultant, Litmus, ph 04 473 3880 <a href="mailto:michele@litmus.co.nz">michele@litmus.co.nz</a></td>
</tr>
</tbody>
</table>
Appendix 8.2: Pretesting – consent form

Survey Pretesting

Consent Form

I (write name) ……………………………………………………………………………

of (write address) …………………………………………………………………………

agree to take part in pretesting a health survey, as outlined in the information provided to me by Litmus (the research company). I understand that:

- I do not have to take part in an interview.
- I can choose not to answer any questions I do not wish to answer (without saying why).
- I can stop and leave the pretesting at any time without saying why I no longer want to take part.
- Litmus will keep my information confidential. I will not be named in any report.
- The pretesting will be recorded with my permission.
- After the pretesting, I understand that we will be discussing the understandability of the questions.
- Recordings, notes, and summaries will be stored securely at Litmus and will not identify me by name. They will be kept for two years and then securely destroyed.

I have read this consent form, and have been given the opportunity to ask questions. I give my consent to participate in this pretesting project.

Signature: __________________________

Date: __________________________
Appendix 8.3: Questionnaire – Waitemata District Health Board

BOWEL SCREENING PILOT (BSP) EVALUATION

WDHB BASELINE SURVEY - 2011

Intro - screening questions

Good afternoon/evening, my name is … from Reid Research Services calling on behalf of Litmus Research and the Ministry of Health.

The Ministry of Health is aiming to better understand what people know and think about cancer and screening for cancer – that is testing for cancer when people do not have any signs or symptoms of cancer. We are currently conducting a short 10-15 minute survey on this subject with people aged 50-74.

Could I please speak with a male in the household who is aged between 50 and 74 years. If two males, who is next to have their birthday?

If no Male or Male refuses, say...

Could I please speak with a female in the household who is aged between 50 and 74 years. If two females, who is next to have their birthday?

Note: As required change intro to ask for Māori or Pacific as required for booster samples. Also check numbers of males and females.

Reintro as required

[It is important that we speak with equal numbers of men and women, so I need to speak with a [man/woman] living in the house aged 50 to 74]

Completing the survey will help the Ministry of Health with planning future cancer services. This is a really important issue for New Zealanders. We hope you can spare 10-15 minutes to take part. Please be reassured the survey is completely confidential. Your answers will be grouped with others who do the survey. Could you spare a little time to answer some questions for me please?

If needed
Just to reiterate, I’m calling from Reid Research etc. [not trying to sell you anything; doing survey for MoH etc]

Reid to add wording about quality control purposes and call recording

Yes
No

If yes continue.
Thank you for agreeing to take part – just to let you know that there will be some personal questions later in the survey and your thoughts on these are very important.
If no, arrange an alternative time. If still no, thank and end. Seek reason for non-participation if possible.

Code gender
Numbers of Males and Females to be tracked - looking for approx. 50% of each across whole sample
**DO NOT READ OUT**
1. Male
2. Female

We need to make sure we have a range of people answering the survey. Can I check a couple of things with you?

S1. Are you a New Zealand resident?
1. Yes - Continue
2. No – Screen out
3. Don't know/Refused – Screen out

S2. Can I also please check that you live within the Waitemata DHB area?
1. Yes – Continue to S5
2. Don't Know - Continue to S3
3. No – Alt+S [make xmas day appointment and ask for Suburb]
4. Refused – Screen out

S3. Which of the following cities do you live in?
[Interviewer to read out options 1-4]
1. The old Waitakere City which is now part of Auckland City
2. The old North Shore City which is now part of Auckland City
3. Rodney District Council Area
4. Or another city - Alt+S [make xmas day appointment and ask for Suburb]
5. Don't Know - Alt+S [make xmas day appointment and ask for Suburb]
6. Refused – Screen out

Interviewer Instruction: [Alt+S [make xmas day appointment and ask for Suburb]]
**Ask respondents if ok if we will call them back in the next few days**

Spec Check suburb- reallocate to either Waitemata or National sample as required.

No QS4

S5. Which of the following age groups do you fit in to? (READ OUT)
1. Less than 50 years – Recontact if possible - Else Screen out
2. 50-54 years
3. 55-59 years
4. 60-64 years
5. 65-69 years
6. 70-74 years
7. 75+ years – Recontact if possible - Else Screen out
98. Refused (DO NOT READ) Screen Out
NB If need to recontact – ALT B to check responses at Gender and S1

S6. Which ethnic group/s do you belong to? (code all that apply)
1. New Zealand European/Pakeha/Kiwi/New Zealander
2. Māori
3. Samoan
4. Cook Island Maori
5. Tongan
6. Niuean
7. Other Pacific
8. Chinese
9. Indian
10. Other Asian eg Japanese
11. Other such as Dutch, Other European etc – (not specified)
98. Refused

Interviewer Instruction: If Fijian, check if Fijian Indian code as Indian else as Other Pacific

Interviewer note: check English language levels and ability to conduct remainder of survey. Thanks and close if necessary.

Before we begin, I should stress the importance of answering the questions as accurately as possible. Please feel free to take as much time as you need before answering. Also, if there are any questions you would rather not answer, just say so.

1A. Which of the following do you think is the most commonly diagnosed cancer for men in New Zealand? (read out list, rotate, record one only)
   1. Prostate cancer
   2. Lung cancer
   3. Melanoma or skin cancer
   4. Bowel cancer
   98. Don’t know/Refused (DO NOT READ)
   5. None of these (DO NOT READ)

   If Don’t Know at Q1A skip to Q2A

1B. And which do you think is the next most commonly diagnosed cancer for men? (read out list, rotate, record one only)
   Spec Instruction: Remove option (codes 1-4) mentioned at Q1A from list offered
   1. Prostate cancer
   2. Lung cancer
   3. Melanoma or skin cancer
   4. Bowel cancer
   98. Don’t know/Refused (DO NOT READ)
   5. None of these (DO NOT READ)

2A. Which of the following do you think is the most commonly diagnosed cancer for women in New Zealand? (read out list, rotate, record one only)
   1. Cervical cancer or cancer of the cervix
2. Lung cancer
3. Melanoma or skin cancer
4. Breast cancer
5. Bowel cancer
98. Don't know/Refused (DO NOT READ)
6. None of these (DO NOT READ)

If Don't Know at Q2A skip to instruction before Q3M

2B. And which do you think is the next most commonly diagnosed cancer for women? (read out list, rotate, record one only)

Spec Instruction: Remove option (codes 1-5) mentioned at Q2A from list offered
1. Cervical cancer or cancer of the cervix
2. Lung cancer
3. Melanoma or skin cancer
4. Breast cancer
5. Bowel cancer
98. Don't know/Refused (DO NOT READ)
6. None of these (DO NOT READ)

Now I'm going to ask whether you have had certain screening tests for cancer in the last two years – so that's in 2010 or 2011. Just so we are clear, a screening test is a test you have when you don't have any symptoms or signs of cancer.

(If Male, ask 3M; if Female, ask 3F1 and 3F2)

3M. [Men only] In the last two years, have you had a screening test for prostate cancer? This may have been a blood test or a rectal examination done by your doctor. [If necessary, remind that they wouldn't have had any symptoms or signs]

1. Yes
2. No
98. Don't know
99. No response/Refused

If respondent is male, skip to Q4

3F1. [Women only] In the last two years have you had a breast screening mammogram, an x-ray of the breast?

1. Yes
2. No
98. Don't know/Can't remember
99. No response/Refused
97. Not Applicable/Don't need to (mammaryectomy)

3F2. [Women only] Thinking now about the last three years, have you had a cervical smear test (sometimes known as a Pap smear test)?

1. Yes
2. No
98. Don't know/Can't remember
99. No response/Refused
4. **In the last two years have you had a screening skin cancer check?** This may have been a MoleMap or a visual check of a mole or freckles by a health professional such as your doctor.
   1. Yes
   2. No
   98. Don’t know/Can’t remember
   99. No response/refused

5. **Have you had any other screening tests for cancer in the last two years where you’ve had no signs or symptoms of cancer but you or your doctor were checking that everything was ok?**
   If **Yes**, could you please tell me/describe what it was?
   *If ‘about to have a screening test’ code as a No.*
   1. Yes (Waitemata DHB’s Bowel Screening Programme or FOBT) (see interviewer note below with description)
   2. Yes (bowel screening or some other bowel screening test, may include mention of ‘FOBT’ test or ‘colonoscopy’ – see interviewer notes below)
   3. Yes, for another form of cancer eg liver, stomach cancer
   4. No
   98. Don’t know/Can’t remember
   99. No response/Refused

**Interviewer notes**
Waitemata DHB’s Bowel Screening Programme including the FOBT: Respondent may have recently received an invitation in the mail to participate in **Waitemata DHB’s Bowel Screening Programme**. Four weeks after that they will have received a test kit with instructions (including a step-by-step diagram) about how to use the at-home poo test kit. This kit is called the ‘iFOBT’ or ‘FOBT’. People use the kit to collect a small poo sample following the instructions on the booklet. They put this in a small container, which is then put into a zip-lock bag and posted along with a completed consent form to the laboratory, in the freepost envelope provided.
Some people may have received their test results, by the time of the survey. These could be positive or negative. If positive, these people will have been contacted by either their doctor or the Screening Coordination Centre to book in for a colonoscopy. A colonoscopy is a test that examines the colon using a narrow, lighted tube that is inserted in the bottom. Beforehand, people need to drink a special mixture to clear out their bowel. This test is done in the hospital.

Respondents may also describe collecting a poo sample at home that was not part of the Waitemata DHB’s Bowel Screening Programme. This may or may not have been to test for cancer (eg, don’t code to Yes if testing was for something like food poisoning).

If (Code 1 or 2 - ‘Yes’ in Q5) answer Q5A and Q5B without asking respondent else skip to Q6

5A. **Interviewer note** Did the person describe the WDHB BSP or FOBT at-home poo test kit?
5B. **Interviewer note** Did the person describe a colonoscopy?

1. Yes
2. No

6. Before we go any further, I'll now 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 or poo from the body. Bowel cancer may also be called colon cancer, rectal or colorectal cancer. Have you ever been diagnosed with bowel cancer?

   1. Yes
   2. No
   98. Don't know/Can't remember
   99. No response/Refused

   *If no, go to Q7, else continue.*

6A. Was your bowel cancer diagnosed as a result of iFOBT testing in the Bowel Cancer Screening programme being run in your area right now (where you would have received a test kit in the mail)?

   1. Yes
   2. No
   98. Don't know/Can't remember
   99. No response/Refused

All responses to Q6A end survey as per script below. **Track numbers of SCREEN OUTS-Counted as part of overall Quota**

The rest of the questions in this survey relate to bowel cancer screening for people who have never had bowel cancer themselves. We're sure you appreciate the importance of this research. However, the rest of the questions are not relevant to people who have been diagnosed with bowel cancer – we do however, have a few demographic questions to ask you before we finish up. We do appreciate your time in completing the first part of the survey; it's still very helpful for us.

Thank and ask demos.

7. Using a scale of 1 to 5, how confident or unconfident are you that you would notice a bowel cancer symptom, where 1 is not at all confident and 5 is very confident?

   1. Not at all confident
   2. Not confident
   3
   4. Confident
   5. Very confident
   98. Don't know (DO NOT READ)
   99. No response/Refused (DO NOT READ)

8. And have you ever experienced any symptoms or signs that you thought might be bowel cancer? You don't need to tell me what the symptoms are.
1. Yes
2. No
98. Don’t know/Can’t remember
99. No response/Refused

9. **Has anyone in your immediate family had bowel cancer? (That is people who are related to you)**
   1. Yes
   2. No
   98. Don’t know/Can’t remember
   99. No response/Refused

*If Yes Code 1 at Q9 ask Q9A else skip to Q10*

9A. **Could you please tell me which of the following people have had bowel cancer…**

Interviewer Instruction: Read out codes 1-6 and code all that apply
   1. Mother
   2. Father
   3. Brother/Sister
   4. Son/Daughter
   5. Aunt/Uncle
   6. Grandparent
   7. Someone Else
   8. None of the above
   99. No response/Refused

10. **What symptoms are you aware of that are warning signs of bowel cancer? Any other symptoms?**
   *Code multiple response.*

   *Interviewer Note: The respondent does not have to mention/include timeframe “for several weeks” to code as a 1*
   1. A change in normal pattern of going to the toilet that continues for several weeks or a change in toilet habits (such as runny poos/diarrhoea or not going very often/constipation)
   2. A feeling that the bowel doesn’t empty completely after using the toilet
   3. Blood in poos/bleeding
   4. Other
   98. Don’t know
   99. No response/Refused

   *For any not mentioned. Do you think this is a symptom or a warning sign for bowel cancer?*
   *Code Yes or No for each.*
   A change in your normal pattern of going to the toilet that continues for several weeks (such as runny poos/diarrhoea or not going very often/constipation)?
   A feeling that your bowel doesn’t empty completely after using the toilet?
   Blood in your poos?
1. Yes
2. No
d. Don’t know/Not sure
99. No response/Refused

11. The following items I’m going to read out may or may not increase a person’s chance of developing bowel cancer. I’d like you to tell me on a scale of 1 to 5 where 1 is strongly disagree and 5 is strongly agree how much you agree or disagree that each of these can increase a person’s chance of developing bowel cancer.

How much do you agree or disagree that (INSERT STATEMENT) where 1 is strongly disagree and 5 is strongly agree?

- Eating red or processed meat once a day or more can increase a person’s chance of developing bowel cancer
- Eating fewer than 5 servings of fruit and vegetables a day can increase a person’s chance of developing bowel cancer
- Having a diet low in fibre can increase a person’s chance of developing bowel cancer
- Doing less than 30 minutes of moderate activity 5 times a week can increase a person’s chance of developing bowel cancer
- Being overweight can increase a person’s chance of developing bowel cancer
- Having a close relative who has had bowel cancer can increase a person’s chance of developing bowel cancer

1  Strongly disagree
2  Somewhat disagree
3
4  Somewhat agree
5  Strongly agree
98  Don’t know (DO NOT READ)
99  No response/Refused (DO NOT READ)

12. How likely or unlikely is it that you personally would develop bowel cancer in your lifetime, using a scale of 1 to 5 where 1 is very unlikely and 5 is very likely?

1  Very unlikely
2  Quite unlikely
3
4  Quite likely
5  Very likely
98  Don’t know (DO NOT READ)
99  No response/Refused (DO NOT READ)

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

*Interviewer note: Check Q5, if coded 1 ‘Yes (Waitemata DHB’s Bowel Screening Programme or FOBT)’ clarify, We’re not meaning here the Waitemata DHB Bowel Screening Programme.*
1. Yes
2. No
98. Don’t know
99. No response/Refused

If yes skip to Q14A, else continue

14. Do you know of any tests that you can do or a doctor can request to check for bowel cancer?
   1. Yes
   2. No
   98. Don’t know
   99. No response/Refused

Ask A14A if Yes at Q13 OR Q14 else skip to Q15

14A. What are the names of the tests? (Multiple responses allowed, check those mentioned below, and prompt with ‘What else?’ If can’t name the test ask ‘Can you describe it to me?’)
   1. Colonoscopy (including ‘CT colonography)
   2. FOBT (faecal occult blood test)
   3. FOBT (faecal occult blood test) from Waitemata DHB/sent in the mail
   4. FOBT test from chemist/over the counter (BowelScreen Aotearoa on packaging)
   97. Other
   98. Can’t give name/Don’t remember
   99. Unwilling to answer/No response

If described take-home test from the pharmacy (Code 4), skip to Q16 (Note: Must make specific mention of test being seen/bought at the chemist/over the counter - need to have coded ‘FOBT test from chemist/over the counter (BowelScreen Aotearoa on packaging)’ above.

15. Have you seen or heard about a take-home bowel screening test that you can buy from a chemist? (Prompt: It may have said ‘BowelScreen Aotearoa’ on the packet…?)

   Interviewer Note: Must be a bowel screening test-not a bowel cleanser or detox
   1. Yes
   2. No
   98. Don’t know
   99. No response/Refused

[Check back to Q5A, if coded Yes OR Q14A coded 2, 3 or 4, code Yes at Q16 without asking. If Yes in Q5A skip to Q17A; if code 2, 3 or 4 in Q14A skip to Q17]

16. One screening test for bowel cancer is the faecal occult blood test, or FOBT for short. This test can detect tiny amounts of blood in your poo. Samples can be collected at home, usually by smearing a small amount of poo or bowel motion into a
small container that is then sent to a laboratory for testing. Have you heard of such a test before?
1. Yes
2. No
98. Not sure/Don’t know
99. No response/Refused

If no, not sure or no response skip to Q18, if yes to Q5A skip to Q17A, else continue
17. Have you ever done a test (a FOBT TEST) [like the one I just described]? If needed: to test for bowel cancer.
   1. Yes
   2. No
   98. Don’t know
   99. No response/Refused

If no/DK/No response/Refused, skip to Q18, if yes continue
17A. How many times have you done a FOBT test in the past 5 years?
   [or If Yes to Q5A say:
   You mentioned earlier you have done a FOBT at-home test in the last two years. How many in total have you done in the past 5 years?]
   1. None - more than 5 years ago
   2. 1
   3. 2-3
   4. 4-5
   5. 6 or more
   98. Don’t know/Can’t recall
   99. No response/Refused

At Q14A - If answer included FOBT (faecal occult blood test) from Waitemata DHB/sent in the mail (code 3) skip Q18 and say at Q19 “As you are aware the Waitemata DHB has started mailing ….etc

18. Have you heard or seen any information about a bowel cancer screening programme being run in your area, by the Waitemata District Health Board hospitals?
   1. Yes
   2. No
   98. Don’t know/Can’t recall
   99. No response/Refused

19. This programme has started mailing out invitations with an FOBT home poo test kit for people to complete and send back to the lab for analysis. Have you received a letter or kit in the mail?
   1. Yes – Received a letter AND a kit Interviewer: Clarify received letter AND kit
   2. Yes – Received a letter only at this stage, not the kit yet
   3. No
   4. No - but someone else in household has received a letter and/or kit
   98. Don’t know
99. No response/Refused

If Yes – received letter AND kit in Q19 ask Q20
If Yes – received a letter only at this stage, not the kit yet in Q19, ask Q26
Else skip to Q29

20. **Was the information provided with the at-home poo test kit easy to understand?**
1. Yes
2. No
98. Don’t know/Haven’t looked at it yet
99. No response/Refused

21. **Have you completed and returned the at-home test kit for testing?**
1. Yes
2. No
98. Don’t know
99. No response/Refused

(If no/dk/no response/refused ask Q21A, else skip to Q23)

21A. **Do you intend to complete and return the at-home test kit sometime soon?**
1. Yes
2. No
98. Don’t know
99. No response/Refused

(If no ask Q22, else skip to Q29)

22. **What are your reasons for not intending to complete and return the kit? Any other reasons?** *Code multiple Do not read out*
1. Inconvenience/no time
2. Don’t think I’m at risk
3. Embarrassment
4. Messy/yucky
5. Not clean doing it at home
6. Do other bowel tests(eg colonoscopy)already
7. Might not be conclusive/give an accurate result
8. Would rather go to doctor
9. No family history of bowel cancer
10. No reason in particular
11. Other
98. Don’t know
99. No response/Refused

Now go to Q29

23. **Have you received your results yet?**
1. Yes
2. No
98. Don’t know
24. **Who did you receive these from?** Code multiple response
   1. Doctor or nurse from GP Practice
   2. Bowel Screening Programme Coordination Centre
   3. Someone else
   98. Don’t know/Not sure who
   99. No response/Refused

25. **Did they provide you with all the information you needed?**
   1. Yes
   2. No
   98. Don’t know
   99. No response/Refused

   *If no ask Q25A, else continue*

25A. **What other information would you have liked?** Code multiple response

   *Do not read out*
   1. What the next steps are
   2. What’s involved with further tests
   3. How to prevent bowel cancer
   4. What to do to stay healthy
   5. Where to go for further information
   6. Other/Something else
   98. Don’t know
   99. No response/Refused

   *Now go to Q29*

   *If Yes – received a letter only at this stage, not the kit yet in Q19 ask Q26, else skip to Q29*

26. **Was the information in the letter easy to understand?**
   1. Yes
   2. No
   98. Don’t know/Haven’t looked at it yet
   99. No response/Refused

27. **Do you intend to complete and return the at-home test kit for testing?**
   1. Yes
   2. No
   98. Don’t know
   99. No response/Refused

   *(If no ask Q28, else skip to Q29)*

28. **What are your reasons for not intending to complete and return the kit? Any other reasons?** Code multiple Do not read out
   1. Inconvenience/no time
2. Don’t think I’m at risk
3. Embarrassment
4. Messy/yucky
5. Not clean doing it at home
6. Do other bowel tests (e.g., colonoscopy) already
7. Might not be conclusive/give an accurate result
8. Would rather go to doctor
9. No family history of bowel cancer
10. No reason in particular
11. Other
12. Not sure what is involved
98. Don’t know
99. No response/Refused

Check back to Q5B, if coded Yes OR Q14A coded 1, code Yes at Q29 without asking. If Yes in Q5B skip to Q31; if code 1 in Q14A skip to Q30

29. The next couple of questions are about colonoscopies, another test to check for bowel cancer. This test examines the colon (the longest part of the large intestine) using a narrow, lighted tube that is inserted in the bottom. Beforehand, you need to drink a special mixture to clear out the bowel. The colonoscopy is done in hospital or a clinic and you’d usually be given medicine to make you sleepy. Before I described this test just now, had you ever heard of a colonoscopy?
   1. Yes
   2. No
   98. Not sure/Don’t know
   99. No response/Refused

If no/DK/No response/Refused skip to Q33, if yes to Q5B skip to Q31, else continue

30. Have you ever had a colonoscopy?
   1. Yes
   2. No
   98. Don’t know
   99. No response/refused

If no/DK/No response/Refused, skip to Q33, if yes continue

31. How many colonoscopies have you had in the past 5 years, that’s from January 2007? [If Yes to Q5B: You mentioned earlier you have had a colonoscopy in the last two years. How many in total have you done in the past 5 years, that’s from January 2007?]
   1. None in the past 5 years (skip to Q33)
   2. 1
   3. 2-3
   4. 4-5
5.6 or more  
98. Don’t know/Can’t recall  
99. Refused

32. **And have you had any others more than 5 years ago, that is how many between 2001 and December 2006?**
   1. None at all between 2001 and 2006  
   2. None - had a colonoscopy more than 10 years ago (ie before 2001)  
   3. 1  
   4. 2-3  
   5. 4-5  
   6. 6 or more  
   98. Don’t know/Can’t recall  
   99. Refused

*If Yes at Q21 ask, else continue*

32A. **Was this a result of the at-home poo test kit you recently sent in the mail?**
   1. Yes  
   2. No  
   98. Don’t know/Can’t recall  
   99. Refused

33. **The next few questions are about your opinion on different types of tests. First, let’s think about the FOBT or at-home poo test I described earlier (so that’s the test where a poo sample is smeared into a small container that is then sent to a laboratory).**

   Using a scale of 1 to 5, where 1 is strongly disagree and 5 is strongly agree, how much do you agree or disagree that an at-home poo test could be

   **Interviewer Note**-Be careful with “Inconvenient” and “Inaccurate” that the respondent is understanding properly

   - Embarrassing?  
   - Painful?  
   - Messy?  
   - Inconvenient?  
   - Inaccurate?

   1. Strongly disagree  
   2. Somewhat disagree  
   3.  
   4. Somewhat agree  
   5. Strongly agree  
   98. Don’t know (DO NOT READ)  
   99. No response/Refused (DO NOT READ)

34. **And thinking now about a colonoscopy that we just talked about (so that’s the test that examines the colon using a narrow, lighted tube inserted into the bottom). Using**
a scale of 1 to 5, where 1 is strongly disagree and 5 is strongly agree, how much do you agree or disagree that a colonoscopy could be

Interviewer Note-Be careful with “Inconvenient” and “Inaccurate” that the respondent is understanding properly

- Embarrassing?
- Painful?
- Messy?
- Inconvenient?
- Inaccurate?

1 Strongly disagree
2 Somewhat disagree
3
4 Somewhat agree
5 Strongly agree
98 Don’t know (DO NOT READ)
99 No response/Refused (DO NOT READ)

If No/D/K/no response/refused to Q19 ask, else skip to Q38

35. If you received an invitation letter, which stated your doctor’s support, followed by an FOBT or at-home poo test kit in the mail as part of a bowel cancer screening programme how likely or unlikely are you to do the test and send it off to the lab?

Using a scale from 1 to 5, where 1 is not at all likely and 5 is very likely.

1 Not at all likely
2 Not likely
3
4 Somewhat likely
5 Very likely
98 Don’t know (DO NOT READ)
99 No response/Refused (DO NOT READ)

If DK/No response/Refused, skip to Q38, else continue

If 1 or 2 in Q35 skip to Q37, else continue

36. For what reasons do you say that? (DO NOT READ) Any other reasons?

1. Health checks are important
2. Want to know bowel cancer status
3. As a precaution/prevention measure
4. Because my doctor supports/endorses it/government programme
5. Have a family history or personal experience of bowel cancer or other cancer
6. Might have symptoms
7. The simplicity or easiness of the test
8. Less embarrassing
9. For peace of mind/reassurance
10. Can do the test at home/convenient
11. No reason in particular
12. Other
98. Don't know
99. No response/Refused

If 3, 4 or 5 in Q35 skip to Q38, else continue

37. For what reasons do you say that? (DO NOT READ) Any other reasons?
   1. Only people with a family history or symptoms need to do the test
   2. 'What will be, will be' / Don't really want to know
   3. Would prefer to see my doctor
   4. The test sounds messy/inconvenient/complicated
   5. Don't want to do the test in my home/would rather be tested in hospital/clinic
   6. Not concerned
   7. Don't like getting things like that in the mail/don't know who sent it to me
   8. Recently done an FOBT/at-home test or taken a poo sample to lab/doctor for testing
   9. Do other bowel tests (eg colonoscopy) already
   10. Lack of time/too busy
   11. Might not be conclusive/give the correct result
   12. Might turn out to be expensive
   13. No other reason in particular
   14. Other
   98. Don't know
   99. No response/Refused

38. I'd like you to tell me on a scale of 1 to 5 how much you agree or disagree with each of these following statements about bowel cancer.
Using a scale of 1 to 5 where 1 is strongly disagree and 5 is strongly agree how much do you agree or disagree that (INSERT STATEMENT)?

- Having a test like the at-home poo test seems like more trouble than it's worth
- It is important to check for bowel cancer even if you don't have symptoms
- Treating bowel cancer in the early stages increases a person's chance of survival
- At-home poo tests are necessary even if there is no family history of bowel cancer

   1. Strongly disagree
   2. Somewhat disagree
   3.
   4. Somewhat agree
   5. Strongly agree
   98. Don't know (DO NOT READ)
   99. No response/Refused (DO NOT READ)

Closing - demographics
[Pre-amble to closing, as per Reid Research usual practice, then ask demographic questions below]

D1. Including yourself, how many people aged 50-74 live in your household?
That is counting the respondent
   1.1
   2.2
   3.3 or more
   98. Don’t know (DO NOT READ)
   99. No response/Refused (DO NOT READ)

Ask D1a only if the respondent is Maori (S6=2) – regardless of any other ethnic group, including Pacific. Do not ask if D1=1 or 98 or 99. Code as 1 in D1a if D1=1 and S6=2.
D1a. Thinking now about the people aged 50-74 living in your household. Including yourself, how many would identify as Maori?
That is counting the respondent
   1.1
   2.2
   3.3 or more
   98. Don’t know (DO NOT READ)
   99. No response/Refused (DO NOT READ)

Ask D1b only if the respondent is Pacific (S6=3-7), regardless of any other ethnic group, including Māori. Do not ask if D1=1 or 98 or 99. Code as 1 in D1b if D1=1 and S6=3-7.
D1b. Thinking now about the people aged 50-74 living in your household. Including yourself, how many would belong to a Pacific ethnic group, such as Samoan, Tongan, Cook Island Maori, or Niuean?
That is counting the respondent
   1.1
   2.2
   3.3 or more
   98. Don’t know (DO NOT READ)
   99. No response/Refused (DO NOT READ)

D2. Could you please tell me your postcode?
   1. Record __________________________ (record a maximum of 4 digits)
   98. Don’t know (DO NOT READ)
   99. No response/Refused (DO NOT READ)

D3. Which of the following best represents your household’s total annual/yearly gross income – that’s before tax?
   1. Under $15,000
   2. $15,001-$20,000
   3. $20,001-$25,000
   4. $25,001-$40,000
   5. $40,001-$60,000
   6. $60,001-$100,000
   7. $100,001+
Thanks very much for your time today.

Excluding those screened out due to previous diagnosis of bowel cancer:
We are asking people who took part in this survey if they agree to be resurveyed again in 2013. Would you mind if we recontacted you, it will be only once, to ask you similar health questions in two years’ time?

1. Yes
2. No

If Yes, collect

First Name and Surname______________________,  
phone 1__________________  
phone 2 ____________________

We are also asking people who took part in this survey if they agree to having their survey responses linked with data from Waitemata DHB’s Bowel Screening Programme to see if the Programme is running as it should. Do you agree to having your survey responses linked to your data in the Bowel Screening Programme database? Your identifying information such as name, address and date of birth will be kept totally confidential from the researchers. Do you agree to this?

1. Yes
2. No

If Yes at question above and Yes here ask for alias name, address, date of birth, (not exact age now deleted).

If No at question above and Yes here, collect Name 1, alias name, address, date of birth, (not exact age now deleted) and phone numbers

If you are interested in further information about bowel cancer or have any concerns at all we recommend you contact your doctor or practice nurse or else phone the Healthline on 0800 611 116  (If required mention the WDHB website www.BowelScreeningWaitemata.co.nz)

Closing salutation and appreciation of time / thank you as per Reid Research usual practice.
Appendix 8.4: Questionnaire – non-Waitemata District Health Board (National)

BOWEL SCREENING PILOT (BSP) EVALUATION

NATIONAL SURVEY - 2011

Intro - screening questions

Good afternoon/evening, my name is … from Reid Research Services calling on behalf of Litmus Research and the Ministry of Health.

The Ministry of Health is aiming to better understand what people know and think about cancer and screening for cancer – that is testing for cancer when people do not have any signs or symptoms of cancer. We are currently conducting a short 10-15 minute survey on this subject with people aged 50-74.

Could I please speak with a male in the household who is aged between 50 and 74 years. If two males, who is next to have their birthday?

If no Male or Male refuses, say...

Could I please speak with a female in the household who is aged between 50 and 74 years. If two females, who is next to have their birthday?

Note: As required change intro to ask for Māori or Pacific as required for booster samples. Also check numbers of males and females.

Reintro as required

[It is important that we speak with equal numbers of men and women, so I need to speak with a [man/woman] living in the house aged 50 to 74]

Completing the survey will help the Ministry of Health with planning future cancer services. This is a really important issue for New Zealanders. We hope you can spare 10-15 minutes to take part. Please be reassured the survey is completely confidential. Your answers will be grouped with others who do the survey. Could you spare a little time to answer some questions for me please?

If needed
Just to reiterate, I’m calling from Reid Research etc. [not trying to sell you anything; doing survey for MoH etc]

Reid to add wording about quality control purposes and call recording

Yes
No

If yes continue.
Thank you for agreeing to take part – just to let you know that there will be some personal questions later in the survey and your thoughts on these are very important.

If no, arrange an alternative time. If still no, thank and end.
Seek reason for non-participation if possible.

Code gender
Numbers of Males and Females to be tracked - looking for approx. 50% of each across whole sample
DO NOT READ OUT
1. Male
2. Female

We need to make sure we have a range of people answering the survey. Can I check a couple of things with you?

S1. Are you a New Zealand resident?
1. Yes - Continue
2. No – Screen out
3. Don’t know/Refused – Screen out

S2. Which of the following age groups do you fit in to? (READ OUT)
1. Less than 50 years – Recontact if possible - Else Screen out
2. 50-54 years
3. 55-59 years
4. 60-64 years
5. 65-69 years
6. 70-74 years
7. 75+ years – Recontact if possible - Else Screen out
98. Refused (DO NOT READ) Screen Out

NB If need to recontact – ALT B to check responses at Gender and S1

S3. Which ethnic group/s do you belong to? (code all that apply)
1. New Zealand European/Pakeha/Kiwi/New Zealander
2. Māori
3. Samoan
4. Cook Island Maori
5. Tongan
6. Niuean
7. Other Pacific
8. Chinese
9. Indian
10. Other Asian eg Japanese
11. Other such as Dutch, Other European etc – (not specified)
98. Refused

If Fijian, check if Fijian Indian code as Indian else as Other Pacific

Interviewer note: check English language levels and ability to conduct remainder of survey.
Thanks and close if necessary
S4. Which District Health Board area do you live in?

Read out… (eg, if in Auckland)

1. Auckland,
5. Counties Manukau
18. Waitemata – Alt S, record suburb and ask respondent if ok to call back in a few days - move to Waitemata sample once suburb is checked
50. None of these/DK/Refused - goes to whole list as below

1. Auckland
2. Bay of Plenty
3. Canterbury
4. Capital and Coast (Wellington/Kapiti Coast)
5. Counties Manukau
6. Hawkes Bay
7. Hutt Valley
8. Lakes
9. MidCentral (Palmerston North area)
10. Nelson-Marlborough
11. Northland
12. South Canterbury
13. Southern (Otago/Southland)
14. Tairawhiti (Gisborne/East Cape)
15. Taranaki
16. Waikato
17. Wairarapa
18. Waitemata – Alt S ask for suburb etc Xmas day
19. West Coast
20. Whanganui
98. Other/Don’t know (DO NOT READ) Alt S ask for suburb etc Xmas day
99. No response/Refused (DO NOT READ) Screen out

All DHBs to be tracked for numbers of completes

Before we begin, I should stress the importance of answering the questions as accurately as possible. Please feel free to take as much time as you need before answering. Also, if there are any questions you would rather not answer, just say so.

1A. Which of the following do you think is the most commonly diagnosed cancer for men in New Zealand? (read out list, rotate, record one only)

1. Prostate cancer
2. Lung cancer
3. Melanoma or skin cancer
4. Bowel cancer
98. Don’t know/Refused (DO NOT READ)
5. None of these (DO NOT READ)
If Don’t Know at Q1A skip to Q2A

1B. And which do you think is the next most commonly diagnosed cancer for men? (read out list, rotate, record one only)

Spec Instruction: Remove option (codes 1-4) mentioned at Q1A from list offered
1. Prostate cancer
2. Lung cancer
3. Melanoma or skin cancer
4. Bowel cancer
98. Don’t know/Refused (DO NOT READ)
5. None of these (DO NOT READ)

2A. Which of the following do you think is the most commonly diagnosed cancer for women in New Zealand? (read out list, rotate, record one only)

1. Cervical cancer or cancer of the cervix
2. Lung cancer
3. Melanoma or skin cancer
4. Breast cancer
5. Bowel cancer
98. Don’t know/Refused (DO NOT READ)
6. None of these (DO NOT READ)

If Don’t Know at Q2A skip to instruction before Q3M

2B. And which do you think is the next most commonly diagnosed cancer for women?

(Read out list, rotate, record one only)

Spec Instruction: Remove option (codes 1-5) mentioned at Q2A from list offered
1. Cervical cancer or cancer of the cervix
2. Lung cancer
3. Melanoma or skin cancer
4. Breast cancer
5. Bowel cancer
98. Don’t know/Refused (DO NOT READ)
6. None of these (DO NOT READ)

Now I’m going to ask whether you have had certain screening tests for cancer in the last two years – so that’s in 2010 or 2011. Just so we are clear, a screening test is a test you have when you don’t have any symptoms or signs of cancer.

(If Male, ask 3M; if Female, ask 3F1 and 3F2)

3M. [Men only] In the last two years, have you had a screening test for prostate cancer?
This may have been a blood test or a rectal examination done by your doctor. [If necessary, remind that they wouldn’t have had any symptoms or signs]
1. Yes
2. No
98. Don’t know
99. No response/Refused
If respondent is male, skip to Q4

3F1. [Women only] In the last two years have you had a breast screening mammogram, an x-ray of the breast?
   1. Yes
   2. No
   98. Don’t know/Can’t remember
   99. No response/Refused
   97. Not Applicable/Don’t need to (mastectomy)

3F2. [Women only] Thinking now about the last three years, have you had a cervical smear test (sometimes known as a Pap smear test)?
   1. Yes
   2. No
   98. Don’t know/Can’t remember
   99. No response/Refused
   97. Not applicable/Don’t need to (hysterectomy / Doctor says too old)

4. In the last two years have you had a screening skin cancer check? This may have been a MoleMap or a visual check of a mole or freckles by a health professional such as your doctor.
   1. Yes
   2. No
   98. Don’t know/Can’t remember
   99. No response/refused

39. Have you had any other screening tests for cancer in the last two years where you’ve had no signs or symptoms of cancer but you or your doctor were checking that everything was ok?
   If Yes, could you please tell me/describe what it was?
   If ‘about to have a screening test’ code as a No.

   1. Yes (bowel screening or some other bowel screening test, may include mention of ‘FOBT’ test or ‘colonoscopy’ – see interviewer notes below)
   2. Yes, for another form of cancer eg liver, stomach cancer
   3. No
   98. Don’t know/Can’t remember
   99. No response/Refused

Interviewer notes
FOBT: Some tests for bowel cancer screening are called an FOBT or faecal occult blood test. People use the FOBT to collect a small sample from their poo while at home, to send to a lab for testing.
Colonoscopy: This test examines the colon (the longest part of the large intestine) using a narrow, lighted tube that is inserted in the bottom. Beforehand, people need to drink a special mixture to clear out the bowel. The colonoscopy is done in hospital or a clinic and people are usually given medicine to make them sleepy.
If (Code 1 - ‘Yes’ in Q5) answer Q5A and Q5B without asking respondent else skip to Q6

5A. **Interviewer note** Did the person describe the FOBT at-home poo test kit?
   Yes
   No

5B. **Interviewer note** Did the person describe a colonoscopy?
   Yes
   No

40. Before we go any further, I’ll now 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 or poo from the body. Bowel cancer may also be called colon cancer, rectal or colorectal cancer. Have you ever been diagnosed with bowel cancer?
   1. Yes
   2. No
   98. Don’t know/Can’t remember
   99. No response/Refused

If no, continue; if yes/dk/no response, end survey as per script below. Track numbers of SCREEN OUTS - Counted as part of overall Quota

The rest of the questions in this survey relate to bowel cancer screening for people who have never had bowel cancer themselves. We’re sure you appreciate the importance of this research. However, the rest of the questions are not relevant to people who have been diagnosed with bowel cancer – we do however, have a few demographic questions to ask you before we finish up. We do appreciate your time in completing the first part of the survey; it’s still very helpful for us.

Thank and ask demos

41. Using a scale of 1 to 5, how confident or unconfident are you that you would notice a bowel cancer symptom, where 1 is not at all confident and 5 is very confident?
   1. Not at all confident
   2. Not confident
   3
   4. Confident
   5. Very confident
   98. Don’t know (DO NOT READ)
   99. No response/Refused (DO NOT READ)

42. And have you ever experienced any symptoms or signs that you thought might be bowel cancer? You don’t need to tell me what the symptoms are.
   1. Yes
   2. No
   98. Don’t know/Can’t remember
   99. No response/Refused

43. Has anyone in your immediate family had bowel cancer? (That is people who are related to you)
1 Yes
2 No
98 Don’t know/Can’t remember
99 No response/Refused

If Yes Code 1 at Q9 ask Q9A else skip to Q10

9A. Could you please tell me which of the following people have had bowel cancer...

   Interviewer Instruction-Read out all codes 1-7 and code all that apply
   1. Mother
   2. Father
   3. Brother/Sister
   4. Son/Daughter
   5. Aunt/Uncle
   6. Grandparent
   7. Someone else
   8. None of the above
   99 No response/Refused

44. What symptoms are you aware of that are warning signs of bowel cancer? Any other symptoms?

   Code multiple response.

   1. A change in normal pattern of going to the toilet that could continue for several weeks or a change in toilet habits (such as runny poos/diarrhoea or not going very often/constipation)
   2. A feeling that the bowel doesn’st empty completely after using the toilet
   3. Blood in poos/bleeding
   97. Other
   98. Don’t know
   99. No response/Refused

   For any not mentioned, Do you think this is a symptom or a warning sign for bowel cancer?

   Code Yes or No for each.

   A change in your normal pattern of going to the toilet that continues for several weeks (such as runny poos/diarrhoea or not going very often/constipation)?
   A feeling that your bowel doesn’t empty completely after using the toilet?
   Blood in your poos?

   1. Yes
   2. No
   98. Don’t know/Not sure
   99. No response/Refused

45. The following items I’m going to read out may or may not increase a person’s chance of developing bowel cancer. I’d like you to tell me on a scale of 1 to 5 where 1 is strongly disagree and 5 is strongly agree how much you agree or disagree that each of these can increase a person’s chance of developing bowel cancer.
How much do you agree or disagree that (INSERT STATEMENT), where 1 is strongly disagree and 5 is strongly agree?

- Eating red or processed meat once a day or more can increase a person’s chance of developing bowel cancer
- Eating fewer than 5 servings of fruit and vegetables a day can increase a person’s chance of developing bowel cancer
- Having a diet low in fibre can increase a person’s chance of developing bowel cancer
- Doing less than 30 minutes of moderate activity 5 times a week can increase a person’s chance of developing bowel cancer
- Being overweight can increase a person’s chance of developing bowel cancer
- Having a close relative who has had bowel cancer can increase a person’s chance of developing bowel cancer

1 Strongly disagree
2 Somewhat disagree
3
4 Somewhat agree
5 Strongly agree
6 Don’t know (DO NOT READ)
7 No response/Refused (DO NOT READ)

46. How likely or unlikely is it that you personally would develop bowel cancer in your lifetime, using a scale of 1 to 5 where 1 is very unlikely and 5 is very likely?

1 Very unlikely
2 Quite unlikely
3
4 Quite likely
5 Very likely
6 Don’t know (DO NOT READ)
7 No response/Refused (DO NOT READ)

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

1 Yes
2 No
98 Don’t know
99 No response/Refused

*If yes skip to Q14A, else continue*

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

1 Yes
2 No
98 Don’t know
99 No response/Refused
Ask A14A if Yes at Q14 else skip to instruction before Q15

14A. What are the names of the tests? (Multiple responses allowed, check those mentioned below, and prompt with ‘What else?’ If can’t name the test ask ‘Can you describe it to me?’)

1. Colonoscopy (including ‘CT colonography)
2. FOBT (faecal occult blood test)
3. FOBT test from chemist/over the counter (BowelScreen Aotearoa on packaging)
97. Other
98. Can’t give name/Don’t remember
99. Unwilling to answer/No response

If described take-home test from the pharmacy (Code 3), skip to Q16 (Note: Must make specific mention of test being seen/bought at the chemist/over the counter - need to have coded ‘FOBT test from chemist/over the counter (BowelScreen Aotearoa on packaging)’ above

15. Have you seen or heard about a take-home bowel screening test that you can buy from a chemist? (Prompt: It may have said ‘BowelScreen Aotearoa’ on the packet...?)

  Interviewer Note: Must be a bowel screening test-not a bowel cleanser or detox
1. Yes
2. No
98. Don’t know
99. No response/Refused

[Check back to Q5A, if coded Yes OR Q14A coded 2 or 3, code Yes at Q16 without asking.
If Yes in Q5A skip to Q17A; if code 2 or 3 in Q14A skip to Q17]

16. One screening test for bowel cancer is the faecal occult blood test, or FOBT for short. This test can detect tiny amounts of blood in your poo. Samples can be collected at home, usually by smearing a small amount of poo or bowel motion into a small container that is then sent to a laboratory for testing. Have you heard of such a test before?

  1. Yes
  2. No
  98. Not sure/Don’t know
  99. No response/Refused

If no, not sure or no response skip to Q18, if yes to Q5A skip to Q17A, else continue

17. Have you ever done a test (a FOBT TEST) [like the one I just described]? If needed: to test for bowel cancer.

  1. Yes
  2. No
  98. Don’t know
  99. No response/Refused
If no/DK/No response/Refused, skip to Q18, if yes continue

17A. How many times have you done a FOBT test in the past 5 years?

[or If Yes to Q5A say:
You mentioned earlier you have done a FOBT at-home test in the last two years. How many in total have you done in the past 5 years?]

1. None - more than 5 years ago
2. 1
3. 2-3
4. 4-5
5. 6 or more
98. Don’t know/Can’t recall
99. No response/Refused

[Check back to Q5B, if coded Yes OR Q14A coded 1, code Yes at Q18 without asking. If Yes in Q5B skip to Q20; if code 1 in Q14A skip to Q19]

18. The next couple of questions are about colonoscopies, another test to check for bowel cancer. This test examines the colon (the longest part of the large intestine) using a narrow, lighted tube that is inserted in the bottom. Beforehand, you need to drink a special mixture to clear out the bowel. The colonoscopy is done in hospital or a clinic and you’d usually be given medicine to make you sleepy.
Before I described this test just now, had you ever heard of a colonoscopy?

1. Yes
2. No
98. Not sure/Don’t know
99. No response/Refused

If no/DK/No response/Refused skip to Q22, if yes to Q5B skip to Q20, else continue

19. Have you ever had a colonoscopy?

1. Yes
2. No
98. Don’t know
99. No response/refused

If no/DK/No response/Refused, skip to Q22, if yes continue

20. How many colonoscopies have you had in the past 5 years, that’s from January 2007? [If Yes to Q5B: You mentioned earlier you have had a colonoscopy in the last two years. How many in total have you done in the past 5 years that’s from January 2007?]

1. None in the past 5 years
2. 1
3. 2-3
4. 4-5
5. 6 or more
21. And have you had any others more than 5 years ago, that is how many between 2001 to December 2006?
   1. None at all between 2001 and 2006
   2. None - had a colonoscopy more than 10 years ago (ie before 2001)
   3. 1
   4. 2-3
   5. 4-5
   6. 6 or more
   98. Don't know/Can't recall
   99. Refused

22. The next few questions are about your opinion on different types of tests. First, let’s think about the FOBT or at-home poo test I described earlier (so that’s the test where a poo sample is smeared into a small container that is then sent to a laboratory). Using a scale of 1 to 5, where 1 is strongly disagree and 5 is strongly agree, how much do you agree or disagree that an at-home poo test could be
   Embarrassing?
   Painful?
   Messy?
   Inconvenient?
   Inaccurate? That is, might give an incorrect result?
   1  Strongly disagree
   2  Somewhat disagree
   3
   4  Somewhat agree
   5  Strongly agree
   98. Don't know (DO NOT READ)
   99. No response/Refused (DO NOT READ)

23. And thinking now about a colonoscopy that we just talked about (so that’s the test that examines the colon using a narrow, lighted tube inserted into the bottom). Using a scale of 1 to 5, where 1 is strongly disagree and 5 is strongly agree, how much do you agree or disagree that a colonoscopy could be
   Embarrassing?
   Painful?
   Messy?
• Inconvenient?
• Inaccurate? That is, might give an incorrect result?

1  Strongly disagree
2  Somewhat disagree
3
4  Somewhat agree
5  Strongly agree
98. Don’t know (DO NOT READ)
99. No response/Refused (DO NOT READ)

24. If you received an invitation letter, which stated your doctor’s support, followed by an FOBT or at-home poo test kit in the mail as part of a bowel cancer screening programme how likely or unlikely are you to do the test and send it off to the lab? Using a scale from 1 to 5, where 1 is not at all likely and 5 is very likely.

1  Not at all likely
2  Not likely
3
4  Somewhat likely
5  Very likely
98. Don’t know (DO NOT READ)
99. No response/Refused (DO NOT READ)

If DK/No response/Refused, skip to Q27, else continue

If 1 or 2 in Q24 skip to Q26, else continue

25. For what reasons do you say that? (DO NOT READ) Any other reasons?

1. Health checks are important
2. Want to know bowel cancer status
3. As a precaution/prevention measure
4. Because my doctor supports/endorses it/government programme
5. Have a family history or personal experience of bowel cancer or other cancer
6. Might have symptoms
7. The simplicity or easiness of the test
8. Less embarrassing
9. For peace of mind/reassurance
10. Can do the test at home/convenient
11. No reason in particular
12. Other
98. Don’t know
99. No response/Refused

If 3, 4 or 5 in Q24 skip to Q27, else continue

26. For what reasons do you say that? (DO NOT READ) Any other reasons?

1. Only people with a family history or symptoms need to do the test
2. ‘What will be, will be’/Don’t really want to know
3. Would prefer to see my doctor
4. The test sounds messy/inconvenient/complicated
5. Don’t want to do the test in my home/would rather be tested in hospital/clinic
6. Not concerned
7. Don’t like getting things like that in the mail/don’t know who sent it to me
8. Recently done an FOBT/at-home test or taken a poo sample to lab/doctor for testing
9. Do other bowel tests (e.g., colonoscopy)
10. Lack of time/too busy
11. Might not be conclusive/give the correct result
12. Might turn out to be expensive
13. No reason in particular
14. Other
98. Don’t know
99. No response/Refused

27. I’d like you to tell me on a scale of 1 to 5 how much you agree or disagree with each of these following statements about bowel cancer.
Using a scale of 1 to 5 where 1 is strongly disagree and 5 is strongly agree how much do you agree or disagree that (INSERT STATEMENT)?

- Having a test like the at-home poo test seems like more trouble than it’s worth
- It is important to check for bowel cancer even if you don’t have symptoms
- Treating bowel cancer in the early stages increases a person’s chance of survival
- At-home poo tests are necessary even if there is no family history of bowel cancer

1  Strongly disagree
2  Somewhat disagree
3
4  Somewhat agree
5  Strongly agree
6  Don’t know (DO NOT READ)
7  No response/Refused (DO NOT READ)

Closing - demographics

[Pre-amble to closing, as per Reid Research usual practice, then ask demographic questions below]

D1. Including yourself, how many people aged 50-74 live in your household?
   That is counting the respondent
   1.1
   2.2
   3.3 or more
98. Don’t know (DO NOT READ)
99. No response/Refused (DO NOT READ)
Ask D1a only if the respondent is Maori (S3=2) – regardless of any other ethnic group, including Pacific. Do not ask if D1=1 or 98 or 99. Code as 1 in D1a if D1=1 and S3=2.

D1a. Thinking now about the people aged 50-74 living in your household. Including yourself, how many would identify as Maori?

*That is counting the respondent*

1.1
2.2
3.3 or more
98. Don’t know (DO NOT READ)
99. No response/Refused (DO NOT READ)

Ask D1b only if the respondent is Pacific (S3=3-7), regardless of any other ethnic group, including Māori. Do not ask if D1=1 or 98 or 99. Code as 1 in D1b if D1=1 and S3=3-7.

D1b. Thinking now about the people aged 50-74 living in your household. Including yourself, how many would belong to a Pacific ethnic group, such as Samoan, Tongan, Cook Island Maori, or Niuean?

*That is counting the respondent*

1.1
2.2
3.3 or more
98. Don’t know (DO NOT READ)
99. No response/Refused (DO NOT READ)

D2. Could you please tell me your postcode? (allow maximum of 4 digits)

1. Record ______________________
98. Don’t know (DO NOT READ)
99. No response/Refused (DO NOT READ)

D3. Which of the following best represents your household’s total annual/yearly gross income - that’s before tax?

1. Under $15,000
2. $15,001-$20,000
3. $20,001-$25,000
4. $25,001-$40,000
5. $40,001-$60,000
6. $60,001-$100,000
7. $100,001+
98. Don’t know (DO NOT READ)
99. No response/Refused (DO NOT READ)

Thanks very much for your time today.

If you are interested in further information about bowel cancer or have any concerns at all we recommend you contact your doctor or practice nurse, or else phone the Healthline on 0800 611 116.

(If required mention the WDHB website www.BowelScreeningWaitemata.co.nz)
Closing salutation and appreciation of time / thank you as per Reid Research usual practice.
Thank you for your interest in this project. Your information will assist in understanding [Māori/Pacific people] perceptions of the Bowel Screening Pilot, being rolled out in Auckland. Please read this information before deciding whether or not to take part. If you decide to take part, we thank you. If you decide not to take part, we thank you for your time taken to consider our request.

<table>
<thead>
<tr>
<th>What is the purpose of the project?</th>
<th>Litmus (a research company) has been asked by the Ministry of Health to find out how the Bowel Screening Pilot is working in Auckland. The purpose of the project is to determine if organised bowel screening could be introduced to all of New Zealand in a way that is effective, safe and acceptable.</th>
</tr>
</thead>
<tbody>
<tr>
<td>What will I be asked to do?</td>
<td>We are talking with [Māori/Pacific people] who live in the Waitemata DHB region to complete a health survey and then explore their responses to the questions. The interview will take about 45 minutes. There are no right or wrong answers.</td>
</tr>
<tr>
<td>What types of questions will you ask me?</td>
<td>We will be asking you questions that we have developed for a phone survey that is currently being undertaken. We will then talk about your answers and the reasons for them. You do not have to answer any questions that you feel uncomfortable with.</td>
</tr>
<tr>
<td>Why have you asked me to participate?</td>
<td>We are speaking with people who potentially could be invited to participate in a bowel screening programme if it was available nationally – so that’s people aged 50-74 years.</td>
</tr>
<tr>
<td>How will the researchers ensure my personal information is confidential?</td>
<td>We will ensure your contribution is kept confidential. What you say in the health survey will be written down, with your permission. Notes will be kept securely at the Litmus Office or in secure storage for up to 2 years, and then securely destroyed. Your name and address and any other identifying information will not be used in any reporting.</td>
</tr>
<tr>
<td>Can I change my mind and withdraw from the project?</td>
<td>You may stop the interview at any time. You do not need to give a reason and there will be no disadvantage to you of any kind.</td>
</tr>
<tr>
<td>Who will be doing the pretesting?</td>
<td>The interview is being done by [name of researcher]. For more information about Litmus go to <a href="http://www.litmus.co.nz">www.litmus.co.nz</a>.</td>
</tr>
<tr>
<td>What if I have any questions?</td>
<td>If you have any questions about this project, please contact: Michele Grigg, Principal Consultant, Litmus, ph 04 473 3880 <a href="mailto:michele@litmus.co.nz">michele@litmus.co.nz</a></td>
</tr>
</tbody>
</table>
Appendix 8.6: Qualitative interviews with Māori and Pacific – consent form

Qualitative interviews – Bowel Screening Pilot Evaluation

Consent Form

I (write name) ………………………………………………………………………

of (write address) …..…………………………………

…………………………

agree to take part in a health survey, as outlined in the information provided to me. I understand that:

- I do not have to take part in an interview.
- I can choose not to answer any questions I do not wish to answer (without saying why).
- I can stop and leave the interview at any time without saying why I no longer want to take part.
- Litmus will keep my information confidential. I will not be named in any report.
- My responses will be written down with my permission.
- After the health survey, I understand that we will be discussing some of my response to the questions.
- Notes and summaries will be stored securely at Litmus and will not identify me by name. They will be kept for two years and then securely destroyed.

I have read this consent form, and have been given the opportunity to ask questions. I give my consent to participate in this project.

Signature: __________________________

Date: _________________