Evaluation of the Bowel Screening Pilot – 2013 Follow-up WDHB Population Survey Findings

Ministry of Health

Manatū Hauora

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Preface

This report has been prepared for the Ministry of Health by Liz Smith and Michele Grigg from Litmus Limited. We acknowledge Reid Research Services Limited (for conducting the telephone surveys). We also sincerely thank James Reilly from Statistical Insights Limited for his work in preparing the survey data for analysis.

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Please contact 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. Baseline surveys were conducted in November-–December 2011; one with 50–74 year olds (the eligible screening population) living within WDHB and one with 50–74 year olds living outside of WDHB. This report presents findings from a follow-up survey of WDHB residents, undertaken in October 2013. The purpose of this follow-up survey is to identify changes in awareness, attitudes, knowledge and involvement with the BSP over time, within the BSP area.

1.2 Methodology

The baseline WDHB and national survey were conducted in late 2011, before promotion of the BSP became widespread. The follow-up survey of WDHB residents was conducted in late 2013, almost two years following the full launch of the BSP in that area. Questionnaires for all three of the surveys were developed incorporating advice from a range of experts. They were also extensively pretested and piloted with members of the public (living outside WDHB). The 2013 WDHB follow-up survey is largely similar to the 2011 survey, to ensure consistency in measurement over time.

All of the surveys were administered using computer-assisted telephone interviewing (CATI). The 2013 survey of WDHB residents was conducted over a three-week period in October 2013. The two 2011 surveys were conducted over a three-week period in November-–December 2011.

As with the 2011 survey, a main sample of 500 respondents was interviewed, plus a booster sample of 200 respondents (100 Māori and 100 Pacific). Each of the main and booster samples comprised a mix of randomly selected respondents (from the White Pages) and a sample recontacted from the 2011 WDHB survey (who agreed to be recontacted and for whom a name and phone number were available). 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 baseline and follow-up WDHB surveys provide further detail on a topic in which little was previously known in New Zealand. Key findings from the baseline and follow-up surveys of WDHB residents are as follows.

- There is reasonable awareness of bowel cancer prevalence for men in New Zealand; although awareness is unchanged from 2011. While recognition of bowel cancer as

the second most commonly diagnosed cancer for women is increasing, awareness continues to be relatively low as more respondents continue to perceive cervical cancer as the second commonly diagnosed cancer. Māori have lower awareness of bowel cancer prevalence for men and women.

- Since 2011, awareness that a family history and a diet low in fibre are risk factors for bowel cancer has statistically significantly increased. There is lower awareness of the risks related to obesity, little moderate exercise, eating red meat and few fruit and veg, and, for some, disagreement these are bowel cancer risks. Māori, Pacific respondents and those with a low income tend to be less aware of the risk factors, particularly the link in having a close family member with bowel cancer.

- Confidence in the ability to notice bowel cancer symptoms has increased, although Pacific respondents are less confident they will recognise symptoms. Reflecting these changes is an increase in the unprompted awareness of bowel cancer symptoms particularly blood in bowel motions and changes in toilet habits. Māori and Pacific respondents are less aware of these symptoms at an unprompted level compared to the Other ethnic group. When prompted, some Pacific respondents said these are not symptoms of bowel cancer.

- Compared to 2011, there is no change in respondents' perceived risk of developing bowel cancer (one in 10).

- Since the launch of the BSP, there has been a statistically significant increase in unprompted and prompted awareness of the BSP iFOBT and a decline in unprompted mention of colonoscopy. The decline in unprompted mention of colonoscopy may reflect the prominence of the BSP and its use of the iFOBT.

- There is a statistically significant increase in the unprompted mention of having done the WDHB BSP bowel cancer test since 2011 reflecting its launch in 2012. Overall there is no change in the proportion of respondents who report their doctor has suggested they do a test for bowel cancer. Although there is a statistically significant increase in Pacific respondents reporting their doctor has suggested they do a test for bowel cancer.

- Perceptions of the FOBT are changing with a statistically significant increase in disagreement that the FOBT is embarrassing, painful, messy, inconvenient and inaccurate. Pacific respondents are more likely to perceive the FOBT as inconvenient, embarrassing, inaccurate and painful than the Other group. Some respondents continue to be unsure about the accuracy of the FOBT.

- In contrast, respondents are less likely to consider colonoscopies to be inaccurate, but more likely to view them as embarrassing, painful and inconvenient. Pacific respondents are more likely to perceive colonoscopies as inaccurate, messy and painful.

- Overall nearly all respondents agree that early treatment of bowel cancer will increase the odds of survival and that it is important to check for bowel cancer without the presence of symptoms. Respondents agree that at-home FOBTs are necessary even for those without a family history of bowel cancer, and disagree they are more trouble than they are worth. However, one quarter of Pacific respondents agree they are too much trouble.

- Awareness of the BSP is very high with nine in ten respondents aware of the Pilot. While awareness of the BSP has increased for Māori and Pacific respondents, their awareness remains statistically significantly lower than the Other ethnic group.

- Nearly three quarters of respondents had received the BSP letter and kit, while two in ten had not. Of those who had received a BSP kit, three quarters said they had completed and returned it. Based on the total sample this equates to half of respondents participating in the BSP, similar to the BSP Register participation rate of 54%. Reasons for taking part reflect the importance of health checks, wanting to know their bowel cancer status and for peace of mind.

- Two thirds of those respondents who had not received a BSP kit self-reported they would be very likely to take part in a bowel cancer screening programme if they received an iFOBT kit in the mail. Māori and Pacific people were less likely to agree they would take part than the Other group. Those not wanting to take part cite a preference for seeing their doctor, a lack of concern, a laissez faire attitude of what will be will be and that they do other bowel tests (e.g. colonoscopy). For Māori and Pacific, a reluctance to do the test at home and the perception the FOBT is messy was also mentioned.

1.4 Implications for the Bowel Screening Pilot

Results from the baseline and first two-year follow-up survey in WDHB provide information to inform ongoing development of the BSP. The following implications have been identified for ongoing BSP operations.

- While awareness, knowledge and attitudes to bowel cancer and bowel cancer screening has increased since the launch of the BSP, ongoing health promotion on bowel cancer prevalence, risk factors and the breath of symptoms is needed particularly for Pacific people and Māori.

- The positive predisposition towards doing the at-home iFOBT test as part of a bowel screening programme noted in 2011 continues. To increase participation in the BSP, requires all eligible participants to receive the BSP kit and promotions are needed that prompt people act on their intent.

- Pacific people are emerging as the underscreened population. Health promotion and community awareness raising activities are needed to support their engagement with the BSP and to make an informed consent about whether or not to take part. Particular focus is needed on reassuring Pacific people about the bowel screening tests both the iFOBT and colonoscopy to address concerns about embarrassment, inconvenience, mess and pain.

- Health promotion and community awareness raising activities are needed to further enhance Māori participation.

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. 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.[1] Included in these are a set of telephone population surveys. The population surveys inform a number of the evaluation questions.[2] Baseline population surveys were conducted in November–December 2011; one with 50–74 year olds (the eligible screening population) living within WDHB and one with 50–74 year olds living outside of WDHB (hereafter referred to as the 'National' survey). This report presents findings from a follow-up survey of WDHB residents, undertaken in October 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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1 Refer to the *Evaluation Plan for the Bowel Screening Pilot 2011–2016* (Litmus, 2011) for details of evaluation activities.

2 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 overall 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. The 2011 WDHB survey was designed to collect a baseline assessment of awareness and knowledge of bowel cancer and the BSP. This survey was conducted before promotions of the BSP became widespread. The purpose of the 2013 WDHB follow-up survey is to enable changes in awareness, attitudes and knowledge to be identified over time within the BSP area, following the first 18 months of the BSP's operation.

All of the surveys play an important role in informing decisions for a possible national roll-out of a bowel screening programme. Record linkage of survey data with the BSP Programme Register (the 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.[3]

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 was taken. Section 2.6 of the BSP Evaluation Plan[4] documents the implications of not conducting a follow-up national population survey.

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

[4] Litmus Limited (2011) *Evaluation Plan for the Bowel Screening Pilot 2011–2016*.

3. Survey methodology

This section outlines the:

- process used to design and test 2011 and 2013 questionnaires
- survey design of the baseline questionnaires
- sample design and sampling approach, including sample management
- survey weighting processes
- survey response rates and representativeness
- sample description
- analysis notes
- methodological limitations.

3.1 Questionnaire design, pretesting and piloting

The content of the 2011 questionnaires was developed following review of overseas literature reporting on surveys for bowel screening programmes and assessments of bowel cancer screening.[5] The WDHB and national surveys were developed to ensure consistency of cross-survey comparisons. The report of findings from those surveys details the process used to test and pilot the questionnaires before they went into the field (Litmus 2012).

As with the 2011 surveys, the 2013 survey was conducted by Reid Research Services Limited on behalf of Litmus. The 2013 questionnaire was developed with only small modifications to the 2011 WDHB questionnaire to minimise the potential effect the change could have on the comparisons between the two surveys:

- For those respondents who agreed in 2011 to be reinterviewed in 2013, the survey introduction was modified to reflect their agreement to be re-contacted (refer section 3.2).
- Updating of dates to reflect the time period (i.e. questions measuring whether respondents had screening tests in the last two years – 2012 or 2013).
- Question 18a was added to find out where respondents had heard or seen any information about the BSP. WDHB requested the question to inform their promotion of the BSP.
- New codes were added on reasons for not intending to complete and return the BSP iFOBT kit reflecting findings from qualitative interviews with eligible participants who do not return the kit (Litmus 2013). These codes were not read out.
- Question 22a was added to identify reasons for completing the BSP kit.
- Question 24 and 24a were added to explore whether participants with a positive iFOBT had received their results from their general practice.

[5] Australian Institute of Health and Welfare (2005), Chang et al (2010), Christou and Thompson (2010), Fisher et al (2009), University College of London and Cancer Research United Kingdom (2011), Wolf et al (2005).

- Two new statements were added to question 38 to measure respondents' preference for receiving positive iFOBT results from their GP or practice nurse versus someone else from the screening programme.

All respondents to the 2013 survey were offered the chance to enter a prize draw for one of ten $50 Warehouse vouchers. Respondents were also asked if they would consent to being recontacted for a further follow-up survey in 2015 (should one take place).

As in 2011, 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 2013 questionnaire 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 7–27 October 2013 using computer-assisted telephone interviewing (CATI) technology. The average interview duration was 19.2 minutes.

The 2013 and 2011 WDHB questionnaires are contained in the Appendices.

3.2 Baseline survey (2011) sample design and sampling approach

For the 2011 WDHB survey, a randomised sample of 500 eligible respondents aged 50–74 years living 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 (e.g. by age, gender and ethnicity) due to the costs of finding these sub-populations using randomised digit dialling. Weighting was applied on completion of the survey. The WDHB main survey sample (n=500) was selected through randomised digit dialling and included only telephone prefixes falling within the WDHB area (i.e. previous Waitakere City, previous North Shore City and Rodney Regional Council areas).

The 2011 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 telephone directories, ensuring a spread of telephone prefixes. The manual selection methodology incorporated further randomisation by selecting a random 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. Further booster samples were generated using telephone prefixes based on 2006 census data in areas that had a high component of high Māori/Pacific populations.

Ethnicity screening[6] 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.

6 The following screening question was used: S6. Which ethnic group/s do you belong to? (code all that apply): 1. New Zealand European/Pākehā/Kiwi/New Zealander; 2. Māori; 3. Samoan; 4. Cook Island Māori; 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-Screen Out (Random Booster only).

All respondents from the baseline 2011 WDHB survey (main and booster samples) were asked for their consent to be recontacted with the intention that a portion would be invited to participate in the follow-up 2013 survey. This enabled collection of longitudinal data and an examination of changing attitudes and behaviours over time. It was planned that the sample for the follow-up 2013 WDHB survey would be composed of a portion of previous respondents and a fresh sample from the eligible WDHB population.

Further methodological details for the 2011 surveys, along with the survey findings, can be found in the 2011 survey report to the MoH (Litmus 2012): http://www.health.govt.nz/publication/evaluation-bowel-screening-pilot.

3.3 Follow-up survey (2013) sample design and sampling approach

The final survey and sample design was determined prior to the 2011 surveys, following discussion with the MoH about a number of options for the best possible way of collecting the data, while ensuring survey objectives were met. Details of considerations are outlined in the report of the 2011 survey findings (Litmus 2012).

The 2013 survey also employed a CATI survey method. As with the 2011 survey, a main sample of 500 respondents was interviewed, plus booster samples of 100 Māori and 100 Pacific respondents to ensure adequate numbers of Māori and Pacific in the resulting overall sample. This resulted in a total survey sample of 700 respondents. The composition of each of the two samples was a mixture of randomly selected respondents and a sample of respondents who were recontacted from the 2011 WDHB survey (sampled from those who agreed at the end of that survey to be recontacted and for whom name and contact phone number were available).

The main reason for recontacting a proportion of 2011 respondents in 2013 is that this provides a more reliable measure of any changes in knowledge and attitudes. These measures of change are affected both by real shifts in individuals' attitudes and by random variation introduced by sample selection. Recontacting a proportion of respondents from 2011 reduces the second source of variation, thus making measures of change more reliable than drawing a fresh sample.

Main sample

Half of the 500 main sample respondents were randomly selected from the Telecom White Pages (n=250). The other half of the main sample (n=250) was sourced from a randomly selected sample of respondents to the 2011 WDHB survey (who agreed to be recontacted and for whom name and contact phone number were available).

Table 1 lists the numbers called and completed for each of the two samples. Details of the sampling approach used for each are outlined below.

Table 1: Total numbers called and interviews completed, Waitemata District Health Board survey, main sample (randomly selected and recontacted), 2013

Sample	Numbers called (includes disconnects)[7]	Completed interviews
Randomly selected	2717	250
Recontacted	430	250

Source: Reid Research Services Limited, 2013

Randomly selected sample

These interviews (n=250) were completed with a random sample of people who fit the eligibility criteria for the survey: 50–74 years, New Zealand residents, telephone numbers with a prefix from within the WDHB area (i.e. old Waitakere City, old North Shore City and Rodney Regional Council areas).

Sample was manually selected from the White Pages, ensuring a spread of phone prefixes within the WDHB area. The total number of pages containing qualifying numbers were counted and based on the total required sample, the 'nth' number was selected every 'nth' page. The generated numbers were checked and cleaned for any duplicate numbers, and stored in an Excel file which was randomised. VOXCO software further randomised this sample when it was imported for calling.

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.

People who had previously been diagnosed with bowel cancer and therefore not eligible to participate in the BSP were asked a limited number of questions only. People who were diagnosed with bowel cancer by the BSP (three respondents) were asked as appropriate the full suite of questions. Interviewers were briefed on the sensitivity needed interviewing people diagnosed with bowel cancer and informed that if any reluctance or distress was noted to seek the respondent's consent on whether to continue or stop the interview.

Minimum (40%) and maximum (60%) gender quotas were applied. No other quotas were applied (e.g. by 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).

Recontacted sample

These interviews (n=250) were completed from a sample sourced from the database of people who agreed to be recontacted from the WDHB 2011 baseline survey.[8] The interviews were completed from a sample base of 430 possible contacts – for whom a name and contact phone number were available. Respondents were re-asked the following questions from the 2011 survey:

[7] 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).

[8] Note that 86% of 2011 WDHB survey respondents agreed to be recontacted and provided contact details to Reid Research Services Limited.

- if they still lived in the WDHB area
- age group
- ethnicity
- gender (which was recorded, not asked).

One respondent indicated they had moved out of the WDHB area. Fourteen respondents were 75 years or older when they were recontacted (and were interviewed).[9]

As in 2011, minimum (40%) and maximum (60%) gender quotas were applied. No other quotas were applied (e.g. by ethnicity). Weighting was applied on completion of the survey (see below for further details).

Booster samples

As with the main sample, the 2013 booster sample (n=200) was selected through both random selection, and through recontacting a sample of 2011 WDHB survey respondents. Table 2 lists the numbers called and completed for each of the two booster samples. Details of the sampling approach used for each are outlined below.

Table 2: Total numbers called and interviews completed, Waitemata District Health Board survey, booster sample (randomly selected and recontacted), 2013

Sample	Numbers called (includes disconnects)[10]	Completed interviews
Randomly selected	11553	122 (59 Māori and 63 Pacific)
Recontacted	174	78 (41 Māori and 37 Pacific)

Source: Reid Research Services Limited, 2013

Randomly selected booster sample

These interviews (n=122) were completed with a random sample of people who fit the eligibility criteria for the survey: 50–74 years, New Zealand residents, telephone numbers with a prefix from within the WDHB area (i.e. old Waitakere City, old North Shore City and Rodney Regional Council areas) and who identified as Māori and/or Pacific ethnicity.

This sample targeted suburbs in the WDHB area known to have high proportion of Pacific/ Māori populations. The sample was manually selected from the White Pages, ensuring a spread of phone prefixes. The total number of pages containing qualifying numbers were counted and based on the total required sample, the 'nth' number was selected every 'nth' page. The generated numbers were checked and cleaned for any duplicate numbers, and stored in an Excel file which was randomised. VOXCO software further randomised this sample when it was imported for calling.

[9] When these people undertook the baseline WDHB survey in 2011 they were 74 years old and were therefore prioritised by the BSP to receive a kit in the first year of the pilot – they were therefore eligible at that point in time.

[10] 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).

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.

Minimum and maximum ethnicity quotas were applied. No other quotas were applied. Weighting was applied on completion of the survey (see below for further details).

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 occurred with one respondent in the randomly selected booster sample.

People who had previously been diagnosed with bowel cancer (i.e. not by the BSP) were asked a limited number of questions only.

Recontacted booster sample

These interviews (n=78) were completed from a sample sourced from the database of people who agreed to be recontacted from the WDHB 2011 baseline survey. The interviews were completed from a sample base of 174 possible contacts – for whom a name and contact telephone number were available and they had identified as being of Māori and/or Pacific ethnicity. Forty-one interviews were completed with people identifying as Māori ethnicity, from a sample base of 87 possible contacts. Thirty-seven interviews were completed with people identifying as Pacific ethnicity, from a sample base of 87 possible contacts.

Respondents were re-asked the following questions from the 2011 survey:

- if they still lived in the WDHB area
- age group
- ethnicity
- gender (which was recorded, not asked).

None of the respondents interviewed had moved out of the WDHB area. Two respondents were 75 years or older when they were recontacted (and were interviewed).[11]

Minimum and maximum ethnicity quotas were applied. No other quotas were applied. Weighting was applied on completion of the survey (see below for further details).

Sample management

The four separate files (randomly selected main, recontacted main, randomly selected booster, recontacted booster) were imported into VOXCO software to enable the sample to be separated and managed independently. The four files were worked simultaneously. Sample was then scattered by VOXCO to further randomise the sample.

[11] When these people undertook the baseline WDHB survey in 2011 they were 74 years old and were therefore prioritised by the BSP to receive a kit in the first year of the pilot – they were therefore eligible at that point in time.

For the numbers that were filed 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 VOXCO program prioritised the return of 'no contact' sample, before issuing any new 'virgin' sample. For example, a 'no answer' was delayed by three hours and then reissued to the next available interviewer, an engaged number was phoned again 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.

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. This ensures that population sub-groups are represented in the correct proportions in the survey results. Individual respondents in over-sampled groups, such as Māori and Pacific, generally need to receive lower weights than respondents in under-sampled groups.

Inverse probability weights were applied to adjust for the selection of one eligible person from each household. Booster samples were combined, with the main samples using Wells' method.[12]

The weights were also adjusted to make good use of the data from reinterviewed respondents. The appropriate adjustments depend on the nature of the analysis being performed, so three different weights were calculated to enable the various types of analyses required. For comparisons of 2013 results against 2011 results, the weights of non-recontacted respondents were reduced by 38% before post-stratification. This figure (0.38) is the average correlation observed between 2011 and 2013 responses (from reinterviewed respondents) across a wide range of questions. This follows the general approach described by Kish,[13] and was done separately for each of the 2011 and 2013 datasets. Data from the 2011 survey was reweighted using Kish's approach to provide more reliable comparisons with 2013.

Some analyses by ethnicity were based on the larger sample obtained by combining the 2011 and 2013 data. For these analyses, the weights of non-recontacted respondents were increased by 46% (for Māori) or 35% (for Pacific and Other ethnic group) before post-stratification, again following Kish. These figures were the average correlations observed between 2011 and 2013 responses within each broad ethnic group (Māori, Pacific, and the Other ethnic group).

For direct tabulation of 2011 responses against 2013 responses, using data from recontacted respondents only, the inverse probability Wells weights were post-stratified without further adjustment.

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[12] For details, see Wells (1998).

[13] For details, see section 12.4 in *Survey Sampling* by Kish (1965).

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.[14]

The respondents aged 75+ in the 2013 survey were not included directly in the post-stratification. Their weights were instead multiplied by the average post-stratification adjustment factor for 70-74 year olds in the same broad ethnic group.

The maximum margin of error for weighted percentages on the full sample of 700 eligible respondents in the WDHB region was ±5.1%, based on a design effect of 1.87.[15,16]

3.4 Response rates and representativeness

Participation in the survey was voluntary, and informed consent was obtained before participation. Response rates for each survey are shown in Table 3.

Table 3: Achieved response rates, Waitemata District Health Board randomly selected main and booster samples, and main and booster recontact sample 2013 compared to 2011 response rates

Samples		Survey 2013 (%)	Survey 2011 (%)
Recontact samples	Main sample	58.1	-
	Booster sample	47.3	-
Randomly selected samples	Main sample	32.0	22.4
	Booster sample	10.1	6.6

The response rates for the randomly selected samples were calculated following the Standard Definitions published by the American Association for Public Opinion Research.[17] 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).

[14] Walker and Martin (2007).

[15] 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.

[16] 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 1.87 used is fairly conservative, being the 90th percentile of design effects calculated for each item gathered in the survey.

[17] American Association for Public Opinion Research (2011).

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

Response rate = 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 (i.e. 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 e2 is estimated as the other eligibility rate e1 multiplied by the proportion of residential telephone numbers among numbers whose residential status could be determined.

The calculations for the recontact samples are simpler, in that there is no household selection stage and almost all the selected people are eligible. The response rate formula here is as follows:

Response rate = I/(I + (P+R+O) + e*NC))

The components used to calculate the 2013 response rates are listed in Table 4.

Table 4: Components of the response rate, Waitemata District Health Board randomly selected main and booster samples, and main and booster recontact sample 2013, and response rate for random main and booster samples in 2011

	Recontact sample		Randomly selected sample	
Response rate component	**Main**	**Booster**	**Main**	**Booster**
I = Complete interviews	250	78	250	122
P = Partial interviews	3	3	0	0
R = Refusals	12	17	96	253
NC = Non-contact	128	54	96	225
NE = Ineligible	0	6	1539	8538
O = Other	37	16	95	295
Unknown residential status (UH)	-	-	92	210
Unknown eligibility (UO)	-	-	549	1910
Total	430	174	2717	11553
Eligibility rate (e)	100.0%	94.2%	-	-
Eligibility rate (e1)	-	-	39.6%	15.2%
Eligibility rate (e2)	-	-	28.6%	10.4%
Response rate 2013	**58.1%**	**47.3%**	**32.0%**	**10.1%**
Response rate 2011	-	-	*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.

Compared to 2011, the response rate for the WDHB survey has increased for the randomly selected samples by 9.6% for the main sample and 3.5% for the booster sample. As noted a small prize draw was used to encourage people to complete the survey. The increased response rates may reflect other factors such as survey timing (in 2013 the survey was undertaken in October, compared to mid-November to mid-December in 2011), and increasing awareness of cancer and screening for cancer due to BSP promotional activities in WDHB.

Feedback from Reid Research Services Limited is that there are perhaps several contributing factors influencing the reasonable, but not exceptional response rates achieved in the surveys. 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.

- 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.
- 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.

Response rates are one indicator of survey quality. Their importance derives from the possibility that any difference between the responders and non-responders may bias the results. 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 data from non-respondents has not been collected, 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 the 2013 WDHB survey, there was a noticeable shortfall among the younger cohort eligible to be interviewed (e.g. 39% aged 50–59 years old in WDHB, versus 54% in the Census). There were also shortfalls among Māori, Pacific people and males, although these were 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 5 shows the weighted sample for each of the two WDHB surveys by key demographic variables.

Table 5: Weighted sample by key demographic variables, Waitemata District Health Board, 2011 and 2013

	2011 Waitemata District Health Board survey		2013 Waitemata District Health Board survey[18]	
Variable	**n**	**%[19]**	**n**	**%[20]**
Gender				
Male	341	48.7	341	48.7
Female	359	51.3	359	51.3

[18] The numbers add to 699 for age, ethnicity and income due to rounding in weighting the data.

[19] Percentages may not add to 100% due to rounding.

[20] Percentages may not add to 100% due to rounding.

Variable	2011 Waitemata District Health Board survey		2013 Waitemata District Health Board survey[18]	
	n	%[19]	n	%[20]
Age group				
50–54	197	28.0	192	27.4
55–59	178	25.5	176	25.1
60–64	137	19.4	134	19.1
65–69	106	15.3	105	15.0
70–74	82	11.7	80	11.4
75 plus	0	0	12	1.7
Ethnicity[21]				
Māori	30	4.3	30	4.3
Pacific	25	3.6	25	3.6
Asian	29	4.1	26	3.7
Other	616	88.0	618	88.3
Household income				
<$25,000	71	10.1	77	11.0
$25,001-$40,000	77	11.0	61	8.7
$40,001–$60,000	90	12.8	95	13.5
$60,001–$100,000	133	19.0	159	22.7
>$100,001	185	26.4	194	27.7
Don't know	39	5.6	44	6.3
No response/refused	105	15.0	69	9.8
Family history of bowel cancer[22, 23]				
Yes	162	23.1	158	22.5
No	529	75.5	523	74.7
Don't know/can't remember	3	0.4	12	1.7
No response/refused	1	0.1	0	0
TOTAL	**700**	**100.0**	**700**	**100.0**

[21] Prioritised ethnicity.

[22] 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).

[23] Bases are less than n=700 for family history of bowel cancer, as n=5 in 2011 and n=7 in 2013 who have previously been diagnosed with bowel cancer (not through the BSP) were not asked this question.

3.6 Analysis

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

- A comparison of results from the 2011 and 2013 WDHB 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[24] and allowing for the average correlation in the recontacted sample used in Kish's weighting approach. 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 people differ from the Other ethnic group (i.e. non-Māori and non-Pacific). However, moderate differences may be obscured by random sampling variation.
- Information is reported in the text for key sub-groups (e.g. ethnicity, age group, gender, household income and family history of bowel cancer) where differences within groups are statistically significant. Differences between key sub-groups that are statistically significant are denoted on the graphs by an asterisk (*).
- Responses from the 2011 and 2013 recontact samples have been tabulated and presented in the text to explore individual-level changes in knowledge and attitudes over the last 18 months.
- The 2011 and 2013 samples for Māori, Pacific and the Other ethnic groups were combined to enable more power to compare differences across these groups. Differences between percentages were tested at the 95% confidence level using a t-test, adjusted using a conservative design effect for each group and allowing for the average correlation in the recontacted sample used in Kish's weighting approach. Statistically significant differences for each group are noted as such in the text.
- All data presented is weighted (refer section 3.3).
- 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 questionnaire (refer to the questionnaire in the Appendices for details). The bases shown below the graphs are the actual numbers of people interviewed (i.e. 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 the Other ethnic (which comprises mainly New Zealand European and Other European but excludes Māori, Pacific and Asian). Prioritisation was conducted using Statistics New Zealand's classification for ethnicity output.[25]

[24] The design effects used were 1.67 for the 2011 survey and 1.87 for the 2013 survey. These allow 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 values used here are the 90th percentile of design effects calculated for each item gathered in the survey.

[25] Statistics New Zealand (2009).

3.7 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 critical information. The 2011 surveys collected baseline measures of knowledge, awareness and attitudes before the launch of the BSP in early 2012. This 2013 follow-up survey in WDHB allows tracking of 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 the 2011 baseline and the follow-up 2013 WDHB survey reported here) 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 from each of the Māori and Pacific ethnic groups. While the survey results have a key role in informing the evaluation, the small sample sizes restrict the amount of sub-group analysis.

While the randomly selected general samples were identified using random digit dialling, the randomly selected booster samples targeted telephone number prefixes with high Māori/Pacific populations, 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 randomly selected 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 WDHB surveys (using a conservative measure) were reasonable, but not exceptional.

Survey length was restricted and only closed questions used. In-depth qualitative evaluation activities with the eligible population provide important information to ensure more detailed understanding about the responses received from the population surveys.[26]

We have no evidence to indicate the surveys provide biased estimates. Findings from the two baseline surveys and this follow-up survey 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.

[26] See Litmus Limited (2011) for the full set of planned evaluation activities.

4. Findings

This section presents findings from the two WDHB telephone surveys (baseline and follow-up):

- 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 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
- self-reported levels of participation in WDHB's BSP.

Key summary points are presented in boxes throughout this section.

In addition, differences *between the baseline and follow-up WDHB 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 is only reported in the text where differences *within these groups* are statistically significant, and are denoted on the graphs with an asterisk (*).

Māori, Pacific and the 'Other ethnic group' referred to in the text and graphs are based on prioritised ethnicity. The 'Other ethnic group' includes those people not identifying as Māori, Pacific or Asian.

The combined 2011 and 2013 Māori, Pacific and Other group data are referred to as relevant as the 'combined 2011 and 2013 ethnic sub-groups'. The Other combined group in this case excludes respondents identifying as Māori and Pacific and includes Asian.

The '2011 and 2013 recontact sample' is referred as appropriate to demonstrate individual-level changes in knowledge and attitudes.

The abbreviation 'FOBT' is used to refer to awareness and attitudes to the test per se, and 'iFOBT' is used when referring to the BSP test.

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

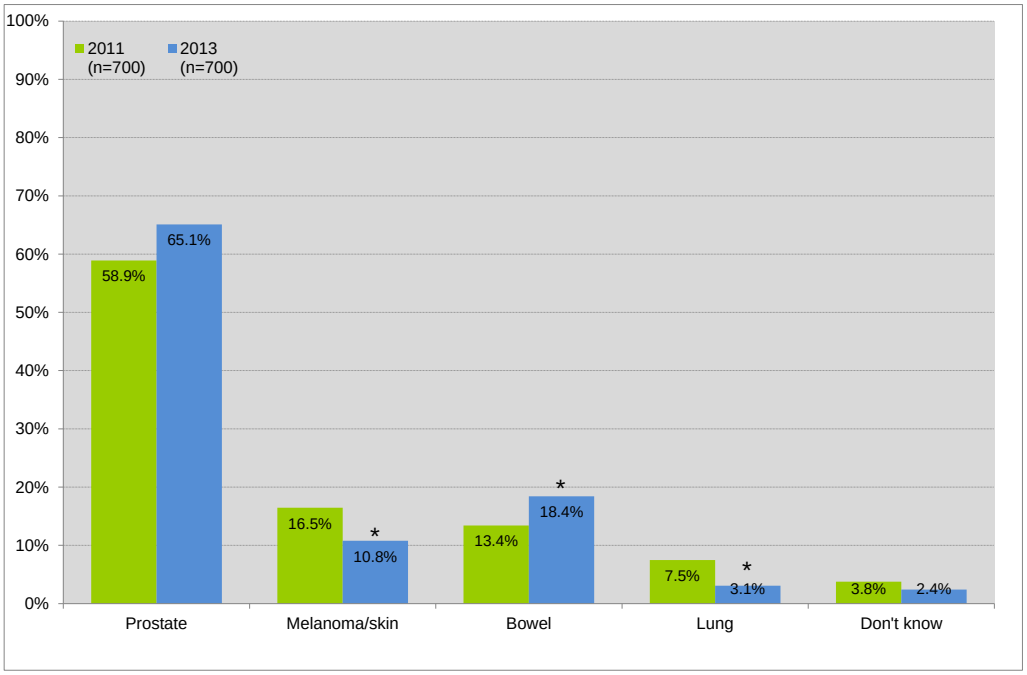
Bowel cancer has the second highest incidence for both men and women in New Zealand, following prostate cancer for men and breast cancer for women.[27] Among Māori, however, bowel cancer is the third most diagnosed cancer, lung cancer has the highest incidence rate.[28]

In the 2013 survey, prostate cancer continues to be perceived as the most commonly diagnosed cancer for men in New Zealand (indicated by 65% of WDHB respondents in 2013 and 59% in 2011) (Figure 1).[29]

Mention of bowel cancer as the most commonly diagnosed cancer among men has significantly increased from 13% in 2011 to 18% in 2013. The proportion of Māori who perceive bowel cancer as the most commonly diagnosed cancer among men has statistically significantly increased from 5% in 2011 to 24% in 2013[30]. Those who have been recently screened are more likely[31] to perceive bowel cancer as the most commonly diagnosed cancer among men than those who have not been recently screened (20% compared to 8%).

Compared to 2011, there is a significant decrease in the mention of melanoma and lung cancer as the most commonly diagnosed cancer amongst men.

Figure 1: Perception of the most commonly diagnosed cancer among New Zealand men, Waitemata District Health Board, 2011 and 2013



Base: All respondents
Source: BSP Evaluation telephone surveys, 2011 and 2013

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27 http://www.health.govt.nz/publication/cancer-new-registrations-and-deaths-2010 accessed 7 January 2014.

28 Ibid.

29 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.

30 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).

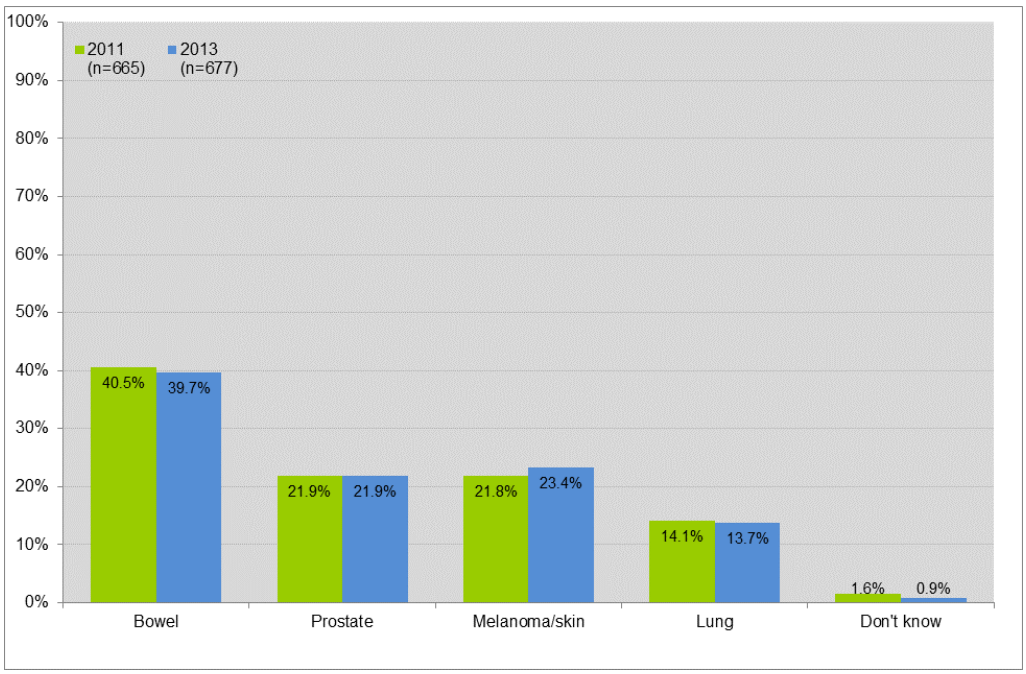
31 More likely also refers to statistically significant increases.

Consistent with the 2011 survey findings, bowel cancer is often thought to be the second most commonly diagnosed cancer among men (41% in 2011 and 40% in 2013), followed by melanoma/ skin cancer and prostate cancer (Figure 2).

Analysis of the combined 2011 and 2013 ethnic sub-groups highlights that Māori respondents (31%) are less likely than the Other ethnic group (39%) to say that bowel cancer is second most commonly diagnosed cancer among men. No statistically significant differences are noted for Pacific respondents with 40% mention of bowel cancer.

In 2013, those aware of the FOBT (41%) were more likely to mention bowel cancer as the second most commonly diagnosed cancer among men than those not aware of the FOBT (26%).

Figure 2: Perception of the second most commonly diagnosed cancer among New Zealand men, Waitemata District Health Board, 2011 and 2013



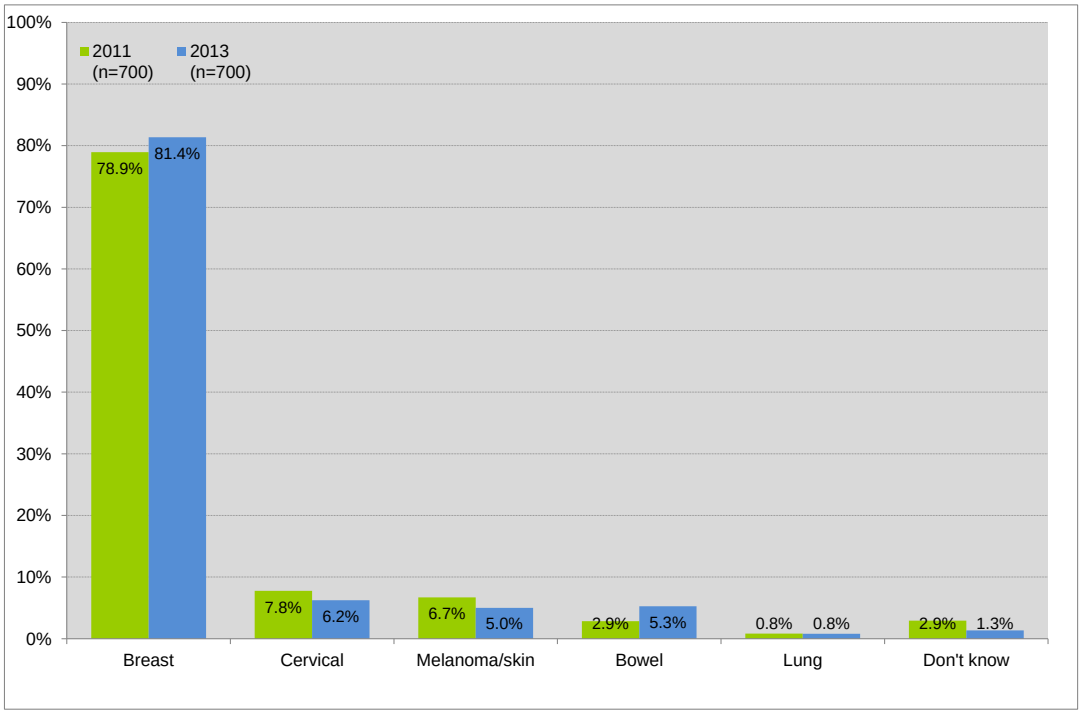
Base: All respondents not answering 'don't know' for most common cancer
Source: BSP Evaluation telephone surveys, 2011 and 2013

For women, breast cancer continues to be mentioned by the majority of respondents as the most commonly diagnosed cancer (81% in 2013 and 79% in 2011) (Figure 3). However, cervical cancer continues to be perceived to be the second most commonly diagnosed cancer among women, ranked as such by 41% of WDHB respondents in 2013 and 43% in 2011 (Figure 4).

Compared to 2011, mention of bowel cancer as the second most commonly diagnosed cancer among women has statistically significantly increased from 13% in 2011 to 21% in 2013. However, at 21% of mentions, awareness of the prevalence of bowel cancer risk for women remains relatively low.

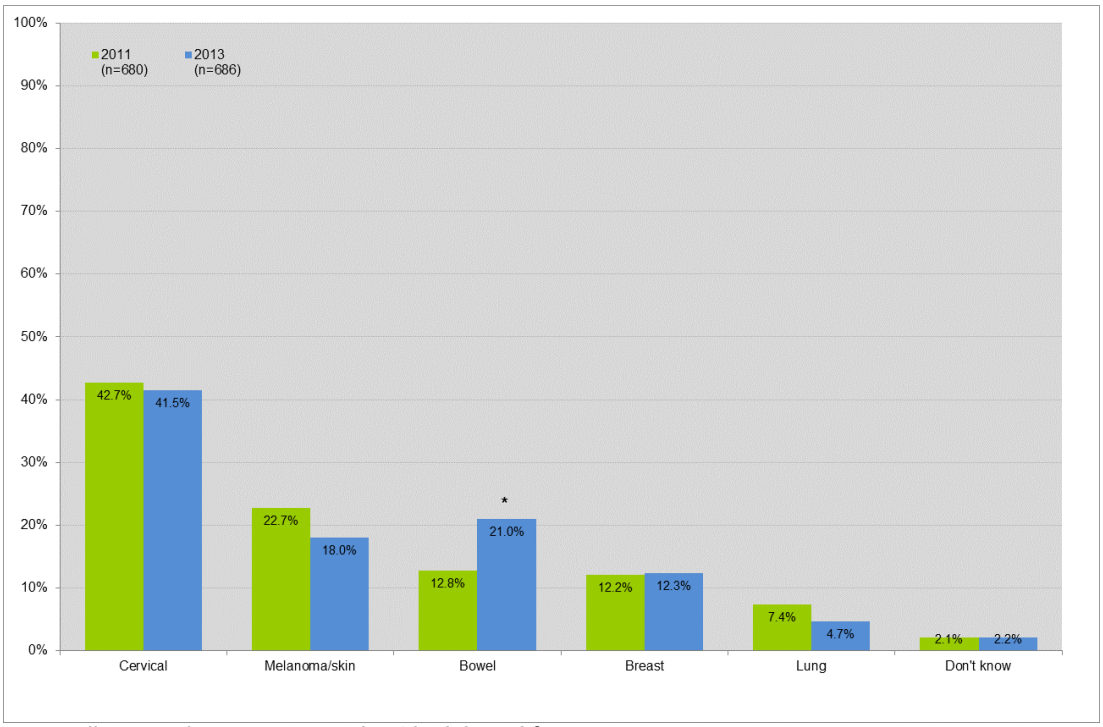
Māori respondents (10%) are less likely than the Other ethnic group (21%) to say that bowel cancer is the second most commonly diagnosed cancer among women. No statistically significant differences are noted for Pacific respondents (16% mention bowel cancer).

Figure 3: Perception of the most commonly diagnosed cancer among New Zealand women, Waitemata District Health Board, 2011 and 2013



Base: All respondents
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 4: Perception of the second most commonly diagnosed cancer among New Zealand women, Waitemata District Health Board, 2011 and 2013



Base: All respondents not answering 'don't know' for most common cancer
Source: BSP Evaluation telephone surveys, 2011 and 2013

Summary: There is reasonable awareness of bowel cancer prevalence for men in New Zealand; awareness is unchanged from 2011. While recognition of bowel cancer as the second most commonly diagnosed cancer for women is increasing, awareness continues to be relatively low as more respondents continue to perceive cervical cancer as the second commonly diagnosed cancer. In 2013, Māori have lower awareness of bowel cancer prevalence for men and women compared to the Other ethnic group. There is no difference in awareness of bowel cancer prevalence by Pacific respondents.

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.

Most recognised risk factors

In 2013, having a close relative who had bowel cancer (73% strongly agreed or somewhat agreed) (Figure 5) and having a diet low in fibre (72%) (Figure 6) had the highest level of agreement as risk factors for increasing the risk of bowel cancer. Compared to 2011, agreement with having a close relative who had bowel cancer as a risk factor has increased (from 65% strongly agree or somewhat agree in 2011 to 73% in 2013) (Figure 10).

Analysis of the recontact sample shows a dynamic shift in opinion from disagree to agree that a diet low in fibre increases the risk of bowel cancer, and a general upward shift in agreement that having a close relative who has had bowel cancer increases the risk of cancer.

Being overweight is acknowledged by 58% (strongly agree or somewhat agree) as a bowel cancer risk factor (Figure 7). Recontact data analysis shows amongst individuals there is a small shift in attitude from neutral and disagree ratings to agree with this statement.

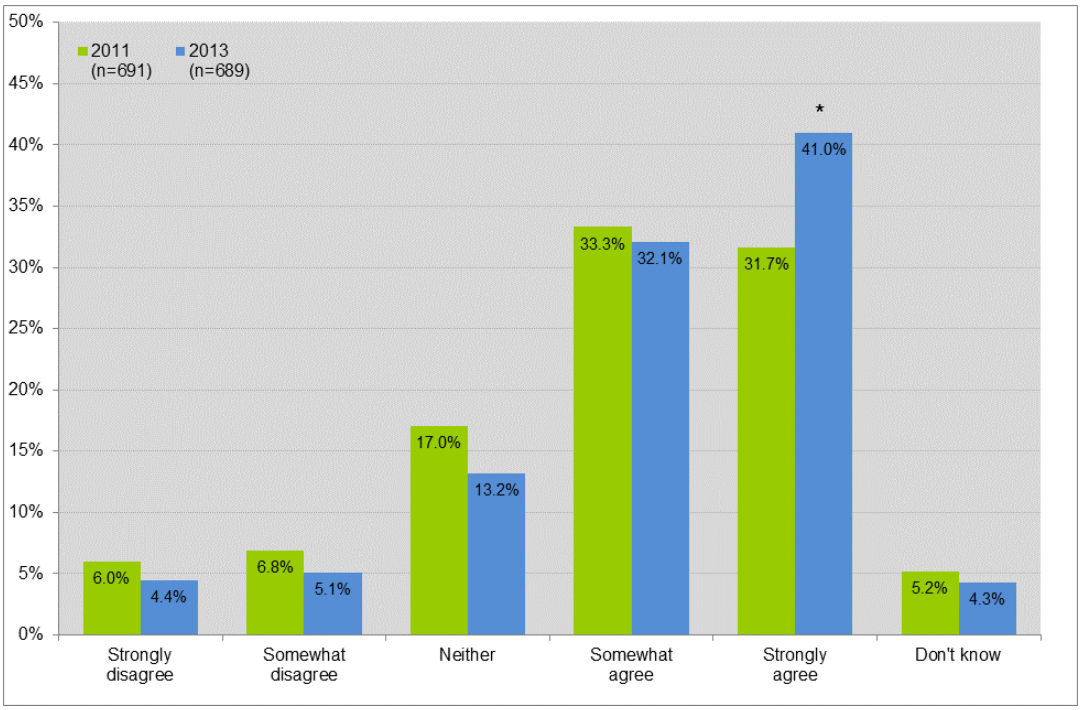
Least recognised risk factors

Moderate exercise is the least well known factor for reducing the risk of bowel cancer. In 2013, there has been an increase in the proportion of respondents who disagree that doing less than 30 minutes moderate exercise five days a week can increase the odds of bowel cancer (41% either strongly or somewhat disagree in 2013 compared to 35% in 2011) (Figure 8). Analysis of the recontact sample shows there is fairly fixed views on the role of moderate exercise as a risk factor.

There is mixed understanding about eating red meat and fewer than five servings of fruit and vegetables a day as bowel cancer risk factors. Just under half agree that these risk factors can increase the risk (46% and 47% respectively), while 22% strongly or somewhat disagree that eating red meat and 37% disagree that eating fewer fruit and vegetables can increase the chance of developing bowel cancer (Figures 9 and 10).

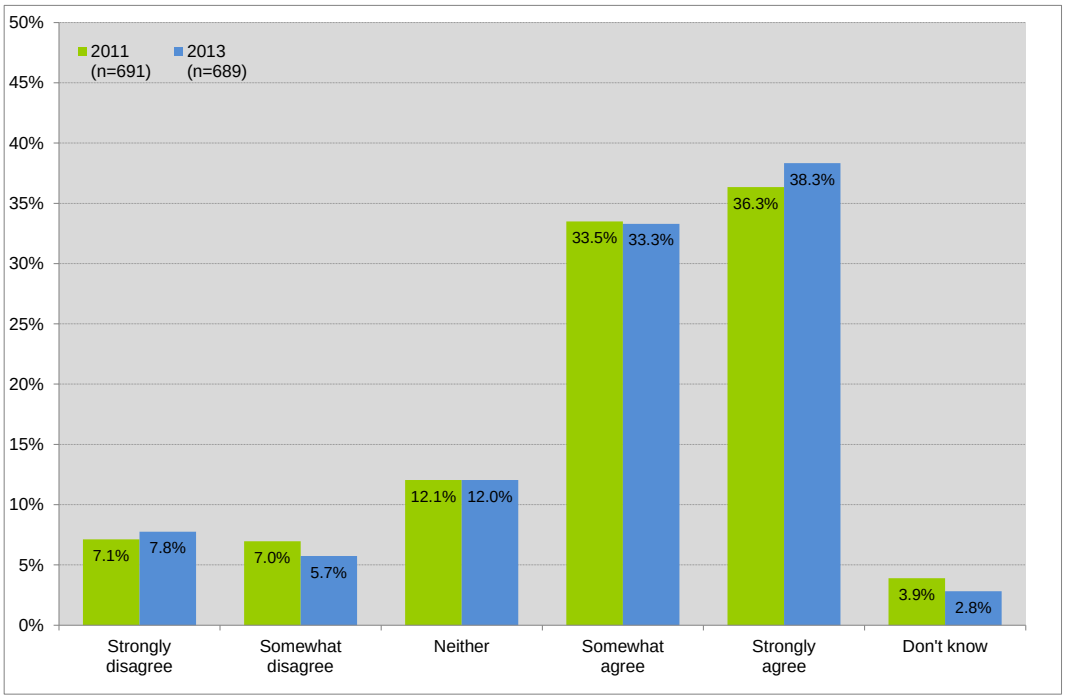
Analysis of the recontact sample shows that individual attitudes about the risks of eating red meat are fairly constant over time. In contrast, opinions often change about the risks of eating fewer than five servings of fruit and vegetables with many of those that agreed in 2011 moving to disagree in 2013 and vice versa.

Figure 5: Agreement with the statement 'having a close relative who has had bowel cancer can increase a person's chance of developing bowel cancer', Waitemata District Health Board, 2011 and 2013



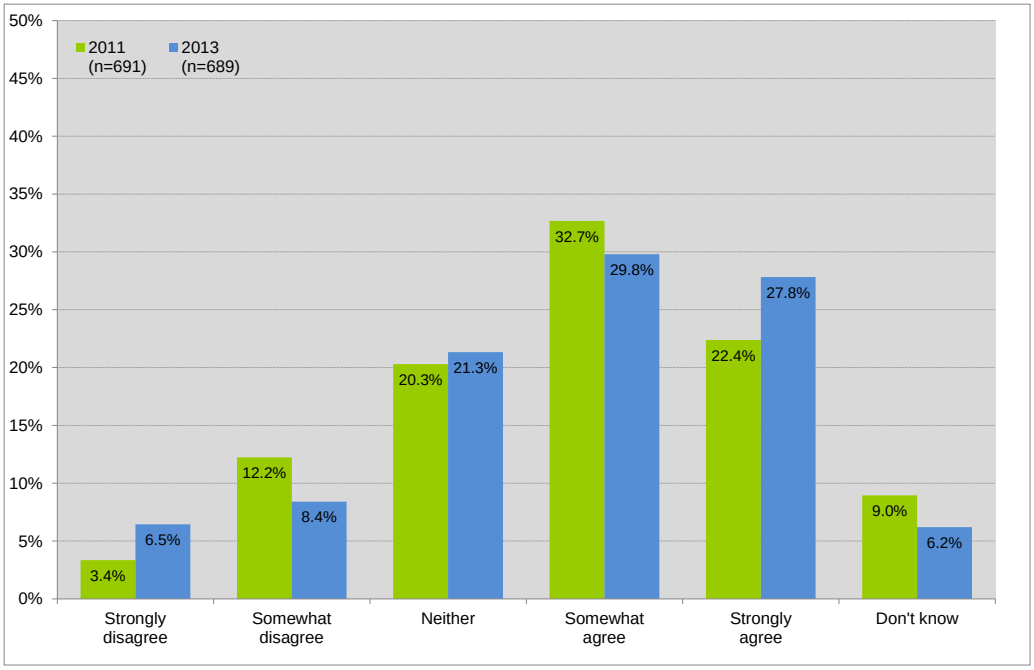
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 6: Agreement with the statement 'having a diet low in fibre can increase a person's chance of developing bowel cancer', Waitemata District Health Board, 2011 and 2013



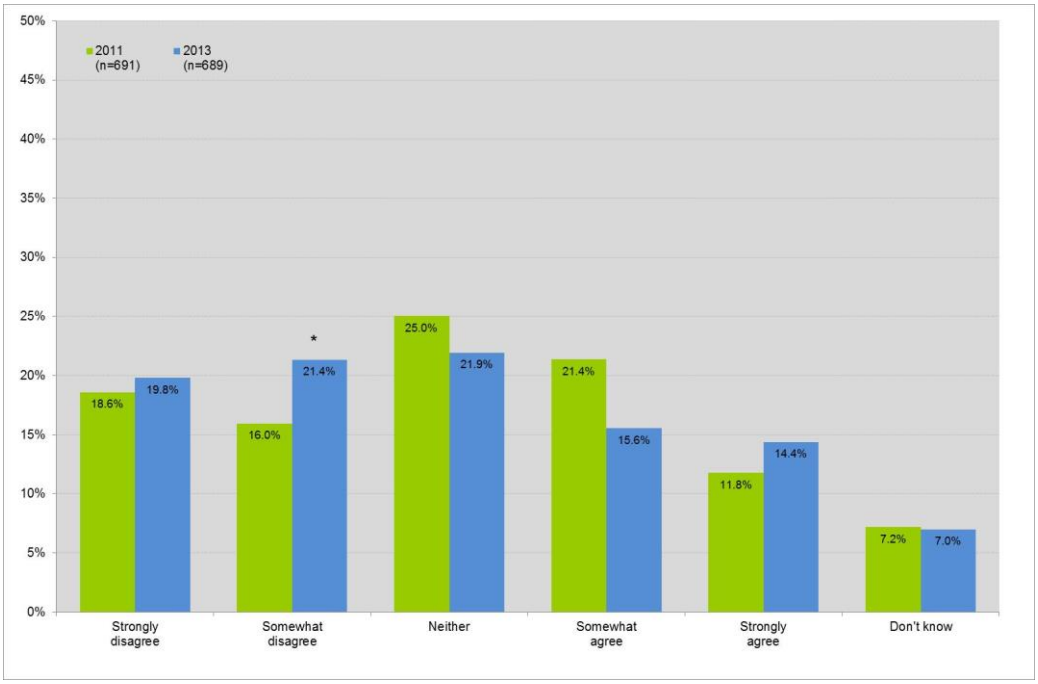
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 7: Agreement with the statement 'being overweight can increase a person's chance of developing bowel cancer', Waitemata District Health Board, 2011 and 2013



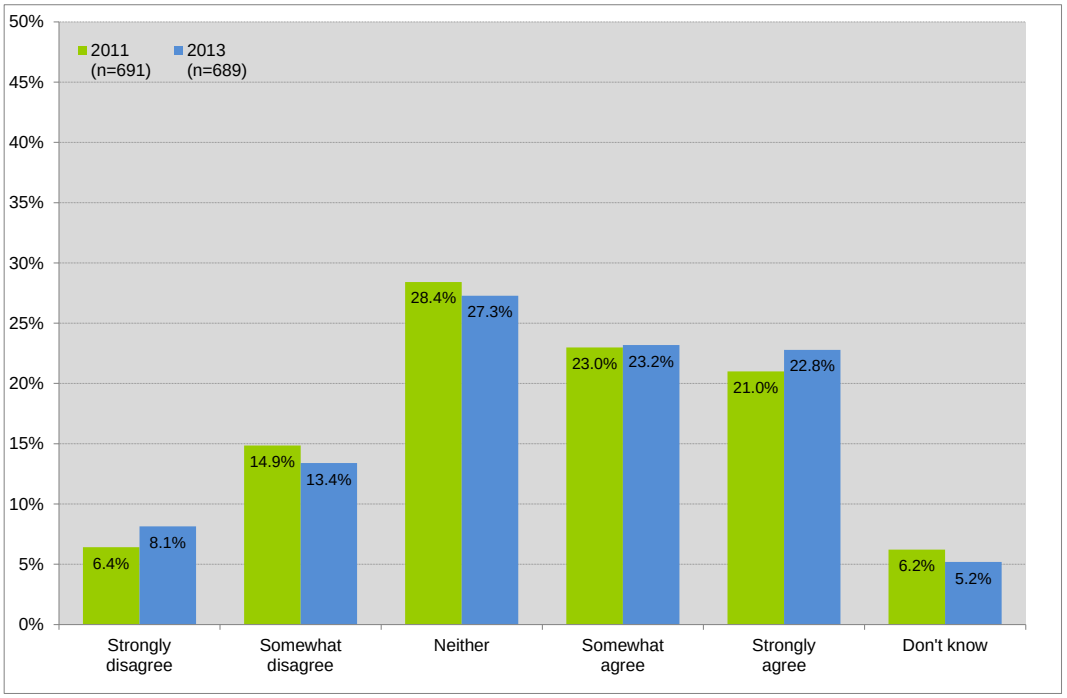
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

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, 2011 and 2013



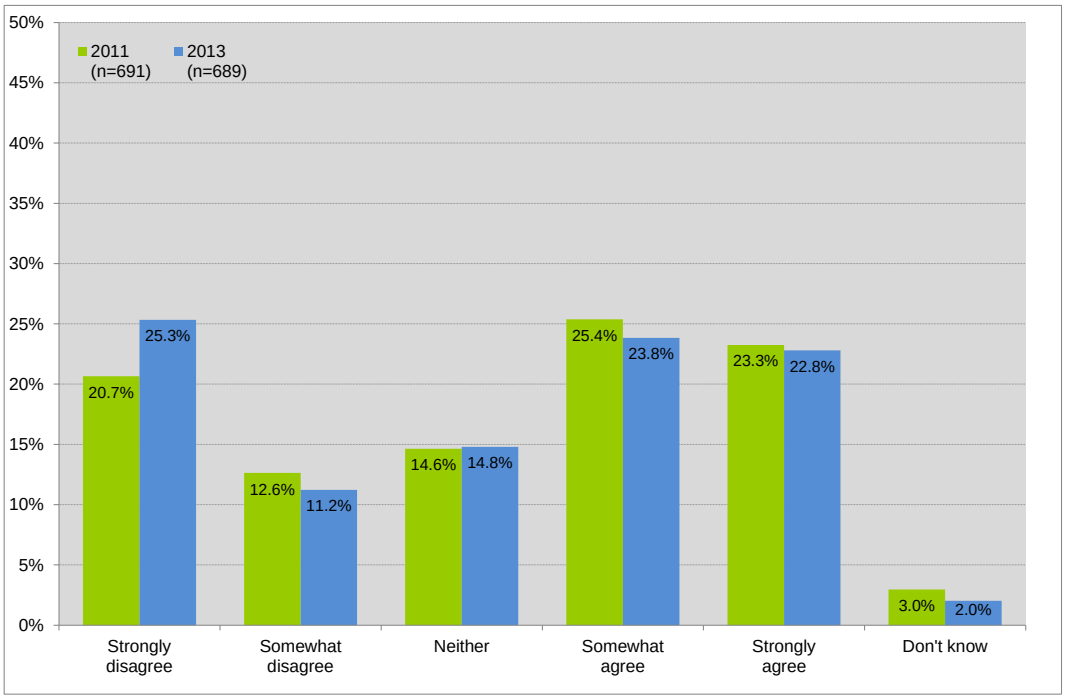
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 9: 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, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 10: 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, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

For levels of agreement, or otherwise, with bowel cancer risk factor statements, there are a number of statistically significant differences among sub-groups:

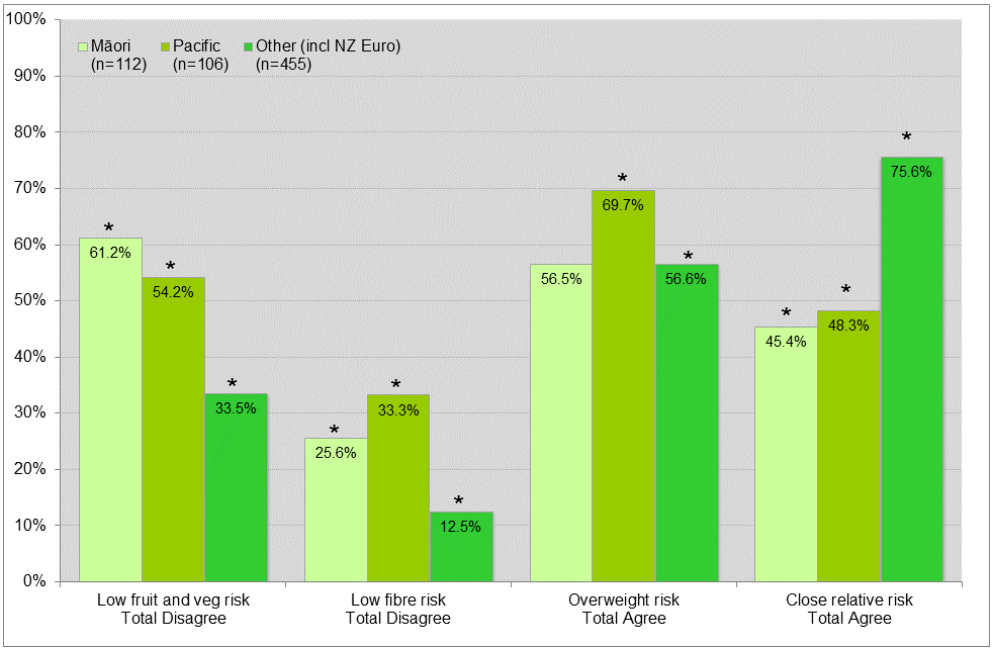
- Māori respondents tend to be less well informed about the risk factors for bowel cancer than the Other ethnic group (Figure 11), indicated by Māori respondents being:
  - less likely to agree that having a close relative with bowel cancer is a risk factor for bowel cancer (45% and 76% respectively)
  - less likely to agree that having a diet low in fibre can increase a person's chance of developing bowel cancer (49% and 74% respectively)
  - less likely to agree (in the combined 2011 and 2013 data) that doing less than 30 minutes moderate activity a day can increase a person's chance of developing bowel cancer (24% and 32% respectively)
  - more likely to <u>disagree</u> that eating fewer than five servings of fruit and vegetables a day can increase a person's chance of developing bowel cancer (61% and 34% respectively).
- Pacific respondents are more aware that being overweight is a risk factor for bowel cancer than the Other ethnic group (70% and 57% somewhat or strongly agree respectively) (Figure 11). In contrast, Pacific respondents were less aware of other risk factors than the Other ethnic group, specifically:
  - less likely to agree that having a close relative with bowel cancer is a risk factor for bowel cancer (48% and 76% respectively)
  - less likely to agree that having a diet low in fibre can increase a person's chance of developing bowel cancer (41% and 74% respectively)

  - more likely to disagree that eating fewer than five servings of fruit and vegetables a day can increase a person's chance of developing bowel cancer (54% and 34% respectively).

- Those respondents with a household income of less than $25,000 per annum are more likely to agree that being overweight is a risk factor for bowel cancer than those on over $100,000 per annum (77% and 56% respectively) (Figure 12). In contrast, they were less aware of other risk factors compared to households on over $100,000 per annum, specifically:
  - less likely to agree that having a close relative with bowel cancer is a risk factor for bowel cancer (59% and 80% respectively)
  - more likely to disagree that eating fewer than five servings of fruit and vegetables a day can increase a person's chance of developing bowel cancer (55% and 29% respectively).
- Women are more likely than men to agree that having a close relative who has had bowel cancer can increase a person's chance of developing bowel cancer (79% and 67% respectively).
- Those aged 65–75 are more likely to disagree that eating fewer than five servings of fruit and vegetables a day can increase a person's chance of developing bowel cancer than those aged 50–64 (46% and 33% respectively).

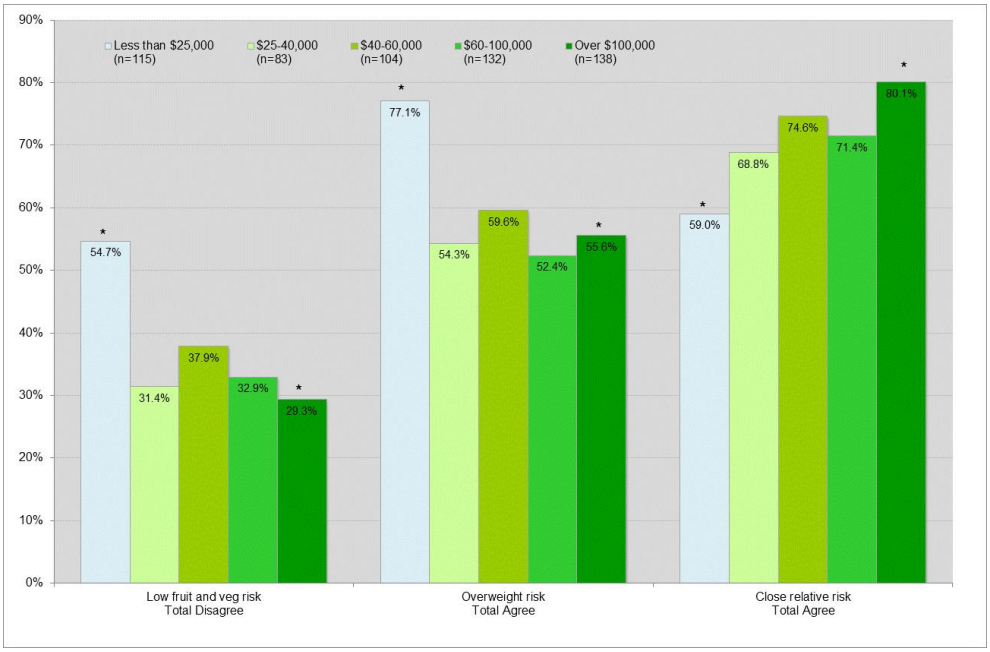
Compared to 2011, agreement has significantly increased that having a close relative who has had bowel cancer can increase a person's chance of developing bowel cancer amongst women (70% in 2011 to 79% in 2013), those aged 50-64 years (67% in 2011 to 75% in 2013), and respondents in the Other ethnic group (67% in 2011 to 76% in 2013).

Figure 11: Differences in understanding of bowel cancer risk factors by ethnicity, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2013

Figure 12: Differences in understanding of bowel cancer risk factors by household income, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2013

Summary: Three quarters of respondents are aware that a family history and a diet low in fibre are risk factors for bowel cancer. Since 2011, awareness of these risk factors has statistically significantly increased. Awareness of the risk related to obesity and bowel cancer is mentioned by around half and in particular Pacific and low income respondents. There is lower awareness of the risks related to little moderate exercise, eating red meat and few fruit and veg, and, for some, disagreement these are bowel cancer risks. Māori, Pacific respondents and those with a low income tend to be less aware of the risk factors, particularly the link in having a close family member with bowel cancer.

Recognising bowel cancer symptoms

Confidence recognising symptoms

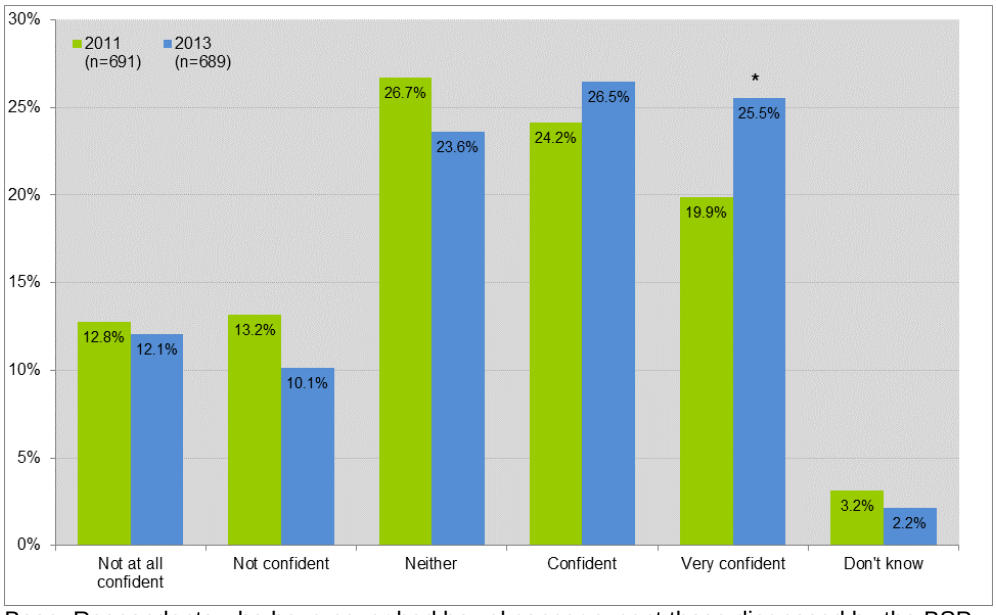
Since to 2011, confidence in noticing bowel cancer symptoms has increased from 44% being confident or very confident to 52% in 2013 (Figure 13). In particular, men's confidence in noticing bowel cancer symptoms has statistically significantly increased from 40% in 2011 to 50% in 2013 (confident and very confident combined).

At an individual level, analysis of the recontact sample shows there is an overall shift in confidence due to a proportion of people who are not confident becoming more confident and very few who were confident becoming less confident.

In 2013, 22% of WDHB respondents are either not confident or not at all confident in noticing symptoms. Based on the 2011 and 2013 combined ethnicity data, Pacific respondents are statistically significantly less confident than the Other group – 34% of Pacific respondents are either not at all or not confident in noticing symptoms compared to 23% of Others.

Younger respondents (aged 50–64 years) are significantly less likely (49%) than the older cohort (65–74 years) (61%) to be either confident or very confident in recognising symptoms.

Figure 13: Confidence in noticing bowel cancer symptoms, Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Unprompted awareness of bowel cancer symptoms

Since 2011 unprompted awareness that blood in the bowel motions as a symptom of bowel cancer has statistically significantly increased, and continues to be the most frequently mentioned symptom (72% in 2011 and 83% in 2013) (Figure 14). Unprompted awareness of this symptom has statistically significantly increased from 2011 to 2013 for:

- men (70% to 83%) and women (74% to 83%)
- those aged 50–64 (70% to 82%) and 65–75 (77% to 86%)
- Māori (40% to 69%), Pacific (30% to 56%), and Other (76% to 85%).

Changes in toileting patterns continues to be the second most frequently mentioned symptom with unprompted mentions increasing since the 2011 survey (46% in 2011 and 56% in 2013) (Figure 14). Across the sub-groups unprompted mention of changes in toileting patterns has statistically significantly increased from 2011 to 2013 for:

- men (34% to 48%)
- those aged 50–64 (46% to 57%)
- Other ethnic group (48% to 60%).

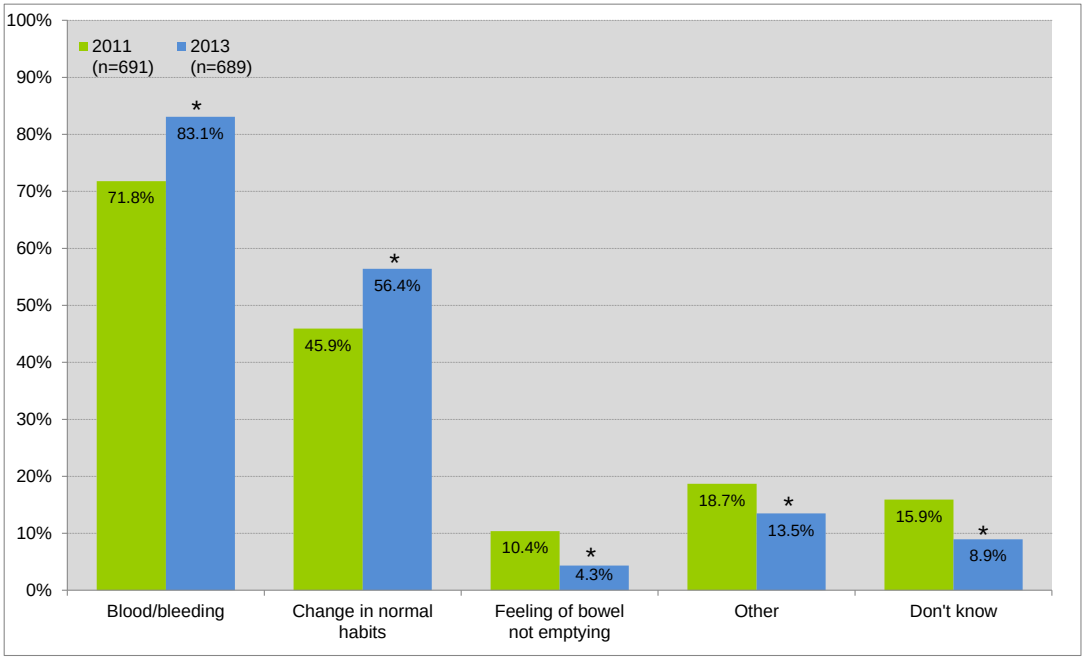
Compared to 2011, mention of a feeling that the bowel does not completely empty has statistically significantly decreased from 10% in 2011 to 4% in 2013. The statistically significant decrease in awareness of this symptom from 2011 was evident across men (3%) and women (6%), younger and older age groups (4% and 4% respectively) and the Other ethnic group (4%).

Fewer respondents are also commenting that they don't know any bowel cancer symptoms (9% in 2013 compared to 16% in 2011).

While one third of Pacific respondents (35%) do not know any symptoms of bowel cancer in 2013, this is a significant decline from 55% in 2013. A significant decrease in those not knowing any symptoms was also evident for men (11%), the younger age group (9%) and the Other ethnic group (7%).

Based on the combined 2011 and 2013 ethnicity data, one third of Māori (34%) say they do not know any bowel cancer symptoms.

Figure 14: Awareness (unprompted) of specific bowel cancer symptoms, Waitemata District Health Board, 2011 and 2013



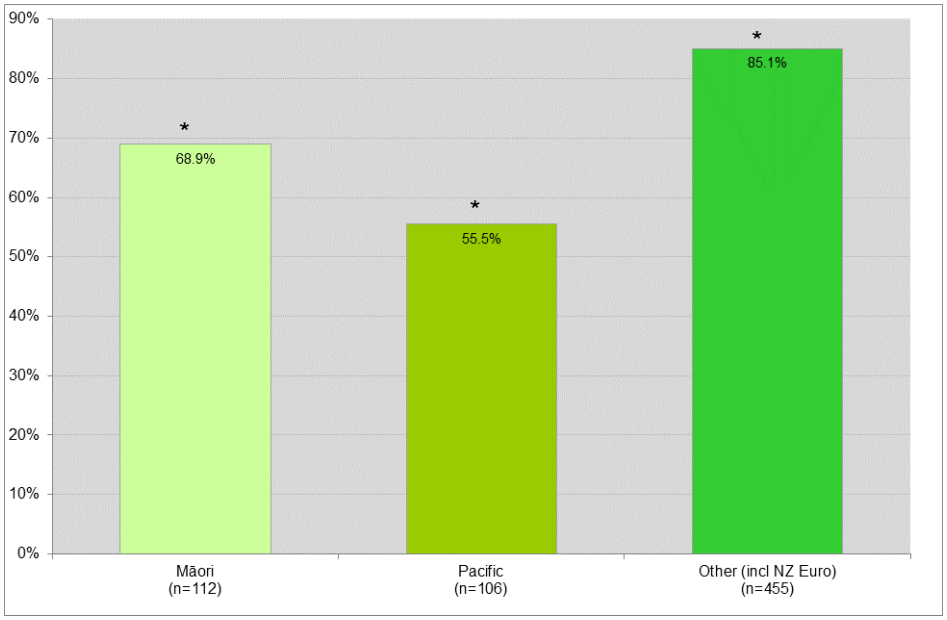
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

In 2013, there are a number of statistically significant differences among sub-groups in their unprompted knowledge about bowel cancer symptoms:

- Māori compared to the Other group are less likely to mention blood in bowel motions (69% and 85% respectively) and a change in bowel normal toilet habits (28% and 60% respectively) as symptoms of bowel cancer (Figures 15 and 16).
- Pacific respondents compared to the Other group are less likely to mention blood in bowel motions (56% and 85% respectively) and a change in bowel normal toilet habits (31% and 60% respectively) as symptoms of bowel cancer (Figures 15 and 16).
- Females are more likely than men to mention a change in bowel normal toilet habits as a symptom of bowel cancer (64% and 48% respectively) (Figure 17).

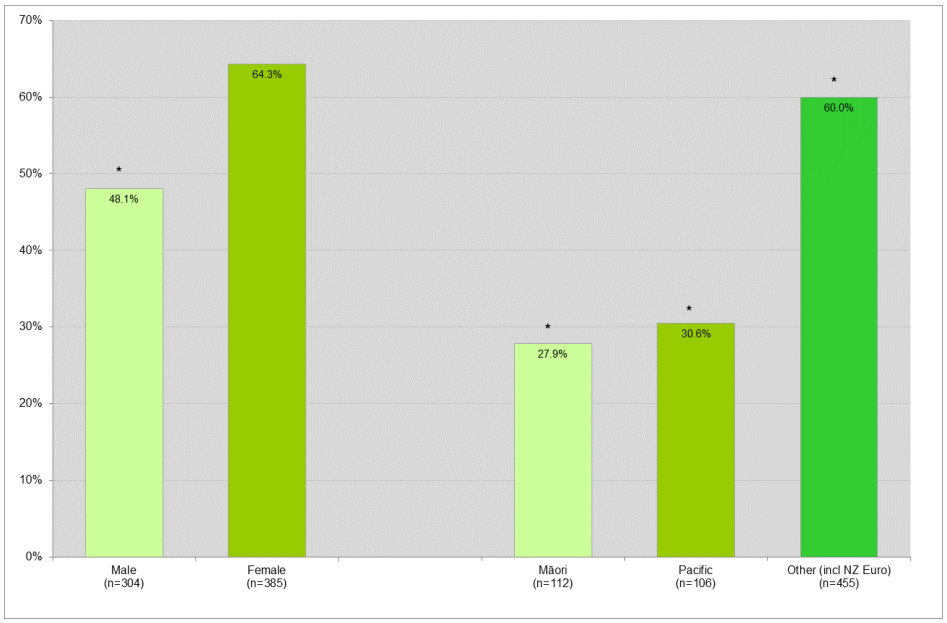
- Those aware of bowel cancer prevalence and confident they can identify bowel cancer are more likely to mention a change in toilet habits as a symptom than those not aware or less confident (Figure 18).

Figure 15: Awareness (unprompted) of blood/ bleeding as bowel cancer symptom by ethnicity, Waitemata District Health Board, 2013



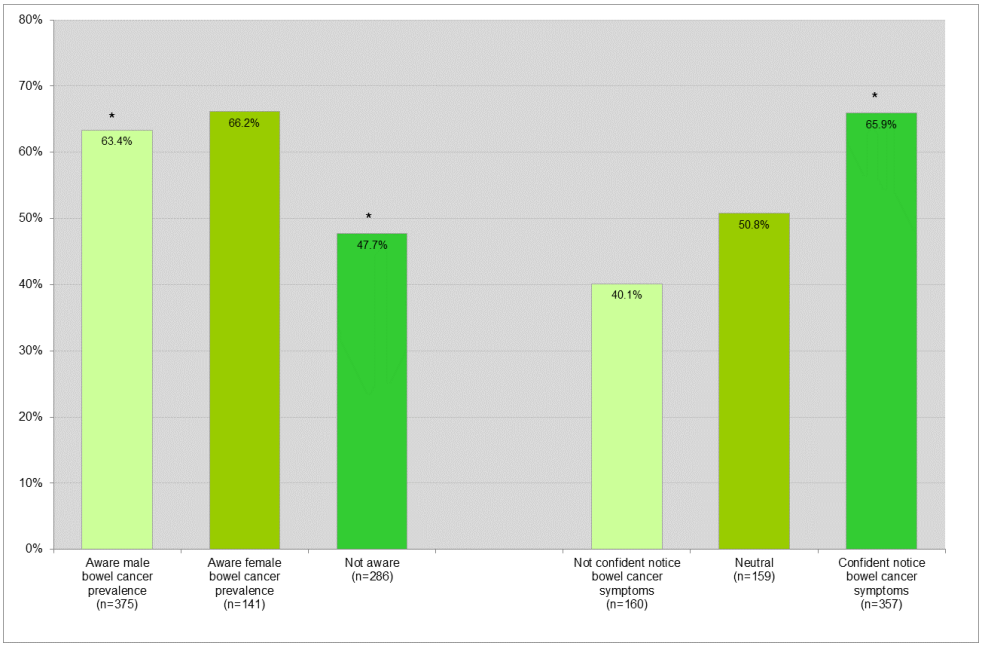
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone survey 2013

Figure 16: Awareness (unprompted) of change in normal bowel habits as bowel cancer symptom by gender and ethnicity, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone survey 2013

Figure 17: Awareness (unprompted) of change in normal bowel habits as bowel cancer symptom by awareness of bowel cancer and confidence to notice symptoms, Waitemata District Health Board, 2013

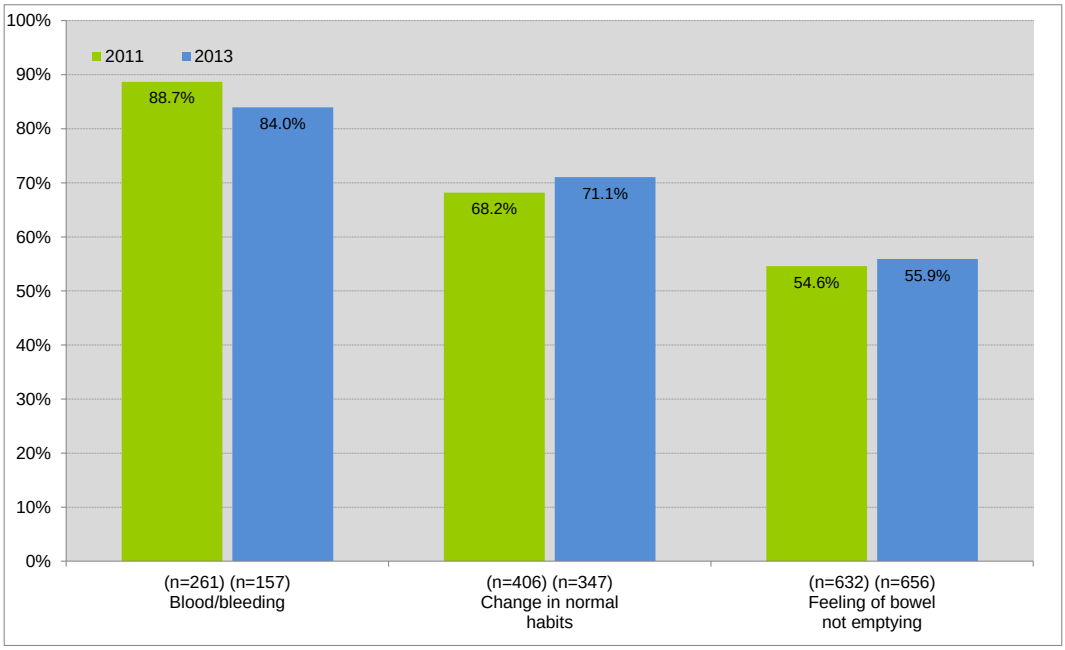


Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone survey 2013

Prompted 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 18). Blood in the bowel motions continues to be the most recognised symptom (84% in 2013) followed by a change in normal toileting patterns (71% in 2013). However, there has been no statistically significant change between the two surveys. There are lower levels of awareness about the symptom of the bowel not emptying completely (56% in 2013), with the remaining respondents either believing it isn't a symptom (25%) or unsure (19%).

Figure 18: Awareness (prompted) of specific bowel cancer symptoms, Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP AND did not state specific symptoms (unprompted)
Source: BSP Evaluation telephone surveys, 2011 and 2013

When prompted, **Pacific respondents** are less likely than the Other ethnic group to agree that blood in the bowel motion is a symptom of bowel cancer (65% and 87% respectively). One quarter of those Pacific respondents (27%) who were prompted said that blood in the bowel motion is *not* a symptom.

Pacific respondents are also less likely than Māori to agree that a change in toileting patterns is a symptom of bowel cancer (58% and 78% respectively). When prompted, 29% said this change is *not* a symptom.

Summary: Confidence in the ability to notice bowel cancer symptoms has increased, although Pacific respondents are less confident they will recognise symptoms. Reflecting these changes is an increase in the unprompted awareness of bowel cancer symptoms particularly blood in bowel motions and changes in toilet habits. Māori and Pacific respondents are less aware of these symptoms at an unprompted level compared to the Other ethnic group. When prompted, some Pacific respondents said these are not symptoms of bowel cancer.

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 in WDHB.

Awareness of bowel screening tests

Aware of any bowel screening test

WDHB respondents' awareness of bowel cancer screening tests has statistically significantly increased over the last 18 months. In 2013, 73% of WDHB respondents indicated they knew of tests they can do, or a doctor can request, to check for bowel cancer, compared to 42% in 2011. Awareness of bowel cancer tests have statistically significantly increased from 2011 to 2013 for:

- women (52% to 77%) and men (30% to 69%)
- those aged 50–64 (43% to 73%) and 65–75 (38% to 73%)
- Māori (32% to 51%), and Other (43% to 76%).

In 2013, awareness of bowel cancer tests is statistically significantly higher for those who received a BSP invitation letter and kit than those who did not (78% compared to 58%), those aware of the FOBT than those not aware (78% compared to 41%), and those recently screened for bowel cancer than those not screened (82% compared to 55%).

While awareness of bowel cancer tests has increased for Māori respondents, in 2013 Māori and Pacific respondents' awareness of tests is statistically significantly lower than the Other ethnic group (51% Māori, 37% Pacific and 76% Other). Compared to 2011, awareness of bowel cancer tests has not statistically significantly increased for Pacific people.

Unprompted mention of bowel screening tests

Those respondents *who stated they know of bowel screening tests (73%)* were asked to name a test (unprompted). In 2013, over one third of these respondents mentioned (unprompted) the BSP iFOBT (38%)[32]; a significant increase from the pre-launch benchmark measure of 1% in 2011 (Figure 19). Unprompted mention of the BSP iFOBT as a bowel screening test has statistically significantly increased across the following sub-groups from a lowly 0%-3% in 2011 to:

- women (40%) and men (37%) in 2013
- those aged 50–64 (38%) and 65–75 (38%) in 2013
- Māori (34%), Pacific (21%) and Other (39%) in 2013 (Figure 20).

In 2013, unprompted mention of the BSP iFOBT is statistically significantly higher for those who received a BSP invitation letter and kit than those who did not (42% compared to 21%), and those who have experienced FOBT than those who haven't (45% compared to 24%).

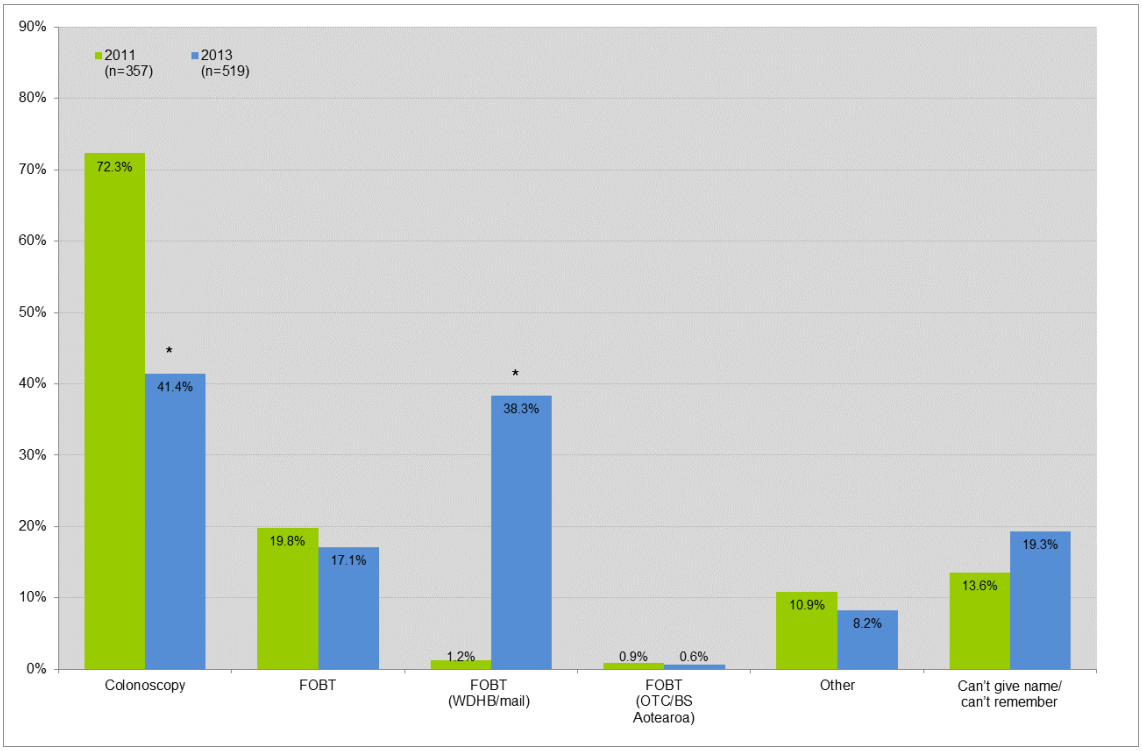
[32] Recalculating on the WDHB survey base of n=689, 31% of WDHB respondents, who have never had bowel cancer except those diagnosed via the BSP, mentioned unprompted WDHB BSP iFOBT.

Unprompted mention of the BSP iFOBT by Pacific respondents is statistically significantly lower than the Other ethnic group (21% compared to 39%).

Unprompted mention of colonoscopies including CT colonography has statistically significantly declined from 72% in 2011 to 41% in 2013 (Figure 19). This decline is evident across men and women (45% and 38%), younger and older age groups (40% and 45%), and Māori and the Other ethnic group (21% and 44%).

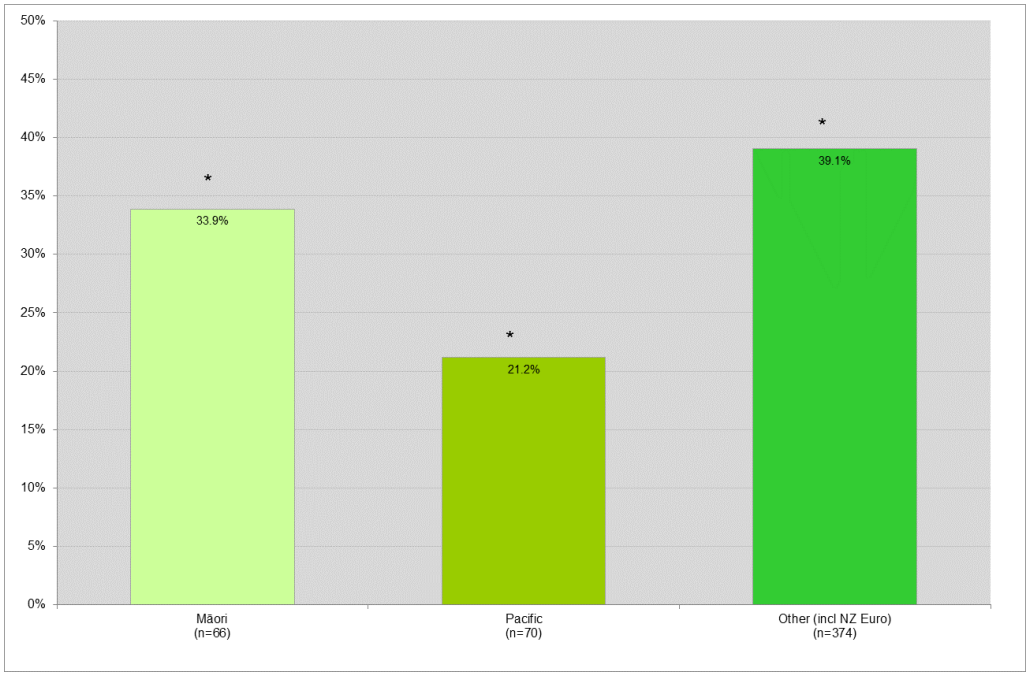
In 2013, Māori and Pacific respondents are less likely to mention colonoscopies than the Other ethnic group (21%, 20% and 44% respectively) (Figure 21).

Figure 19: Awareness (unprompted) of specific bowel cancer screening tests, Waitemata District Health Board, 2011 and 2013



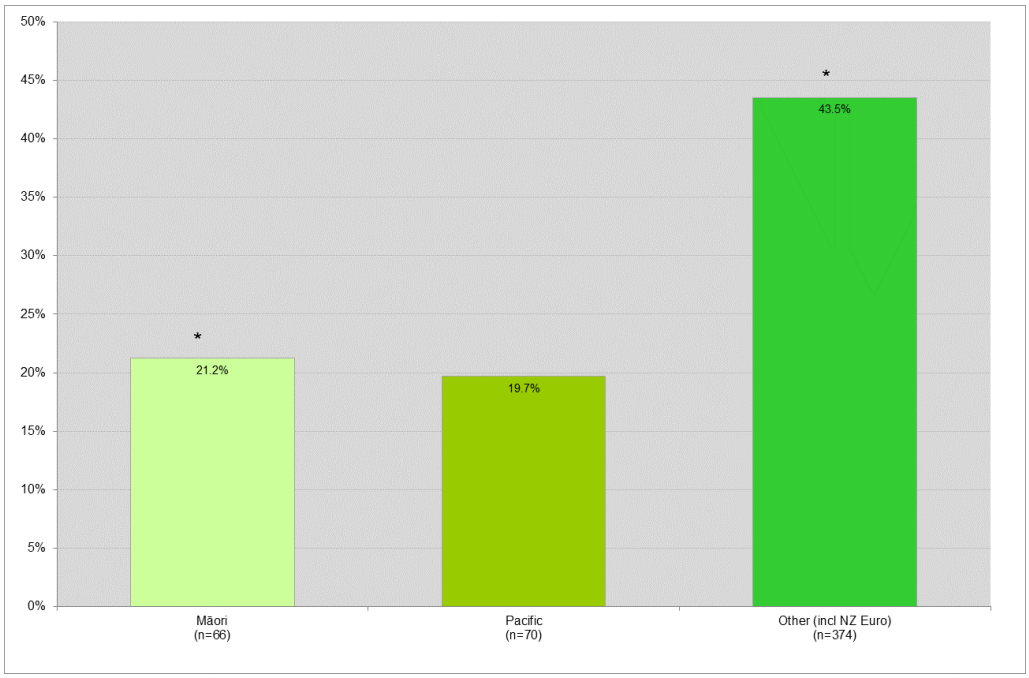
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP AND were aware of tests in previous question
Source: BSP Evaluation telephone surveys, 2011 and 2013
Note: FOBT = faecal occult blood test; WDHB = Waitemata District Health Board; OTC = over the counter; BS = BowelScreen.

Figure 20: Awareness (unprompted) of the BSP iFOBT by ethnicity, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP AND were aware of tests in previous question
Source: BSP Evaluation telephone surveys, 2013
Note: NZ Euro = New Zealand European

Figure 21: Awareness (unprompted) of colonoscopies by ethnicity, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP AND were aware of tests in previous question
Source: BSP Evaluation telephone surveys, 2013

Total awareness of bowel screening tests (prompted and unprompted)

Those who didn't mention one or more of the bowel screening tests (unprompted) were provided with an explanation of the FOBT[33] and a colonoscopy[34] and were asked if they had ever heard of either test before having the tests described to them. Responses to this prompted question were grouped with unprompted responses to the earlier question about knowing of any tests for bowel cancer to create a measure of total awareness.

Since the baseline measure, there has been a statistically significant increase in total awareness of the FOBT test (49% in 2011 to 90% in 2013) (Figure 22). Note this is *total response (unprompted and prompted)*. This statistically significant increase in total awareness from 2011 to 2013 is evident across the following sub-groups:

- women (51% to 91%) and men (48% to 89%)
- those aged 50–64 (48% to 89%) and 65–75 (54% to 91%)
- Māori (51% to 84%), Pacific (40% to 77%), Asian (41% to 82%) and Other (50% to 91%).

While total awareness of the FOBT has statistically significantly increased for Pacific respondents, awareness for Pacific people of the FOBT continues to be statistically significantly lower than the Other ethnic group (77% compared to 91%).

In 2013, those respondents who are aware of the BSP were statistically significantly more likely (90%) than those not aware (59%) to say they have heard of the FOBT. Similarly those who had received the BSP invite and kit had higher awareness of the FOBT (95%) than those who had not received the kit (70%).

In 2013, total awareness of colonoscopy *(unprompted and prompted)* continues to be very high at 91% (Figure 22). In 2013, Pacific people continue to have a lower awareness of colonoscopy as a test for bowel cancer (62%) compared to the Other ethnic group (93%). Based on the 2011 and 2013 combined ethnic groups, Māori (81%) also have a lower total awareness of colonoscopy than the Other group (92%).

Respondents were also asked a prompted question about the take-home bowel screening test that can be purchased from a pharmacy - the BowelScreen Aotearoa kit - which was launched in New Zealand in April 2011, to measure prompted levels of awareness. In 2013, total awareness of the pharmacy kit *(unprompted and prompted)* had statistically significantly increased to 32% compared to 21% in 2011 (Figure 22).[35, 36] In 2013, awareness of the pharmacy kit increased across the following sub-groups: men (35%), women (30%), those aged 50–64 (34%), Māori (22%), Pacific (29%) and the Other ethnic group (34%).

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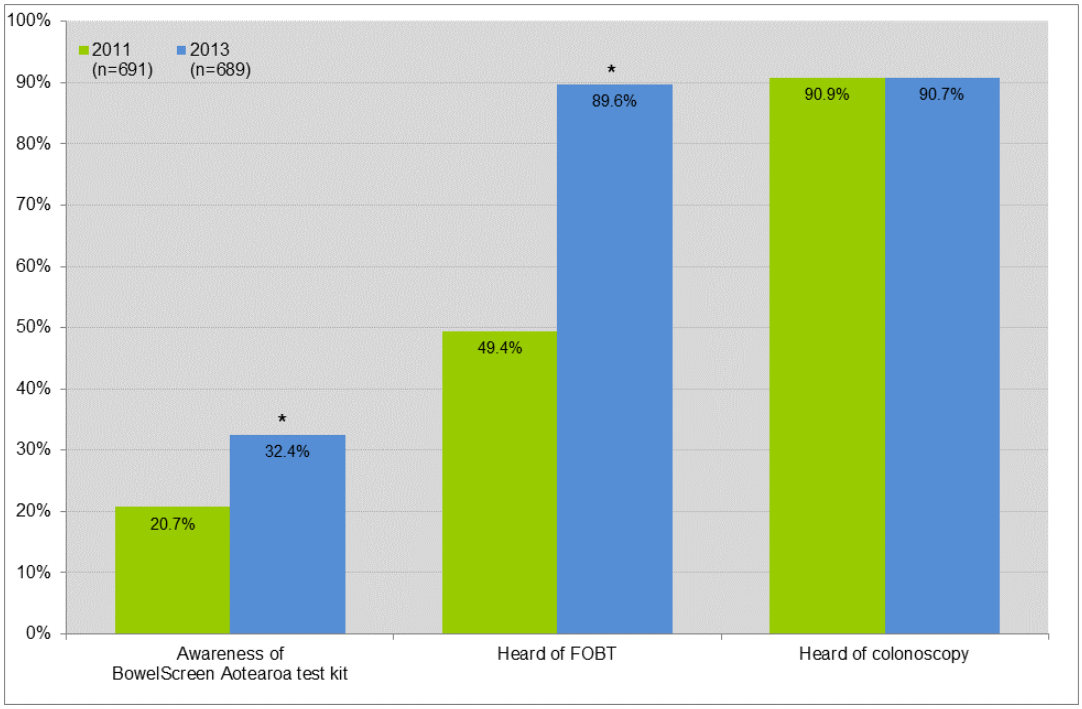
[33] The explanation provided was: "One screening test for bowel cancer is the faecal occult blood test, or FOBT for short. This test can detect tiny amounts of blood in your poo. Samples can be collected at home, usually by smearing a small amount of poo or bowel motion into a small container that is then sent to a laboratory for testing."

[34] The explanation provided was: "The colonoscopy is 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." `

[35] http://www.beatbowelcancer.org.nz/news.html#kits accessed 1 December 2013.

[36] Interviewers took care to ensure respondents weren't referring to bowel cleansing or detox kits.

Figure 22: Total awareness (prompted and unprompted) of bowel cancer screening tests, Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013
Note: FOBT = faecal occult blood test

Summary: Since the launch of the BSP, there has been a statistically significant increase in unprompted and prompted awareness of the BSP iFOBT and a decline in unprompted mention of colonoscopy. The decline in unprompted mention of colonoscopy may reflect the prominence of the BSP and its use of the iFOBT.

4.3 Previous bowel cancer experience

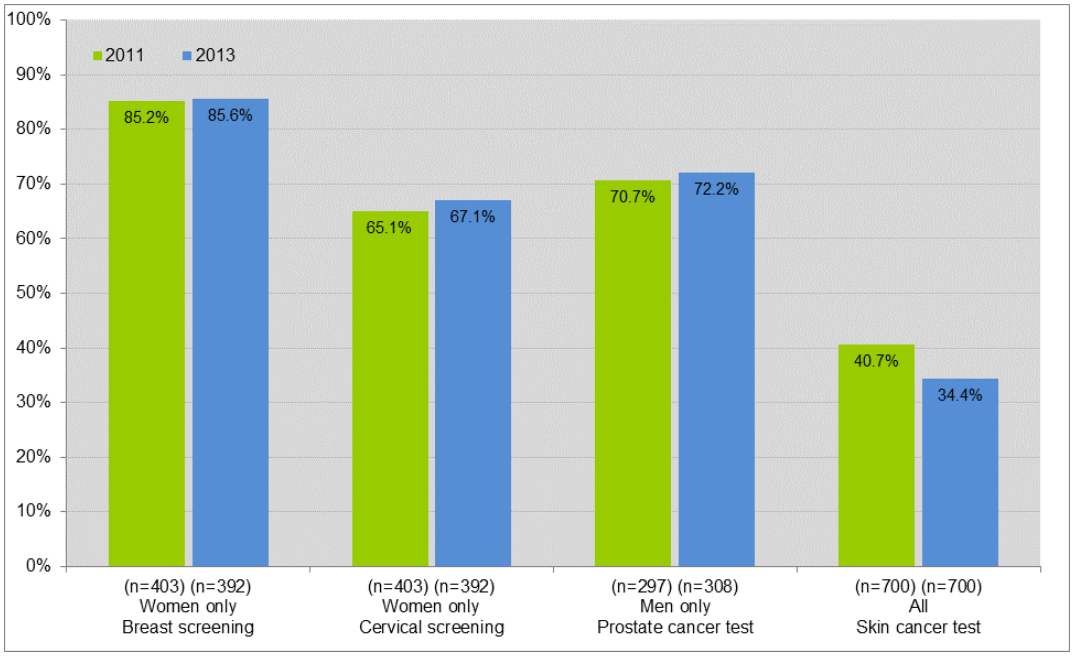
This section outlines respondents' previous experience with cancer screening and testing, bowel cancer and bowel screening tests.

Previous cancer screening and testing, including bowel cancer

Self-reported uptake of specific cancer screening and cancer tests shows no statistically significant difference between 2011 and 2013 (Figure 23):

- breast screen in previous two years[37] (85% of women in 2011 and 86% in 2013)[38]
- cervical screen in previous three years[39] (65% of women in 2011 and 67% in 2013)[40]
- prostate cancer test in previous two years (71% of men in 2011 and 72% in 2013)
- skin cancer check in previous two years (41% in 2011 and 34% in 2013).

Figure 23: Self-reported uptake (prompted) of cancer screening tests, Waitemata District Health Board, 2011 and 2013



Base: All respondents
Source: BSP Evaluation telephone surveys, 2011 and 2013

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37 Two-yearly breast screening is freely available to women aged 45–69 years http://www.nsu.govt.nz/current-nsu-programmes/breastscreen-aotearoa.aspx Accessed 1 December 2013.

38 Compared to 64% of women aged 50–69 in the 'BreastScreen Waitemata and North' area (note comparable data not publicly available) http://www.nsu.govt.nz/files/BSA/BSA_IMR_Screening_and_Assessment_Jan_2009_to_Dec_2010.pdf Accessed 1 December 2013.

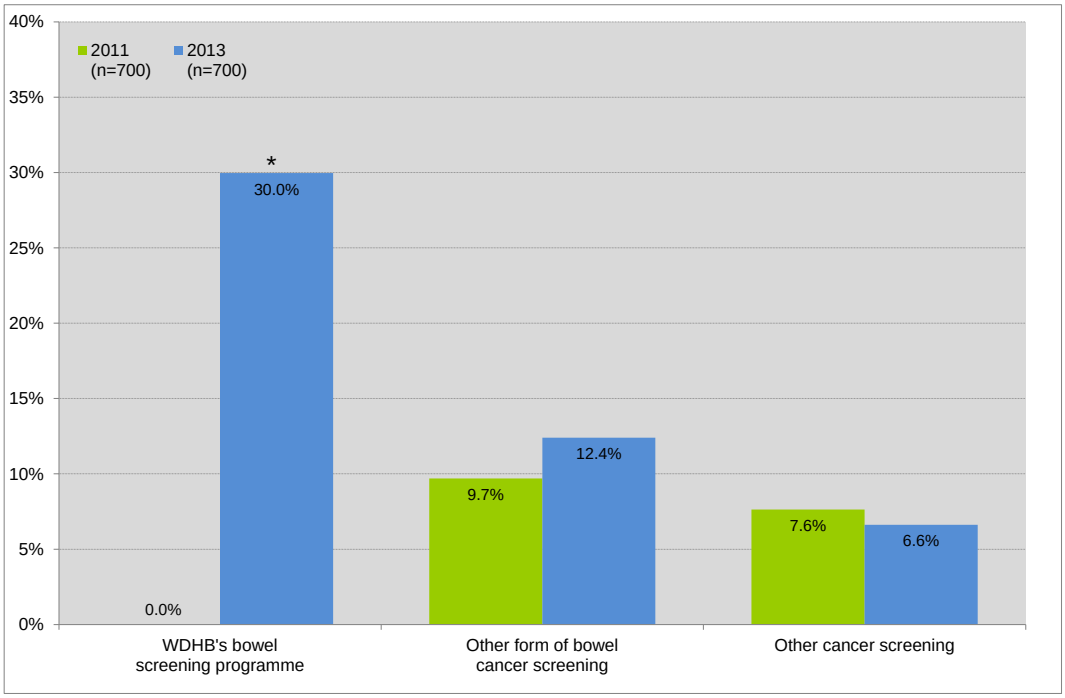
39 Three-yearly cervical smear tests are recommended for women aged 20–70 years (some health providers do not charge for the cervical smear) http://www.nsu.govt.nz/current-nsu-programmes/national-cervical-screening-programme.aspx Accessed 1 December 2013.

40 Compared to 75% of women aged 25–69 in WDHB women screened in previous three years, as at December 2010 (note comparable data not publicly available) http://www.nsu.govt.nz/files/NCSP/NCSP_Monitoring_Report_34__FINAL_errata_Oct_2012.pdf Accessed 1 December 2013.

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. Three in ten respondents mentioned WDHB's BSP (30%), a statistically significant increase in unprompted mention from the baseline in 2011 before the launch of the BSP (Figure 24).

One in ten (12%) had previously had some form of bowel screening test and mentions included FOBTs and/or colonoscopies. (Figure 24).

Figure 24: Unprompted mention of having a bowel cancer screening test or other cancer screening test (not already mentioned) in previous two years, Waitemata District Health Board, 2011 and 2013

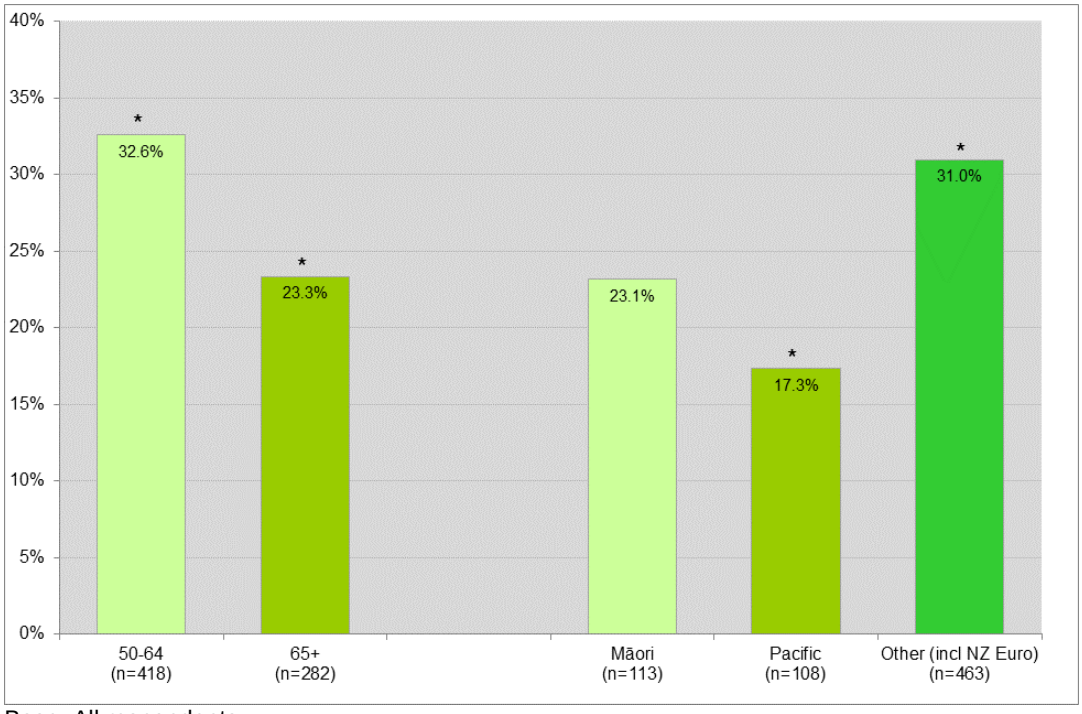


Base: All respondents
Source: BSP Evaluation telephone surveys, 2011 and 2013

In 2013 unprompted mention of having done the WDHB BSP screening test was statistically significantly lower for Pacific respondents (17%) compared to the Other ethnic group (31%), and those in the older age group (23% compared to 33% for those aged 50–64) (Figure 25).

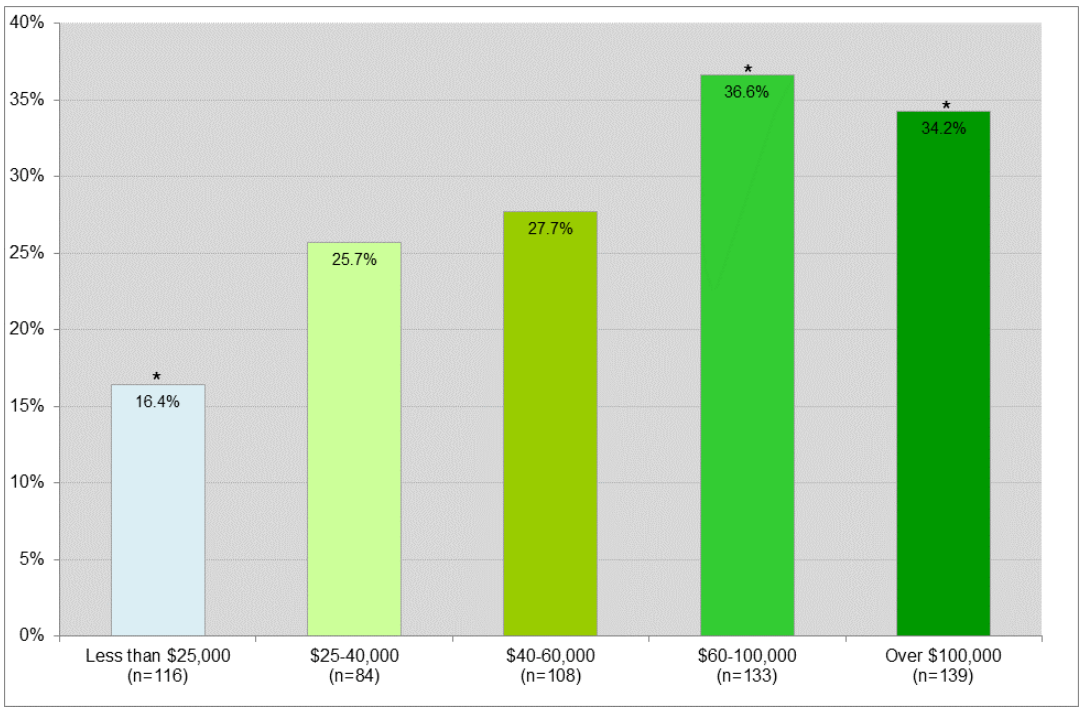
Those with household incomes of under $25,000 were statistically significantly less likely to mention the WDHB BSP test (16%) than those on higher incomes (37% for $60-100,000 and 34% over $100,000) (Figure 26).

Figure 25: Unprompted mention of having WDHB BSP screening test in previous two years by age and ethnicity, Waitemata District Health Board, 2013



Base: All respondents
Source: BSP Evaluation telephone survey, 2013

Figure 26: Unprompted mention of having WDHB BSP screening test in previous two years by income, Waitemata District Health Board, 2013



Base: All respondents
Source: BSP Evaluation telephone survey, 2013

Diagnosis of bowel cancer

Respondents were asked to indicate if they had ever been diagnosed with bowel cancer. Fourteen respondents said they have, of which three were diagnosed as a result of the BSP. The 11 respondents whose bowel cancer was not diagnosed via the BSP were subsequently asked the demographic questions, thanked for their time and agreement to participate, and were asked no further questions (Figure 27).

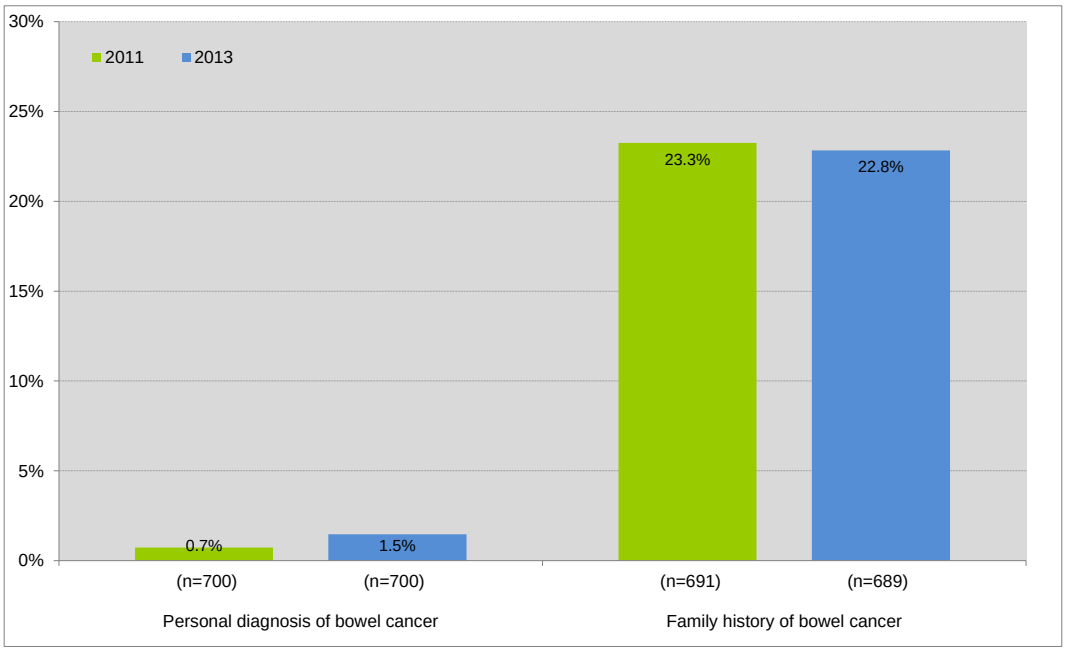
The three respondents diagnosed with bowel cancer via the BSP completed the survey. Care was taken to ensure participation in the survey was not upsetting or stressful.

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') remains unchanged (Figure 27). Twenty-three percent of respondents report that they have history of bowel cancer in their family in 2011 and 2013. Grandparents (27%), father (24%), mother (23%), aunt or uncle (15%) and brother or sister (11%) were mentioned as the family members who had bowel cancer.

About 2% don't know whether they have history of bowel cancer in their family.

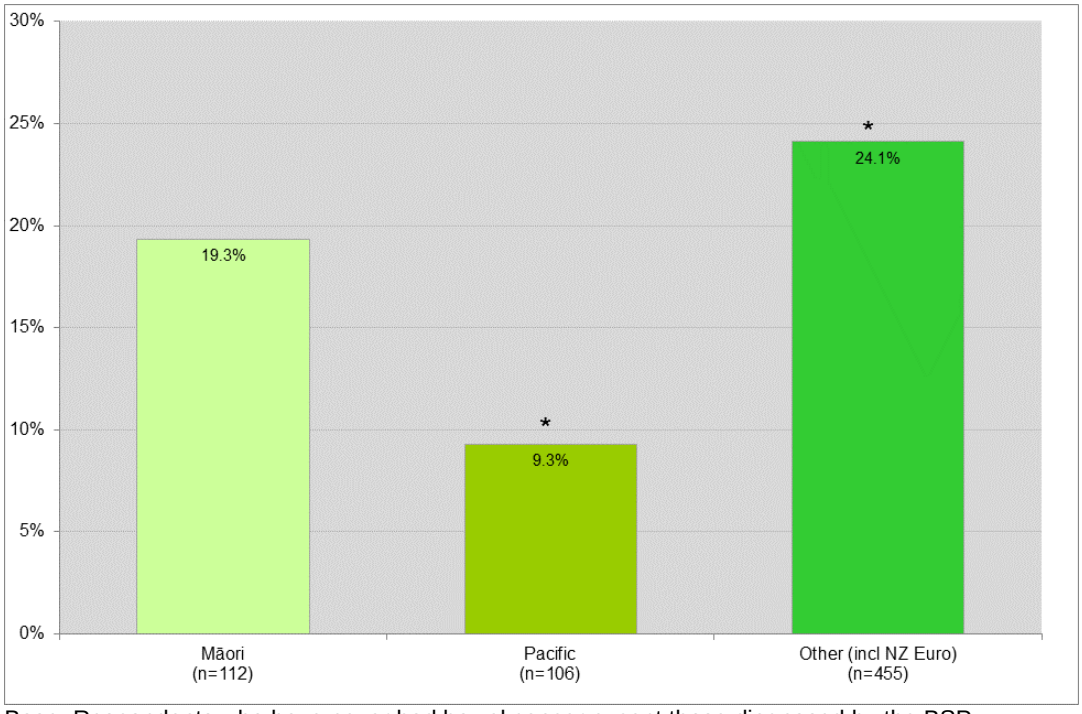
Figure 27: Personal diagnosis of bowel cancer and family history of bowel cancer, Waitemata District Health Board, 2011 and 2013



Base: All respondents (Personal diagnosis); respondents who have never had bowel cancer (Family history)
Source: BSP Evaluation telephone surveys, 2011 and 2013

Pacific respondents continue to be statistically significantly less likely (9%) than respondents of the Other ethnic group (24%) to report that someone in their immediate family has had bowel cancer (Figure 28).

Figure 28: Family history of bowel cancer by ethnicity, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2013
Note: NZ Euro = New Zealand European

Testing for bowel cancer

Two in ten respondents not diagnosed with bowel cancer report previous experience of symptoms or signs that they thought might be bowel cancer, which is unchanged from 2011 (20% in 2011 and 19% in 2013) (Figure 29).

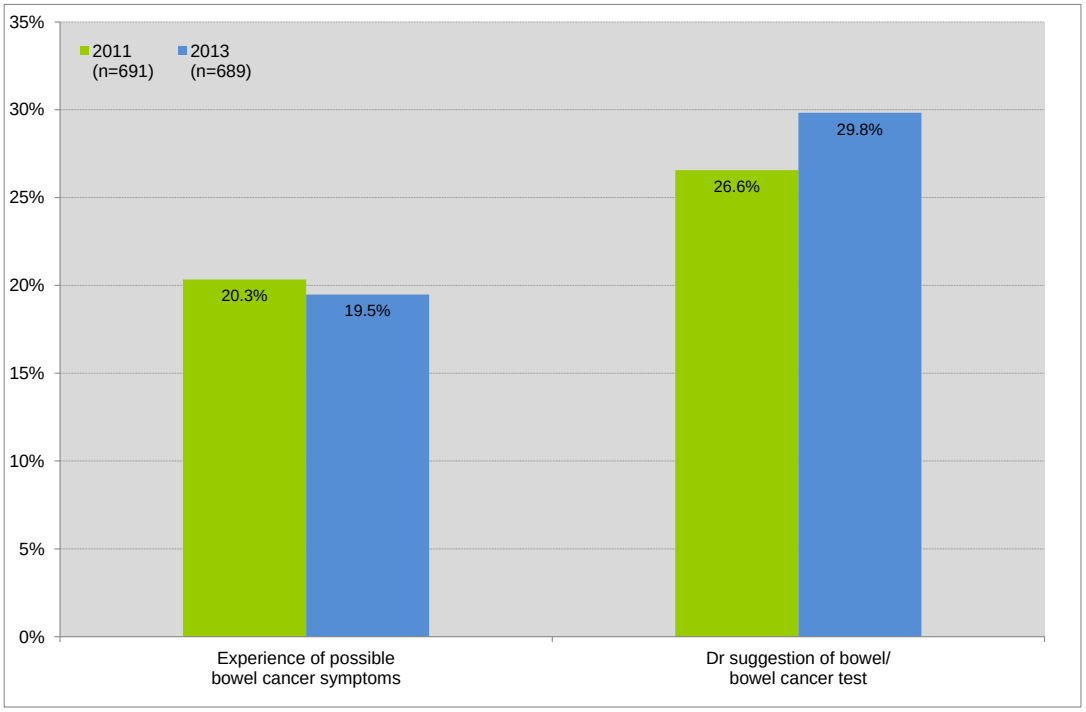
The 2011 and 2013 combined ethnicity data shows that the Other ethnic group are statistically significantly more likely (20%) than Māori (13%) and Pacific (10%) respondents to report they had previously experienced symptoms or signs they thought might be bowel cancer.

In 2013, 30% stated that a doctor has suggested in the past that they do a test to check for bowel cancer or the functioning of their bowels. This is consistent with the 2011 finding of 27% (Figure 29).

Compared to 2011, there is a statistically significant increase in Pacific respondents stating that a doctor has suggested doing a bowel cancer test (14% in 2011 and 44% in 2013). In 2013 Pacific respondents are statistically significantly more likely (44%) to have had a doctor suggest a test for bowel cancer than Māori (25%) (Figure 30).

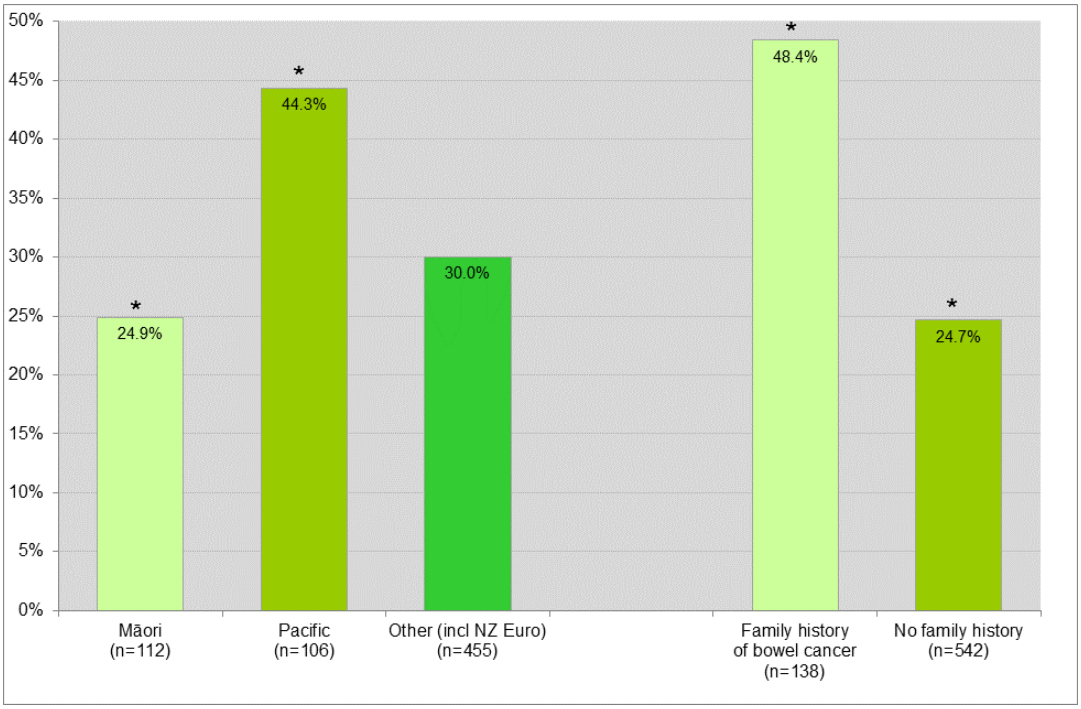
Based on the combined ethnicity data, Māori continue to be less likely (18%) to have had a doctor suggest a bowel cancer test than the Other ethnic group (28%). Those with a family history of bowel cancer continue to be statistically significantly more likely (48%) to have had a bowel cancer test suggested by a doctor than those with no family history (25%) (Figure 30).

Figure 29: Previous experience of bowel cancer symptoms and suggestion by doctor to do a bowel cancer test, Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013
Note: Dr = doctor

Figure 30: Suggestion by doctor to do a bowel cancer test by ethnicity and family history of bowel cancer, Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2013

Experience of FOBT and colonoscopy

Reflecting the launch of the BSP, in 2013 there is a significant increase in the proportion of people who have ever done an FOBT (of any type) from 34% in 2011 to 50% in 2013 (Figure 31). This statistically significant increase is evident across the following sub-groups:

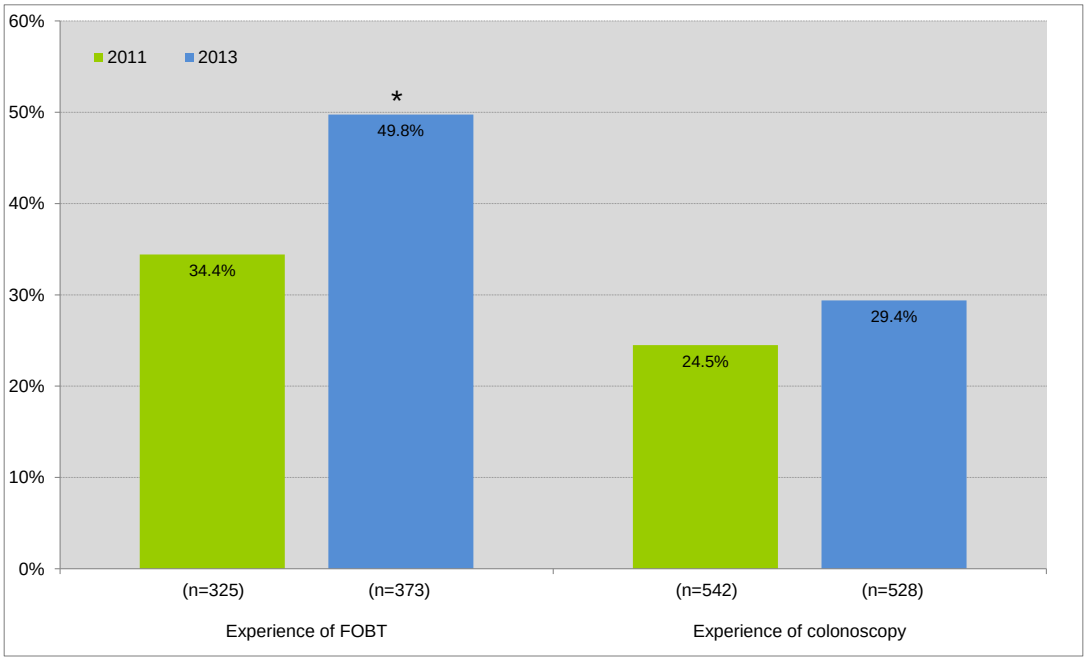
- women (29% to 47%)
- those aged 50–64 (31% to 43%) and 65–75 (43% to 65%)
- Māori (26% to 47%), and Other (35% to 51%).

In 2013, those aged 65–74 years are significantly more likely (65%) to have done an FOBT than 50–64 year olds (43%). Pacific respondents are less likely (31%) to have ever done an FOBT than the Other ethnic group (51%) (Figure 32).

The proportion of respondents who have ever had a colonoscopy remains unchanged at 29% (Figure 31).

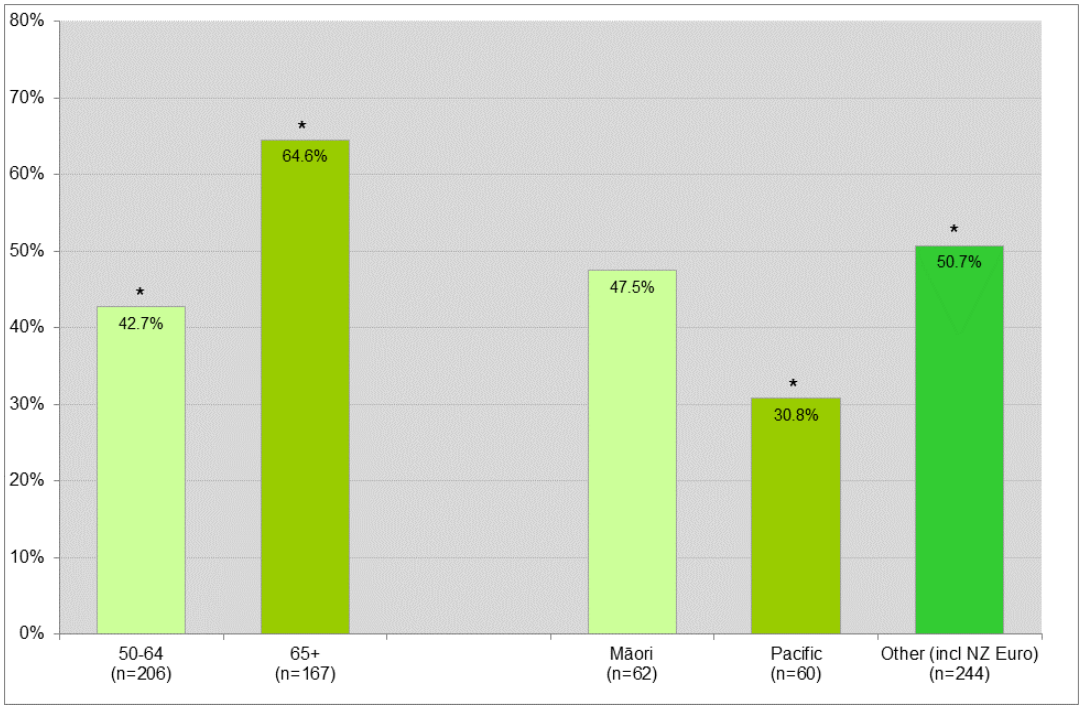
Based on the combined 2011 and 2013 ethnicity data, Pacific respondents are significantly less likely (14%) than the Other ethnic group (27%) to ever have had a colonoscopy.

Figure 31: Previous experience of FOBT and previous experience of colonoscopy, Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP AND have heard of FOBT or colonoscopy
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 32: Previous experience of FOBT by age and ethnicity, Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP AND have heard of FOBT
Source: BSP Evaluation telephone surveys, 2013

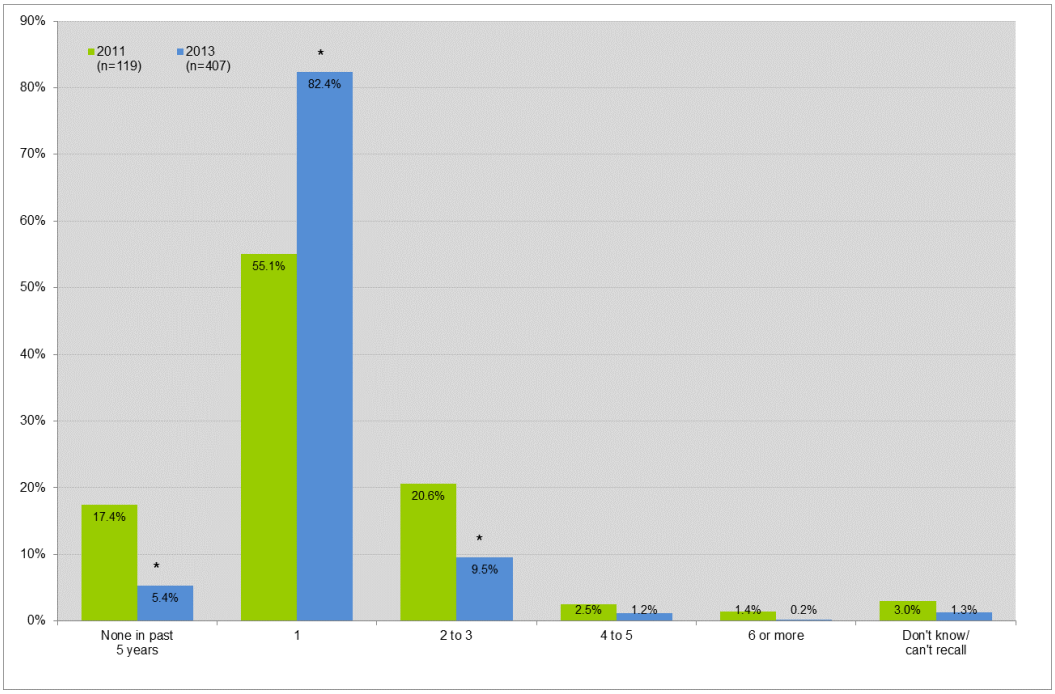
Among those who had ever done an FOBT and reflecting the launch of BSP in 2012, 82% say they have done an FOBT test *once* during the previous five years - a significant increase from 55% in 2011. The proportion of respondents who have not done an FOBT test in the last five years statistically decreased significantly to 5% from 17% in 2011 (Figure 33).[41]

Compared to 2011, the statistically significant increase in respondents who have ever done an FOBT once in the last five years is particularly evident across the following sub-groups:

- men (58% to 82%) and women (52% to 83%)
- those aged 50–64 (59% to 83%) and 65–75 (47% to 82%)
- Other ethnicity (55% to 84%).

[41] Recalculating on the WDHB survey base of n=689, 58% of WDHB respondents, who have never had bowel cancer, have done an FOBT in the past five years.

Figure 33: Number of FOBT in previous five years, Waitemata District Health Board, 2011 and 2013

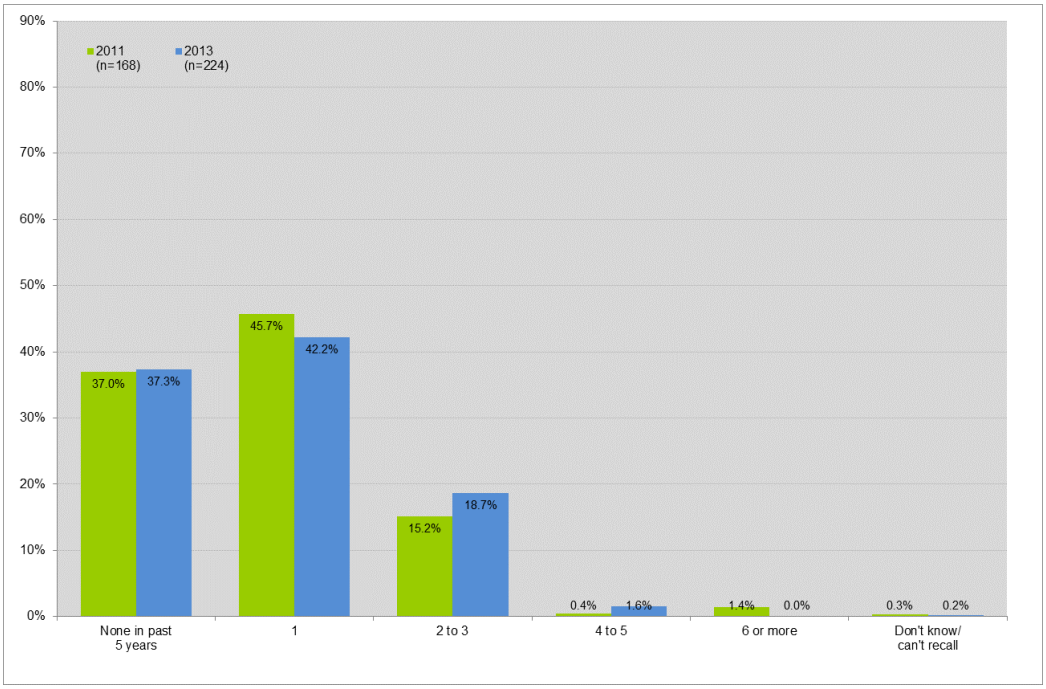


Base: Respondents who have never had bowel cancer except those diagnosed by the BSP AND have ever done an FOBT
Source: BSP Evaluation telephone surveys, 2011 and 2013

In 2013 among those who have ever had a colonoscopy, the most common frequency over the previous five years is once (42% in 2013 which is comparable to 46% in 2011) (Figure 34). About one third of respondents who have ever had a colonoscopy indicate they have not had the procedure within the past five years (37% in 2011 and 2013 respectively).[42]

[42] Recalculating on the WDHB survey base of n=689, 21% of WDHB respondents, who have never had bowel cancer, have had a colonoscopy in the past five years.

Figure 34: Number of colonoscopies in previous five years, Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP AND have ever had a colonoscopy
Source: BSP Evaluation telephone surveys, 2011 and 2013

Summary: There is a statistically significant increase in the unprompted mention of having done the WDHB BSP bowel cancer test since 2011 reflecting its launch in 2012. Correspondingly there is a statistically significant increase in the proportion of people who have done an FOBT once in the last five years. Overall there is no change in the proportion of respondents who report their doctor has suggested they do a test for bowel cancer. Although there is a statistically significant increase in Pacific respondents reporting their doctor has suggested they do a test for bowel cancer.

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.

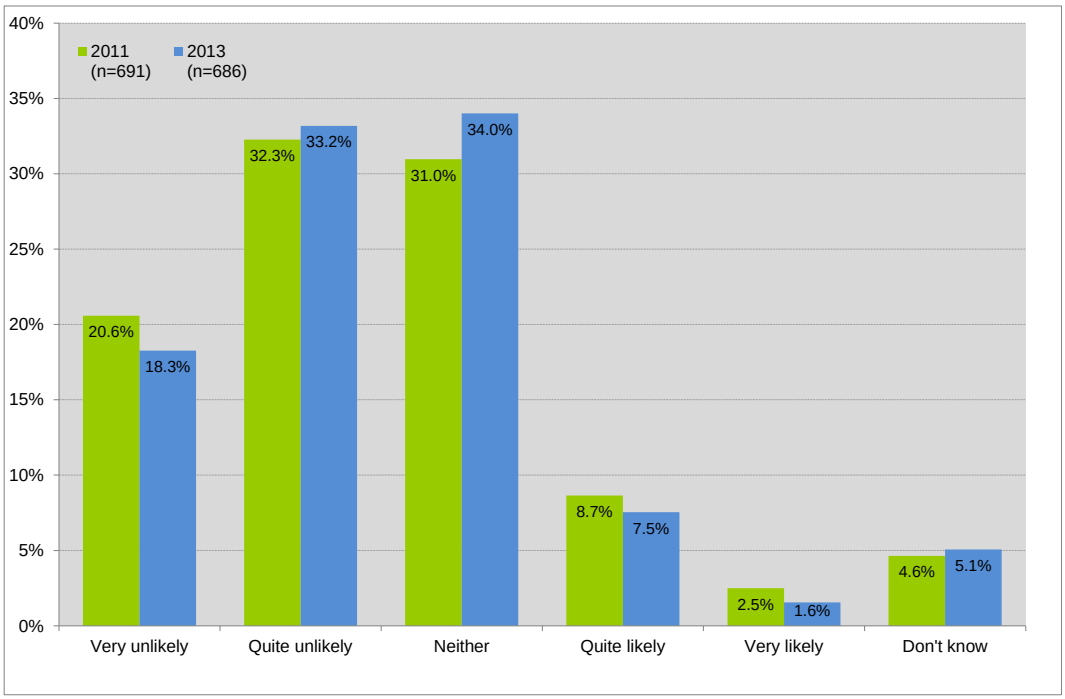
Perceived risk of bowel cancer

Respondents who never had bowel cancer were asked to indicate their views on how likely or unlikely it is that they will develop bowel cancer in their lifetime. Compared to 2011, there is no change in respondents' perceived risk of developing bowel cancer. One in 10 (9% in 2013) feel they would be either quite or very likely to develop bowel cancer (Figure 35). In 2013 Pacific are statistically significantly more likely (22%) to consider they are likely to develop bowel cancer than the Other group (9%)[43], as are those who have a family history of bowel cancer (19%, compared to those who don't 6%).

One third continue to be not sure either way (34% in 2013). About half feel they are unlikely to develop bowel cancer (51% in 2013), with the majority of these stating they are quite, rather than very, unlikely. Older WDHB respondents (65–74 years) are statistically significantly more likely (62%) than the younger group (50–64 years, 47%) to feel they are unlikely to develop bowel cancer.

Analysis of the recontact sample shows that individuals' attitudes about their perceived risk of developing bowel cancer have remained fairly static.

Figure 35: Perceived likelihood of developing bowel cancer within lifetime, Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

[43] Based on the combined 2011 and 2013 ethnicity data.

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 36–42).

Compared to 2011, there is a statistically significant increase in total disagreement[44] that the FOBT is embarrassing, painful, messy, inconvenient and inaccurate (Figures 36–40). Statistically significant increases (from 2011 to 2013) in the level of disagreement with these statements were noted across the sub-groups:

- Painful – men (86% to 93%) and women (85% to 94%), those 50–64 (88% to 94%) and those 65–75 (79% to 94%) and Other ethnicity (88% to 96%).
  - Analysis of the recontact sample shows a strong shift in attitude to disagree with the statement that the FOBT is painful.
- Embarrassing – men (74% to 85%) and the Other ethnic group (79% to 85%)
  - Analysis of the recontact sample shows a general shift in attitude from agree to disagree that the FOBT is embarrassing.
- Inconvenient – men (64% to 78%) and women (67% to 81%), those 50–64 (64% to 78%) and those 65–75 (67% to 84%), and Other (67% to 81%)
  - Analysis of the recontact sample shows a strong shift in attitude to disagree with the statement that the FOBT is inconvenient.
- Messy – men (49% to 72%) and women (43% to 58%), those 50–64 (45% to 65%) and those 65–75 (48% to 65%) and Māori (39% to 68%) and Other ethnicity (47% to 65%).
  - As noted above, in 2013 men are statistically significantly more likely than women to disagree that the FOBT is messy.
  - Analysis of the recontact sample shows a strong shift in attitude to disagree that the FOBT is messy.
- Inaccurate – men (31% to 52%) and women (34% to 53%), those 50–64 (31% to 52%) and those 65–75 (37% to 54%), and Māori (32% to 52%), Pacific (27% to 46%) the Other group (32% to 53%).
  - Analysis of the recontact sample shows a strong shift in attitude to disagree with the statement that the FOBT is inaccurate.

In 2013, the majority of respondents disagree that the FOBT is painful (94%), embarrassing (84%) and inconvenient (79%) (Figures 36–38). Agreement that the FOBT was embarrassing was statistically significantly higher amongst:

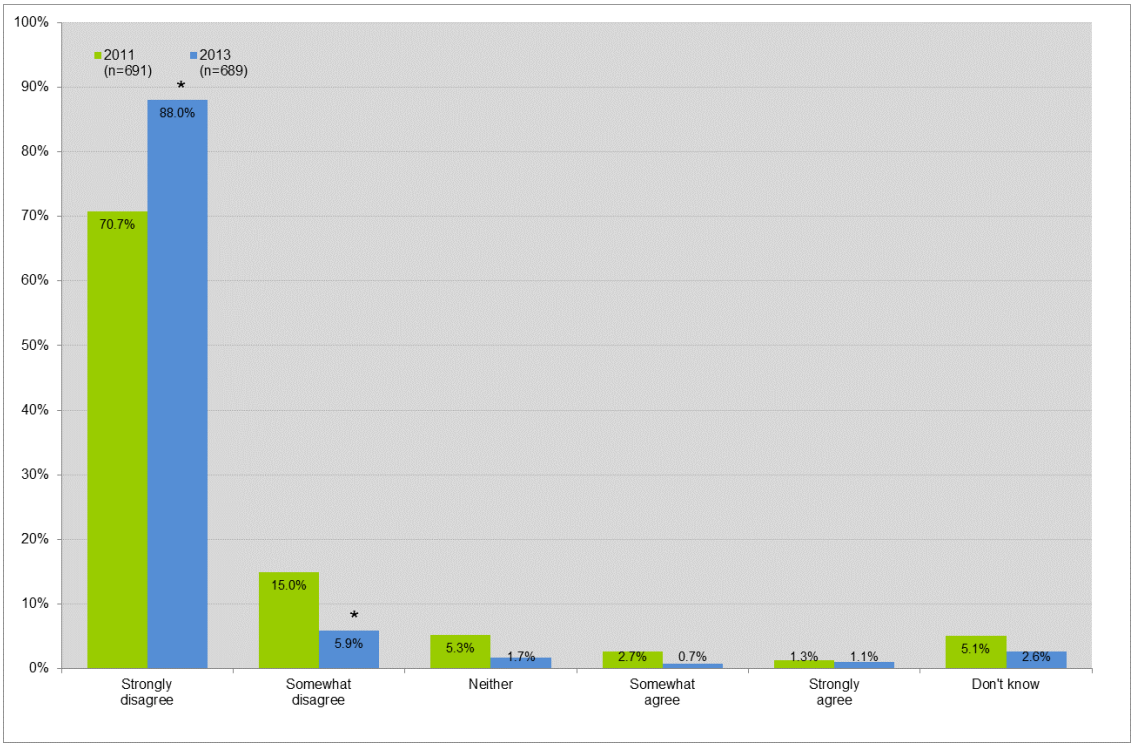
- Pacific respondents (26% compared to the Other group 9%)
- those with no previous experience of an FOBT (19%) than those with experience (8%),
- those who have not recently done screening tests (23%) than those who have (9%)
- those who did not intend to return a BSP kit (24%) to those who have (7%) (Figures 41 and 42).

In 2013, two thirds of respondents (65%) disagree that the FOBT is messy (Figure 39). While half of respondents disagree that the FOBT is inaccurate (53%), one in five are not sure with 21% noting they don't know) (Figure 40)

[44] Strongly disagreed and somewhat disagreed combined.

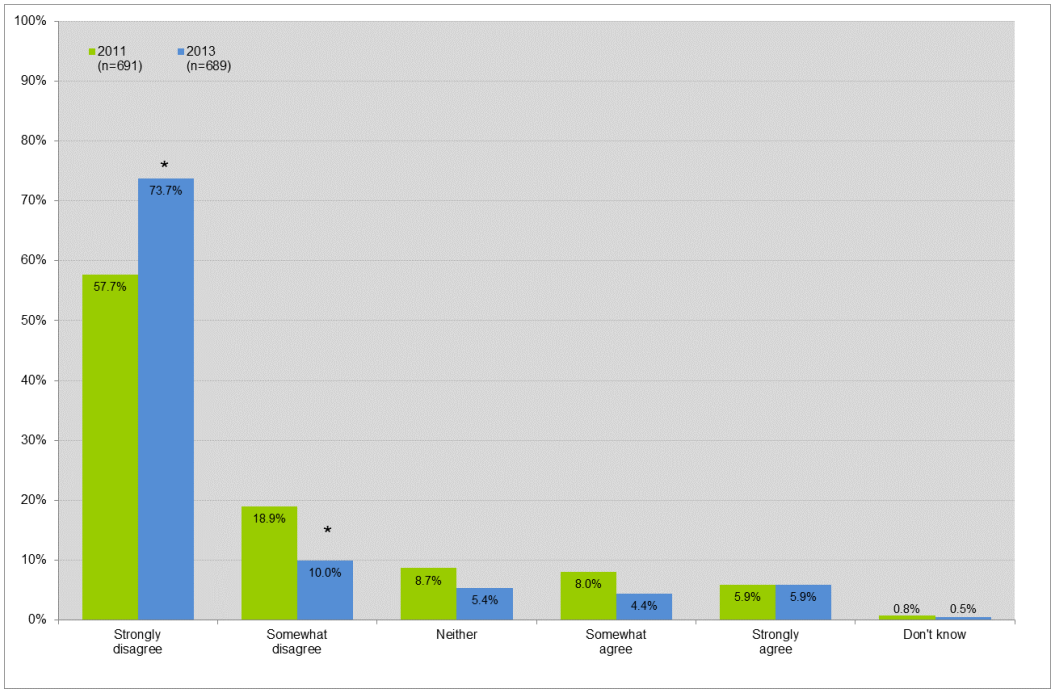
Pacific respondents compared to the Other ethnic group are statistically significantly more likely to agree (strongly and somewhat agree combined) that the FOBT is inconvenient (33%), embarrassing (26%), inaccurate (21%), and painful (10%) (Figure 41). Based on the combined 2011 and 2013 ethnicity data, Pacific are also statistically significantly more likely to agree the FOBT is messy (36%).

Figure 36: Agreement that the FOBT could be painful, Waitemata District Health Board, 2011 and 2013



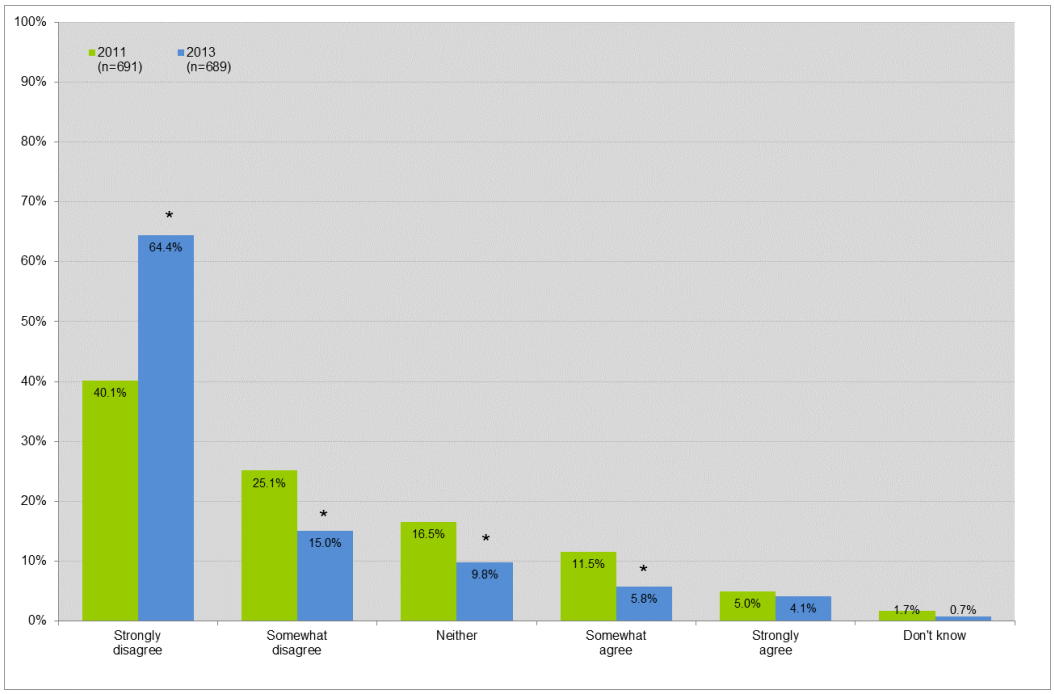
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 37: Agreement that the FOBT could be embarrassing, Waitemata District Health Board, 2011 and 2013



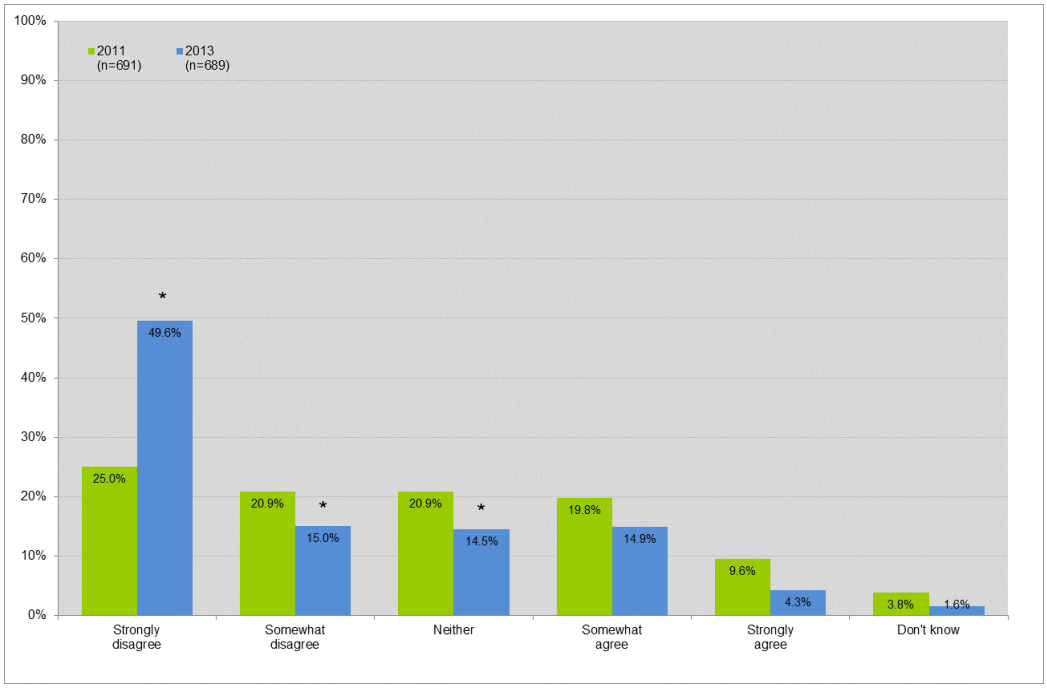
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 38: Agreement that the FOBT could be inconvenient, Waitemata District Health Board, 2011 and 2013



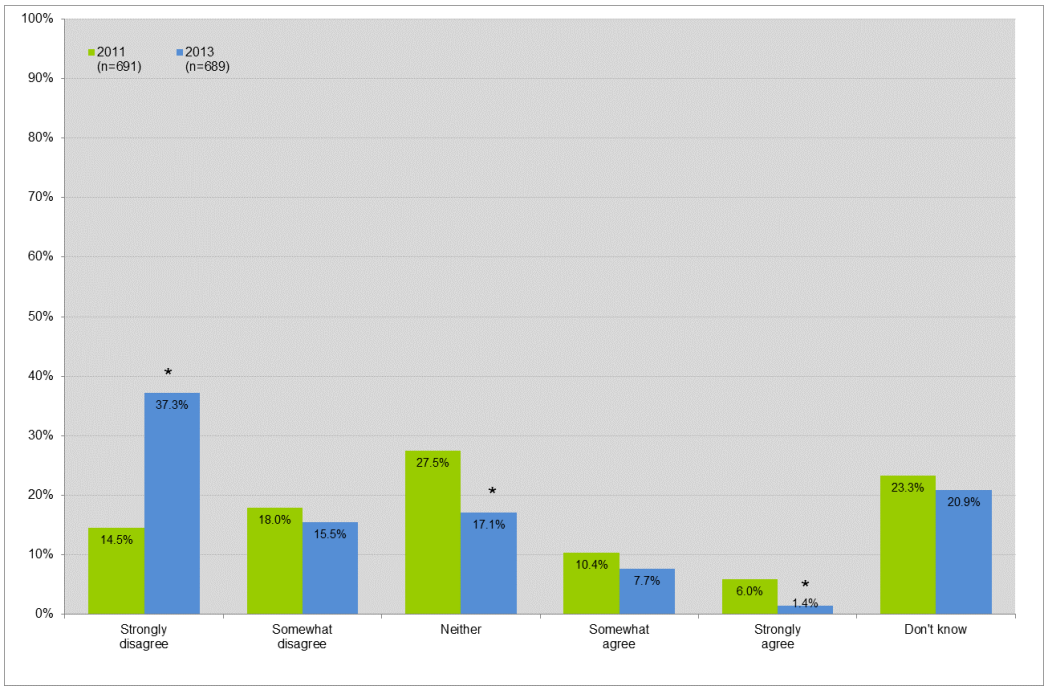
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 39: Agreement that the FOBT could be messy, Waitemata District Health Board, 2011 and 2013



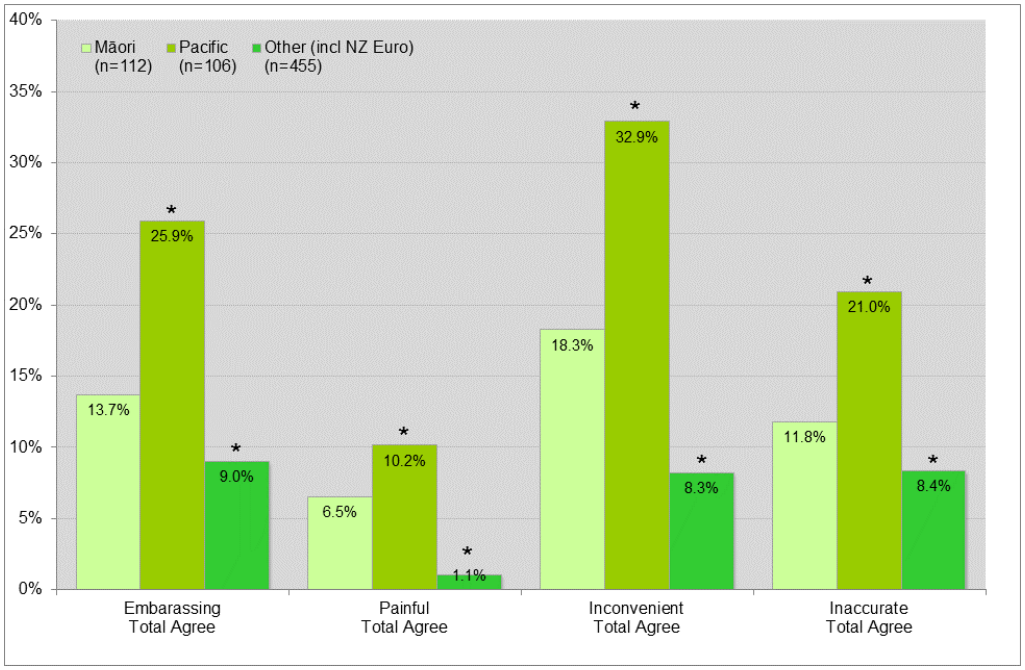
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 40: Agreement that the FOBT could be inaccurate, Waitemata District Health Board, 2011 and 2013



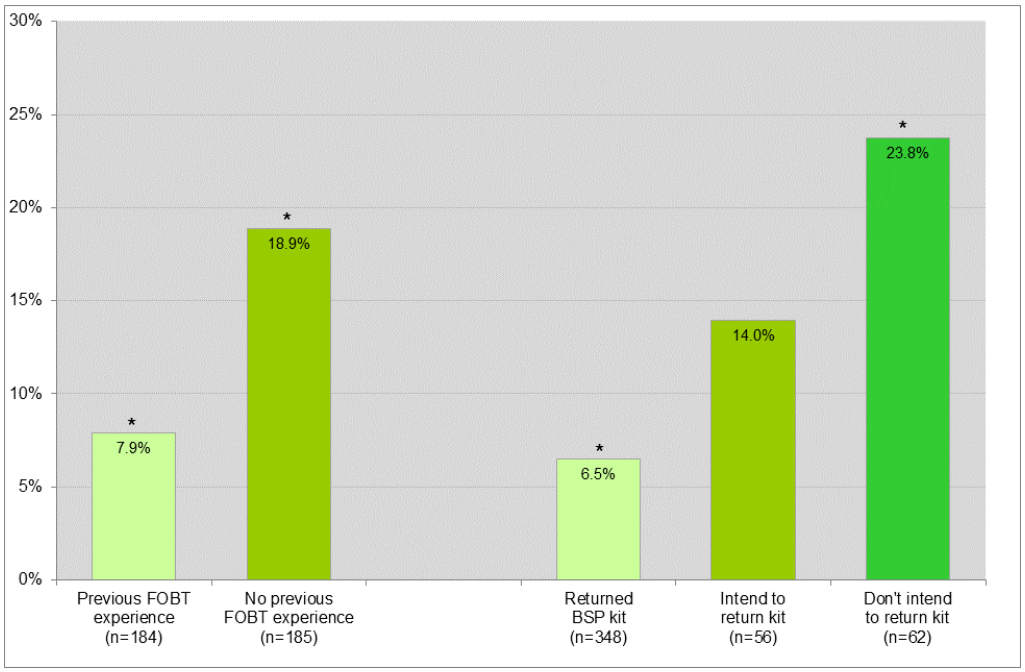
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 41: Agreement on statements about the FOBT by ethnicity, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2013

Figure 42: Agreement that the FOBT is embarrassing by experience of FOBT and whether returned BSP kit, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2013

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 43–50). Views on colonoscopies continue to differ from those of FOBTs. In particular, respondents are less likely to consider colonoscopies to be inaccurate, but more likely to view them as embarrassing, painful and inconvenient.

Since 2011, disagreement that colonoscopies are inaccurate has statistically significantly increased from 66% to 72% in 2013 (strongly and somewhat disagree combined) (Figure 43). The Other ethnic group are statistically significantly less likely to agree that colonoscopies are inaccurate (6%) than Māori (28%) and Pacific respondents (27%) (Figure 48).

Across the other aspects of colonoscopies (and unlike views on the FOBT), opinion is more polarised (Figure 44–47). Around half of respondents disagree that colonoscopies are embarrassing (51%), inconvenient (49%) and painful (44%) and one third agree they are (35%, 34% and 32% respectively). While half of respondents disagree that colonoscopies are messy (54%), around one quarter believe they are (24%).

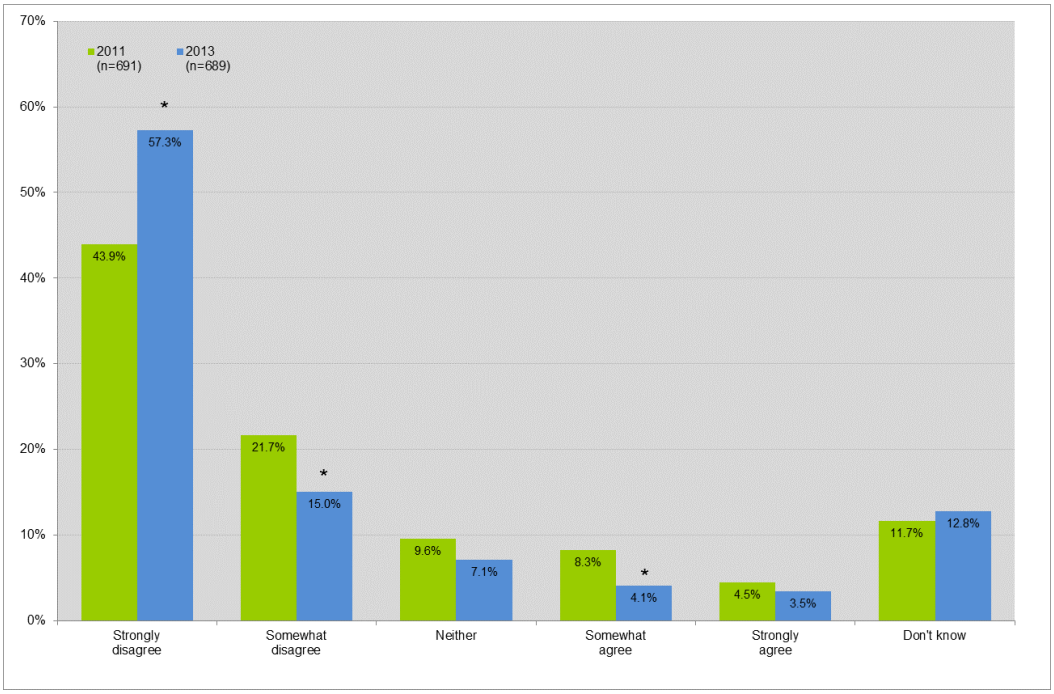
Those who have never had a colonoscopy are more likely to agree that colonoscopies are embarrassing (44%) or painful (41%) than those who have had one (22% and 15% respectively). The younger age group are more likely to perceive colonoscopies as embarrassing (38%) than the older group (25%). Women (37%) and the Other group (32%) are more likely to agree they are painful than men (26%) and Māori (20%) respectively (Figure 49 and 50).

Based on the combined 2011 and 2013 ethnicity data, Pacific respondents are more likely to agree that colonoscopies are painful (40%), inaccurate (34%), and messy (36%).

Analysis of the recontact sample shows attitudes:

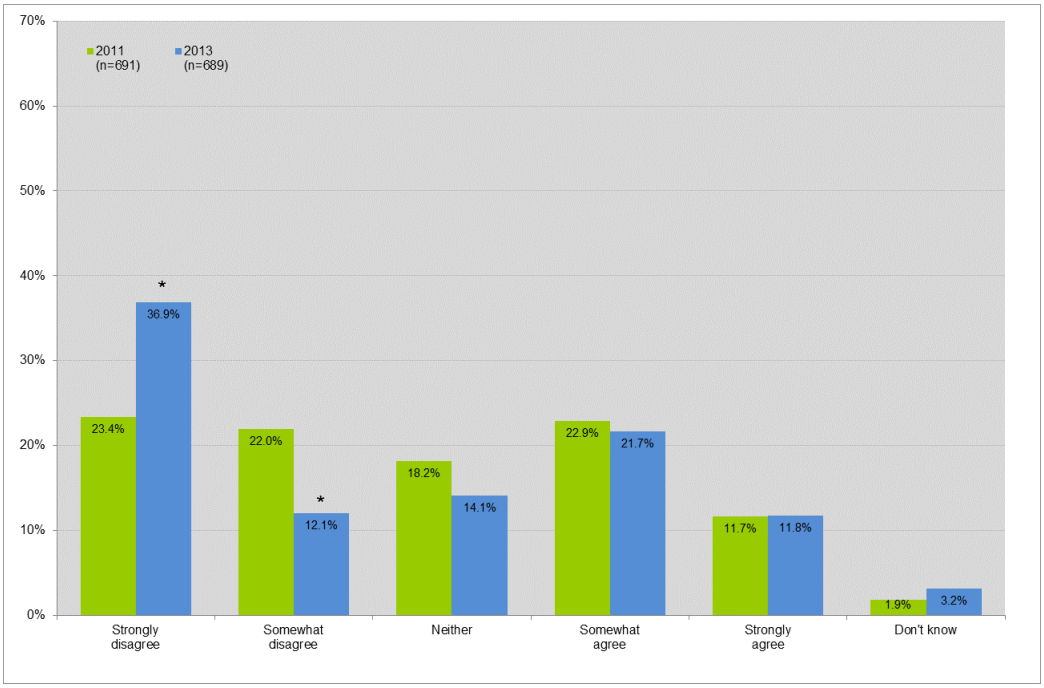
- are fairly static that colonoscopies are embarrassing
- have shifted somewhat from neutral to disagree towards colonoscopies being messy and inconvenient
- are not firmly, fixed with a moderate proportion of those agreeing that colonoscopies are painful in 2011 now disagreeing and vice versa
- have markedly shifted from agreement to disagreement that colonoscopies are inaccurate.

Figure 43: Agreement that colonoscopies could be inaccurate, Waitemata District Health Board, 2011 and 2013



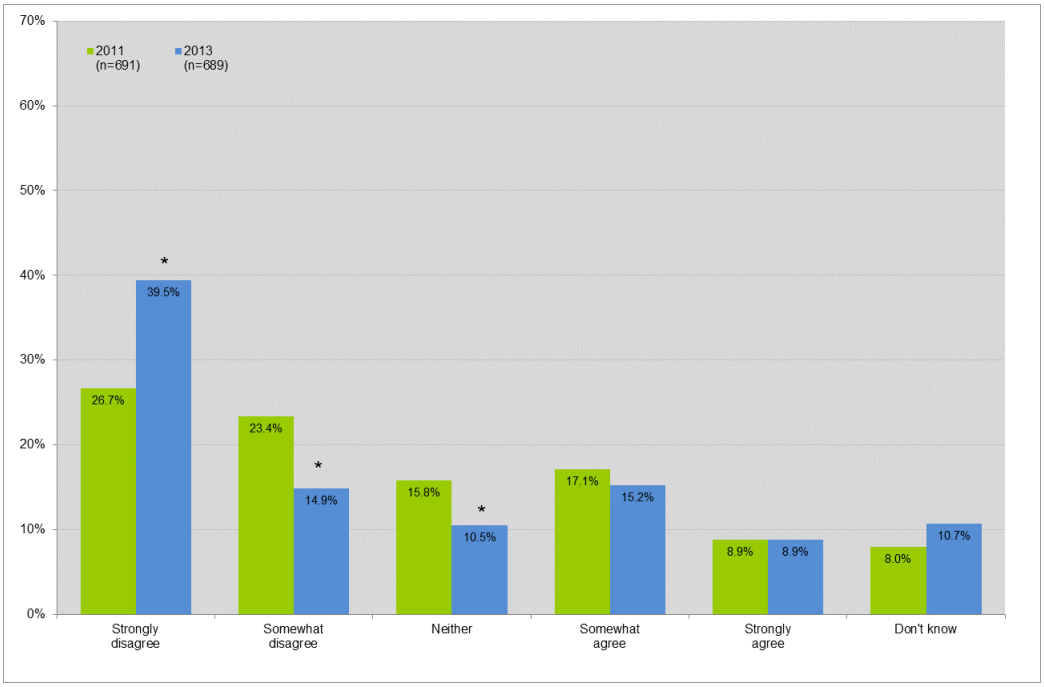
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 44: Agreement that colonoscopies could be inconvenient, Waitemata District Health Board, 2011 and 2013



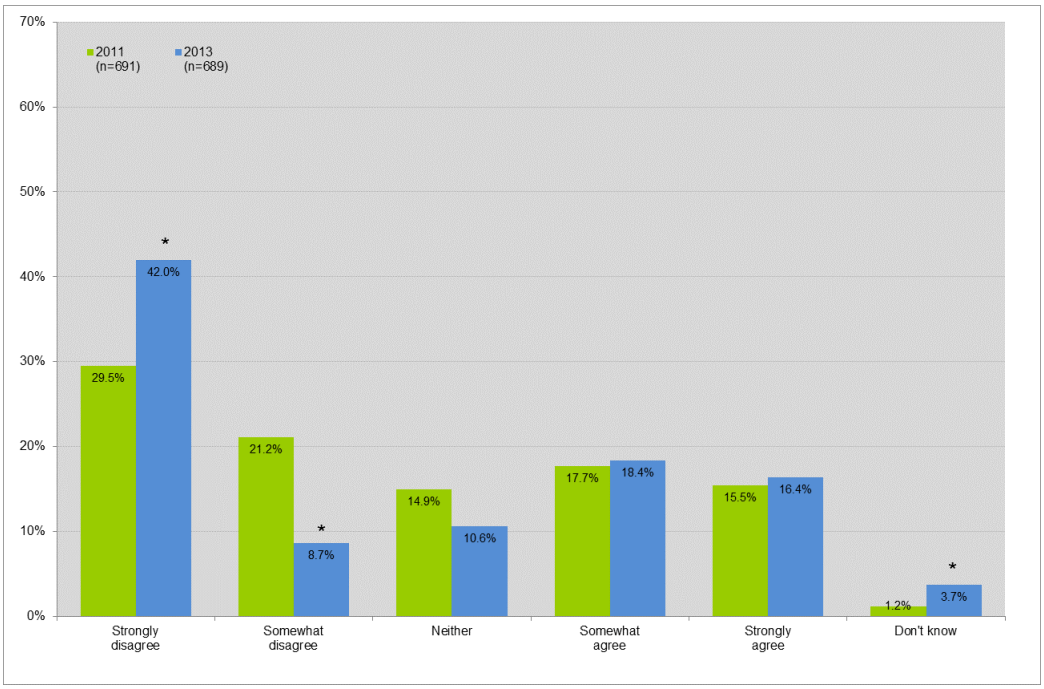
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 45: Agreement that colonoscopies could be messy, Waitemata District Health Board, 2011 and 2013



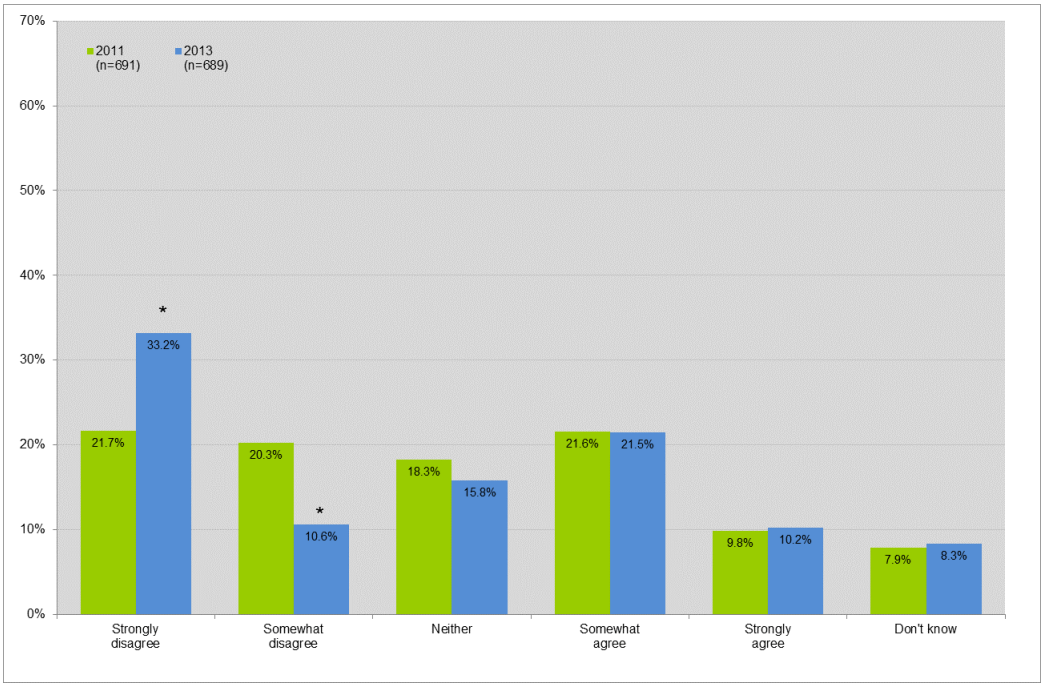
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 46: Agreement that colonoscopies could be embarrassing, Waitemata District Health Board, 2011 and 2013



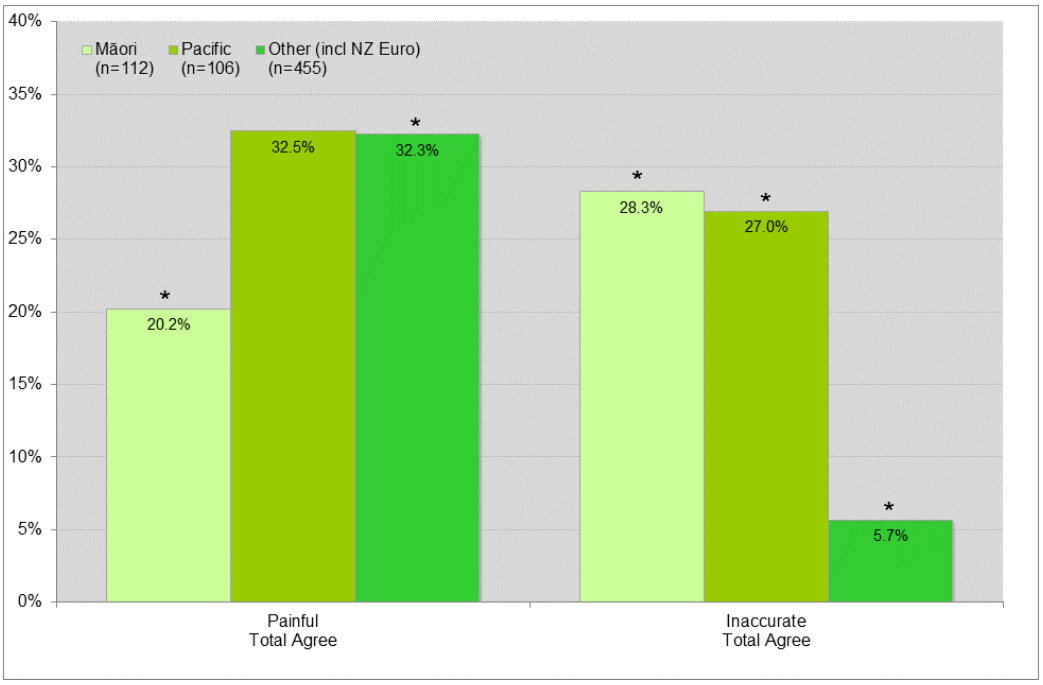
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 47: Agreement that colonoscopies could be painful, Waitemata District Health Board, 2011 and 2013



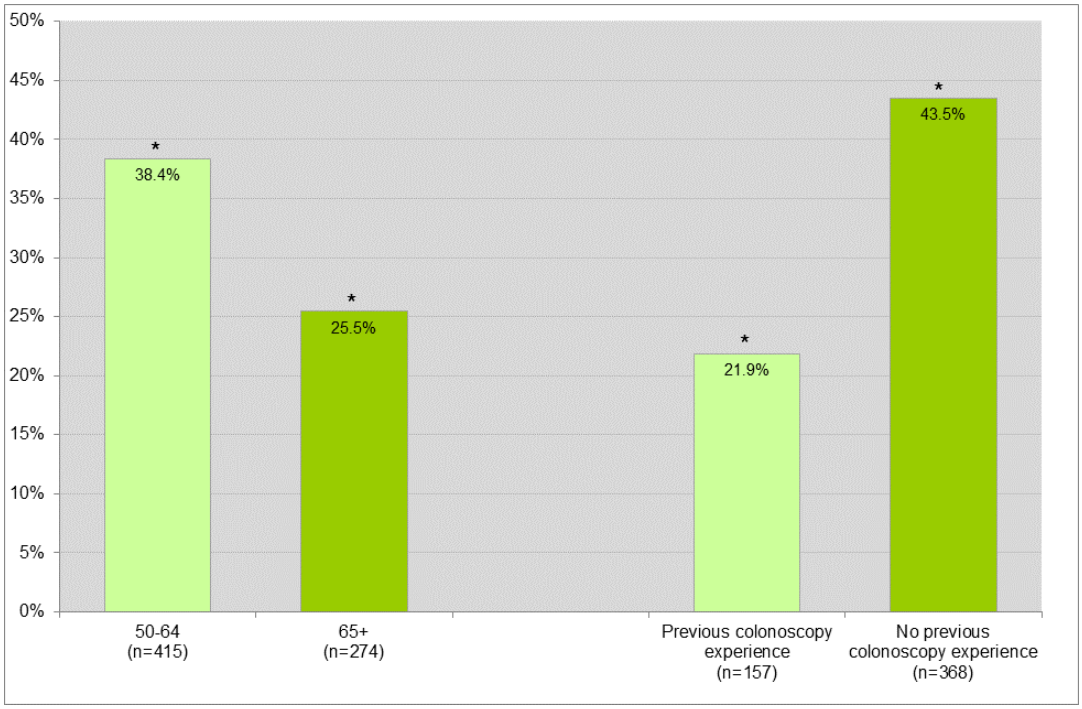
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 48: Agreement about colonoscopies by ethnicity, Waitemata District Health Board, 2013



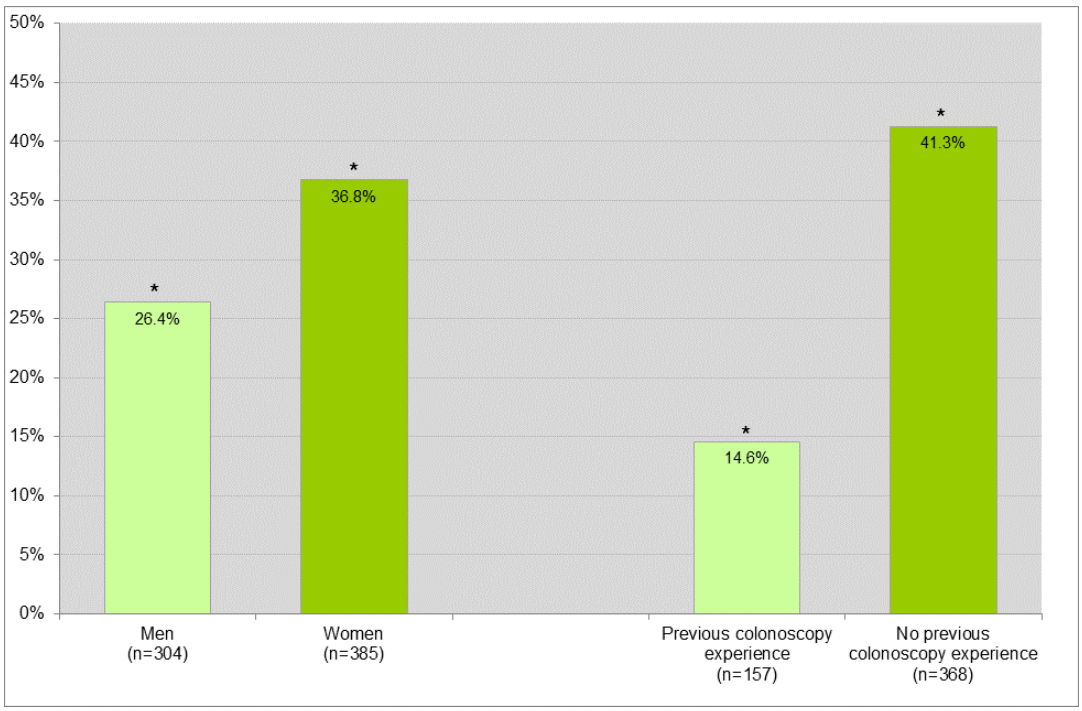
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys 2013

Figure 49: Agreement that colonoscopies could be embarrassing by age and previous experience, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys 2013

Figure 50: Agreement that colonoscopies could be painful by gender and previous experience, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys 2013

Summary: Compared to 2011, there is no change in respondents' perceived risk of developing bowel cancer.

Perceptions of the FOBT are changing with a statistically significant increase in disagreement that the FOBT is embarrassing, painful, messy, inconvenient and inaccurate. Pacific respondents are more likely to perceive the FOBT as inconvenient, embarrassing, inaccurate and painful than the Other group. Some respondents continue to be unsure about the accuracy of the FOBT.

In contrast, respondents are less likely to consider colonoscopies to be inaccurate, but more likely to view them as embarrassing, painful and inconvenient. Pacific respondents are more likely to perceive colonoscopies as inaccurate, messy and painful.

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 each. Specifically, they were asked to indicate how much they agree or disagree with the following statements (Figures 51–56):

- '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'.

Two extra attitudinal questions were asked in the 2013 survey, to identify respondent preference for notification of FOBT results:

- 'It is very reassuring if your GP or a practice nurse is the one who tells you if you have a positive FOBT test result'
- 'You are happy for someone else from the screening programme to contact you if you have a positive FOBT result'.

Nearly all WDHB respondents agree (97%) that early treatment of bowel cancer will increase the odds of survival and 91% strongly agree (Figure 51).

There is strong agreement (87%) with the importance of checking for bowel cancer without the presence of symptoms with 75% strongly agreeing with this statement (Figure 52). Agreement about the importance of checking for bowel cancer without the presence of symptoms is higher amongst:

- Pacific respondents (90%) than those from the Other ethnic group (81%) (based on the combined 2011 and 2013 ethnic data).
- Those with a family history of bowel cancer (95%) than those without (84%)
  - Compared to 2011, there is a significant increase in agreement with the importance of checking for bowel cancer without the presence of symptoms amongst those with and without a family history of bowel cancer (87% and 75% respectively in 2011).
- Those recently screened for bowel cancer (89%) than those not (69%).

There is a high level of agreement that at-home FOBTs are necessary even without a family history of bowel cancer with 84% agreement overall (Figure 53). From 2011, there has been a statistically significant increase in those agreeing with this statement from 68% to 84%. This increase is evident across gender, age and the Other ethnic group, those with no family history and those aware of the FOBT. Māori (68%) are less likely to agree that at-home FOBTs are necessary even without a family history of bowel cancer than Pacific (80%) and Other respondents (75%) based on the combined 2011 and 2013 ethnicity data.

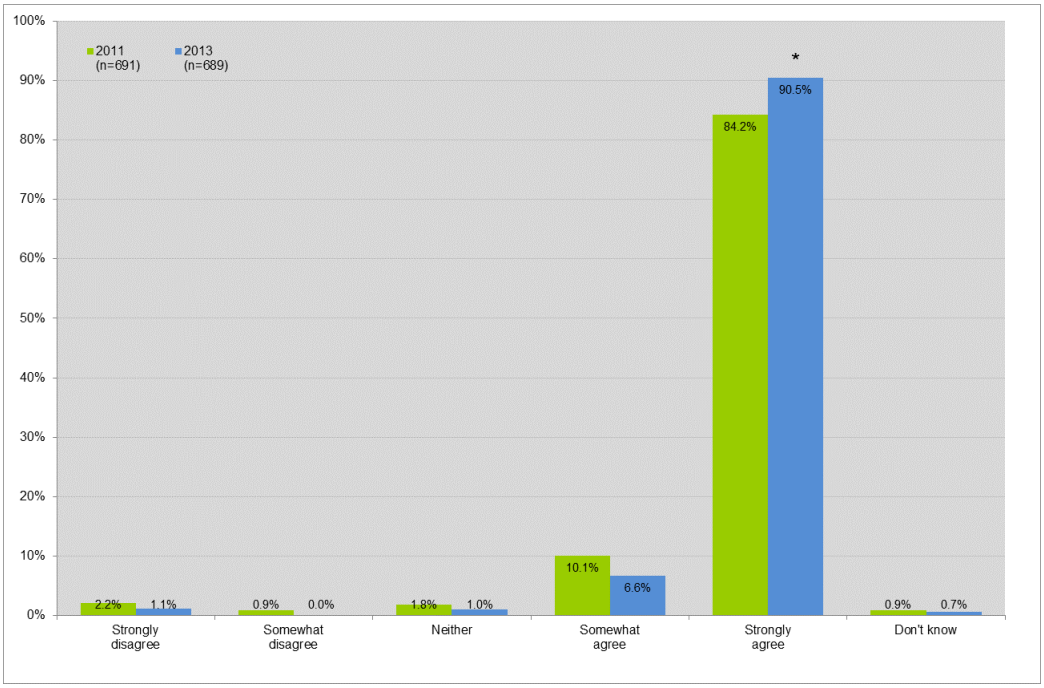
Disagreement with the statement that at-home FOBTs are more trouble than they are worth has increased from 75% in 2011 to 84% in 2013 (Figure 54). In 2013, three quarters of respondents (77%) strongly disagree with this statement. Total disagreement with this statement has increased for men, both age groups and the Other ethnic group. In contrast, Pacific respondents (28%), those not aware of the FOBT (28%) and those who have not heard of the BSP (23%) are more likely to agree that at-home FOBTs are more trouble than they are worth than the Other ethnic group (8%), those aware of the FOBT and BSP (7% and 9%).

Two new attitudinal questions were asked in the 2013 survey to identify whether respondents had a preference about who tells them about FOBT results (Figures 55–56). The findings highlight that both are acceptable. Eight in ten (80%) agree it is very reassuring for their GP or practice nurse to tell them if they have a positive FOBT test result. Similarly, 76% are happy to be contacted by someone else from the BSP to tell them about a positive FOBT result. Māori (87%) are more likely to agree than the Other ethnic group (75%) that they are happy for the screening unit to contact them.

Analysis of the recontact sample shows the following changes in attitudes at an individual level:

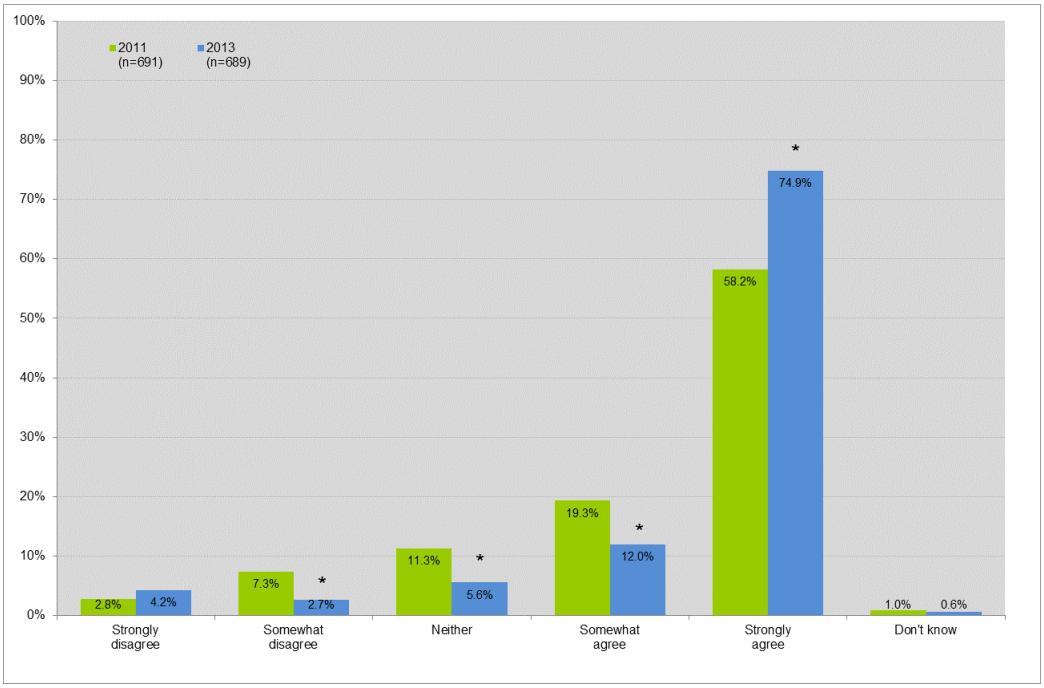
- A marked increase in disagreement that FOBT tests are more trouble than they are worth
- A shift from neutral and disagree to agreement that it is important to check for bowel cancer even if you don't have symptoms, and from moderate agreement to strong agreement
- A marked shift to agreement that doing an FOBT is necessary even if there is no family history of bowel cancer
- Opinions on treating bowel cancer in early stages increases a person's chance of survival have become even more strongly in agreement.

Figure 51: Level of agreement with the statement 'treating bowel cancer in the early stages increases a person's chance of survival', Waitemata District Health Board, 2011 and 2013



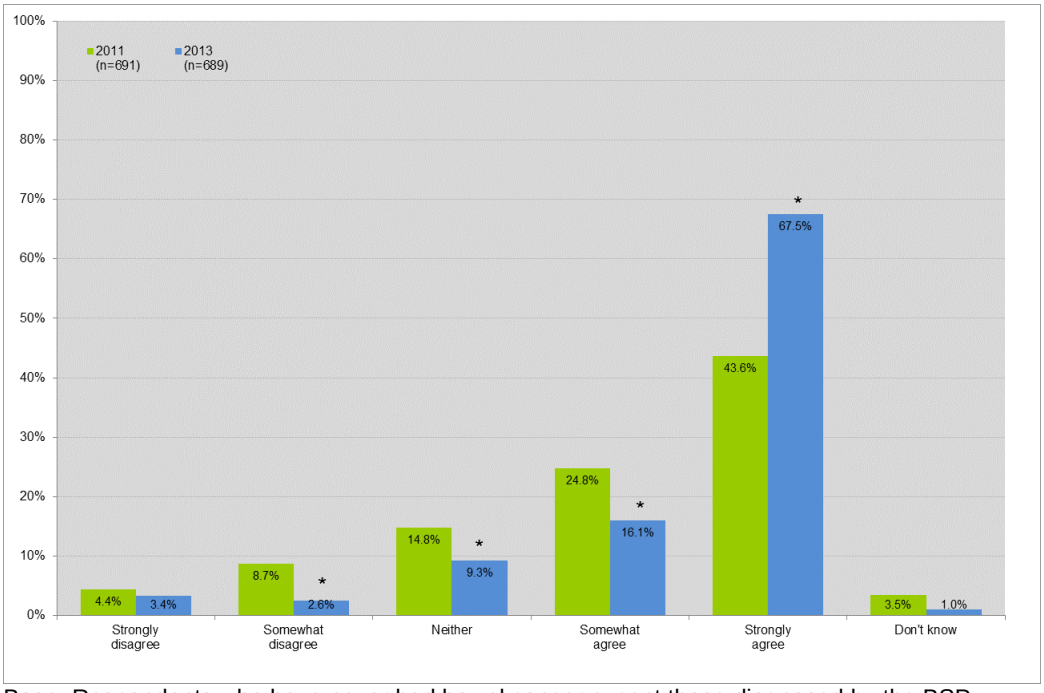
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 52: 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, 2011 and 2013



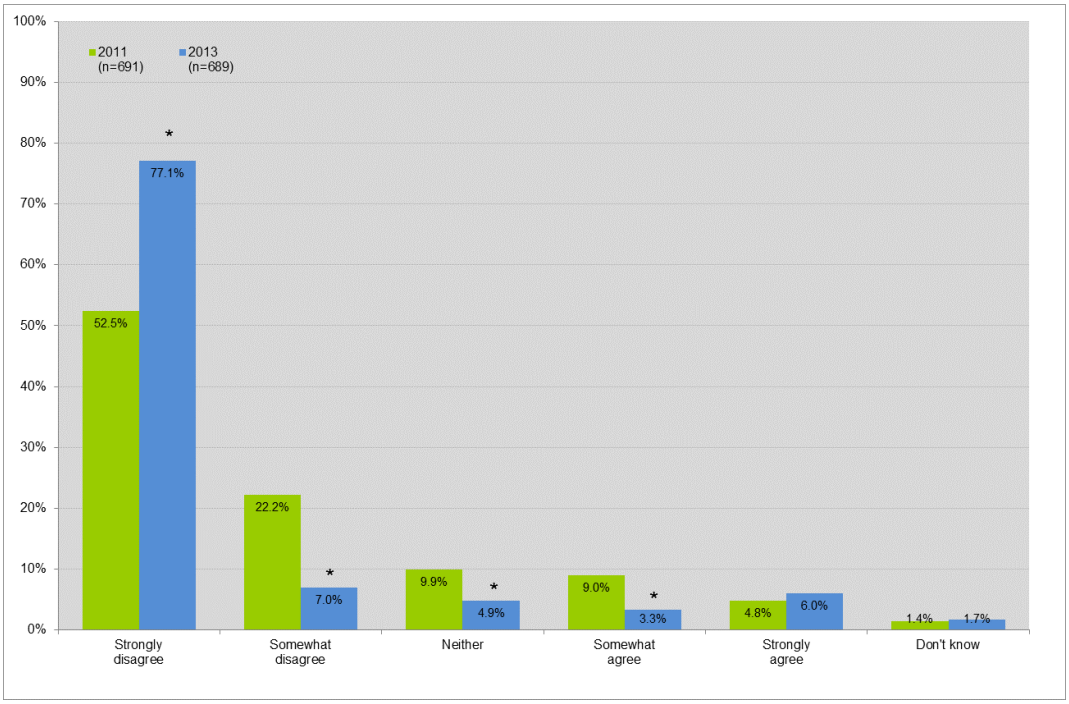
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 53: 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, 2011 and 2013



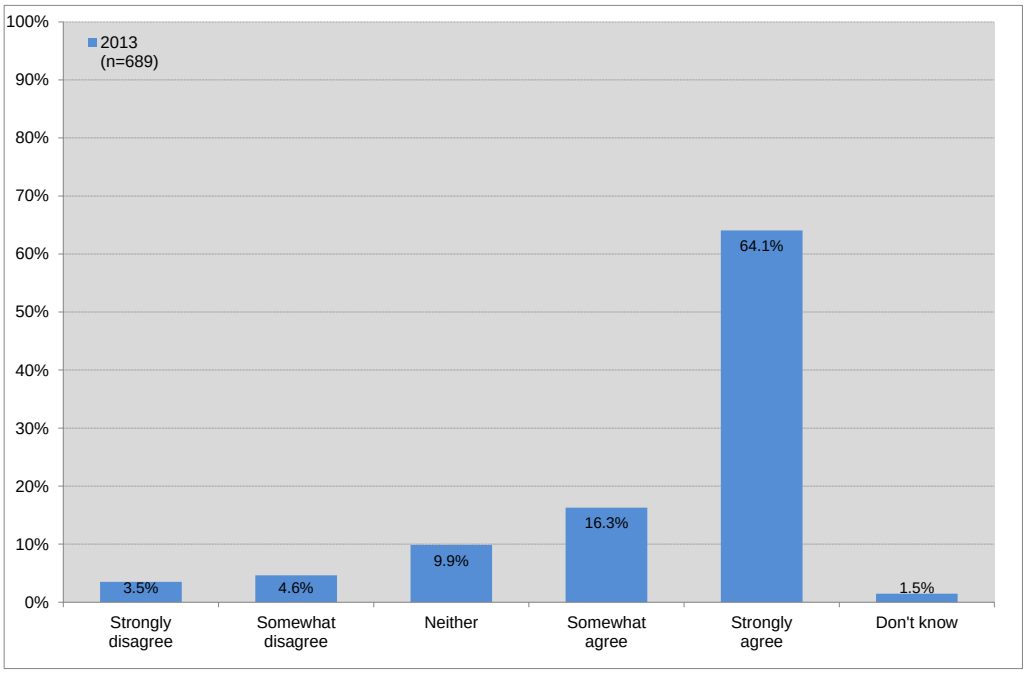
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 54: 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, 2011 and 2013



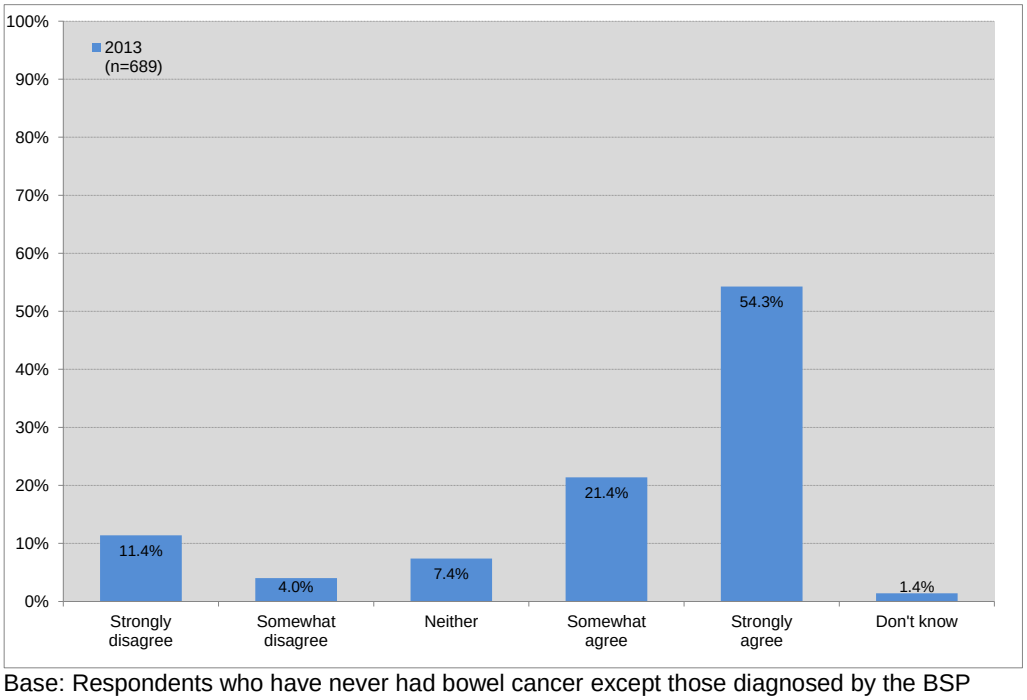
Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 55: Level of agreement with the statement 'it is very reassuring if your GP or practice nurse is the one who tells you if you have a positive FOBT test result', Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone survey, 2013
Note: Not asked in 2011

Figure 56: Level of agreement with the statement 'you are happy for someone else from the screening programme to contact you if you have a positive FOBT result', Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone survey, 2013
Note: Not asked in 2011

Summary: Overall nearly all respondents agree that early treatment of bowel cancer will increase the odds of survival and that it is important to check for bowel cancer without the presence of symptoms. Respondents agree that at-home FOBTs are necessary even for those without a family history of bowel cancer, and disagree they are more trouble than they are worth. However, one quarter of Pacific respondents agree they are too much trouble.

Respondents find it very reassuring to receive positive FOBT results from their general practice, although they are also happy to receive positive results directly from the screening programme.

4.5 Participation in the Waitemata District Health Board bowel screening pilot

A number of questions asked if people had recently received a BSP invite letter and/or iFOBT kit in the mail. Subsequent questions asked if people had completed, or intended to complete, the kit, if the information they received was easy to understand, whether or not they had been notified of their results, and, if so, if they had proceeded to having a colonoscopy.

Awareness of the Waitemata District Health Board Bowel Screening Programme

WDHB respondents who had not previously mentioned the WDHB BSP specifically, (31% had mentioned it spontaneously), 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 WDHB. Of those prompted, 83% recognised it and 17% did not.

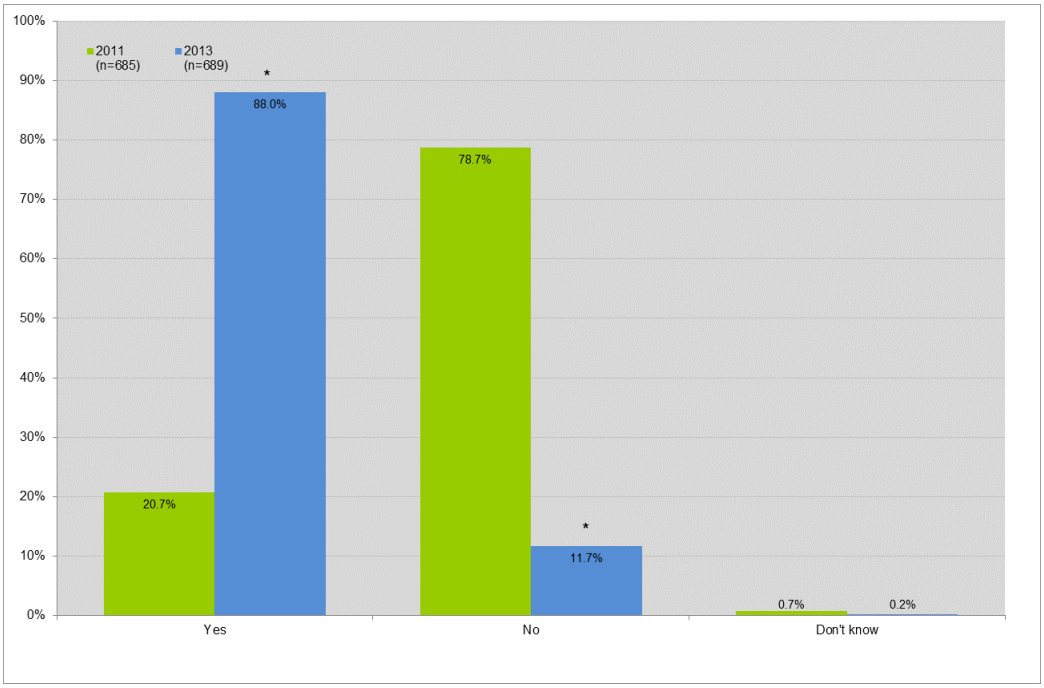
In total 88% of WDHB respondents have seen or heard about the BSP *(unprompted and prompted*); this is a statistically significant increase in awareness of the BSP from the baseline measure of 21% in 2011 (Figure 57). This statistically significant increase in total awareness of the BSP from 2011 to 2013 is evident across the following sub-groups:

- women (25% to 90%) and men (16% to 86%)
- those aged 50–64 (20% to 88%) and 65–75 (24% to 87%)
- Māori (18% to 75%), Pacific (21% to 72%), Asian (17% to 73%) and Other (21% to 90%).

In 2013, awareness of the BSP is statistically significantly lower for Māori and Pacific respondents than the Other ethnic group (75%, 72% and 90% respectively). Awareness of the BSP is higher amongst the following sub-groups:

- for those who received a BSP invitation letter and kit than those who did not (96% compared to 62%)
- those aware of the FOBT than those not aware (92% compared to 53%)
- those recently screened for bowel cancer than those not screened (97% compared to 63%).

Figure 57: Total awareness (prompted and unprompted) of the bowel cancer screening programme being run by Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Information sources on the BSP

Those respondents aware of the WDHB BSP (both unprompted and prompted) were asked where did they hear or see any information about the WDHB bowel cancer screening programme. Reflecting the promotion of the BSP, respondents noted the following key sources of information as their top-of-mind first response: the BSP letter and kit (44%), community newsletters (12%), WDHB (12%), and general practice (7%) (Table 6).

Table 6: Information sources mentioned about WDHB BSP, Waitemata District Health Board, 2013

Where did you hear or see any information about the WDHB bowel cancer screening programme?	First mention	Other mention
Unweighted Total: Respondents who have never had bowel cancer except those diagnosed by the BSP	**574**	**563**
Letter/Kit	44.4%	10.1%
Community Newsletter	12.3%	6.4%
Waitemata DHB	11.5%	4.5%
GP/ Practice Nurse	6.9%	5.8%
NZ Herald/ Dominion Post	5.4%	5.3%
Family/ friends, etc.	5.4%	5.3%
Television	3.6%	10.6%
Brochure	1.4%	3.6%
Internet	0.1%	0.6%
Pharmacy	0.1%	0.4%
Community event/ hui	0.1%	0.6%
Other source mentioned	6.8%	8.3%
Nowhere else	–	42.5%
Don't know	2.2%	3.2%
No response	0.0%	2.6%

Receipt of letter and kit

All respondents (excluding those who had bowel cancer not diagnosed through the BSP) were informed that a bowel cancer screening programme is being run in WDHB and that the programme has been mailing out invitations with an iFOBT home test kit for people to complete and send back to the lab for analysis. Respondents were asked whether they had received a letter or kit in the mail.

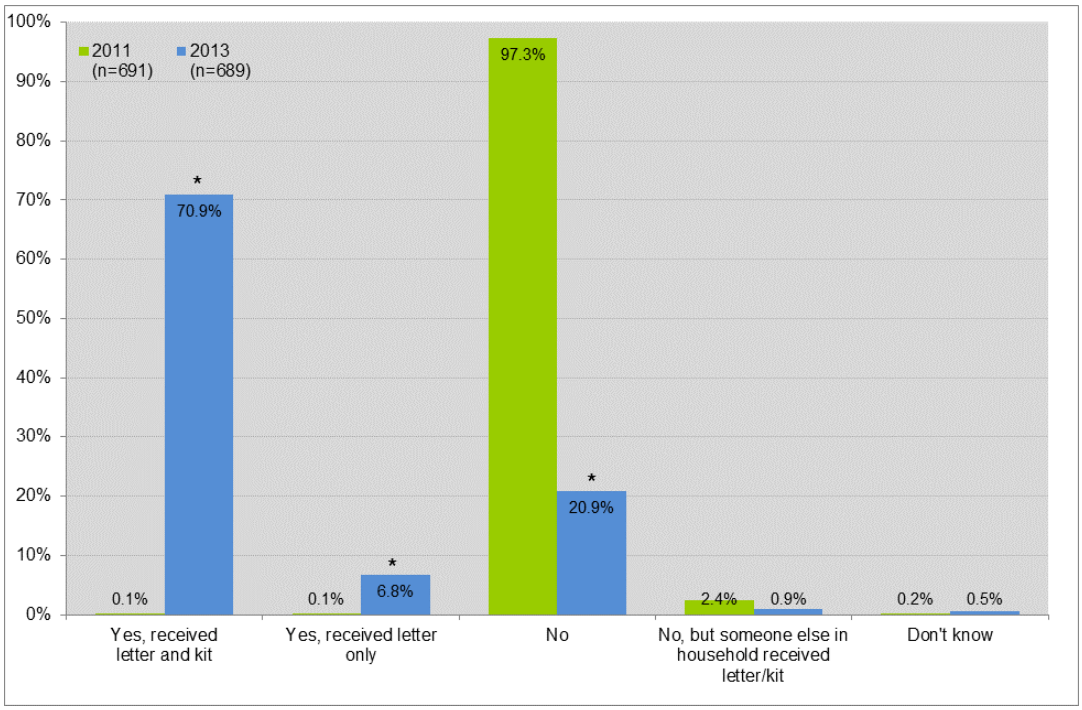
In 2013, 71% of respondents had received a letter and kit, 7% had only received the letter, and 21% had not received either (Figure 58). The significant increase in results from 2011 is due to the baseline survey being completed before the official launch of the BSP in January 2012. Men (27%) are more likely than women (15%) to say they have not received a BSP letter or kit.

Two in ten eligible respondents not receiving a BSP letter and kit is higher than expected given the 2013 survey was undertaken three months before the completion of screening round one.

Discussions with the BSP Coordination Centre highlighted that for screening round one there are 132,165 persons listed on the BSP Register of eligible status who should have received a letter and invite by the end of December 2013. At the time of the survey 124,635 had been sent a letter and a kit, therefore it is to be expected that around 6% of people eligible to participate in the BSP had not received them (due to the birthdate invite strategy and migration into region).

The BSP Coordination Centre receive about 60 return mail letters per week (i.e. no one of that name at this address); this represents approximately 6,000 pieces of returned mail up to October 2013 (about 5%). This accounts for about 10% of eligible people not receiving a BSP letter or kit at the time of the 2013 survey. However, it could be assumed that the returned mail is only a proportion of the mail sent to incorrect addresses (as noted in Litmus 2014, incorrect addresses on the BSP Register is an ongoing challenge). Assuming the 60 return letters represents about one third of the incorrectly addressed letters, the proportion of eligible BSP participants who may not have received a letter is closer to 20%, which aligns to the survey result.

Figure 58: Receipt of BSP letter or kit in the mail, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP
Source: BSP Evaluation telephone surveys, 2011 and 2013

Completion of kit

Nearly all respondents who received the BSP kit (94%) stated that the information provided in the FOBT test kits was easy to understand; 5% said they did not know as they had not read it yet. Of those respondents who had only received the invitation letter information, 87% say it is easy to understand. Small sub-sample sizes limited the ability to detect any statistically significant differences by ethnicity.

Nearly three quarters of respondents (73%) who received a BSP iFOBT have completed and returned it for testing. Completion is statistically significantly higher amongst the older age group (86%) than those aged 50–64 years (68%). Pacific respondents (55%) who received the BSP kit have a statistically significantly lower completion rate than the Other group (74%). No significant difference was noted for Māori respondents.

The reasons given for completing the BSP iFOBT include:

- health checks are important (40%)
- for peace of mind and/or reassurance (33%)
- want to know bowel cancer status (21%)
- as a precaution and/or prevention measure (20%)
- doctor supports the BSP (5% total and 12% for Pacific respondents who completed the BSP iFOBT)
- have a family history or personal experience of cancer (7%)[45].

Of those who have completed their BSP iFOBT kit, 92% have received their results. The majority of those who received their results (97%) said they received all the information they needed.

As similar to the BSP Register results, 7% who completed the BSP kit had a positive iFOBT result. Of the 23 people with a positive result, 16 heard about the positive result from their general practice, four received a letter from the BSP and three can't remember. All bar one have had a colonoscopy through the BSP[46].

Those who had received a kit and not completed it were asked whether they intend to complete the kit sometime soon. One third indicated their intent to complete the BSP iFOBT kit (39%). This intention to complete the BSP iFOBT kit was statistically significantly higher amongst men (55%) than women (28%), and Pacific respondents (79%) compared to the Other group (38%).

More than half (57%) of those who had received a BSP kit and not completed it stated they did not intend returning it. This represents 11% of the total sample of 689 respondents eligible to participate in the BSP. Small sub-sample sizes limited the ability to detect any statistically significant differences by ethnicity.

Recalculating the receipt and completion of the BSP iFOBT on the total sample of respondents eligible to participate in the BSP demonstrates that of those who received a letter and a kit (Figure 59):

- 52% completed the iFOBT which is in line with the BSP Register's participation rate of 55%[47].
- 8% intend to complete their kit. Added to the 52% who have completed this gives a potential participation rate of 59% which is similar to the noted intention of those who have not yet received their BSP iFOBT kit (see below on intention to participate in the BSP)

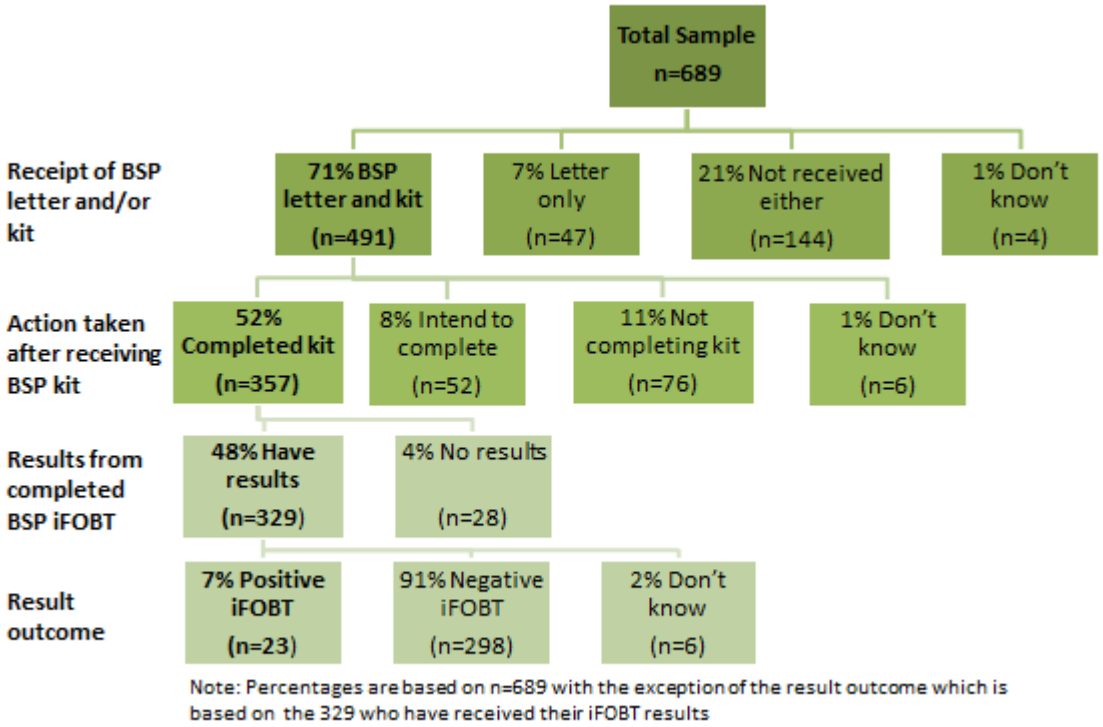
[45] Multiple response was allowed.

[46] This may reflect they are waiting for their colonoscopy.

[47] http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/bowel-cancer-programme/bowel-screening-pilot/bowel-screening-pilot-results/bowel-screening-pilot-january-2012-june-2013-results accessed 10 January 2014.

- 11% do not intend to complete the BSP iFOBT due:
  - doing other bowel tests (29 respondents)
  - not thinking they are at risk (9 respondents)
  - inconvenience/ no time (5 respondents)
  - would rather go to their doctor (5 respondents).

Figure 59: Receipt of BSP letter or kit in the mail, action taken and outcomes, Waitemata District Health Board, 2013



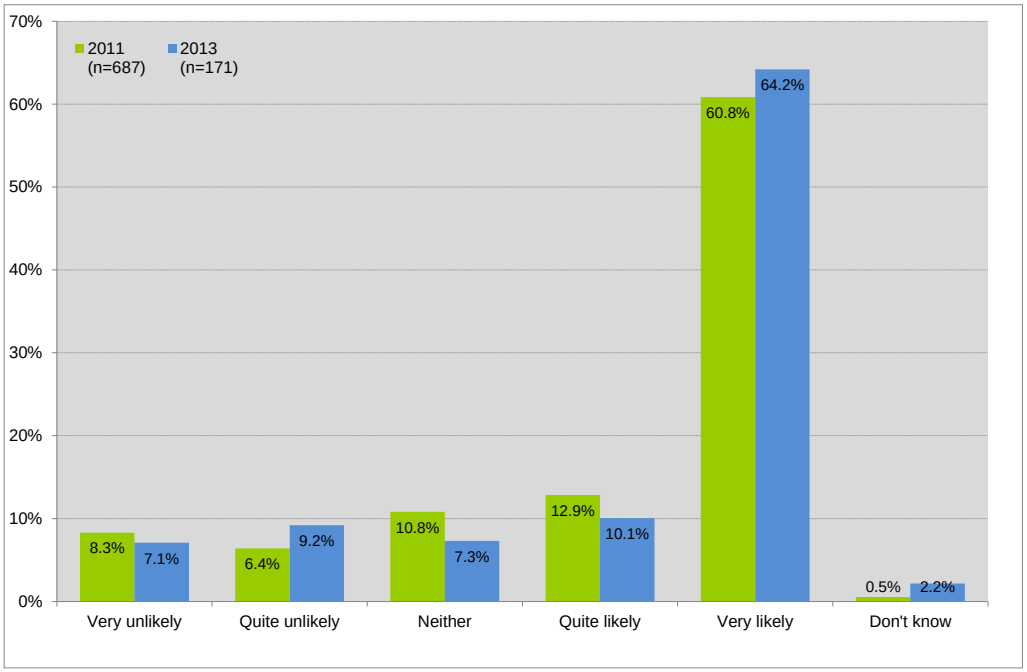
Intention to participate in the BSP

Respondents who had not received a BSP letter or kit 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 iFOBT kit that they would need to complete before sending to a laboratory.

Consistent with 2011, nearly two thirds self-reported they would be *very* likely to participate in such a programme (64% in 2013 and 61% in 2011). An additional 10% said they would be somewhat likely to participate, bringing total potential participation to 74% in 2013 (Figure 60).

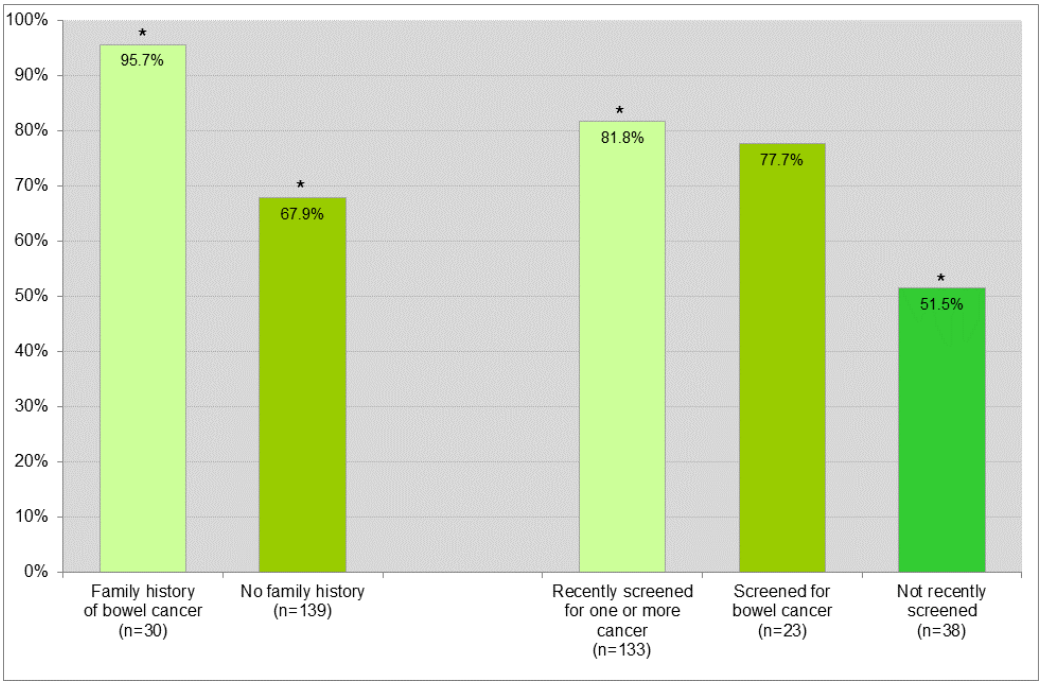
Those with a family history of bowel cancer (96%) and those who had been tested recently (82%) were statistically significantly more likely to self report they would participate than those with no family history (68%) and not been screened (52%) (Figure 61). The Other ethnic group (73%) are more likely to say they will take part than Māori (62%) and Pacific (63%) respondents (based on the combined 2011 and 2013 data).

Figure 60: Likelihood of participating in a bowel screening programme involving an at-home FOBT kit, Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP, AND not received a BSP kit
Source: BSP Evaluation telephone surveys, 2011 and 2013

Figure 61: Likelihood of participating in a bowel screening programme involving an at-home FOBT test kit by family and screening history, Waitemata District Health Board, 2013

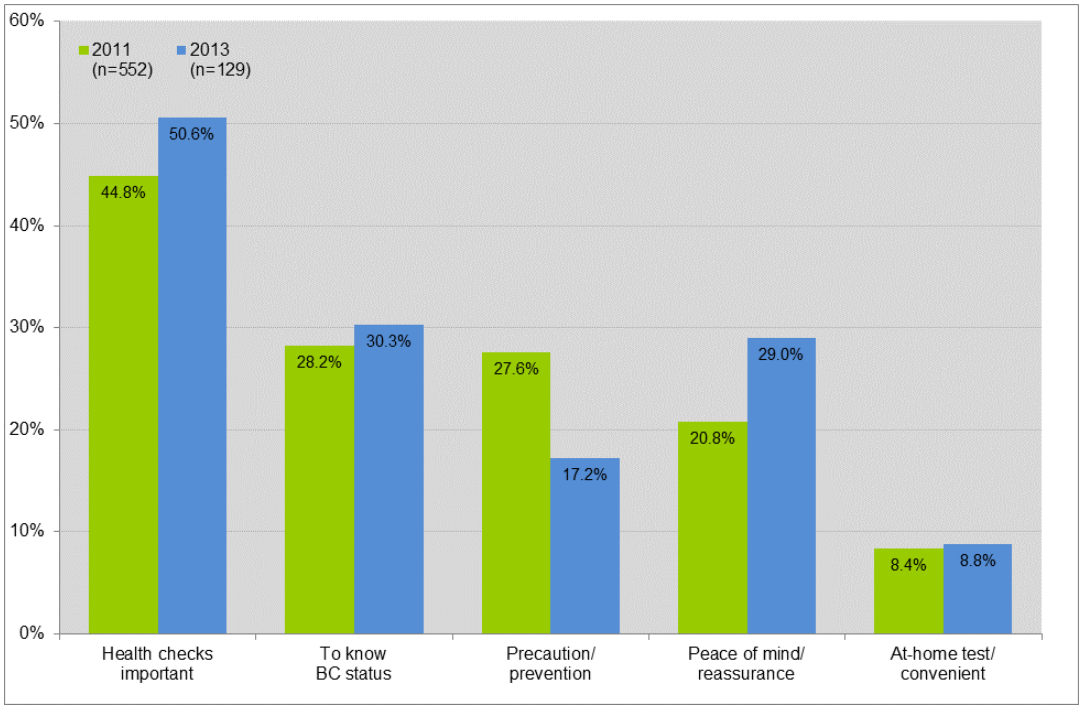


Base: Respondents who have never had bowel cancer except those diagnosed by the BSP, AND not received a BSP kit
Source: BSP Evaluation telephone surveys, 2013

Those respondents who said they would be likely to participate in a bowel screening programme involving the iFOBT kit were asked to give their reasons for this. Answers were coded to a pre-identified list of reasons.[48] In 2013 the following continue to be the main reasons respondents provide for wanting to participate (Figure 62):

- health checks are important (51%)
- want to know bowel cancer status (30%)
- for peace of mind and/or reassurance (29%)
- as a precaution and/or prevention measure (17%)
- can do the test at home and/or convenience (9%).[49]

Figure 62: Main reasons for participating in a bowel screening programme involving an at-home FOBT test kit, Waitemata District Health Board, 2011 and 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP, not received a BSP kit AND said they are likely to do an FOBT
Source: BSP Evaluation telephone surveys, 2011 and 2013
Note: BC = bowel cancer

[48] The list of reasons was identified during pretesting of the questionnaires.

[49] Multiple response was allowed.

Those respondents who have received an iFOBT kit and not completed it were asked to give their reasons for this. In 2013 the most frequently cited reasons for not participating were doing other bowel tests (38%), and not perceiving themselves to be at risk (12%).

Table 7: Main reasons for not participating in a bowel screening programme, Waitemata District Health Board, 2013

Base: Respondents who have never had bowel cancer, received a BSP kit AND not returned the kit	Total
Unweighted total:	62
Do other bowel tests (e.g. colonoscopy) already	38%
Don't think I'm at risk	12%
No reason in particular	9%
Would rather go to doctor	7%
Inconvenience/no time	7%
Doing/sending the test goes against my cultural beliefs	4%
Messy/yucky	4%
Not eligible to take part	3%
Don't want to put poo in the mail	3%
Embarrassment	2%
No family history of bowel cancer	1%
Not clean doing it at home	1%
Other	22%
Don't know	1%

Using the combined 2011 and 2013 ethnicity data the reasons the small proportion of respondents reported being unlikely to participate in a bowel screening programme were analysed to determine if there were any noted differences by ethnicity. The main reasons given by all ethnic groups on why they wouldn't take part are (Table 8[50]):

- would prefer to see doctor
- not concerned
- what will be will be/ don't really want to know
- do other bowel tests.

Māori and Pacific respondents also noted they don't want to do the test at home and the test sounds messy. These findings reflect the qualitative feedback from Māori and Pacific non-responders (Litmus 2013).

[50] Multiple response was allowed.

Table 8: Main reasons for not intending to participate in a bowel screening programme involving an at-home FOBT test kit, Waitemata District Health Board, combined 2011 and 2013 ethnicity data

Base: Respondents who have never had bowel cancer, not received a BSP kit AND said they are unlikely to do an FOBT	Māori	Pacific	Other
Unweighted Total:	43	36	87
Would prefer to see my doctor	28%	12%	20%
Not concerned	22%	13%	28%
What will be, will be/ don't really want to know	20%	15%	2%
Don't want to do the test in my home/would rather be tested	13%	12%	4%
Do other bowel tests (e.g. colonoscopy) already	7%	3%	11%
Lack of time/too busy	6%	2%	6%
The test sounds messy/inconvenient/complicated	6%	9%	6%
Recently done an FOBT/at-home test or taken a poo sample to lab/doctor for testing	3%	0%	1%
Might not be conclusive/ give the correct result	2%	2%	5%
Only people with a family history or symptoms need to do the test	2%	4%	13%
Don't want to put poo in the mail	2%	3%	0%
Don't like getting things like that in the mail/ don't know who sent it to me	0%	0%	9%
No other reason in particular	8%	14%	3%
Other	17%	20%	11%

Summary:

Awareness of the BSP is very high with nine in ten respondents aware of the Pilot. Given the BSP kit and letter are the main source of information about the BSP, those who have received an invitation letter and kit have the highest level of awareness. While awareness of the BSP has increased for Māori and Pacific respondents, their awareness remains statistically significantly lower than the Other ethnic group.

Nearly three quarters of respondents had received the BSP letter and kit, while two in ten had not. Of those who had received a BSP kit, three quarters said they had completed and returned it. Based on the total sample this equates to half of respondents participating in the BSP, similar to the BSP Register participation rate of 54%. Pacific people are less likely to have completed the kit than the Other group. No statistically significant difference was noted for Māori respondents.

Two thirds of those respondents who had not received a BSP kit self-reported they would be *very* likely to take part in a bowel cancer screening programme if they received an iFOBT kit in the mail. Māori and Pacific people were less likely to agree they would take part than the Other group. Reasons for taking part reflect the importance of health checks, wanting to know their bowel cancer status and for peace of mind. Those not wanting to take part cite a preference for seeing their doctor, a lack of concern, a laissez faire attitude of what will be will be and that they do other bowel tests (e.g. colonoscopy). For Māori and Pacific, a reluctance to do the test at home and the perception the iFOBT is messy was also mentioned.

5. Discussion

This report provides a follow-up measure of the WDHB eligible population's awareness, knowledge and attitudes towards bowel cancer and bowel cancer screening. The follow-up measure is compared to the baseline information, collected from WDHB in 2011. 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 BSP iFOBT.

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

Moderate knowledge of bowel cancer prevalence: Awareness of the bowel cancer burden for men and women continues to differ. There is reasonable recognition of the bowel cancer prevalence for men. While there has been a small increase in the recognition of the bowel cancer prevalence for women, 'high profile' female cancers (i.e. breast and cervical cancer) continue to dominate the perceived burden of cancer. 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.

Increasing but continuing variance in awareness of bowel cancer symptoms and risk factors: The perceived risk of getting bowel cancer continues to be low. Positively, there is an increase in respondents' reported confidence in recognising the symptoms of bowel cancer. More than half of respondents are now confident that they would recognise a symptom, in particular increased awareness of blood in bowel motions and a change in toilet habits. Confusion continues about whether the bowel not completely emptying is a symptom of bowel cancer.

Since 2011, there is a statistically significant increase in recognition that a diet low in fibre and a family history of bowel cancer are risk factors for bowel cancer. The influence of exercise, red meat and a diet containing sufficient fruit and vegetables continues to be less well recognised as risk factors, and some disagree they are risk factors. There continues to be an opportunity for improving people's knowledge of the full range of risk factors for bowel cancer and symptoms of the disease.

Increased awareness of FOBT: Reflecting the BSP launch and distribution of BSP letters and kits, there is a statistically significant increase in awareness of the FOBT. Since 2011 perceptions of the FOBT have changed with a statistically significant increase in disagreement that the FOBT is embarrassing, painful, messy, inconvenient and inaccurate. At an individual level there is a marked shift in more favourable attitudes towards the FOBT. Some respondents however continue to be unsure about the accuracy of the FOBT, and those who have not returned the BSP iFOBT kit are more likely to find them embarrassing.

In contrast, more respondents are less likely to consider colonoscopies to be inaccurate, but more likely to view them as embarrassing, painful and inconvenient. Those who have never had a colonoscopy are more likely to view it as painful and embarrassing.

Recognised importance of bowel screening: Responses to attitudinal questions about bowel screening indicate the ongoing recognition of the importance of checking for bowel cancer. Since the launch of the BSP, there is stronger agreement that testing is important even when there are no symptoms or no family history of bowel cancer. Greater acceptance of the FOBT is noted with rejection that the test is 'more trouble than it's worth'.

Increased awareness of the BSP: Awareness of the BSP is very high and the BSP kit and letter are the main sources of information about the Pilot. Those who have received an invitation letter and kit have the highest level of awareness.

Participation in the BSP: Nearly three quarters of respondents had received the BSP letter and kit, while two in ten had not. The level of respondents not receiving a kit is higher than expected given the timing of the survey. Potential reasons for not receiving a BSP kit include distribution strategy, migration into WDHB region, and the BSP Register containing incorrect contact details.

Of those who had received a BSP kit, three quarters said they had completed and returned it, with older people and those in the Other ethnic group being more likely to complete. Based on the total sample, this equates to half of respondents participating in the BSP, similar to the BSP Register participation rate of 54%. Reasons for taking part reflect the importance of health checks, wanting to know their bowel cancer status and for peace of mind.

Two-thirds of those respondents who had not received a BSP kit self-reported they would be very likely to take part in a bowel cancer screening programme if they received an iFOBT kit in the mail. Those not wanting to take part cite a preference for seeing their doctor, a lack of concern, a laissez faire attitude of 'what will be will be' and that they do other bowel tests.

Variation in the underscreened populations' responses: Differences in responses by Māori and Pacific respondents were noted across the survey. These differences are noted below to offer insight into the reasons that may underlie their lower levels of participation in the BSP[51].

- **Māori** have low awareness of the prevalence of bowel cancer and the risk factors of bowel cancer, in particular, having a close family relative with bowel cancer and a diet low in fibre. Awareness of bowel cancer symptoms is also low particularly with regard to a change of bowel habits. Although awareness of bowel cancer tests including the FOBT and colonoscopies has increased since 2011, it remains lower than the Other ethnic group. Likewise awareness of the BSP has increased but is also comparatively low.

  Māori are the least likely to have their doctor suggest a bowel cancer test. There is no statistically significant difference in Māori participation in the BSP based on the findings of the survey. Māori who have not participated mentioned the reasons given above and some also note a reluctance to do the test at home.

  The survey suggests that for Māori low awareness and knowledge are likely drivers to lower participation noted in the BSP Register participation rates. For Māori, these patterns could be a reflection of the lower levels of health literacy amongst this group.[52]

- **Pacific people**[53] are less aware of the risk factors for bowel cancer, in particular, having a close family relative with bowel cancer and a diet high in fibre; although they are more aware than others of the risks associated with being overweight. One third do not know any bowel cancer symptoms.

  Pacific people are not confident that they can identify bowel cancer symptoms, although they continue to be statistically significantly more likely to feel they may develop bowel cancer. Pacific people have low awareness of bowel cancer symptoms and when promoted some disagree that changes noted are related to bowel cancer. Pacific people are also less likely to note a family history of bowel cancer.

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[51] Between January 2012 and June 2013, the participation rate for Pacific people was 25%, Māori was 43%, and the Other population group was 58%. http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/bowel-cancer-programme/bowel-screening-pilot/bowel-screening-pilot-results/bowel-screening-pilot-january-2012-june-2013-results accessed 5 December 2013.

[52] http://www.healthliteracy.org.nz/about-health-literacy/health-literacy-statistics/ Accessed 27 February 2012.

[53] Differences between specific Pacific ethnicities, however, cannot be determined from the survey.

Pacific people have a low level of awareness of bowel cancer tests including FOBT. Further, when told about bowel cancer tests they are more likely to perceive the test as inconvenient, embarrassing, inaccurate and painful, and colonoscopies as inaccurate, messy and painful.

Compared to 2011, there is a statistically significant increase in Pacific people saying their GP has suggested they do a bowel cancer test. The latter may reflect the increasing activities to encourage and support Pacific people to participate in the BSP.

Pacific respondents' awareness of the BSP is lower (although it has increased since 2011). Pacific respondents are also the least likely to have completed the BSP kit, although they have high levels of agreement that it is important to check for bowel cancer even without symptoms. Reasons for not completing reflect those mentioned above as well as perceiving the kit as messy and not wanting to do it at home.

For Pacific people the survey suggests that, like Māori, the lack of awareness and knowledge about the prevalence of bowel cancer, symptoms, risk factors and the BSP contribute to non-participation. Pacific people also hold negative views of the iFOBT (and colonoscopies) which are likely to be impeding their participation.

A number of other key statistically significant sub-group distinctions are evident within WDHB.

- *Women* are more likely than men to agree that having a close relative with bowel cancer is a risk factor, and to mention a change in bowel normal toilet habits as a symptom of bowel cancer. Men are more likely than women to say they have not received a BSP letter or kit. Women are more likely to perceive colonoscopies as painful.
- *The younger cohort* is less confident at recognising bowel cancer symptoms than the older cohort within the 50–74 age group. The older cohort is more likely to have ever done an FOBT.
- Those respondents with a *household income of less than $25,000 per annum* are more likely to agree that being overweight is a risk factor for bowel cancer than those on over $100,000 per annum. In contrast, they were less aware of other risk factors, less confident at recognising bowel cancer symptoms, and less likely to mention the WDHB BSP test.
- Those with no previous experience of an FOBT, have not recently done screening tests and did not intend to return a BSP kit are more likely to agree that the FOBT is embarrassing.

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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 unlikely due to chance and therefore 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.

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.

For clarification, in this report the following abbreviations have been used:

- BSP – Bowel Screening Pilot
- DHB – District Health Board
- iFOBT – immunochemical faecal occult blood test [54]. A single sample iFOBT test is being used in the BSP. The test is known as OC-Sensor.
- FOBT – faecal occult blood test
- GP – General Practitioner
- The Ministry – Ministry of Health
- MoH – Ministry of Health
- The Pilot – the Bowel Screening Pilot/BSP
- WDHB - Waitemata District Health Board
- The Register – BSP information system.

[54] Referred to internationally as Faecal Immunochemical Test for Haemoglobin (FIT)

8. Appendix

Appendix 8.1: Waitemata District Health Board Questionnaire, 2013

Appendix 8.2: Waitemata District Health Board Questionnaire, 2011

Appendix 8.1: Waitemata District Health Board Questionnaire, 2013

BOWEL SCREENING PILOT (BSP) EVALUATION

WDHB FOLLOW-UP SURVEY - 2013

[Intro -Screening questions for Random Main/Random Booster]

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 15 minute survey on this subject with people aged 50-74.

To thank you for your time you will go into a draw to win one of 10 $50 Warehouse vouchers.

Intro adjusted according to quotas for Males and Females

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 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?

To thank you for your time you will go into a draw to win one of 10 $50 Warehouse vouchers.

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

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.

To assess the quality of my interviewing my Supervisor may listen to this call.

GENDER –*Question to be available for all sample <u>including Re-contacts</u>*
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

<u>[Intro -Screening questions for Recontact Main and Recontact Booster]</u>

[Re-contacts from 2011 intro starts here]

Good morning/afternoon, my name is (insert name) from Reid Research Services, calling on behalf of Litmus Research and the Ministry of Health.

May I please speak with…(insert re-contact name)

We are calling because you kindly took part in a survey back in 2011, and you agreed for us to contact you again – the information you provided then was really useful, and we're hoping that you are still happy to take part in this follow-up survey?

To thank you for your time you will go into a draw to win one of 10 $50 Warehouse vouchers

The survey will take 15 minutes.

INTERVIEWER NOTE: If told respondent is unwell/has passed away please say the following in a gentle and sensitive way:

We do apologise for contacting you at this time - [2011 respondent name] kindly took part in our survey in 2011, and [his/her] contribution was so helpful and very much appreciated. We are sorry to have bothered you - please accept our [condolences / best wishes - depending on circumstances].

Say if required
The Survey was for the Ministry of Health and is aiming to understand what people know and think about screening for cancer with planning for future cancer services. This is a really important issue for New Zealanders. Please be assured the survey is completely confidential. Your answers will be grouped with others who do the survey.

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

To assess the quality of my interviewing my Supervisor may listen to this call.

Code gender (see GENDER above)

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 – Screen out if from Random Main/Random Booster, Continue if a Re-contact
4. Refused – Screen out Screen out if from Random Main/Random Booster, Continue if a Re-contact

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 - Screen out if from Random Main/Random Booster, Continue if a Re-contact
5. Don't Know - Alt+S [ask for Suburb]**
6. Refused – Screen out Screen out if from Random Main/Random Booster, Continue if a Re-contact

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

No S4

S5. Which of the following age groups do you fit in to? (READ OUT)

Interviewer Instruction-Do not Recontact for someone else in the household, if from Recontact Main or Recontact Booster

1. Less than 50 years – if from Random Main/Random Booster 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 – If from Random Main/Random Booster- Recontact if possible - Else Screen out -If from Recontact Main or a Recontact Booster- Do not screen out-Continue
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/Pākehā/Kiwi/New Zealander
2. Māori
3. Samoan
4. Cook Island Māori
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-Screen Out (Random Booster only)

Screen out based on ethnicity for Māori/Pacific Boosters only

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.

Please take as much time as you need before answering, and if there are any questions you would rather not answer, just say so.

1A. Which of the following do you think is <u>the most</u> 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 <u>next most</u> 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 <u>the most</u> 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 <u>next most</u> 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 2012 or 2013. Just so we are clear, a screening test is a test you have when you <u>don't have</u> 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 check 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 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 Waitemata DHB's 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)
   i.e ***No mention*** *of Waitemata DHB's Bowel Screening Programme or Waitemata DHB's FOBT)*

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 will probably have 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 will 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 Endoscopy Unit / hospital 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 any FOBT at- home poo test kit (includes a FOBT test from the doctor, from chemist, over the counter) or WDHB Bowel Screening programme.*

1. Yes
2. No

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

If No / DK / can't remember 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. We're sure you appreciate the importance of this research, however the rest of the questions are not relevant for people who have been diagnosed with bowel cancer outside of the screening programme. We 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.

If yes at Q6A, continue to Q7, with following script before Q7:
The rest of the questions in this survey relate to bowel cancer screening – we're sure you appreciate the importance of this research, and hope that you can help us with some more information. Are you ok to continue?

1. Yes
2. No-Thank and close

Interviewer note: *If the respondent brings up their own, or a family member/friend's diagnosis with bowel cancer, please remain sensitive to this if they choose to continue with the survey – if you sense reluctance or distress with questions being asked at any point between here and the end of the survey, please (gently) check again that the respondent is fine to continue, and give them the chance to stop if it is too much.*

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 <u>not</u> 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
98. 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)**

Skip to Q13 if Yes to Q6

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 <u>from chemist/over the counter</u> (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: <u>Must</u> make specific mention of test being seen/bought at the chemist/over the counter - need to have coded 'FOBT test <u>from chemist/over the counter</u> (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 go to Q18A/Q18B and then say at Q19 "As you are aware the Waitemata DHB has been 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

If yes, ask:

18B. *Where did you hear or see any information about the bowel cancer screening programme?*

(Do not read out, code first mention)

Interviewer Instruction. Code first mention at Q18A and all others at Q18B.

01 Television
02 NZ Herald/ Dominion Post
03 Community newsletter
04 Brochure
05 Community event/ hui
06 GP/ Practice Nurse
07 Internet
08 Letter/ Kit
09 Waitemata DHB
10 Family/ friends etc..
11 Other source
12 Pharmacy
98. Don't know/Can't recall Go to Q19
99. No response/Refused Go to Q19

18C. Anywhere else?….(*Where did you hear or see any information about the bowel cancer screening programme?)*

(Do not read out, code all others)

01 Television
02 NZ Herald/ Dominion Post
03 Community newsletter
04 Brochure
05 Community event/ hui
06 GP/ Practice Nurse
07 Internet
08 Letter/Kit
09 Waitemata DHB
10 Family/ friends etc..
11 Other source

12 Pharmacy
97. Nowhere else
98.Don't know/Can't recall-
99. No response/Refused

19. This programme has been 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 Q22A

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
12. Don't want to put poo in the mail
13. Doing/sending the test goes against my cultural beliefs / what is culturally comfortable for me
14. Not eligible to take part
10. No reason in particular
11. Other
98. Don't know
99. No response/Refused

Now go to Q29

22a. What were your reasons for completing the kit? *Code multiple Do not read out*

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

23. Have you received your results yet?

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

If yes ask Q24 and Q24A, else skip to Q29

24. Who did you receive these from? *Code SINGLE response*

1. Doctor or nurse from GP Practice
2. Bowel Screening Programme Coordination Centre/ Waitemata DHB letter

4. Endoscopy Unit / hospital – phone call
5. Endoscopy Unit / hospital - letter
3. Someone else
98. Don't know/Not sure who
99. No response/Refused

Q24A. What was your FOBT result?

1. Positive
2. Negative
98. Don't know / can't recall
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

Q25A. 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 (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
13. Don't want to put poo in the mail
14. Doing/sending the test goes against my cultural beliefs / what is culturally comfortable for me
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 colonscopies have you had in the past 5 years, that's from January 2009? ***[****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 2009?]***

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

If Codes 2,3,4,5 at Q31 ask Q31A

31A. 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

32. And have you had any others more than 5 years ago, that is how many between 2003 and December 2008?

1. None at all between 2003 and 2008
2. None - had a colonoscopy more than 10 years ago (ie before 2003)
3. 1
4. 2-3
5. 4-5
6. 6 or more

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
15. Don't want to put poo in the mail
16. Doing/sending the test goes against my cultural beliefs / what is culturally comfortable for me
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
- It is very reassuring if your GP or a practice nurse is the one who tells you if you have a positive FOBT test result
- You are happy for someone else from the screening programme to contact you if you have a positive FOBT 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)**

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 Māori (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 Māori?
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 Māori, 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+
98. Don't know **(DO NOT READ)**
99. No response/Refused **(DO NOT READ)**

Thanks very much for your time today.

We are asking people who took part in this survey if they agree to be resurveyed again in 2015. 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 usual practice.

Appendix 8.2: Waitemata District Health Board Questionnaire, 2011

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
7. The old Waitakere City which is now part of Auckland City
8. The old North Shore City which is now part of Auckland City
9. Rodney District Council Area
10. Or another city - Alt+S [make xmas day appointment and ask for Suburb]
11. Don't Know - Alt+S [make xmas day appointment and ask for Suburb]
12. 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 Māori
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 <u>the most</u> 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 <u>next most</u> 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 <u>the most</u> 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 <u>next most</u> 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 <u>don't have</u> 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

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?*
1.Yes
2.No

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 <u>not</u> 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
98.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 <u>from chemist/over the counter</u> (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: <u>Must</u> make specific mention of test being seen/bought at the chemist/over the counter - need to have coded 'FOBT test <u>from chemist/over the counter</u> (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
99.No response/Refused

If yes ask Q24, else skip to Q29

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
Q25A. 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(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
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 colonscopies 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)**
99No 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 Māori (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 Māori?
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 Māori, 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+
98.Don't know **(DO NOT READ)**
99.No response/Refused **(DO NOT READ)**

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.