

**Interim Evaluation Report of the  
Bowel Screening Pilot  
Screening Round One**

Ministry of Health  
Manatū Hauora

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## DISCLAIMER

The data analysed for the epidemiological analysis were supplied to the Centre for Public Health Research, Massey University by the Ministry of Health. The data sources are the Bowel Screening Pilot Register and the Waitemata District Health Board.

Litmus Limited and The Centre for Public Health Research accepts no liability or responsibility for the data or its use.

## Preface

This interim evaluation report has been jointly prepared for the Ministry of Health by Liz Smith, Litmus; Associate Professor Deborah Read and Associate Professor Barry Borman, Massey University; and Julie Artus, Sapere Research Group.

We sincerely thank Mathu Shanthakumar, Biostatistician, Massey University for her work in preparing the epidemiology data for analysis. We also acknowledge Gary Blick, Senior Managing Economist, Sapere Research Group, for his work on the costing analysis.

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# 1. Executive summary

## 1.1 Background

The Ministry of Health has funded Waitemata District Health Board (WDHB) to run a Bowel Screening Pilot (BSP) over four years from 2012–15. An evaluation of the BSP is being undertaken by Litmus, the Centre for Public Health Research Massey University, 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.

This report is the interim evaluation report of the BSP following the completion of invite distribution for screening round one (January 2012 – December 2013)<sup>1</sup>. The report draws from a range of data and information sources and is structured to address the pilot's ten objectives as relevant at the completion of screening round one.

In reviewing the interim evaluation report of the BSP, the unique features of bowel cancer screening and the pilot need to be acknowledged, specifically:

- Unlike screening for other cancers (e.g. breast, cervical and prostate cancer), screening for colorectal cancer involves as the definitive diagnostic step, direct sight of the organ. As a result, definitive diagnosis (cancerous/ precancerous lesion or not) and treatment (removal of some precancerous lesions) can be accomplished with the same procedure.
- The pilot is dynamic. The pilot's design and implementation activities are being refined through the two screening rounds. In this context, the epidemiological and cost results presented in the interim evaluation report will continue to evolve through screening round two.

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).

## 1.2 Evaluation findings

### *Participation and outcomes objectives<sup>2</sup>*

A BSP using an immunochemical faecal occult blood test (iFOBT) commenced in January 2012 among 50-74 year olds living in the WDHB area. The epidemiological results presented below are based on the participation in, and outcomes from, the first 18 months of the first screening round.<sup>3</sup>

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<sup>1</sup> Note the epidemiological analysis is only for the first 18 months of invites with four months allowed for completion of the pathway.

<sup>2</sup> Appendix 1 contains the epidemiology report completed by the Centre for Public Health Research (CPHR) (Read, Shanthakumar, Borman 2014).

<sup>3</sup> Note that the costing analysis is based on volumes reported for the full two-year screening round.

The results take into account the effects of all demographic factors other than the one under consideration. For example, when considering participation by age group, the results have been adjusted to take account of the potential effects of sex, ethnicity and deprivation (NZDep2006). Unless otherwise stated, all results are statistically significant.

## Participation

The participation rate<sup>4</sup> of eligible people was 53.5% (n=46,409). The Ministry of Health's target is 60% by the end of the four year BSP.

Participation increased with increasing age. Males were slightly less likely to participate than females.

Participation was highest among Europeans (60.3%), followed by Asians (51.3%), 'Other' (43.1%), Māori (42.0%) and Pacific people (23.8%).

Participation declined with increasing deprivation.

Colonoscopy uptake was 86.1%. The uptake rate is an under-estimate because private colonoscopy data were not included.

Colonoscopy uptake was higher among males (87.3%) compared with females (84.4%).

Colonoscopy uptake was less likely among Asians aged 50-59 years (81.1%) than Europeans of the same age (88.3%).

Colonoscopy uptake increased with increasing deprivation.

## Outcomes

Seven percent of those who returned an adequate kit had a positive iFOBT result.

Test positivity increased with increasing age. Males were more likely to have a positive iFOBT result than females.

Māori were slightly more likely to have a positive iFOBT result than Europeans.

Positivity was more likely with increasing deprivation.

The overall detection rate for adenoma was 3.4%, advanced adenoma was 1.9%, and cancer was 0.2%.

The detection rate per iFOBT for adenoma, advanced adenoma and cancer increased with increasing age. Males were more likely to have an adenoma, advanced adenoma, or cancer detected than females.

Māori aged 60-69 years were more likely to have an adenoma detected than Europeans of the same age.

Māori were more likely to have an advanced adenoma detected than Europeans.

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<sup>4</sup> This is a proportion rather than a rate which is occurrence per unit time. "Rate" has been used synonymously with "proportion" in this report to improve readability.



Asians were less likely to have an advanced adenoma detected than Europeans.

Participants from the most deprived areas were more likely to have an adenoma or advanced adenoma detected than participants from the least deprived area. This was also found when participants with advanced adenoma were combined with those with cancer.

Forty-eight per cent of people who had a positive iFOBT had an adenoma detected, 26.9% had an advanced adenoma, and 2.9% had cancer detected. The positive predictive value of a positive iFOBT for cancer of 2.9% is below the range reported internationally in the first screening round of population-based programmes that use the iFOBT (Moss et al 2010; Major et al 2013).

There were some age, sex and ethnic differences in the effectiveness of a positive iFOBT in detecting adenoma, advanced adenoma and cancer.

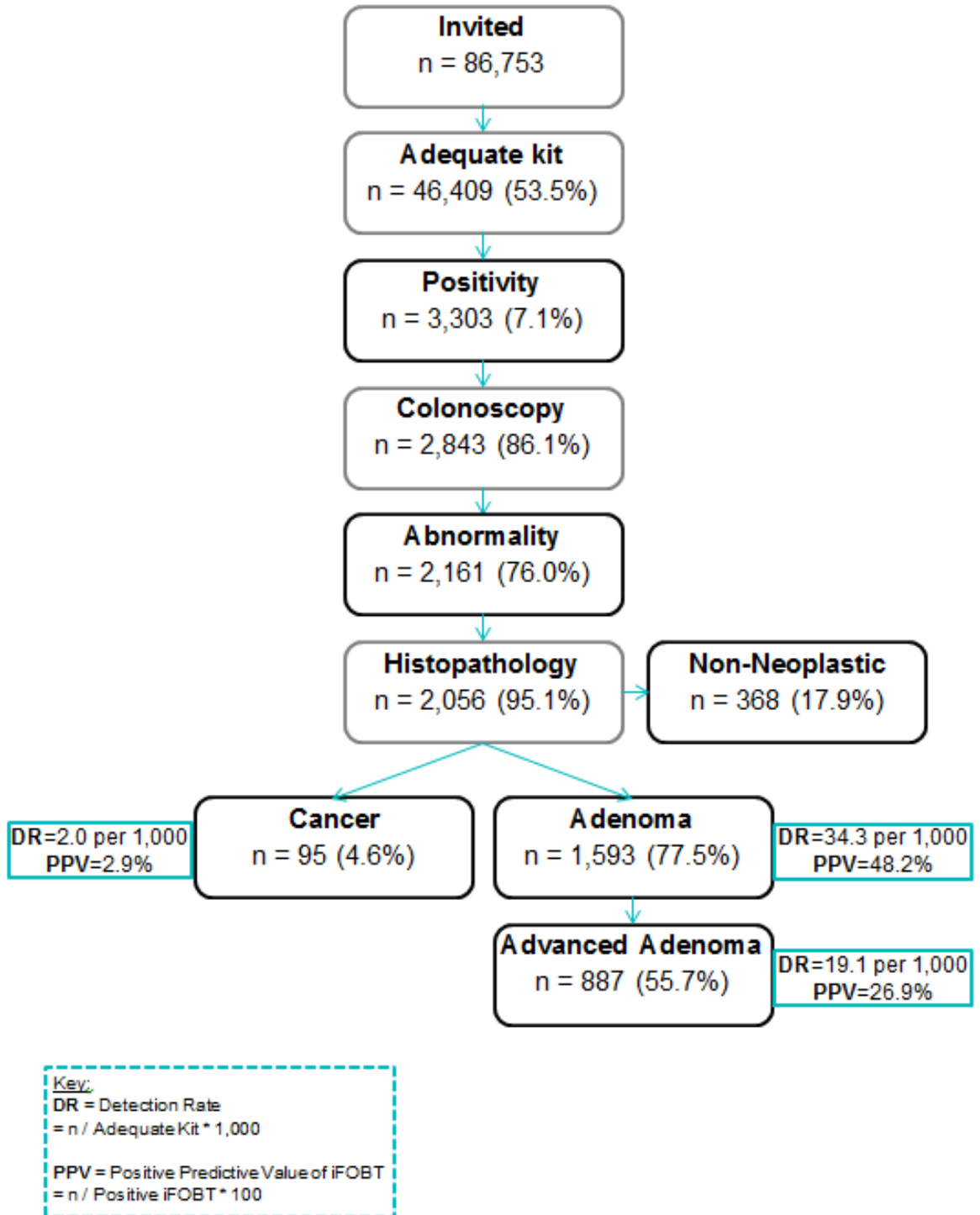
Figure 1 summarises the key findings for those participants who had a positive iFOBT, a completed colonoscopy in the public system, and histopathology results available by the end of October 2013. Some of these participants would have had more than one type of pathology; only the most serious type was recorded.

Ninety-five participants had cancer detected (2.0 per 1,000 screened). Eighty were European, 12 were Asian, 2 were Māori and none was Pacific.

The cancer detection rate increased with increasing age. Males were almost twice as likely to have cancer as females.

Almost 39% (n=37) of those participants with cancer detected had Stage I, the least advanced, and 8.4% (n=8) had Stage IV, the most advanced.

Figure 1: Summary of BSP outcomes



The self-selected population (n=1,895) were analysed separately and are not included in Figure 1. This population comprised people in the eligible population who were not on the BSP Register but who requested screening, and people on the BSP Register who requested screening before they were invited. Unlike the non-self-selected population, there was no statistically significant difference in participation between males and females, and participation was higher among people living in the middle deprivation areas rather than the least deprived areas. This may explain the higher positivity (9.3%) and detection rates for all outcomes for the self-selected group. It is also possible that this group included people who were symptomatic, and therefore motivated to self-select. Eleven people from this group, all European, had cancer detected.

Forty-nine participants were readmitted after their colonoscopy<sup>5</sup>. The most common causes for readmission were bleeding (n=31), abdominal pain (n=7) and perforation (n=5).

The perforation rate was 1.2 per 1,000 colonoscopies and the bleeding rate was 7.7 per 1,000 colonoscopies<sup>6</sup>. There were no colonoscopy-related deaths.

Different definitions for adverse events, particularly for bleeding and follow up periods, make direct comparisons with international data difficult. Complications are more likely following polypectomy. The data supplied did not allow reliable calculation of rates for colonoscopies with polypectomy.

### **Population Register objective**

Having an eligible population database (the Register) was identified by stakeholders as a strength of the BSP enabling the identification of the eligible population, the distribution of kits and monitoring of participation by the eligible population, and informing targeted participant follow-up and Community Awareness Raising (CAR) activities.

While the Register has relevance and utility in the BSP, a number of critical limitations with the Register are impacting adversely on the BSP:

- Ensuring access to the BSP: it is estimated, based on returned mail and the WDHB population survey (Litmus 2014a), that between 5% and 15% of eligible participants may not have received a letter or kit in screening round one potentially due to incorrect address details on the Register.
- Data and IT resource at WDHB and Ministry of Health: feedback indicates that in the early implementation stages there was insufficient dedicated data and IT resource at WDHB<sup>7</sup> and the Ministry of Health which contributed to a lack of timely updates to the Register resulting in challenges to ensure data quality.
- Assessing participation and outcomes: evaluation of participation and outcomes from the BSP is being adversely effected by a lack of clear data definitions and data quality assurances of the Register.

<sup>5</sup> The denominator for readmissions is all colonoscopies (n=4,001), not just publicly funded colonoscopies (n=2,843 Figure 1), as this was how the readmissions data was supplied to CPHR.

<sup>6</sup> See Section 3.1 Adverse events for comparisons with reported data from other programmes.

<sup>7</sup> From September 2013 the data resource at WDHB doubled.

### ***Acceptability to the target population objective***

The acceptability of the BSP (defined by awareness, attitudes and knowledge) varies amongst the eligible population reflecting it is not a homogenous group. Acceptability of the BSP is higher amongst the eligible Other group<sup>8</sup>, and lower amongst eligible Māori and Pacific people.

Since the launch of the BSP, awareness of the BSP has significantly increased amongst the eligible Other group. Knowledge about bowel cancer risk factors, symptoms and bowel cancer tests has also increased. Perceptions of the iFOBT have also become more positive with significant increases in disagreement that the iFOBT is painful, embarrassing, inconvenient, messy and inaccurate.

Compared to the Other group, Māori and Pacific people have lower awareness of bowel cancer risk factors, symptoms and bowel cancer tests including the iFOBT which may reflect their lower levels of participation. Other barriers to participation include a dislike of bowel screening, a preference for seeing their doctor, not being concerned, a fatalistic attitude of 'what will be will be' or not wanting to know, and not wanting to do the test at home. Pacific people also perceive the iFOBT as messy.

BSP participants' experience of the BSP is mainly positive. Pākehā, Māori and Pacific BSP participants interviewed consistently described their experience of the BSP as convenient, the iFOBT as easy to do with timely results and progression along the pathway. For those with a positive iFOBT, the communication about their results was reassuring, and their colonoscopy experience was timely and respectful.

### ***Fair access for all New Zealanders objective***

The current design and implementation of the BSP is not resulting in fair access to the eligible BSP population in WDHB. Significant effort has been placed on trying to deliver the BSP in a way that will facilitate access for eligible Māori and Pacific people. However, feedback highlights that Māori and Pacific leaders could have been more involved in decision-making during the design and implementation of the BSP.

Feedback from eligible Māori and Pacific people who received a kit and did not respond suggest the current design of distributing kits and collecting samples via mail is not effective for all because of literacy, language, and environmental barriers (i.e. not receiving or opening the letter). Further, research highlighted that the initial BSP letters, kit instruction and consent form were not easy to understand. In 2013 the pre-invitation letter, kit instructions and consent form were revised to be more accessible to a wider range of literacy levels. These revised documents were introduced in the second screening round beginning in January 2014.

In screening round one, CAR and communication activities were the key mechanisms employed to raise awareness and increase acceptance and completion of the iFOBT amongst Māori, Pacific and Asian populations. CAR and communication activities were not defined in the BSP programme design. Consequently, the BSP Coordination Centre and the CAR team used a range of tactics to increase awareness and participation.

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<sup>8</sup> In the eligible population surveys, the Other group is non-Māori, non-Pacific, and non-Asian and is predominantly made up of New Zealand European/ Pākehā (Litmus 2014a).

Awareness of the BSP has increased for eligible Māori and Pacific people since the launch of the BSP, although not to the same level as the 'Other' ethnic group (Litmus 2014a). The later suggests that the communication strategies are having an effect. Anecdotal evidence suggests that face-to-face engagement is beneficial in supporting and prompting Māori and Pacific people to act. The evaluation is unable to assess the effectiveness of CAR strategies used. However, it is acknowledged that without them uptake by Māori and Pacific people is likely to have been lower.

### ***Acceptability to providers objective***

The acceptability of the BSP (defined by awareness, attitudes and knowledge) and its design is high amongst providers in the community, primary care and hospital settings. There is support for the BSP to be rolled out as a national screening programme, although there is recognition that further work will be required to ensure equity of participation, adequate workforce capacity, particularly colonoscopy capacity, and that bowel screening does not impact on symptomatic services.

### ***Service delivery and workforce capacity objective***

The implementation of the BSP is consistent with the design of the screening pathway. Some minor service delivery changes have been made to improve efficiency of process.

Across the screening pathway there are a number of critical pressure points on workforce capacity that, if not effectively managed, could have adverse impact on the BSP, specifically:

- Colonoscopist capacity: adequate colonoscopist capacity to meet BSP quality standards continues to be a critical resource challenge for the BSP.
- Impact on treatment services: the increase in the number of cancer patients identified by the BSP is putting pressure on treatment services due to no additional resource being allocated to this service. As the BSP moves into screening round two, the pressure on surgery and oncology is likely to dissipate over time as fewer BSP participants will be identified with late stage cancers.
- Impact of BSP surveillance colonoscopies on symptomatic services: the high level of polyps detected via BSP colonoscopies will, over time, add significantly to the symptomatic colonoscopy lists. The accumulative effect of the surveillance colonoscopies have not yet impacted on the symptomatic list. Monitoring is required to ensure that BSP participants requiring surveillance colonoscopies at one year and later receive timely appointments.

The value added by general practice rather than the screening unit informing participants they have a positive iFOBT result is not clear. Most BSP participants do not have a strong preference on who informs them about a positive iFOBT result so long as their results are timely, convenient, given in a reassuring manner, their general practice is kept informed, and the transition to colonoscopy is well explained, timely and streamlined.

## **Quality monitoring objective**

The review of quality monitoring confirms that BSP has a range of quality standards and processes in place that align with international best practice. Quality standards, risks and issues are actively monitored, reported, discussed and actions taken to address risks of breaching quality standards, and risks emerging.

While WDHB note that reporting against all quality standards is now possible (with exception of the timeliness of the histology result letter), data were not sighted by the evaluation team for all quality standards.

In November 2012, a review of the BSP interim quality standards (Ministry of Health 2012a) was jointly undertaken by Ministry of Health, WDHB and LabPLUS. Overall, no substantive issues were identified with the existing quality standards, although refinements and clarifications were made to the interim quality standards (Ministry of Health 2013c).

One area where the BSP is not operating within the quality standard is the first offer of colonoscopy within 25 working days which is 4% compared to the standard of 50% for the period January 2012 to 31 December 2013. However, 91% received the first offer of colonoscopy within 55 working days, just under the standard of 95%.

Discussions with key stakeholders highlighted potential risks to adhering to quality standards, including:

- not having enough endoscopist capacity to remain within agreed wait times to colonoscopy
- variable awareness of all the BSP quality standards for colonoscopy procedures amongst endoscopists
- a lack of awareness of the BSP quality standards for Computerised Tomographic Colonography (CTC) amongst radiology staff and BSP participants not being appropriately coded
- duplication and potential confusion due to the number of Ministry of Health quality documents for the BSP
- a lack of clarity in the link between the Global Rating Scale (GRS) being used to improve quality of endoscopy in New Zealand and the BSP's quality standards.

## **Costing analysis objective**

### **Costs of development and operation of the pilot during years 1 & 2**

A total of \$13.742 million was incurred in developing and operating the first two years of the Pilot (excluding the costs of treating cancers diagnosed).

The total development cost incurred to develop the pilot is estimated at \$3.148 million (incorporating costs of the WDHB contract to plan and implementation of the pilot; the design and build of the pilot register; and costs of developing promotional materials).

During 2012, the total operating cost for the pilot was \$4,927,000 and during 2013 it was \$5,666,000 (including Ministry of Health oversight costs). This was comprised as follows:

**Table 1: Summary of operating costs for the first screening round<sup>9</sup>**

	Year 1 (2012)	Year 2 (2013)
<b>Pilot operating costs</b>		
<b>Fixed</b>	\$2,780,000	\$2,651,000
<b>Variable</b>	\$1,653,000	\$2,520,000
<b>Sub total</b>	<b>\$4,433,000</b>	<b>\$5,172,000</b>
<b>Additional Ministry of Health operating costs</b>		
<b>Ministry oversight<sup>10</sup></b>	\$495,000	\$495,000
<b>Total</b>	<b>\$4,927,000</b>	<b>\$5,666,000</b>

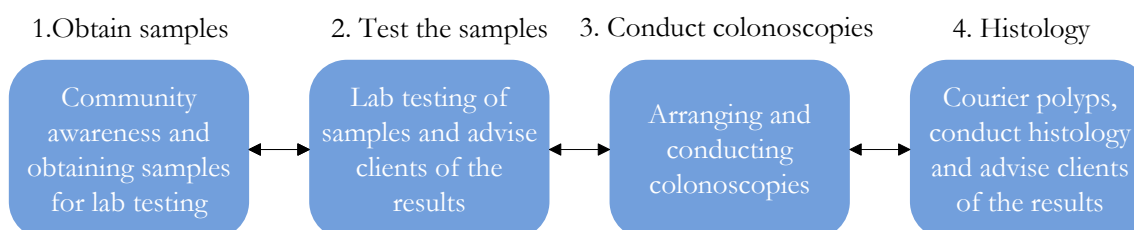
### Estimated lifetime cost of treating cancer detected by the pilot in years 1 and 2

The estimated lifetime cost of treating the 129 cancers detected during years 1 and 2 of the pilot is \$6.178 million.

### Detailed findings regarding operating costs in year 1 and 2

The pilot screening pathway has four stages, as shown in the figure below.

**Figure 2: Four high-level stages of the screening pathway**



Stage three, conducting colonoscopies, absorbs the greatest proportion of resource: 43% of the annual operating cost of the pilot (note that this cost includes overheads assigned to this stage of the pathway, as well as the direct costs of conducting colonoscopies).

The unit cost for particular 'process outcomes' have been developed by dividing the annual operating cost for each stage by a key process outcome measure. These unit costs are estimated as follows:

- Average cost per person returning a sample to the laboratory - \$64 per person, of which \$28 per person relates to promotion, outreach and targeted support efforts and \$36 per person to mail-outs and sample collection activities
- Laboratory testing of iFOBT kits (including notification of results) - \$18 per sample
- Average cost of colonoscopy - \$1,107 per person

<sup>9</sup> Table 11 on page 111 of the report refers.

<sup>10</sup> This is an estimate of the proportion of Ministry of Health staff time spent per year on the BSP, including contract management, monitoring and development of policy advice.

- Average cost of histology tests following colonoscopy - \$190 per person

We also combined the operating costs for stages one and two and divided by the number of people returning a kit for testing to derive a cost per participant screened of \$87.21. In addition, we derived a cost per participant receiving investigation of \$1,268.76 by combining operating costs for stages 3 & 4 and dividing by the number of colonoscopies conducted (acknowledging that most of these participants go on to have histology).

Over years 1 and 2, the average operating cost (excluding development costs) for key screening outcomes was<sup>11</sup>:

- \$82,100 per cancer detected
- \$6,000 per adenoma detected
- \$5,600 per lesion detected (adenomas and cancers)

Note that screening for colorectal cancer includes removing premalignant lesions (adenomas) during the colonoscopy. These adenomas thus never present as cancers, meaning that the incidence of colorectal cancer declines with screening. For this reason, it is important to present the cost of screening per lesion (adenoma and cancer) detected as well as per cancer.

The direct cost of providing services aimed at improving participation of particular population groups (that may be more likely to encounter barriers due to language or cultural reasons) was an average of \$187,000 per year (over years 1-2).

The overall cost of colonoscopy provision was \$1.042 million in year 1 and \$1.550 million in year 2 (with the increase in year 2 driven by higher volumes and a more expensive temporary arrangement to increase capacity).

Primary Health Teams are contracted at a unit price of \$60 to advise any of their patients of a positive iFOBT result. The total cost of this service was estimated at \$119,000 in year 1 and \$169,000 in year 2.

### **Forecast of costs of the full pilot from years 1-4**

We forecast the total cost of the four year screening pathway on the basis of the cost estimates developed for the first two years.

The forecast total operating cost for each of years 3 and 4 is \$5.505 million, including Ministry of Health oversight costs.

The forecast total cost of the pilot over years 1-4 is \$24.753 million. This includes the cost of developing the pilot (\$3.148 million) and the estimated operating cost for years 1 and 2 (total of \$10.594 million), including Ministry of Health oversight costs.

The forecast cost of the pilot over years 1-4, excluding Ministry of Health oversight costs, is \$19.625 million.

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<sup>11</sup> The cost per cancer/adenoma/lesion is derived by dividing the total operating costs of the pilot by the number of cancers/adenomas/lesions detected during the pilot. It is not the sum of the direct costs of detecting a single cancer/adenoma/lesion.



## Estimates of the annual ‘steady state’ operating cost of a national bowel screening programme

In estimating the costs of a national bowel screening programme, we have only considered the direct costs of a national screening programme in a “steady state”. Our estimates do not include development/start-up costs such as workforce development or capital purchases. We have also not included any Ministry of Health oversight and governance costs.

We have made a number of assumptions, including that the pilot model design is replicated and that all key parameters remain the same. We have assumed that the current models for laboratory services, the coordination centre and the IT register are scaled up to manage the increased volumes required for a national programme. We also assume that colonoscopy services will be provided by salaried and contracted colonoscopists, in the same proportion as services provided to the pilot in the second half of year two (July to December 2013).

### National view

The annual operating cost of a national screening programme in steady state, excluding development costs and Ministry of Health oversight is estimated at \$39.073 million. This is 7.8 times higher than our estimate of the annual operating cost of \$5.010 million for the pilot in Year 4.

The results of sensitivity testing undertaken suggest a plausible range for the annual operating cost of a national screening programme in steady state as being between \$26.531 million and \$50.623 million (with the base case estimate at \$39.073 million).

### Regional view

The following table shows the variable and fixed operating costs allocated on a proportional basis (by population share) to each of the DHB regions.

**Table 2: National model - estimated annual operating cost in steady state, by region**

	Northern	Midland	Central	Southern	Total
<b>Regional costs (\$ million)</b>					
Variable operating cost	\$5.862	\$3.483	\$3.435	\$4.568	\$17.348
Fixed operating cost	\$7.592	\$4.311	\$4.250	\$5.572	\$21.724
<b>Annual operating cost</b>	<b>\$13.454</b>	<b>\$7.794</b>	<b>\$7.686</b>	<b>\$10.139</b>	<b>\$39.073</b>
<b>Regional shares (%)</b>					
Share of national population (50-74 years)	34.9%	19.8%	19.6%	25.6%	100.0%
Share of total operating costs	34.4%	19.9%	19.7%	25.9%	100.0%

## 1.3 Conclusions and recommendations

The evaluation will directly address the overarching goal of the BSP on 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* at completion of screening round two (2016). At this stage, the evaluation provides insight to inform three of four aims of the BSP as relevant to this stage of the pilot.

### **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?**

The epidemiology findings are largely similar to those found on other population-based colorectal screening programmes.

The New Zealand participation rate is already higher than what is considered internationally to be the minimum participation rate (Ministry of Health 2012d). The *European Guidelines for Quality Assurance in Colorectal Cancer Screening and Diagnosis* (Segnan et al 2010 p84) notes a minimum participation of at least 45% is acceptable but recommends aiming for a rate of at least 65% (Favre et al 1991; Zorzi et al 2008).

Low participation among people living in the most deprived areas is a high priority to address. More disease was found in this population group, irrespective of age, sex and ethnicity. Research is required to understand the reasons for low participation amongst people living in the most deprived areas.

Strategies are also needed to promote the BSP among the other low uptake groups: Māori, males, Pacific people, and younger age groups. Māori were slightly more likely to have a positive iFOBT result than Europeans and there was suggestive evidence they were more likely to have disease<sup>12</sup>. Males of all ages were more likely to have adenomas and advanced adenomas, and at older ages to have cancer, than females. Pacific people's participation was the lowest, although they were less likely than Europeans to have disease, irrespective of their age, sex and deprivation.

To effectively evaluate screening round two and monitor a potential national roll out, the BSP Register and data management processes need to be comprehensively reviewed to ensure data quality is robust, and there is satisfactory data quality assurance in place.

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

The BSP is acceptable to primary and secondary care providers and to many (but not all) people in the eligible population.

Quality monitoring is in place. Quality standards, risks and issues are actively monitored, reported and discussed and actions are taken to address risks of breaching quality standards, and other risks emerging. Ensuring there is adequate colonoscopist capacity to meet BSP quality standards is a key focus for screening round two.

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<sup>12</sup> Disease refers to 'neoplasia' (adenomas and colorectal cancer).

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

At the end of screening round one, the BSP, as currently delivered, is increasing inequities particularly for Māori and those living in high deprivation areas due to their low participation and high disease burden. Pacific people have the lowest participation rates and face inequities relating to access; however their disease burden is lower.

If the BSP is to meet its equity aim, urgent attention needs to be directed at delivering the pilot in a way that significantly increases the participation rates of Māori and Pacific populations and those living in high deprivation areas. Addressing the existing inequities in the BSP before the completion of the pilot will require:

- Effective engagement with Māori and Pacific leaders to inform the design, implementation, and monitoring of the BSP.
- Deeper understanding of the barriers and enablers to participation for Māori and Pacific populations to inform changes to the BSP design.
- Consideration of alternatives to the use of mail to distribute and collect kits. Anecdotal evidence suggests that for Māori and Pacific people face-to-face engagement has the potential to increase participation if linked to receiving the kit.
- Greater investment in a more strategic and clearly defined pathway for the CAR activities which is evidenced-informed and actively monitored to assess its effectiveness for Māori and Pacific people.

Screening round two of the pilot provides an opportunity to trial differing strategies and approaches to assess whether they increase participation and thus address the existing inequity of access. Investigation will also be required to determine whether progression and experience of the BSP screening pathway is equitable for all participants.

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

At this stage, the costing analysis presents an interim result that may be used by the Ministry of Health to inform understanding of the potential operating cost of a bowel screening programme on a national basis. Detailed understanding of unit costs will enable comparisons with previous forecasts completed by the Ministry of Health to inform policy decisions.

However, the primary use of these results (once updated following the conclusion of the second screening round at the end of 2015) is as a key input to modelling that will be undertaken to support the full cost effectiveness evaluation of the pilot.

## 2. Introduction

### 2.1 Background to BSP

#### *Bowel cancer in New Zealand*

Bowel cancer is a major health issue for New Zealand. As noted by National Bowel Cancer Tumour Standards Working Group (2013) New Zealand has one of the highest bowel cancer rates in the world. In 2010 bowel cancer was the second most common cancer in both men and women; the second highest cause of cancer death for men (after lung cancer) and the third highest for women (after lung and breast) (Ministry of Health 2013). For Māori, bowel cancer is the third most common cause of death from cancer (Ministry of Health 2014). New Zealand has one of the highest death rates from this cancer in the developed world. In 2010 there were 2988 new cases and 1208 deaths (Ministry of Health 2013).

Bowel cancer incidence increases with age with 90% of cases occurring in those over 50 years (New Zealand Guidelines Group 2004). The number of new cases of bowel cancer each year is projected to increase by 15% for men and 19% for women to 3302 by 2016 (Ministry of Health 2002a, 2011a). Concurrently, age-standardised registration and mortality rates for bowel cancer are declining (Ministry of Health 2010a). Among Māori bowel cancer diagnoses, rates are increasing with the fastest rate of increase among Māori males (Ministry of Health 2010a).

#### *Estimates of the cost of bowel cancer*

On the basis of analysis completed by the Ministry of Health (2011) (using 2008 incidence data and 2008/09 national prices), the annual public price of registered cancer in 2008 was estimated at \$511 million. Cancers of the colo-rectum and anus made up some 14% of this total, at an estimated annual public price to New Zealand of \$69.7 million, second only to female breast cancer at 15%.

Further, population growth and structural ageing are dominant forces driving change in cancer registration counts, sometimes overwhelming the effect of changes in cancer risk (Ministry of Health 2002). The Ministry of Health analysis (2011) incorporated incidence projections from 2011 to 2021, leading to an estimated 23% increase in the total price of cancer to \$627 million by 2021. This increase incorporated a significant growth in price relating to colorectal cancer at \$13 million.

#### *The BSP*

The Ministry of Health has funded WDHB to run a 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 Limited, the Centre for Public Health Research Massey University and Sapere Research Group have been funded by the Ministry of Health 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 Ministry of Health. 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?

Ministry of Health specified ten key objectives of the BSP and its evaluation<sup>13</sup>: The interim report has been structured to address each of these objectives as relevant at the completion of invite distribution for screening round one (1 January 2012 – 31 December 2013).

1. *Programme design* - To pilot the use of a Population Register closely linked with primary health care services to invite the target population, along with a Coordination Centre and associated information system to manage the Screening Pathway.
2. *Screening effectiveness* - To assess the early indicators of the effectiveness of bowel screening, including the number and stage of cancers detected, the number and size of adenomas detected, and colonoscopy completion rates.
3. *iFOBT experience* - To assess the performance and acceptability of the chosen iFOBT in the New Zealand context including the positivity rates in New Zealand, positive predictive values for adenomas and cancers, technical repeat rates and false positive rates.
4. *Participation and coverage* - To determine the level of participation and coverage for the eligible and invited populations, including sub-populations (defined by sex, age, ethnicity, socioeconomic status and rural representation).
5. *Quality* - To pilot the agreed quality standards and monitoring requirements along the Screening Pathway and assess the implications for a national programme; in particular to pilot the acceptability and safety of the standards and screening to providers and for different population groups.
6. *Service delivery and workforce capacity* - To monitor the effect, including resource implications of screening activities, on primary care, community health services, laboratory, and secondary and tertiary services and the implications of this for a national programme.
7. *Fair access for all New Zealanders* - To determine whether a bowel screening programme can be delivered in a way that provides fair access for all New Zealanders. In particular, to evaluate the process of adopting a focus in leadership,

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<sup>13</sup> 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.

decision making processes and implementation of the pilot to provide fair access to all eligible people.

8. *Cost effectiveness* - To determine the costs of all services along the Screening Pathway to determine the cost effectiveness of a bowel screening programme. To compare this, where possible, with other preventative programmes in New Zealand and bowel screening trials internationally.
  - Note: The interim report presents a costing analysis, exploring the nature and quantum of costs associated with the design, implementation and operation of the pilot during the first screening round. A full cost effectiveness analysis will be completed at the conclusion of the second screening round.
9. *Acceptability to the target population* - To pilot provision of information and support to the target population to facilitate informed participation and evaluate the knowledge, attitudes and satisfaction of groups of participants (defined by sex, age, ethnicity, socioeconomic status and geographical residence) in the screening pilot, including identifying factors associated with non-participation.
10. *Acceptability to providers* - To evaluate the knowledge and attitudes and acceptability to health professionals and health care providers based in community, primary care and hospital settings.

## 2.2 Unique elements of bowel cancer screening

Bowel cancer has several specific features that make it unique as a cancer to screen for across the population. Screening for this cancer usually involves, either as the first step or as the definitive diagnostic step, direct visualisation of the organ. This is unlike breast where the organ is imaged, cervix where epithelial cells are sampled or prostate where a blood-borne biomarker is assayed. That means that, in many cases, definitive diagnosis (cancerous/precancerous lesion or not) and treatment (removal of some precancerous lesions) can be accomplished with the same procedure – again unlike breast and prostate.

For a programme that begins, as in New Zealand, not with colonoscopy but with iFOBT, there are additional unique elements. First, the sample can be collected at home (although this is now increasingly also being done for direct self-collected sampling of cervical fluid for Human papillomavirus [HPV] testing). Second, iFOBT is probably the lowest cost initial screening test for cancer.

Screening for breast, cervix, and prostate cancers detects and, thus, requires the treatment of, malignant lesions that must then be removed surgically. Some of these cancers (especially in the case of prostate) would never present clinically or cause morbidity and mortality. Thus, screening for each of these three cancers is associated with a rise in incidence, even as there is an accompanying fall in mortality. In contrast, screening for bowel cancer encompasses the removal of some premalignant lesions, some of which would never present as cancers. For bowel cancer, therefore, once the very earliest stages of the programme are completed, both incidence and mortality decline with screening.

## 2.3 Description of the BSP

### *Identification*

All men and women aged 50 to 74 who live in the WDHB area and who are eligible for publicly funded healthcare are eligible to participate in the BSP. Most people in the eligible population will be invited to participate in two screening rounds within the four year BSP period.

Those not eligible to participate in the BSP are people who have had a colonoscopy within the last five years, are on a bowel polyp or bowel cancer surveillance programme, have had or are currently being treated for bowel cancer, have had their large bowel removed, are being treated for ulcerative colitis or Crohn's disease, or are awaiting bowel investigations by their doctor (WDHB 2012c).

Participation in the BSP is by invitation only. The Coordination Centre invites eligible people to participate in the BSP according to their birth date. In 2012 and 2014, invitations will be sent to people whose birthdays fall on an even date. In 2013 and 2015, invitations will be sent to people whose birthdays fall on an odd date. People cannot opt in to the BSP and there are no referrals into the pilot by a health professional.

Identification of the eligible population is undertaken using the BSP Register. Participant details on the Register are taken from the NHI, and individuals who self-register.

### *Pre-invitation*

In the first screening round, initial contact with the eligible population is through a pre-invitation letter that is sent by the Coordination Centre four weeks before the invitation<sup>14</sup>. In the second screening round, pre-invitation letters will only be received by eligible people who have never been invited to participate. Pre-invitation letters are being used in the BSP because they have been shown to increase participation in bowel screening internationally (Cole and Smith 2007). The pre-invitation letter:

- advises people about the BSP and that they are eligible to participate
- includes a generic endorsement by prospective participants' GPs (for people not registered with a GP, the letter is endorsed by the Coordination Centre)
- advises people that they will receive an invitation and an iFOBT kit from the BSP unless they notify the Coordination Centre they do not wish to participate
- includes a detailed booklet to assist people to make an informed decision about participating in the BSP
- advises people who should not participate in the BSP to contact the Coordination Centre.

Pre-invitation letters are sent out to approximately 6,000 eligible participants per month. Incorrectly addressed letters are returned to the Coordination Centre. People who call to opt out of the BSP are recorded as such on the Register.

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<sup>14</sup> Following feedback from WDHB's Kaitiaki Roopu, it is intended that the pre-invitation letters will now be sent two weeks before the invitation. This has not yet been actioned at the time of writing the report.

## **Invitation**

Four weeks after the pre-invitation letter, the Coordination Centre sends an invitation letter to eligible people who have not opted out. The invitation letter is accompanied by:

- a leaflet to assist people to make an informed decision about participating in screening
- an immunochemical faecal occult blood test (iFOBT)<sup>15</sup>.
- a consent form
- a Freepost envelope to send their sample to LabPLUS.

Eligible Māori and Pacific people may receive an invitation via attending a community education session or hui and expressing an interest to take part in the BSP. Health promoters notify the Coordination Centre and an invitation letter and iFOBT kit is sent out. It is not known how many Māori and Pacific people have received an invitation via attending health promotion activities facilitated by the CAR coordinators.

People may opt out of the BSP at this stage by advising the Coordination Centre or their general practice. This decision is recorded on the Register.

## **Participation**

Participants in the BSP take a single sample at home, using the iFOBT kit. Participants post the sample to LabPLUS for testing, using the Freepost envelope provided. They must include their completed consent form.

If a sample is not received by LabPLUS within four weeks and the person has not opted out of the BSP, active follow-up is triggered. Māori, Pacific and Asian people are followed up by CAR personnel by phone or face-to-face after four weeks; everyone else is sent a reminder letter from the Coordination Centre after four weeks.

## **iFOBT test results**

LabPLUS tests iFOBT samples and sends positive and negative results to the BSP Register and participants' GPs within three working days of sample receipt. Results are sent electronically, via HL7 messaging on Healthlink. Results are not sent to participants' GPs if they have indicated this option on their consent form, or where the participant does not have an identified GP. LabPLUS reports to HL7 at the end of each day on which participant results have been sent out to GPs.

For a positive iFOBT result, general practice must contact their participant within ten working days of receiving a positive result from LabPLUS to inform their participant of the result, discuss the implications of the result, provide counselling and advice and refer their participant to the Waitakere Hospital Endoscopy Unit (WHEU) for a screening colonoscopy.

Participants with a positive result who do not have an identified GP or who have not been contacted by their general practice within the ten day period are contacted by the BSP Endoscopy Clinical Nurse Specialist (CNS) within 15 working days of a positive result.

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<sup>15</sup> A single sample iFOBT, also referred to internationally as a Faecal Immunochemical Test, made by Eiken Chemical Co., Ltd., Tokyo is being used in the BSP. The test is known as OC-Sensor. The sensitivity cut off for test positivity is 75 ng HB/mL.



Extensive efforts are made by the CNS to contact the participant using a range of strategies.

If WHEU is unable to contact a participant with a positive iFOBT, the CNS sends the participant and their GP a letter, outlining the positive result and encouraging the participant to contact their general practice or the Coordination Centre. If no contact is made, the participant is placed on the iFOBT two year recall system and remains on the BSP Register. A participant with a positive iFOBT can have a colonoscopy at any time in the future.

For a negative iFOBT result, participants are notified in writing by the Coordination Centre within 15 working days of the result being received on the BSP Register. They are advised they will be recalled to screening in two years, if still eligible. GPs are sent negative results but are not required to do anything.

If the sample is spoilt<sup>16</sup> or documentation is incomplete, spoilt kit follow-up is triggered and the BSP Coordination Centre informed. Māori, Pacific and Asian people are followed up with a phone call (if there is a number to call) or letter the first time they return a spoilt kit. Other populations receive a second test kit and a letter explaining their error, and if they return a second spoilt kit they are followed up with a phone call.

### ***Diagnostic testing: pre-assessment***

All participants with positive iFOBT results are referred for a colonoscopy pre-assessment. The pre-assessment provides an opportunity to assess the participant's fitness for the procedure as well as provide the participant with full information about colonoscopy. Pre-assessments include assessment of a participant's medical conditions, bowel condition, discussion of the bowel preparation process, and checking for cultural, mobility or transport problems. If an interpreter is needed, this is noted on the pre-assessment form and the BSP administrator organises an interpreter for the day of the procedure.

Pre-assessments are conducted over the phone by a CNS or endoscopy nurse. If the CNS determines a participant's clinical condition requires further investigation, the participant will receive a pre-assessment outpatient consultation. The CNS will arrange this with the participant and the Lead Endoscopist.

If a participant declines a colonoscopy after a positive iFOBT, the participant and the participant's GP will receive a letter to confirm this decision, and inform them that the participant may contact the BSP or their GP at any time in the future, if they wish to have the procedure. Otherwise they will be re-invited to participate in the pilot in two years.

Participants deemed fit for colonoscopy are offered an appointment for the procedure during the pre-assessment. Colonoscopy must be completed within 55 working days of the positive iFOBT result. Participants not deemed fit for colonoscopy (and those who have failed a colonoscopy) are referred for an alternative diagnostic investigation, CTC or to have a colonoscopy under general anaesthetic.

Participants assessed as high risk for colonoscopy (e.g. on Warfarin medication) require certain precautions to be taken to minimise risk during the procedure. Participants may also be deemed high risk due to a significant co-morbidity. In this situation, the Endoscopy Unit

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<sup>16</sup> Spoilt kit refers to iFOBT kits where the test has not been performed or labelled correctly. Most spoilt kits are due to date and label issues.

coordinates a multi-disciplinary discussion and facilitates a decision on appropriate management, and keeps the participant's GP involved in this process.

Participants assessed as fit and who consent to colonoscopy are sent an appointment letter which contains:

- written confirmation of their positive result<sup>17</sup>
- appointment date and time
- information about bowel preparation and instructions
- information about the procedure
- details of culturally appropriate support available, if required
- information on links to local support services.

### ***Diagnostic testing: colonoscopy***

BSP colonoscopies are undertaken at the WHEU. The procedure is as follows:

- BSP participants arrive at the hospital and are admitted as a day case.
- An endoscopy nurse goes through the pre-procedure checklist with the participant.
- The endoscopist meets with the participant to get their consent for the procedure.
- The participant's nurse, who will be in the endoscopy room during the procedure, introduces themselves, checks participant's identity and brings them into the endoscopy room.
- The colonoscopy is conducted under 'conscious sedation'; usually there are two nurses and an endoscopist in the room.
- The participant is taken to Recovery where they are kept under observation for a period.
- The endoscopist usually meets with the participant at this time to discuss the outcome of the colonoscopy; the endoscopist will always meet with a participant if the outcome is abnormal.
- The participant's nurse reiterates the outcome and talks with the participant about post-procedure risks and what they need to do in the immediate post-procedure period.

Both gastroenterologists (GEs) and surgeons undertake colonoscopies on the BSP.

Participants with normal colonoscopies are advised they do not need to undergo another iFOBT screening episode for five years and are placed on a five year recall on the Register. Their GP is informed of this.

Participants with a family history of bowel cancer are referred to the New Zealand Familial Gastrointestinal Cancer Registry, a service that offers assessment, diagnosis and surveillance of inherited gastrointestinal cancer syndromes.

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<sup>17</sup> In the early implementation stages of the BSP, participants with a positive iFOBT received a separate letter informing them in writing about their positive result. This letter has now been merged with the colonoscopy appointment letter.

### **Diagnostic testing: histopathology**

LabPLUS is required to provide histopathology results within ten working days. LabPLUS reports histopathology results directly into Concerto (the WDHB patient record system) using a standardised BSP reporting template.

From 2013, the CNS has been reviewing the colonoscopy reports and the histopathology results and advises the BSP administrator of the correct letters to send out to participants, their GP, and WDHB notes. The CNS prepares a spreadsheet of actions taken which is reviewed by the WDHB BSP Clinical Director or WDHB BSP Lead Endoscopist. Where there is any concern or uncertainty, the CNS discusses the results with the BSP Clinical Director or Lead Endoscopist. A formal policy has been developed (*Histology Results Management*) which sets out parameters within which the CNS may make decisions.

### **Diagnostic testing: alternative investigation**

BSP participants assessed as unfit for colonoscopy or with an incomplete colonoscopy are offered a CTC investigation. Occasionally when a colonoscopy fails, the person may proceed to have a colonoscopy under general anaesthetic.

Participants are referred to the Radiology Department by the Endoscopy CNS. Referral is via WDHB's usual referral system. The CTC policy agreed between BSP and Radiology states that when a BSP colonoscopy fails in the morning, the person will have a CTC that afternoon, and when it fails in the afternoon the person will have one the following morning. The exception to this is when the colonoscopy fails on Friday afternoon. Ensuring same or next day referral to CTC means the BSP participant does not have to go through bowel preparation twice.

Participants with an incomplete colonoscopy in which a polypectomy was performed are referred to have a CTC between 30 and 50 days.

Referrals to CTC for BSP participants unfit for colonoscopy are given a unique BSP code on receipt by the Radiology Department. This code flags that the participant must be given a different level of priority to meet the BSP requirement that a date for a CTC must be given within five days and the procedure completed within 20 days.

Results are sent back to the referring clinician (usually the WDHB BSP Clinical Director) using the hospital's usual results system.

### **Surveillance**

Participants requiring ongoing surveillance<sup>18</sup> are exited from the BSP, referred to a surveillance programme, and not recalled for subsequent screening.

WDHB Endoscopy Service is responsible for ensuring participants receive their surveillance colonoscopy within the recommended timeframe (according to guidelines for *Surveillance and Management of Groups at Increased Risk of Colorectal Cancer, Ministry of Health 2004*). The BSP Endoscopy Unit advises participants they have been referred for surveillance and notify participants' GPs. The BSP Endoscopy Unit records surveillance

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<sup>18</sup> Surveillance is defined by the New Zealand Guidelines Group (2004) guidelines 'Surveillance and Management of Groups at Increased Risk of Colorectal Cancer'

requirements on the BSP Register<sup>19</sup> and removes the participant from the screening pathway. The BSP Endoscopy Unit also logs the referral for surveillance in Intelligent Patient Information Systems (iPIMS) where the surveillance period is captured.

### ***Treatment***

Participants diagnosed with cancer or high risk polyps are referred to a colorectal Multi-Disciplinary Meeting (MDM) by the WDHB BSP Clinical Director/WDHB BSP Lead Endoscopist. Referrals are made using a standardised regional bowel cancer MDM form. BSP MDMs are held every two weeks at North Shore Hospital and include representation from Medical Oncology, Pathology, Radiation Oncology, Diagnostic Radiology, Surgery and Nursing. MDMs provide recommendations for culturally appropriate and coordinated care, advice and support. Outcomes of MDMs are communicated to the participant and their GP, and are documented in the medical records.

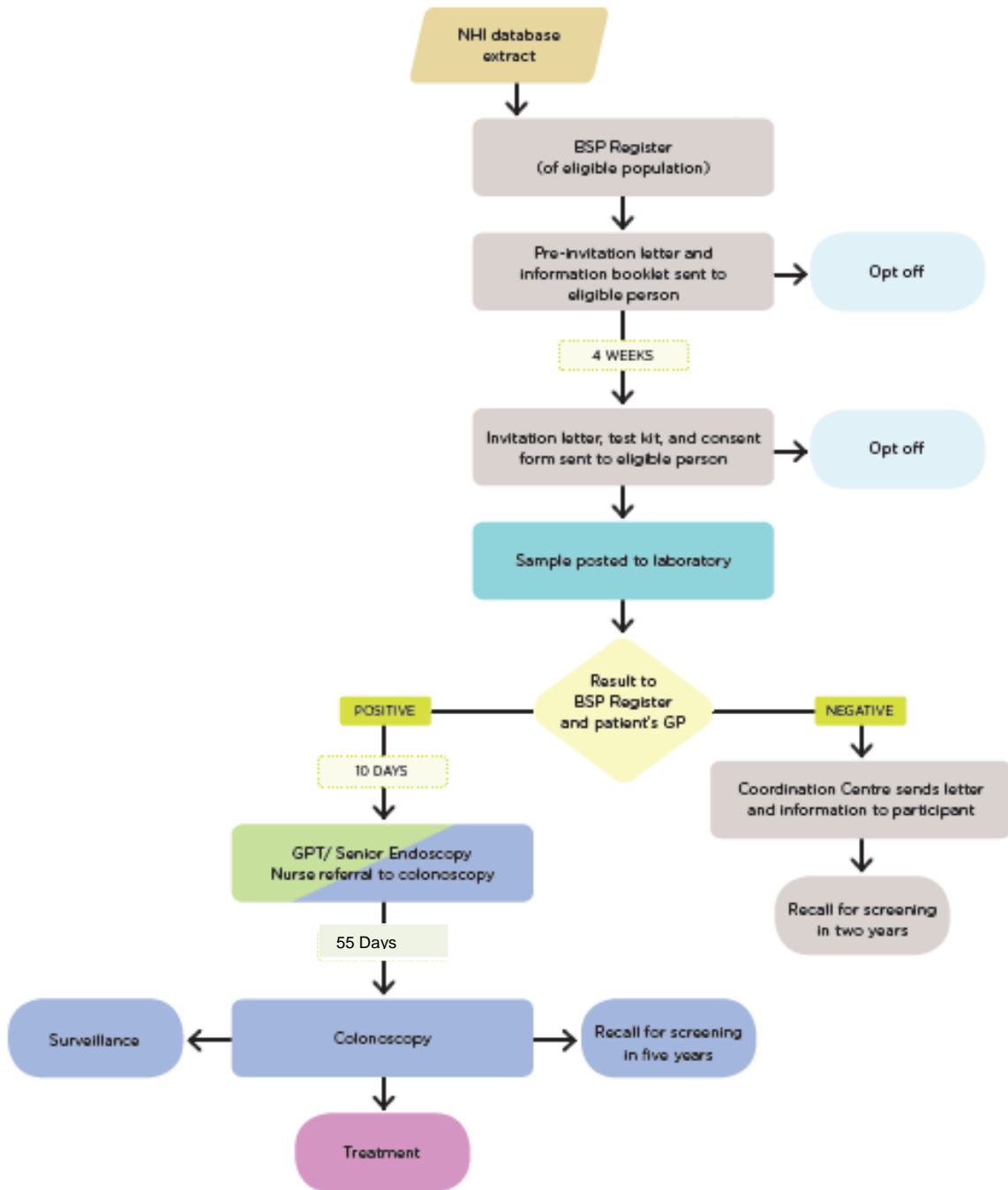
All participants who require chemotherapy and/or radiation therapy are managed by the Auckland Regional Cancer and Blood Service at Auckland District Health Board (ADHB). ADHB is the regional provider of oncology services for the WDHB population.

Participants diagnosed with cancer are not recalled for screening.

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<sup>19</sup> The Register has a field for surveillance but not for the recommended surveillance period.

Figure 3: Overview of screening pathway (WDHB 2012c)



## 2.4 Evaluation methodology

This report is the interim evaluation report of the BSP following the completion of the invite distribution for screening round one (January 2012 – December 2013)<sup>20</sup>. The report draws across a range of data and information sources to address the ten evaluation objectives of the pilot as relevant after the first two years<sup>21</sup>.

The following reports and data sources inform the interim report<sup>22</sup>:

- **BSP epidemiology analysis undertaken by the Centre for Public Health Research (CPHR) (Read, Shanthakumar, Borman 2014).**
  - The scope of the epidemiological analysis was approved by the Ministry of Health. It was based on the evaluation of the United Kingdom (UK) bowel cancer screening pilot (Weller et al 2007).
  - The data were extracted by the Ministry of Health from the BSP Register and WDHB.
  - The results represent the first 18 - 22 months of the first (or prevalence) screening round. The first screening round commenced on 1 January 2012 and was completed on 31 December 2013. The full screening round could not be analysed due to the timing of data extraction and the need to allow sufficient time to pass for those people who were invited in the latter half of 2013 to complete the full screening pathway.
  - This analysis allows four months from the time of invitation for the full screening pathway to be completed.
  - Logistic regression has been used to investigate associations between demographic variables and screening outcomes. The results are given in the Appendix 1 of the full epidemiology report as odds ratios, both unadjusted and adjusted for all other demographic variables, with 95% confidence intervals.
  - Key findings are presented and only counts and percentages together with the adjusted odds ratios are discussed. Adjusted odds ratios allow for the effects of all demographic variables other than the one under consideration. For example, when considering participation by age group, the results have been adjusted to take account of the potential effects of sex, ethnicity and deprivation (NZDep 2006).
  - Unless otherwise stated, the results discussed here are statistically significant<sup>23</sup>.
  - Results for the self-selected population are presented separately.
  - [Appendix 1](#) contains the full epidemiology report including methodology and analysis.

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<sup>20</sup> Note the epidemiological analysis is only for the first 18 months of invites with four months allowed for completion of the pathway.

<sup>21</sup> The *Evaluation Plan for the Bowel Screening Pilot 2011–2016* (Litmus, 2011) details evaluation activities undertaken between 2012 and 2014.

<sup>22</sup> Full details of the research methods used and their limitations can be found in each report. Section 2.3 provides a synthesis of evaluation limitations to consider when reviewing the findings.

<sup>23</sup> The result is deemed to be statistically significant if the 95% confidence interval of the odds ratio does not include 1.

- **Interim costing analysis – costs of the first screening round (2012-2013) undertaken by Sapere Research Group 2014** (Artus, Love, Blick and Poynton, 2014)
  - This costing analysis provides an input to and establishes a baseline for the full economic evaluation that will take place after the second screening round is complete. The scope of the costing analysis was approved by the Ministry of Health.
  - For details of the methodology, including definitions of key terms, assumptions and the modelling approach, see Appendix 2 (which provides a full copy of the Sapere report of the interim costing analysis).
  - In broad terms, two primary costing approaches are applied:
    - Assessment of the cost of the pilot is based on a detailed bottom-up costing model of the screening pathway that determines unit costs for all key programme inputs and applies actual volumes of activity undertaken.
    - Estimates of costs associated with treatment of bowel cancers detected as a result of the pilot are based on estimates of average New Zealand lifetime costs of treating bowel cancer diagnosed at different stages.
  - Primary data sources are:
    - The screening pathway model:
      - Cost data: two detailed six month samples of actual cost data from the pilot; and cost data from the Ministry of Health.
      - Volumes data: information reported by the BSP to the Ministry of Health on a bi-annual basis, identifying activity volumes for key parameters for the full two-year screening round; and data from the Ministry of Health published BSP monitoring indicators for the period to December 2013.
    - The estimated costs of treating cancers:
      - An extract from Ministry of Health national data collections, provided by the University of Otago Health Research Council funded BODE3 programme (Burden of Disease Epidemiology, Equity & Cost-Effectiveness Programme). This data-extract identifies all publically funded health care activity for each New Zealander occurring from July 2006 - June 2011 with national pricing applied.
      - An extract from the New Zealand Cancer Registry (NZCR) from 2011 restricted to relevant ICD codes, to assess the distribution of bowel cancers diagnosed at each stage in New Zealand, prior to the introduction of the BSP.
  - [Appendix 2](#) contains the complete interim costing analysis report and provides the results obtained for key input parameters and tables of the variable and fixed cost components of the screening pathway model.
  - The results present:
    - an analysis of the nature and quantum of costs associated with the design, implementation and operation of the pilot to date;
    - a forecast of estimated total cost of the BSP for two full screening rounds; and

- an extrapolation of high-level estimates of the potential ‘steady state’ cost of operating a bowel screening programme on a national basis (excluding development/start-up costs and the on basis of some broad brush assumptions). This is also presented from a regional perspective.
- A key part of an economic analysis is to take into account the counterfactual and to identify the incremental change that has occurred over and above ‘what would have happened anyway’, in the absence of the pilot. It is important to emphasise that this costing analysis is not an incremental analysis but rather takes a ‘snapshot’ perspective of costs incurred to design and run the pilot in the first two years, with some assumption-based extrapolation to inform understanding of potential future costs. As such, it does not account, for example, for the fact that some cancers detected as a result of pilot screening, may have been detected symptomatically anyway.
- Further, in extrapolating high-level estimates for the operating cost of bowel screening on a national basis, in the absence of key policy decisions about the configuration and implementation approach, we have based our analysis on some broad-brush assumptions about the way a national bowel screening programme may run in ‘steady state’.
- **The reports on the baseline and follow-up surveys of eligible BSP population (Litmus 2012 and 2014a)**
  - The surveys measured 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. The follow-up survey of the eligible screening population living in WDHB was undertaken in October 2013 to identify changes in awareness, attitudes, knowledge and involvement with the BSP over time.
  - All of the surveys were administered using computer assisted telephone interviewing (CATI).
  - In 2013, 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).
  - 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



- Survey weights were applied to the data to ensure population sub-groups are represented in the correct proportions in the survey results.
- Differences between percentages in the 2011 and 2013 WDHB surveys were tested at the 95% confidence level using a t-test, adjusted using a conservative design effect for each survey<sup>24</sup> and allowing for the average correlation in the recontacted sample used in Kish's weighting approach (Kish 1965). Only statistically significant differences between the two surveys are noted in the report.
- Information is reported for key sub-groups (e.g. ethnicity, age group, gender, and household income) where differences within groups are statistically significant.
- **A qualitative report on the eligible population perspectives of the BSP (Litmus 2013)**
  - In 2012, qualitative research was undertaken with the eligible population to understand participants' experience of the BSP screening pathway, and the factors that facilitated or impeded their progression.
    - 12 face-to-face in-depth interviews were conducted with purposively selected BSP participants covering different stages of the BSP screening pathway: four Māori, four Pacific and four Pākehā. Interviews were conducted between 19 and 21 September 2012.
  - In 2012, recognising that Pacific and Māori were potentially emerging as having lower participation rates, qualitative research was undertaken with non-responders in the eligible Pacific and Māori populations to explore their reasons and barriers for not taking part in the BSP.
    - 12 face-to-face interviews were undertaken with six Māori and six Pacific people who had received a pre-invitation, invitation and reminder letter between April and September 2012, had not returned a completed kit and had not contacted the Coordination Centre to opt out of the BSP (non-responders). Interviews were conducted between 3 and 7 December 2012.
  - Both studies followed opt-out recruitment and informed consent procedures. Researchers and participants were ethnically matched. Participants were invited to bring a support person, and received a koha of \$50.
- **The reports on the baseline and repeat attitudes survey with providers (Litmus 2012a and 2014b).**
  - The purpose of the surveys was to assess providers'<sup>25</sup> awareness and knowledge of the BSP, attitudes towards the BSP and its delivery mechanisms, and perceived impact of the BSP on normal services. The surveys also aimed to measure attitudes towards a possible national roll-out of a bowel screening programme.

<sup>24</sup> 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 90<sup>th</sup> percentile of design effects calculated for each item gathered in the survey.

<sup>25</sup> Providers include general practitioners (GPs), practice nurses, other general practice staff, endoscopy staff and radiology staff in Waitakere and North Shore Hospitals.

- A baseline online provider survey was undertaken in November 2011 to January 2012 before the full implementation of the BSP in January 2012. A total of 88 General Practitioners (GPs), 88 practice nurses, eight other general practice staff, 21 endoscopy staff and 30 radiology staff took part in the survey. Response rates for each survey are shown in Table 4.

**Table 4: Achieved response rates in 2011**

Provider group	Respondents (n)	Eligible population (N)	Response rate (%)
General practitioners	88	328 <sup>#</sup>	27%
Practice nurses	88	404 <sup>#</sup>	22%
Other general practice staff*	8	–	–
Endoscopy staff	21	27	78%
Radiology staff	30	49	61%

<sup>#</sup> Figure based on PHO estimates

\* Small number of other general practice staff – combined with practice nurse sample for analysis

- The follow-up online provider survey was undertaken from 14 October to 20 December 2013. A total of 80 GPs, 72 practice nurses, 26 other general practice staff, 18 endoscopy staff and 24 radiology staff took part in the survey. Response rates for each survey are shown in Table 5.

**Table 5: Achieved response rates in 2013**

Provider group	Respondents (n)	Eligible population (N)	Response rate (%)
General practitioners	80	328 <sup>#</sup>	24%
Practice nurses	72	404 <sup>#</sup>	18%
Other general practice staff*	26	–	–
Endoscopy staff	18	26	69%
Radiology staff	24	47	51%

<sup>#</sup> Figure based on PHO estimates

\* Other general practice staff were combined with the practice nurse sample for analysis

- Data were analysed by provider group. The small numbers overall and for particular provider groups prevented detailed analysis due to statistical limitations in making comparisons with small numbers.
- Comparisons have been made between the results in the 2013 follow-up provider survey and the 2011 baseline provider survey. Significant differences noted for endoscopy staff and radiology staff should be treated as indicative only due to their small sub-sample sizes.

- **The 2012 and 2013 immersion visit reports** (Litmus 2013a and 2014).
  - In September 2012, an immersion visit was undertaken to gain a detailed understanding of the early implementation of the BSP, from those who were involved with its design, implementation and day-to-day operations. Focus was placed on how the BSP was being implemented, what was working well and not so well, and in identifying key process improvements to enhance the BSP, as well as lessons for a national roll-out of a bowel screening programme, should it proceed.
  - 62 face-to-face, phone interviews and group discussions with providers across the screening pathway were undertaken (including representatives from Ministry of Health, WDHB, LabPLUS, New Zealand Post, Orangebox, Primary Health Organisations (PHOs) and general practices).
  - In October 2013, a second immersion visit was undertaken which focused on exploring the impact of the BSP on the investigation, surveillance and treatment stages, as well as following up issues identified in the 2012 immersion visit report (Litmus 2013a).
  - 30 face-to-face, phone interviews and group discussions with providers across the screening pathway were undertaken (including representatives from Ministry of Health, BSP Coordination Centre, Gastroenterologists (GE), CTC, Laboratory, endoscopy nurses, BSP colonoscopy surgeons, non-BSP colonoscopy surgeons who do not scope in BSP, oncologist).
  - All interviews followed an informed consent process.
- **The role of general practice report** (Litmus 2014c)
  - The role of general practice in informing BSP participants of a positive iFOBT is a unique element of the BSP. The findings from the first immersion visit (Litmus 2013a) found that while GPs and practice nurses are generally supportive of the BSP, across general practice there is variation in BSP processes and practices.
  - Given this unique role and noted variation, it was agreed the role of general practice in the BSP needed to be more fully understood, particularly with regard to enhancing participants' experience and in considering general practices' role if the Pilot was rolled out nationally. To identify the role and value of general practice in the BSP, a report was developed which drew on the quantitative data from the eligible population and provider surveys (Litmus 2014a & b), interviews with ten general practices including GPs, practice nurses, practice managers and other practice staff as well as face-to-face interviews with five Māori and five Pacific BSP participants.
  - Fieldwork was undertaken in October 2013. All interviews followed an informed consent process.

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).

## 2.5 Data differences

The epidemiology analysis and the costing analysis undertaken to support this study have different perspectives and have used data relating to different periods of time. For full specification of the data sources for each analysis, see Appendices 1 and 2 which provide detailed explanations of methodology.

For the costing analysis, the focus is on measuring the level of activity undertaken by the pilot during specific 'snap-shot' periods of time, to enable understanding of the relationship between volume of activity and costs incurred. For the epidemiology analysis, it is about tracing a cohort of individual participants through the pathway.

In summary, the approaches and differences in data sources are as follows:

- The epidemiology analysis uses data extracted by the Ministry of Health from the BSP Register and WDHB. It reports on the first 18 - 22 months of the first screening round, presenting results for the cohort of participants who were invited to join the programme from 1 January 2012 - 30 June 2013. (The full screening round could not be analysed due to the timing of data extraction and the need to allow sufficient time to pass for those people who were invited in the latter half of 2013 to complete the full screening pathway. The approach adopted allows four months from the time of invitation for the full screening pathway to be completed).
- For the costing analysis, a bottom-up costing model of the screening applies unit prices for key inputs (or programme activities), to volumes of each input delivered. The modelling forecasts cost estimates over different time periods (i.e. for the first screening round during years 1 - 2, and for the duration of the pilot, from years 1 - 4); these results are used subsequently as a basis for scaling up estimates of the operational cost of running a 'steady-state' bowel screening programme on a national basis. The costing analysis is based on two primary data sources:
  - **Cost data:** detailed 'snap-shot' samples of actual cost data from the pilot (relating to costs incurred during the two six-month periods (1 July - 30 December 2012 and 1 January - 30 June 2013) and cost data from the Ministry of Health.
  - **Volumes data:** information reported by the BSP to the Ministry of Health on a bi-annual basis, identifying activity volumes for the full two year screening round and data from the Ministry of Health published BSP monitoring indicators for the period to December 2013.

## 2.6 Limitations

This report draws on a mix of qualitative information and quantitative data. The evaluation team is confident that the results presented in the interim report accurately reflect the information and data provided. Table 6 provides a commentary on the data and information used to inform this report and their quality.

**Table 6: List of data and information used and their quality**

Data sources	Quality rating	Comments on quality
BSP epidemiology analysis	Low	It is recommend that the Ministry of Health comprehensively review the BSP Register and implement a robust data quality assurance programme. The evaluation has identified data quality issues that must be addressed as a high priority for the final evaluation and to monitor a national programme. Data quality issues identified include data definition, data inconsistencies, errors and data capture.
The BSP costing analysis report	Low-medium	Detailed costing data was made available by the pilot and our analysts received significant guidance from pilot staff to ensure we developed a strong understanding of the nature of contracting mechanisms and the unit cost of key inputs. However, issues identified by the epidemiology analysis team in relation to volumes data from the BSP Register are also relevant for the costing analysis; any data inconsistencies and errors in volumes reported may have a significant impact on the reliability of costing forecasts.
2011 Baseline and 2013 follow-up survey of eligible BSP population (Litmus 2012 and 2014a)	Medium-high	In the absence of any other population-level data on awareness and knowledge around bowel cancer and bowel screening, the telephone surveys conducted as part of the BSP evaluation provide useful information. Data limitations: <ul style="list-style-type: none"> <li>Relatively small sample sizes limit the possibility of extensive sub-group analysis and the reliability of comparisons over time.</li> <li>People who were less easily identifiable as Māori or Pacific may be less well represented, relative to those who were more easily identifiable as Māori or Pacific.</li> <li>Non-respondents may have differed from respondents in unknown ways, which would affect the survey results. Weighting will have helped to mitigate the problem.</li> <li>The response rates achieved for the two WDHB surveys (using a conservative measure) were reasonable, but not exceptional.</li> </ul>
The 2011 baseline and the 2013 follow-up survey with providers (Litmus 2012a and 2014b).	Medium	<ul style="list-style-type: none"> <li>The key methodological limitations of the provider surveys are the low GP and practice nurse response rates and an inability to establish whether GP and practice nurse samples are representative of the wider population of WDHB GPs and practice nurses. Consequently, GP and practice nurse findings are indicative and not definitive.</li> </ul>
Qualitative interviews with the eligible population - participants (Litmus 2013)	Medium	<ul style="list-style-type: none"> <li>Findings are dependent on participants' recall of the order of events and experiences on the BSP screening pathway.</li> <li>Undertaking 12 interviews with participants means the diversity of Māori, Pacific and other people may not be covered. On completion of the 12 interviews, no new substantive themes were being identified suggesting that saturation may have been reached.</li> <li>Due to the small sample size, Asian people were not included therefore not all experiences of those participating in the BSP have been explored.</li> </ul>

Data sources	Quality rating	Comments on quality
Qualitative interviews with the eligible population - non-participants) (Litmus 2013)	Medium	<ul style="list-style-type: none"> <li>Sample size: undertaking six interviews with Māori and six with Pacific people means that not all reasons and barriers for non-participation have been identified. However, it is anticipated that significant themes have been identified.</li> <li>Targeted sub-groups: this approach offers no understanding of the reasons/ barriers for Pākehā and Asian men not participating. Further, it also does not address the diversity of Māori or Pacific people eligible to participate.</li> </ul>
The 2012 immersion visit report (Litmus 2013a)	Medium-high	<ul style="list-style-type: none"> <li>The perspective of primary care on the BSP is limited to the participants from six general practices from Waitemata Primary Health Organisation (PHO) and Procure.</li> </ul>
The 2013 immersion visit report (Litmus 2014)	High	<ul style="list-style-type: none"> <li>Good coverage of providers involved in investigation, surveillance and treatment stages of the BSP screening pathway.</li> </ul>
Immersion interviews with general practice and WDHB staff (Litmus 2014c)	Medium	<ul style="list-style-type: none"> <li>The perspective of primary care on the BSP is limited to the participants from ten general practices from Waitemata PHO and Procure.</li> <li>Variations in processes and opinion on general practice were noted across the ten practices.</li> </ul>
Qualitative interviews with BSP participants (Litmus 2014c)	Medium	<ul style="list-style-type: none"> <li>Findings are dependent on participants' recall of the order of events and experiences on the BSP screening pathway.</li> <li>Undertaking ten qualitative interviews means the diversity of Māori and Pacific BSP participants may not be covered, and Asian people and European were not included therefore not all experiences of those participating in the BSP have been explored.</li> <li>Two Māori and five Pacific participants were informed about their iFOBT results by the Endoscopy Unit. Participants were not screened as it was assumed that most would have received their positive iFOBT result via their general practice. Further, the pool from which to draw the purposive sample was too small to screen participants out. The sample achieved enabled the exploration of participants' experience of hearing about their results via the Endoscopy Unit and whether they would have preferred to have received their results from their general practice.</li> </ul>

## 3. Evaluation findings

### 3.1 Participation and outcomes

#### Evaluation objectives addressed in section

*Participation and coverage* - To determine the level of participation and coverage for the eligible and invited populations, including sub-populations (defined by sex, age, ethnicity, socioeconomic status and rural representation).

*iFOBT experience* - To assess the performance and acceptability of the chosen iFOBT in the New Zealand context including the positivity rates in New Zealand, positive predictive values for adenomas and cancers, technical repeat rates and false positive rates.

*Screening effectiveness* - To assess the early indicators of the effectiveness of bowel screening, including the number and stage of cancers detected, the number and size of adenomas detected, and colonoscopy completion rates.

Section 3.1 presents the findings from the epidemiology report (Read, Shanthakumar, Borman 2014). The full report and its appendices are in [Appendix 1](#).

### Acknowledgements

This report was prepared by Dr Deborah Read and the Centre for Public Health Research (CPHR), Massey University for Litmus who are funded by the Ministry of Health to evaluate the bowel cancer screening pilot.

The team thank the Ministry of Health for providing data from the BSP Register and Waitemata District Health Board (WDHB), and Litmus for providing the literature.

We acknowledge and thank Professors John Potter and Steve Haslett<sup>26</sup> for providing peer review.

### Introduction

Colorectal cancer incidence and mortality is high in New Zealand by international standards (National Cancer Institute 2013). In 2010 colorectal cancer was one of the two most common cancers registered and the second most common cause of death from cancer (Ministry of Health 2013). Although the age-standardised registration rate is less for Māori than non-Māori, Robson et al (2006) found differences in stage at diagnosis and survival. Early detection and removal of colorectal cancer or its precursor lesion, adenoma, by population screening can reduce colorectal cancer mortality (Towler et al 1998).

The Ministry of Health has funded Waitemata District Health Board (WDHB) to run a bowel cancer screening pilot (BSP) programme over four years from 2012–15. The BSP began with a 'soft launch' in late 2011, with full operation starting from 1 January 2012.

<sup>26</sup> Professor Steve Haslett reviewed the Appendix BSP Methodology and Analysis.

The BSP offers eligible people, aged between 50-74 years living in the WDHB area, colorectal cancer screening by a single sample immunochemical faecal occult blood test (iFOBT), with colonoscopy as the diagnostic test. Colonoscopy with polypectomy also provides a therapeutic intervention that can prevent colorectal cancer.

Epidemiological analysis of data from the first screening round was carried out to inform the evaluation of the BSP by Litmus, the results of which will contribute to a decision in 2016 on whether or not to implement a national bowel screening programme.

## Methods

The scope of the epidemiological analysis was approved by the Ministry of Health. It was based on the evaluation of the United Kingdom (UK) bowel cancer screening pilot (Weller et al 2007).

The data were extracted by the Ministry of Health from the BSP Register and WDHB.

The results represent the first 18-22 months of the first (or prevalence) screening round. The first screening round commenced on 1 January 2012 and was completed on 31 December 2013. The full screening round could not be analysed due to the timing of data extraction and the need to allow sufficient time to pass for those people who were invited in the latter half of 2013 to complete the full screening pathway. Figure 1 of Appendix 1 in the epidemiological report<sup>27</sup> shows the possible pathway process of a participant in the BSP.

For details of the methodology, including definitions, and results, see the Appendix.

This analysis allows four months from the time of invitation for the full screening pathway to be completed.

Logistic regression has been used to investigate associations between demographic variables and screening outcomes. The results are given in the Appendix as odds ratios, both unadjusted and adjusted for all other demographic variables, with 95% confidence intervals.

Key findings are presented and only counts and percentages together with the adjusted odds ratios are discussed. Adjusted odds ratios allow for the effects of all demographic variables other than the one under consideration. For example, when considering participation by age group, the results have been adjusted to take account of the potential effects of sex, ethnicity and deprivation (NZDep2006).

Unless otherwise stated, the results discussed here are statistically significant<sup>28</sup>.

Results for the self-selected population are presented separately.

The results sections for participation and the various outcomes are each followed by a discussion section that focuses on relevant comparisons with population-based screening programmes in other countries.

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<sup>27</sup> The complete epidemiology report is in Appendix 1.

<sup>28</sup> The result is deemed to be statistically significant if the 95% confidence interval of the odds ratio does not include 1.



## Participation

### *Immunochemical faecal occult blood test (iFOBT) uptake*

During the first 18 months of the first screening round, 86,753 eligible people aged 50-74 years living in the WDHB area were invited to participate. This is the denominator population used in the analysis. For all demographic information about the eligible population see the Appendix 1, Table 1<sup>29</sup>. Details of the exclusion criteria applied to determine the eligible population are also in the Appendix<sup>30</sup>.

About 55% (n=47,310) of those who received an invitation responded by returning a completed kit. The majority (n=46,409; 98%) returned an adequate kit resulting in a participation rate of 53.5%. About 17% of participants required more than one attempt, and some up to five attempts, to achieve an adequate kit<sup>31</sup>.

The *European guidelines for quality assurance in colorectal cancer screening and diagnosis* (European guidelines) regard less than 3% spoilt kits<sup>32</sup> as acceptable and less than 1% as desirable (Moss et al 2010). The BSP meets the acceptable level.

At least 1,456 of those invited did not respond because of an 'invalid/not found' address. This represents 3.3% of non-responders.

For all results see the Appendix 1, Table 2a.

### **Participation increased with increasing age**

People aged 65-69 and 70-74 years were more than twice as likely to participate as people aged 50-54 years (Figure 8).

### **Participation differed by sex and ethnicity**

Males were slightly less likely to participate than females (Figure 9). This difference decreased with increasing age.

Participation was highest among Europeans (60.3%), followed by Asians (51.3%), 'Other' (43.1%), Māori (42.0%) and Pacific people (23.8%).

Asians were slightly less likely to participate than Europeans (Figure 6). Participation was close to that of Europeans for those aged 50-59 years but Asians aged 70-74 years were about half as likely to participate as Europeans of the same age.

Pacific people were about four times less likely to participate than Europeans (Figure 6). In the 70-74 year age group, Pacific people were seven times less likely to participate than Europeans of the same age.

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<sup>29</sup> References to appendices in this section refer to the appendices in the complete epidemiology report in Appendix 1.

<sup>30</sup> There were 7,662 people who were deemed ineligible as they met at least one exclusion criteria.

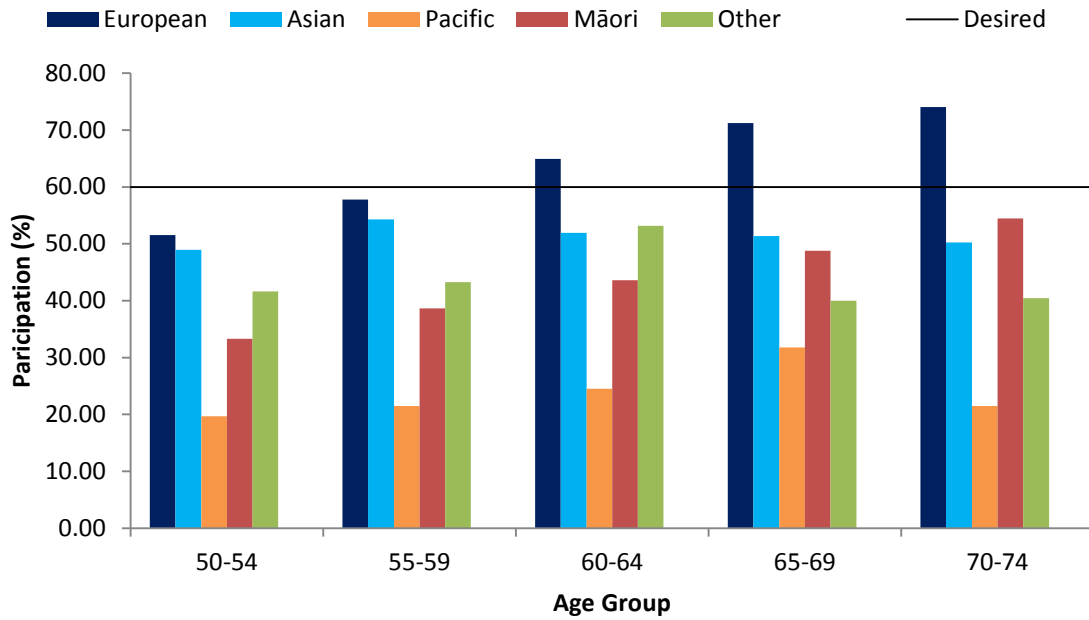
<sup>31</sup> The spoilt kit return rate is expected to fall as a result of introducing a revised consent form and simpler instructions in 2014.

<sup>32</sup> The complete epidemiology report in Appendix 1 refers to 'inadequate' kits in accord with Weller et al 2007 which is synonymous with 'spoilt' kits.

Māori were almost half as likely to participate as Europeans (Figure 6). This difference was similar for each age group.

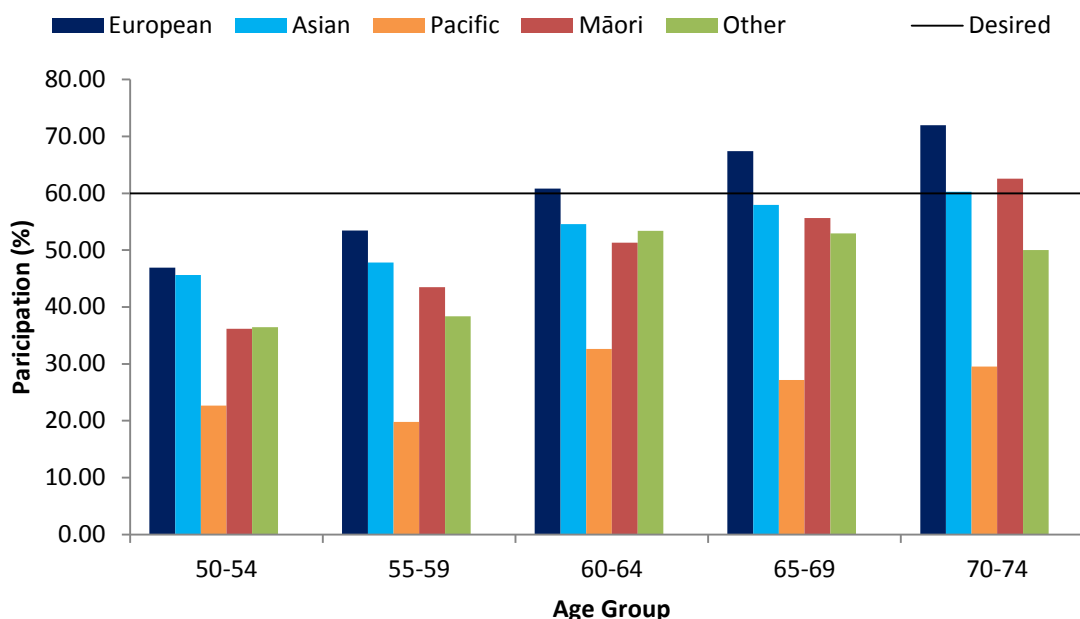
Figures 4 and 5 show the participation of females and males respectively, for each age and ethnic group. European females and males aged 60-74 years, and Asian and Māori males aged 70-74 years met the Ministry's 60% participation target.

**Figure 4: Female participation by age and ethnicity**



Source: BSP Register

**Figure 5: Male participation by age and ethnicity**



Source: BSP Register

### Participation declined with increasing deprivation

Participation among people from the most deprived quintile area (NZDep Index 9-10) was more than 1.5 times less likely than people from the least deprived quintile area (NZDep Index 1-2) (Figure 7).

### Discussion

The success of screening depends on participation. The overall participation rate of 53.5% is below the Ministry's target of 60% by the end of the BSP, but higher than the Australian pilot of 45.4%<sup>33</sup> and the early stages of implementation in Canada (16.1%) (BCSPMESC 2005; Major et al 2013). The Australian pilot did not include 50-54 year olds and no exclusion criteria applied to people living in a pilot site in the relevant age group (BCSPMESC 2005).

The BSP participation rate is similar to the first round of the UK pilot in Scotland (53%), but below that in England of 61%<sup>34</sup> (Steele et al 2010; Weller et al 2007). Participation in the UK pilot may have been higher if the older age group (70-74 years) had been included.

Participation has been found to be higher when the iFOBT is used rather than the guaiac faecal occult blood test (Hol et al 2009). Both Australia and Canada used the iFOBT.

<sup>33</sup> This is the average participation for the two iFOBTs combined that were compared in the Australian pilot. The participation rate was 47.2% for the Magstream and 43.6% for the InSure iFOBT.

<sup>34</sup> Uptake was 58.5% before exclusion criteria were applied.

The European guidelines set a minimum uptake level of 45% as acceptable and recommend at least 65% as desirable (Moss et al 2010). The BSP meets the acceptable level.

Lower participation among males and those from more deprived areas was also found in the Australian pilot. Participation tended to be lower for Aboriginal and Torres Strait Islander people and for people who spoke a language other than English (BCSPMESC 2005).

Lower participation among younger age groups, males, those from more deprived areas and from the Indian sub-continent were also found in the UK pilot, and among younger age groups and males in Canada (Weller et al 2003; Major et al 2013).

## *Colonoscopy uptake*

Of the participants who returned an adequate kit in the first 22 months of the first screening round, 6.1% (n=2,843) had a publicly funded colonoscopy. The outcomes in this report are only for this group (n=2,843) due to uncertainty about data quality, including data completeness, for those participants who opted for a privately funded colonoscopy. Information on private colonoscopy was not included in the UK pilot evaluation (Weller et al 2003).

Almost 11% (n=356) of those with a positive iFOBT were subsequently recorded as being outside the public system. At least 184 of these participants had a privately funded colonoscopy. The data are uncertain for the other 171 participants. It is not clear whether they indicated intent to have privately funded colonoscopy but had not yet done so, had private colonoscopy locally but the results were not available or had not been entered into the BSP, or were going overseas e.g., Asia or outside the WDHB area for colonoscopy.

The number of participants with a positive iFOBT who declined colonoscopy is uncertain due to data quality issues. For example, two participants who 'declined' were also entered as having had a publicly funded colonoscopy with histopathology results. Reasons for declining that were entered in the free text indicated a few people were ineligible to be part of the BSP based on residence and previous colonoscopy.

Of those participants who had a positive iFOBT in the first 22 months of the first screening round (n=3,303), 86.1 % had a colonoscopy in the public system. The colonoscopy was not completed in 0.6% of cases. Seventy-six percent (n=2,161) of colonoscopies had abnormal results.

Thirty-nine (1.2%) participants with a positive iFOBT had CTC<sup>35</sup>.

For all results see the Appendix 1, Table 2b.

### **Colonoscopy uptake differed by sex and Asian ethnicity**

Males were slightly more likely to have a colonoscopy than females. Males aged 70-74 years were more than twice as likely to have a colonoscopy as females of the same age.

Asians aged 50-59 years were half as likely to have a colonoscopy as Europeans of the same age.

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<sup>35</sup> CTC, sometimes called virtual colonoscopy, is a radiological procedure that uses a CT scanner to visualise the bowel.

## Colonoscopy uptake increased with increasing deprivation

Colonoscopy uptake among people from the most deprived quintile areas (NZDep Index 7-8 and 9-10) was twice as likely as people from the least deprived quintile area (NZDep Index 1-2).

### **Discussion**

The colonoscopy uptake rate of 86.1% is consistent with the 87% achieved in Scotland (Steele et al 2010). The BSP colonoscopy uptake rate is an under-estimate because of the exclusion of private colonoscopy data. The BSP rate is higher than uptake in England and Canada, both of which report 80.5%, although private colonoscopy data were not available to Weller *et al* so uptake in England may have been higher (Weller et al 2007; Major et al 2013). The high rate of missing data on the Australian register meant the reported colonoscopy uptake was only 55% in the pilot (BCSPMESC 2005). Uptake in the Australian National Bowel Cancer Screening Program is now 76.3% but this is an under-estimate because of missing data (AIHW 2010).

The European guidelines set the acceptable colonoscopy compliance rate at 85% (Moss et al 2010). Uptake in the BSP meets this standard.

Given the participation of younger Asians in the BSP was only slightly less, and their iFOBT positive rate was slightly higher, than younger Europeans, their lower colonoscopy uptake may reflect that they are returning to Asia or are more likely to go to the private system for their colonoscopy. This requires further investigation.

## Outcomes

For a summary of the outcomes of the BSP, see Figure 1.

### *Immunochemical faecal occult blood test (iFOBT) positivity*

Of the participants who returned an adequate kit in the first 22 months of the first screening round (n=46,409), 7.1% had a positive iFOBT result.

For all results see the Appendix 1, Table 3a.

#### **Positivity increased with increasing age**

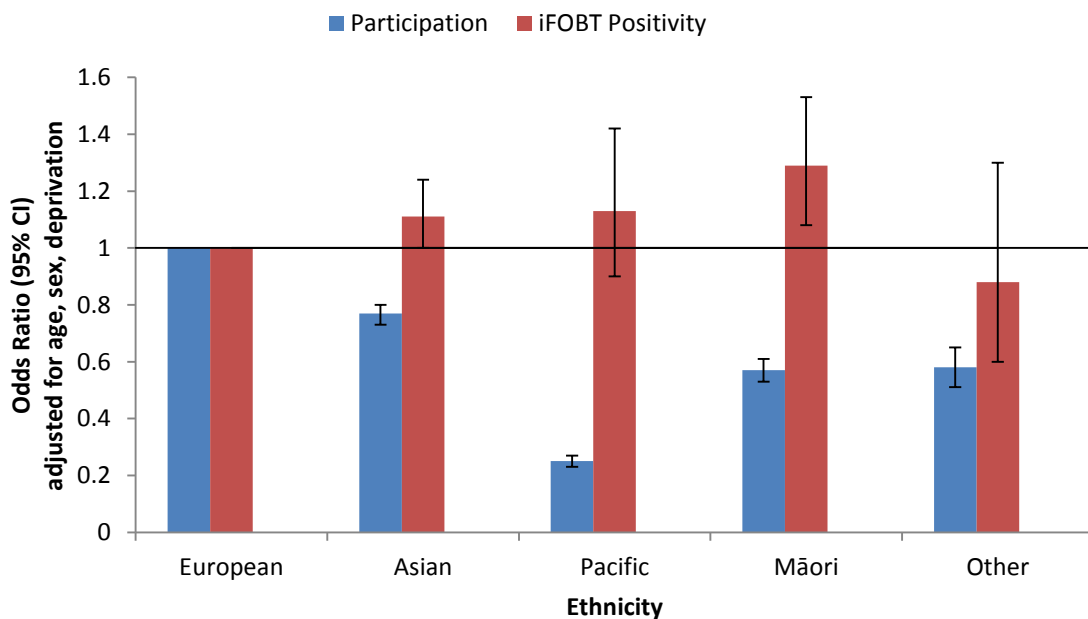
Participants aged 70-74 years were more than twice as likely to have a positive iFOBT result as participants aged 50-54 years (Figure 8).

#### **Positivity differed by sex and Māori ethnicity**

Males were over 1.5 times more likely to have a positive iFOBT result than females (Figure 9). This difference was found for each age group.

Māori were slightly more likely to have a positive iFOBT result than Europeans (Figure 6).

**Figure 6: Participation and iFOBT positivity by ethnicity**

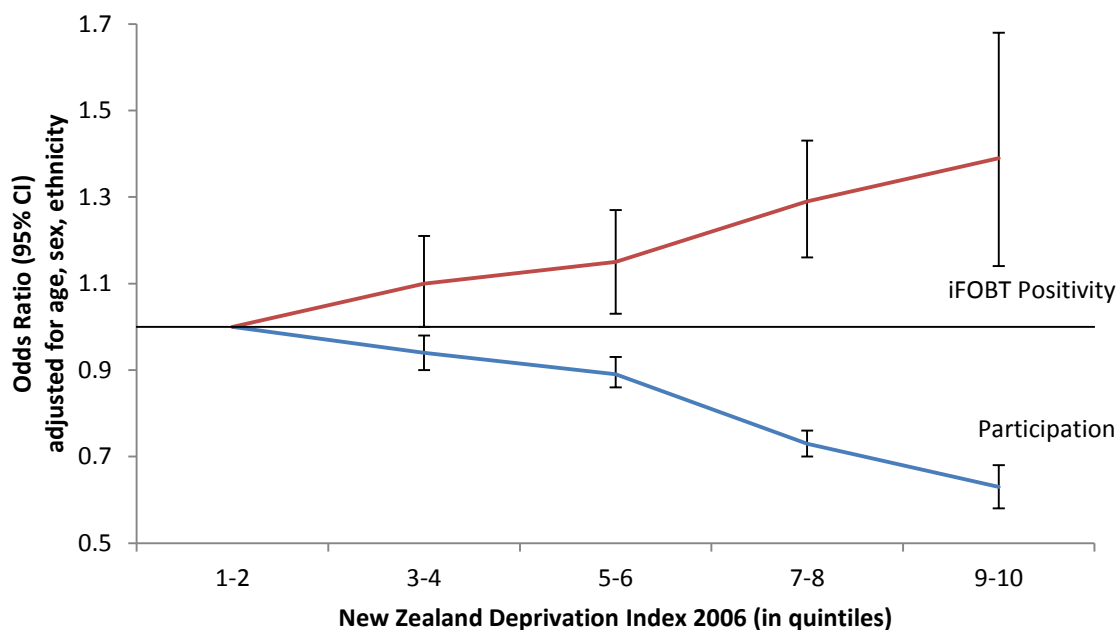


Source: BSP Register

### Positivity increased with increasing deprivation

Positivity among people from the most deprived quintile area (NZDep Index 9-10) was about 1.5 times more likely than people from the least deprived quintile area (NZDep Index 1-2) (Figure 7).

Figure 7: Participation and iFOBT positivity by deprivation quintiles



Source: BSP Register

### Discussion

Comparison of the positivity rate with other population-based screening programmes is limited by the use elsewhere of a guaiac rather than iFOBT and varying iFOBT cut-off levels. The iFOBT is more sensitive for advanced adenomas and cancer than the guaiac faecal occult blood test (Lansdorp-Vogelaar and von Karsa 2010). Guittet et al (2009) found the increase in sensitivity of the iFOBT for colorectal cancer was confined to rectal cancer, which was attributed to the lower amount of bleeding of rectal cancer.

The positivity rates for the iFOBTs used in the Australian bowel cancer screening pilot of 55-74 year olds were 8.2% for Magstream and 9.9% for InSure (BCSPMESC 2005). The BSP positivity rate is similar to the rate (6.6%) seen when 50 year olds were included in the Australian National Bowel Cancer Screening Programme (NBCSP) in 2008 (AIHW 2010).

If the positivity rate is too low, the screening programme will fail to adequately identify adenomas and cancer, whereas if it is too high there will be pressure on colonoscopy capacity.

The BSP positivity rate was within the range (4.4-11.1%) of positive iFOBT rates reported in the first round of population-based screening programmes (Moss et al 2010; Major et al

2013). The positivity rate from the first screening round in the Netherlands using an iFOBT with the same cut-off level and a population of the same age range as the BSP was lower – 5.7% (Hol et al 2009).

A higher positivity rate with increasing age, and in males compared with females, has also been reported in Australia, the UK and Canada (BCSPMESC 2005; Weller et al 2007; Major et al 2013). This reflects the natural history of the disease.

A higher positivity rate in more deprived areas was also found in England (Weller et al 2007).

### **Detection rates of adenoma, advanced adenoma and colorectal cancer**

Following colonoscopy, there were 1,593 participants who had at least one adenoma and no cancer detected. There were 887 participants who had at least one advanced adenoma and no cancer detected. Ninety-five participants had cancer detected. Some of these participants would have had more than one type of pathology; only the most serious type was recorded.

The overall detection rate of adenoma was 3.4%, advanced adenoma was 1.9%, and cancer was 0.2%.

For all results see the Appendix 1, Table 3a.

### **Detection rates increased with increasing age**

This trend reflects the natural history of adenomas and colorectal cancer.

The 70-74 year old participants were almost three times more likely to have an adenoma or advanced adenoma detected than 50-54 year old participants.

The 70-74 year old participants were almost four times more likely to have cancer detected than 50-54 year old participants.

Figure 8 shows increasing participation, iFOBT positivity, and combined advanced adenoma<sup>36</sup> and colorectal cancer with age.

### **Detection rates differed by sex, and Māori and Asian ethnicity**

Males were about twice as likely to have an adenoma, advanced adenoma, or cancer detected than females (Figure 9). The difference between males and females existed at every age group for adenoma and advanced adenoma, and in the 65-69 and 70-74 year age groups for cancer.

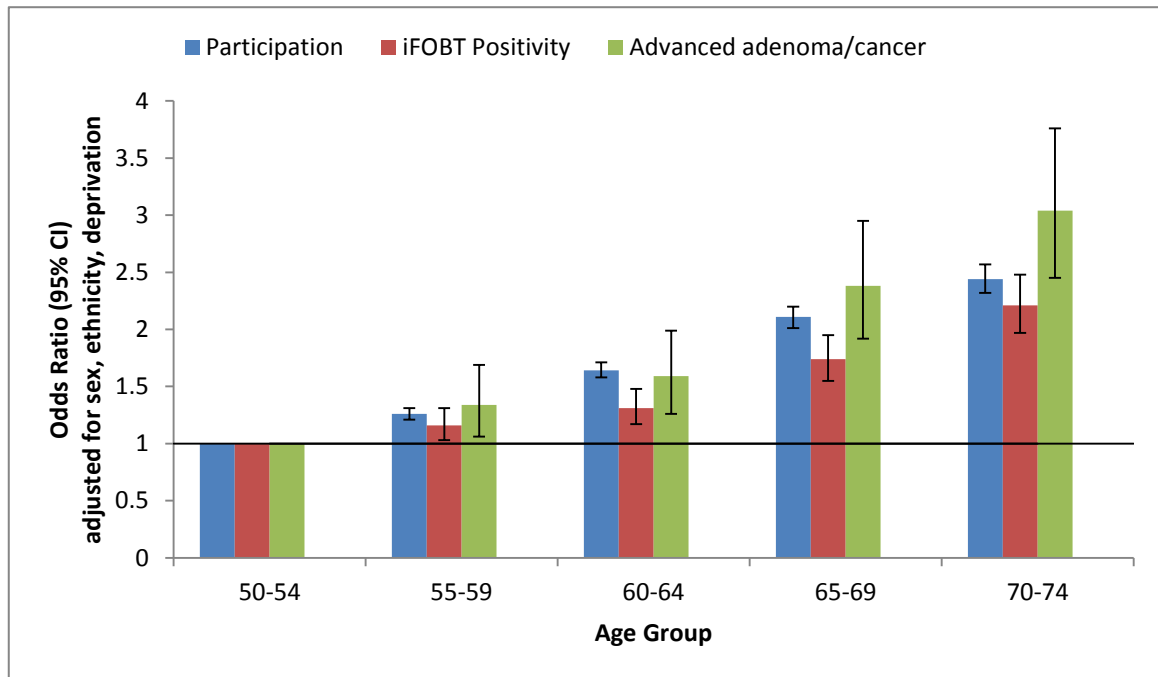
The difference between males and females for adenoma and advanced adenoma decreased with increasing age.

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<sup>36</sup> Advanced adenomas are the highest-risk precursors of colorectal cancer.

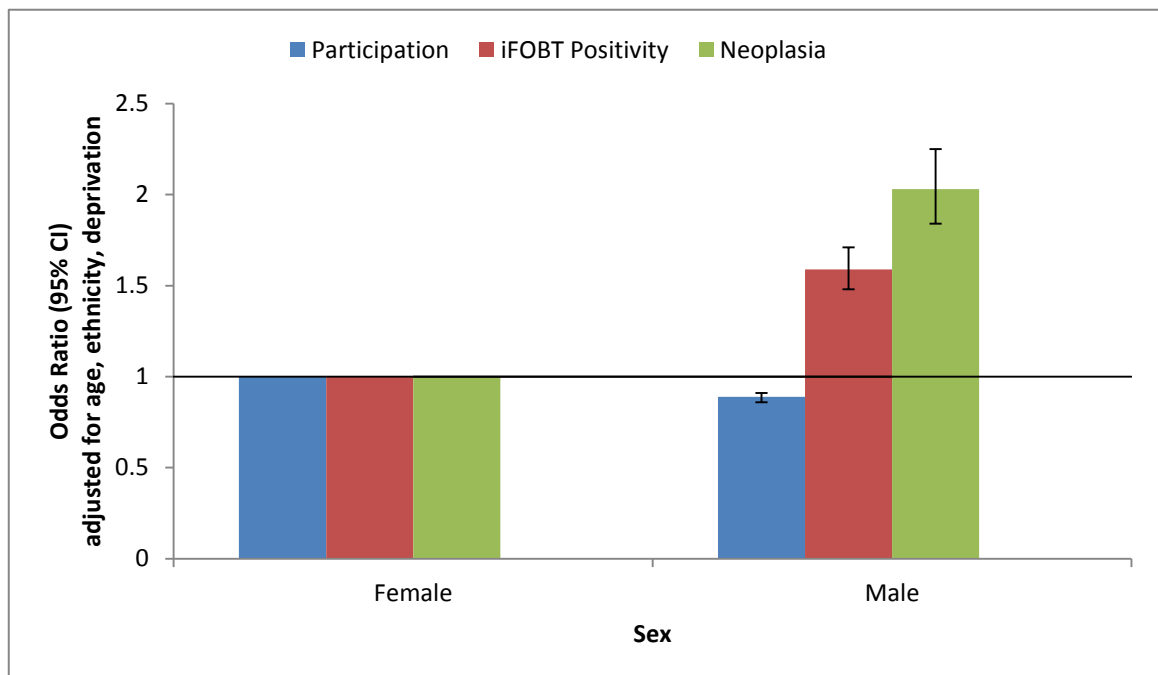


**Figure 8: Participation, iFOBT positivity, and combined advanced adenoma and colorectal cancer by age**



Source: BSP Register

**Figure 9: Participation, iFOBT positivity, and neoplasia<sup>37</sup> by sex**



Source: BSP Register

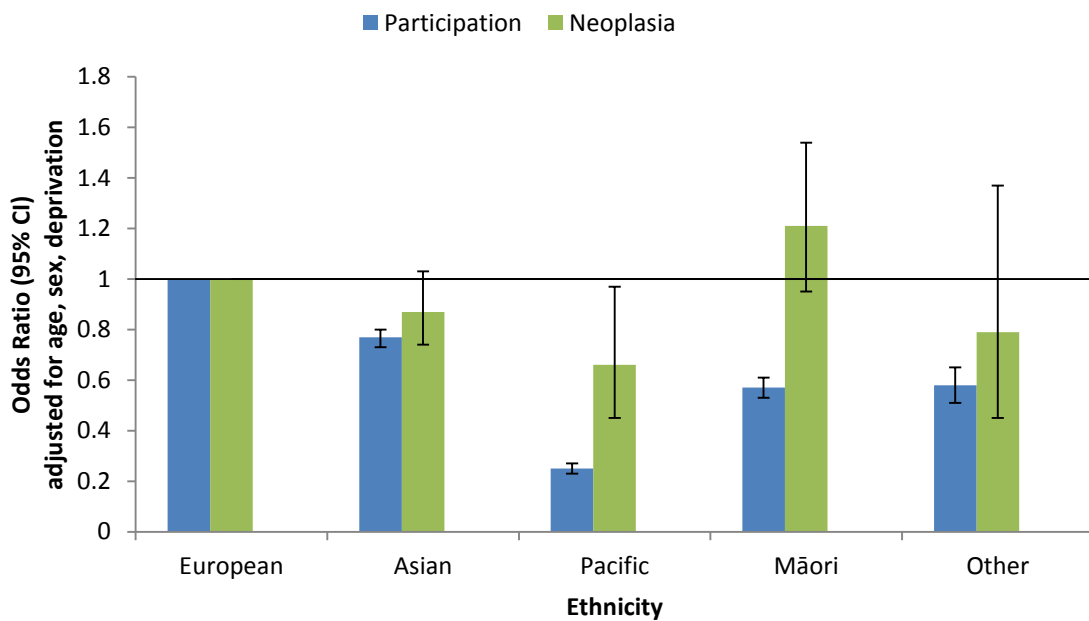
<sup>37</sup> Neoplasia refers to adenomas (including advanced adenoma) and colorectal cancer.

Māori aged 60-69 years were 1.5 times more likely to have an adenoma detected than Europeans of the same age.

Māori were almost 1.5 times more likely to have an advanced adenoma detected than Europeans.

Asians were over 1.5 times less likely to have an advanced adenoma detected than Europeans.

**Figure 10: Participation and neoplasia by ethnicity**

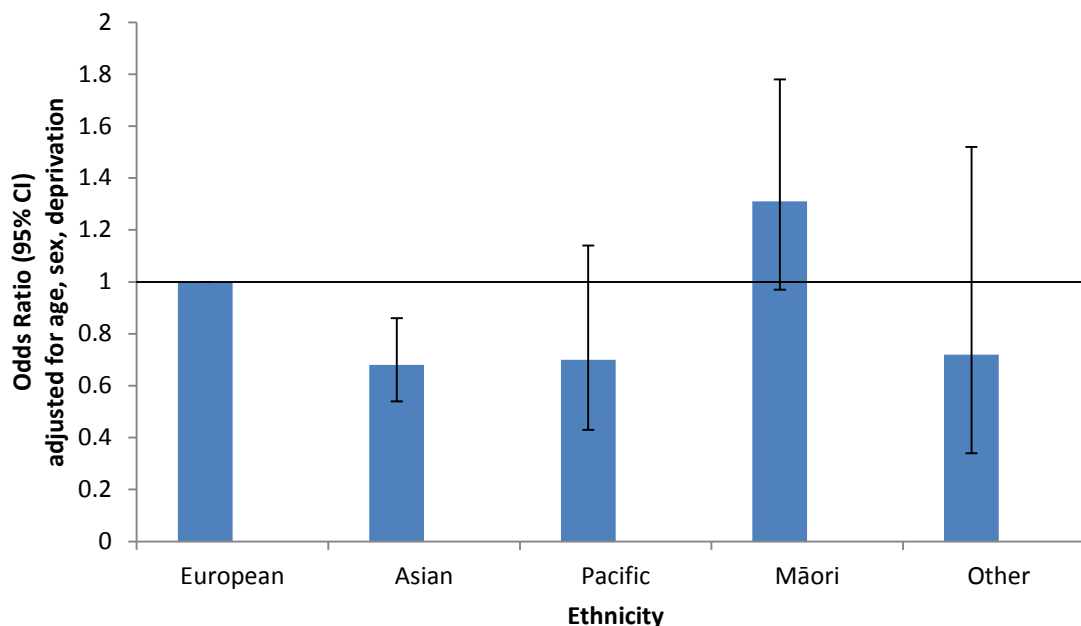


Source: BSP Register

Figure 10 shows Pacific people were less likely than Europeans to have neoplasia detected. There was a suggestion that Asians were less likely and Māori were more likely than Europeans to have neoplasia detected, but this was not statistically significant.

Figure 11 shows Asians were less likely than Europeans to have either advanced adenoma or colorectal cancer detected.

**Figure 11: Combined advanced adenoma and colorectal cancer by ethnicity**



Source: BSP Register

### Detection rates increased with increasing deprivation

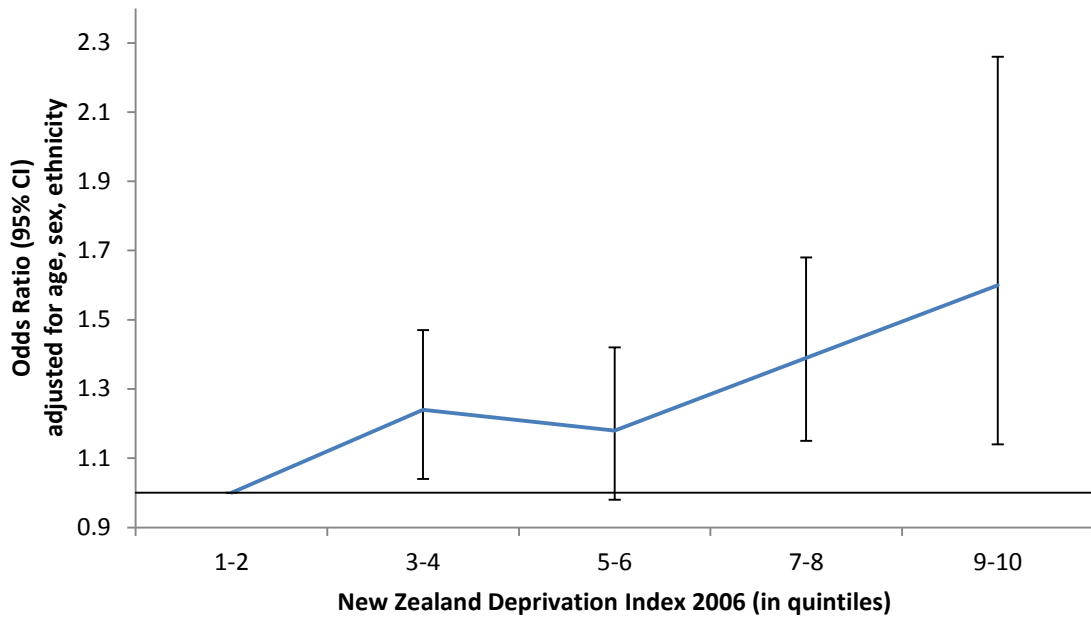
Participants from the two most deprived quintile areas (NZDep 7-8 and 9-10) were about 1.5 times more likely to have an adenoma or advanced adenoma detected than participants from the least deprived quintile area (NZDep Index 1-2).

The results, adjusted for age, sex and ethnicity, also suggest cancer was more likely to be detected among participants living in the most deprived quintile area compared with the least deprived quintile area. However, the results were not statistically significant. When cancer and advanced adenoma were combined, there was a trend of more disease with increasing deprivation (Figure 12). The trend was similar for neoplasia (Figure 13).

The detection rates may be an under-estimate since the dataset only allows four months for completion of the pathway. However, on average, completion occurred within three months. The UK BSP evaluation allowed a three month lag period.

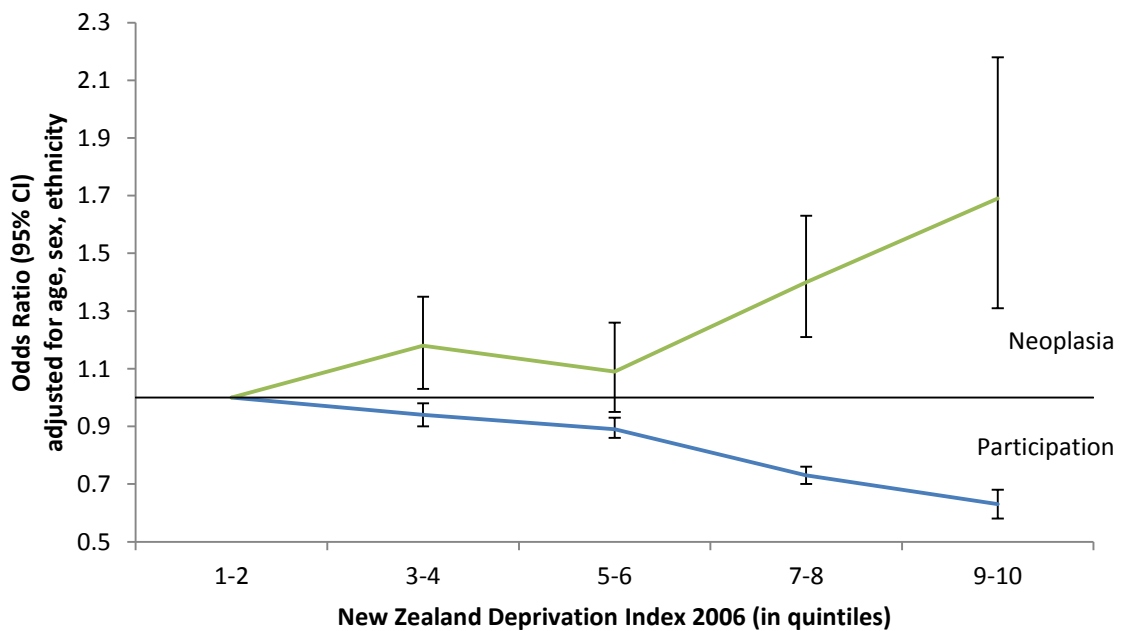
Absence of private colonoscopy data also means that detection rates for the various outcomes are under-estimates.

Figure 12: Combined advanced adenoma and colorectal cancer by deprivation quintiles



Source: BSP Register

Figure 13: Participation and neoplasia by deprivation quintiles



Source: BSP Register

## **Discussion**

The BSP detection rate for adenoma (3.4%) is above the range (1.33-2.23%), and for cancer (0.2%) is at the lower end of the range (0.18-0.95%) reported in the first screening round of population-based programmes that use the iFOBT (Moss et al 2010).

Reliable detection rates are not available for Australia as a whole due to missing histopathology outcome data in the register<sup>38</sup> (AIHW 2010).

The UK *Quality assurance standards for colonoscopy* give a standard of adenoma detected in at least 35% of colonoscopies and cancer detected in at least 2 per 1,000 screened (Chilton and Rutter 2011). The BSP almost meets the detection standard for adenoma and just meets that for cancer.

In a Dutch randomised population-based trial of 50-74 year olds, Hol et al (2009) found the detection rate for advanced adenoma and cancer at an iFOBT cut-off level of 75ng haemoglobin/ml was twice as high as the guaiac faecal occult blood test. This is the cut-off level of the iFOBT used in the BSP (Hol et al 2009).

## **Positive Predictive Values**

The positive predictive value (PPV) of a positive iFOBT for adenoma was 48.2%, advanced adenoma was 26.9%, and cancer was 2.9%. That is, 51.1% of people who had a positive iFOBT had an adenoma or cancer detected, and 29.7% had an advanced adenoma or cancer detected.

For all results see the Appendix 1, Table 3b.

### **There were some age, sex and ethnic differences in the effectiveness of a positive iFOBT in detecting neoplasia**

The PPV was higher for adenoma (1.8 times) and advanced adenoma (1.5 times) among 70-74 year old participants than 50-54 year old participants.

The PPV for adenoma and advanced adenoma was higher for males than females. The difference in effectiveness between males and females was for the younger age groups (50-54, 55-59 and 60-64 years for adenoma, and 50-54 and 55-59 years for advanced adenoma).

The PPV was about twice as high for both adenoma and advanced adenoma among 65-69 and 70-74 year old females as 50-54 year old females.

The PPV for adenoma was about 1.5 times less for Asians than that for Europeans.

The PPV for adenoma for Pacific people was about half that for Europeans.

The PPV for advanced adenoma for Asians was about half that for Europeans.

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<sup>38</sup> 35.5% of people invited in 2008 who had a positive faecal occult blood test had no outcome data recorded in the National Bowel Cancer Screening Register by the end of January 2010.

The PPV for cancer was more than three times as high for 65-69 and 70-74 year old males as 50-54 year old males.

### **Discussion**

The PPV for adenoma was found to be higher for programmes using the iFOBT compared with the guaiac faecal occult blood test in Canada (Major et al 2013). The PPV for cancer did not differ between the test types (Hol et al 2009; Major et al 2013).

Differences in the international prevalence of colorectal cancer will lead to differences in the PPVs.

The PPV of a positive iFOBT was higher in the BSP than the Australian pilot for advanced adenoma (26.9% vs 13.9%) but lower for cancer (2.9% vs 5.3%). However the Australian register had a high rate of missing colonoscopy data (BCSPMESC 2005).

The BSP PPV of a positive iFOBT for cancer of 2.9%<sup>39</sup> is below the range (4.5-8.6%) reported in the first screening round of population-based programmes, whereas the PPV for adenoma of 48.2% is above the reported range (19.6-40.3%) (Moss et al 2010). However, the more recently reported PPV for adenoma and cancer (50.6% and 4.3% respectively) from the three Canadian provincial programmes that use the iFOBT is outside of these ranges, and higher than in the BSP (Major et al 2013).

## Colorectal cancer

Ninety-five participants has cancer detected (2 per 1,000 screened). Eighty were European, 12 were Asian, 2 were Māori and none was Pacific.

The cancer detection rate increased with increasing age. Participants aged 65-69 and 70-74 years were between three and four times more likely to have cancer than participants aged 50-54 years.

Males were almost twice as likely to have cancer as females.

Males aged 65-69 and 70-74 years were more than 2.5 times more likely to have cancer than females of the same age.

Males aged 65-69 and 70-74 years were about six times more likely to have cancer than 50-54 year old males.

The extent of spread of a cancer is known as its stage. There are various staging systems; the BSP has adopted Tumour Node Metastasis (TMN) staging. The staging ranges from Stage 1, the least advanced, to Stage 4, the most advanced.

Most cancers were Stage I (42.6 per 100,000 participants), followed by Stage II (18.4 per 100,000 participants), Stage III (12.7 per 100,000 participants) and Stage IV (8.1 per 100,000 participants) (Appendix 1, Table 4).

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<sup>39</sup> The PPV of a positive iFOBT for cancer increases to 3.1% if the cancers detected among the self-selected population are included.

Almost 39% (n=37) of those participants with cancer detected had Stage I (i.e., confined to the bowel inner lining or muscle wall) and 8.4% (n=8) had Stage IV (i.e., spread to a distant part of the body).

### **Discussion**

The cancer detection rate and the proportion of early-stage cancers was found to be higher for programmes using the iFOBT compared with the guaiac faecal occult blood test in Canada (Major et al 2013).

The BSP cancer detection rate (2.0 per 1,000)<sup>40</sup> is at the lower end of the range (1.8-9.5 per 1,000) reported in the first screening round of population-based programmes that use the iFOBT (Moss et al 2010).

The detection rate for cancer from the three Canadian provincial programmes that use the iFOBT was also higher (2.8 per 1,000), as was the proportion of Stage I or II cancers (76.1% compared with 62.1% in the BSP) (Major et al 2013).

A review of colorectal cancer cases diagnosed in the first two years that the Australian NBCSP was operating found 40% of NBCSP-detected cancers were Stage I and 3% were Stage IV (Ananda et al 2009).

The UK pilot used the guaiac faecal occult blood test so the results are not directly comparable. The cancer detection rate was 1.26 per 1,000 screened in England and 1.99 per 1,000 screened in Scotland (Weller et al 2006). Staging results for the UK pilot after the first invitation round were 48% at Dukes' A and 1% at Dukes' D (UK Colorectal Cancer Screening Pilot Group 2004). After three rounds of invitation for prevalence screening in Scotland, the proportion of cancers detected at Stage I (Dukes' A) was 46.5% and 6% were Stage IV (Dukes' D) (Steele et al 2010). Reports of screening programmes that refer to staging have mostly used the Dukes' staging system (Colorectal Cancer Screening Advisory Group 2006).

## **The self-selected population**

The self-selected population comprised people in the eligible population who were not on the BSP Register (e.g., no National Health Index, moved into the area) but who requested screening, and people on the Register who requested screening before they received an invitation. The latter group included Māori and Pacific people who may have attended a community education session or hui and expressed an interest to take part in the BSP. Health promoters then notified the Coordination Centre and an invitation letter and iFOBT kit was sent out.

There were 1,895 eligible<sup>41</sup> people in this group – 1,555 Europeans, 183 Asians, 43 Pacific and 71 Māori. Ethnicity data were missing for 31 people. The Register records some people as being both self-registered and self-referred (see Appendix – Data Quality). There were 1,580 self-referred people of whom 41 were Pacific and 60 Māori.

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<sup>40</sup> The cancer detection rate increases slightly to 2.2 per 1,000 if the cancers detected among the self-selected population are included. This may reflect a higher likelihood of self-selection because of symptoms among this group.

<sup>41</sup> Eligibility is defined in the Appendix.

Eighty-eight percent (n=1,676) returned an adequate kit compared with 98% of the non-self-selected population.

For all results see the Appendix 1, Table 5.

Participation was highest among people aged 65-69 and 70-74 years. People aged 70-74 years were five times more likely to participate than those aged 50-54 years. Unlike the non-self-selected population, there was no statistically significant difference in participation by sex.

Almost 85% of the self-selected group who returned an adequate kit were European.

Asians were almost half as likely to participate than Europeans and Pacific people were almost three times less likely to participate than Europeans. Whilst Māori were also less likely to participate than Europeans, this difference was not statistically significant. The differences between Māori and European, and Pacific and European participation were less than with the non-self-selected population. This may reflect the fact that Māori and Pacific were able to self-refer.

People living in the NZDep 5-6 quintile area were almost twice as likely to participate as those living in the least deprived quintile area.

Of those who returned an adequate kit, 9.3% had a positive iFOBT result. The positivity rate was higher than in the non-self-selected eligible population.

Almost 90% (n=140) had a publicly funded colonoscopy.

There were 79 people who had at least one adenoma and no cancer detected. There were 47 people who had at least one advanced adenoma and no cancer detected. One Pacific person and three Māori people had an adenoma, one of whom had an advanced adenoma. Eleven people from this group, all European, had cancer detected.

The overall detection rate of adenoma was 4.7%, advanced adenoma was 2.8%, and cancer was 0.7%. These detection rates are higher than those found in the non-self-selected eligible population.

Outcomes did not significantly differ by ethnicity.

A positive iFOBT result and detection of adenoma were more likely among males compared with females, and the 70-74 year age group than the 50-54 year age group.

Positivity was 3.5 times more likely in the most deprived quintile area (NZDep 9-10) compared with the least deprived quintile area (NZDep1-2). Advanced adenoma was between three and seven times more likely in the two most deprived quintile areas (NZDep 7-8 and 9-10) compared with the least deprived quintile area.

## **Discussion**

The lack of difference in participation between males and females, and higher participation among people living in the middle deprivation areas rather than the least deprived areas, may explain the higher positivity and detection rates for all outcomes for the self-selected group. It is also possible that this group included people who were symptomatic, and therefore motivated to self-register or self-refer.



## Adverse events

Data for readmissions for adverse events within 14 to 30<sup>42</sup> days of colonoscopy were supplied as a spreadsheet from the WDHB separately from data provided by the BSP Register. Due to lack of matching with the Register data, these data may include some self-selected people, whose results for other analyses have been presented separately. The rates are based on all colonoscopies recorded in the BSP Register so include privately funded colonoscopies<sup>43</sup>. The data for both the denominator (all colonoscopies) and the numerator (readmissions) may be incomplete.

The post-colonoscopy complications of particular concern in colorectal cancer screening are perforation and bleeding. They are more common following colonoscopy with polypectomy (Chilton and Rutter 2011).

Forty-nine participants were readmitted (Appendix 1, Table 6). The most common causes for readmission were bleeding (n=31), abdominal pain (n=7) and perforation (n=5). All readmissions for bleeding were associated with polypectomy.

The perforation rate was 1.2 per 1,000 colonoscopies and the bleeding rate was 7.7 per 1,000 colonoscopies. The rate for all other complications was 3.0 per 1,000 colonoscopies. There were no colonoscopy-related deaths.

### Discussion

Different definitions for adverse events, particularly for bleeding and follow up periods, make direct comparisons with other reported data difficult.

During the first screening round of the UK pilot, the admission rate for bleeding<sup>44</sup> or abdominal pain was 2.4 per 1,000 colonoscopies. The perforation rate was 0.5 per 1,000 colonoscopies. The follow up period for adverse events post-colonoscopy was not reported (UK Colorectal Cancer Screening Pilot Group 2004).

Adverse event data from the first three years of the National Health Service Bowel Cancer Screening Programme in England found the perforation rate was 0.9 per 1,000 colonoscopies and the bleeding rate was 4.1 per 1,000. There were no colonoscopy-related deaths. The period of follow up was 30 days and included events that did not result in admission (Lee et al 2012). The bleeding rate, although it appears to include an unpublished number of bleeding events that did not result in admission, was lower than that reported in the BSP. This will be affected by the number of polypectomies, but BSP data were not available to explore this.

The UK *Quality assurance standards for colonoscopy* give a standard for perforation of less than 1 in 1,000 colonoscopies and less than 1 in 500 colonoscopies where polypectomy is carried out. The standard for bleeding is less than 1 in 100 colonoscopies where polypectomy is carried out (Chilton and Rutter 2011). The data supplied did not allow reliable calculation of rates for colonoscopies with polypectomy. The BSP monitoring indicator for perforation or bleeding is less than 10 in 1,000 colonoscopies (excluding

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<sup>42</sup> The readmissions time period was 14 days until December 2012 and thereafter 30 days.

<sup>43</sup> The data used by the BSP as monitoring indicators for adverse events excludes privately funded colonoscopies.

<sup>44</sup> The bleeding rate for the UK pilot was not reported separately.

privately funded colonoscopies). This has not been exceeded (personal communication, Ministry of Health).

## Conclusions

The findings are largely similar to those found in other population-based colorectal screening programmes. Where there are differences (e.g., lower PPV of a positive iFOBT for cancer) or the findings cannot be directly compared (e.g., adverse events), these have been noted in the discussion above.

We recommend that the Ministry of Health comprehensively review the BSP Register and implement a robust data quality assurance programme. The evaluation has identified data quality issues that must be addressed as a high priority for the final evaluation and a national programme. Data quality issues include data definitions, data inconsistencies, errors and data capture. Examples are given in the Appendix of the complete epidemiology report.

A further high priority is to address the low participation among people living in the most deprived areas. More disease was found in this population group, irrespective of age, sex and ethnicity.

Further strategies are also needed to promote the BSP among the other low-uptake groups: Māori, males, Pacific people, and younger age groups. Māori were slightly more likely to have a positive iFOBT result than Europeans and there was suggestive evidence they were more likely to have disease. Males of all ages were more likely to have adenomas and advanced adenomas, and at older ages to have cancer, than females. Pacific people's participation was the lowest, although they were less likely than Europeans to have disease, irrespective of their age, sex and deprivation.

Data on ethnicity are obtained from the National Health Index and the screening consent form. Data were missing for 9.9% of non-responders. Although the number of participants with missing ethnicity data was small ( $n=159$ )<sup>45</sup>, given the BSP's aim of equity, we recommend checks for missing ethnicity data in the BSP Register for participants who progress in the pathway beyond the iFOBT, with subsequent data collection at pre-assessment and entry into the Register.

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<sup>45</sup> This increases to 190 if the 31 with missing ethnicity from the self-selected population are included.

## 3.2 Programme design

### Evaluation objective addressed in section

*Programme design* - To pilot the use of a Population Register closely linked with primary health care services to invite the target population, along with a Coordination Centre and associated information system to manage the Screening Pathway.

This section addresses the evaluation objective on Programme design, in particular the use of a Population Register. The evaluative findings in this section draw on the two immersion reports (Litmus 2013a and 2014) and the epidemiology report (Read, Shanthakumar, Borman 2014). Findings on the role of primary care and other providers are in section 3.6.

The key evaluation findings against the objective are presented first followed by a summary of supporting evidence.

### Key evaluation findings

Having an eligible population database (the Register) was identified by stakeholders as a strength of the BSP enabling the identification of the eligible population, the distribution of kits and monitoring of participation, and informing targeted participant follow-up and CAR activities.

While the concept of a Register has utility in the BSP, a number of critical limitations with the Register are impacting adversely on the BSP:

- Ensuring access to the BSP: it is estimated based on returned mail and the WDHB population survey (Litmus 2014a) that between 5% and 15% of eligible participants did not receive a letter or kit in screening round one due to incorrect address details on the Register or migration into WDHB region.
- Data and IT resource at WDHB and Ministry of Health: feedback indicates that in the early implementation stages there was insufficient dedicated data and IT resource at WDHB<sup>46</sup> and the Ministry of Health which contributed to a lack of timely updates to the Register resulting in challenges to ensure data quality.
- Assessing participation and outcomes: evaluation of participation and outcomes from the BSP is being adversely effected by a lack of clear data definitions and data quality assurances of the Register.

### The BSP Population Register

A built-for-purpose information system (the BSP Population Register) was developed to support the BSP. The decision to build a bespoke system was made following an evaluation of other Ministry information systems, including the breast and cervical screening systems. The BSP Population Register is owned and overseen by Ministry of Health. WDHB's work on the Register is based at the BSP Coordination Centre and managed by the BSP Data Manager.

<sup>46</sup> From September 2013 the data resource at WDHB doubled.

National Health Index (NHI) numbers were selected as the primary source of eligible participant information for the Register.<sup>47</sup> The NHI number is a unique number that is assigned to every person who uses health and disability support services in New Zealand. The NHI is an index of information associated with that unique number (including name, address, date of birth, sex, New Zealand resident status and ethnicity).<sup>48</sup> NHI information provides a comprehensive, population-based dataset from which eligible participants can be identified and subsequently invited to take part in the BSP.

In 2012 having an eligible population database was identified as a strength of the BSP enabling the identification, distribution of kits and monitoring of the eligible population, and informing targeted participant follow-up and CAR strategies.

In screening round one using the Register, 136,575 pre-invitation letters and 143,637 iFOBT kits<sup>49</sup> were distributed, and 83,498 reminder letters were sent at four weeks<sup>50</sup> (Artus et al 2014).

Over the course of the first screening round, a number of issues with the Register were highlighted, specifically:

### **Incorrect participant address and contact details**

- Incorrect participant addresses are due to NHI details uploaded to the Register being out of date. As a result, around 5% of pre-invitation letters are returned to the BSP Coordination Centre as not living at this address<sup>51</sup>. To resolve this issue, the BSP Coordination Centre uses WDHB's iPIMs, looks up the White Pages and contacts general practices to find correct contact details for returned mail.

The population survey (Litmus 2014a) identified that 21% of respondents said they had not received a letter or the kit by October 2013<sup>52</sup>. At the time of the survey around 6% of people eligible to participate in the BSP had not received their letter or kit (due to the birthdate invite strategy). Further, the Register was not being updated to include eligible people migrating into the WDHB area. On this basis, it is estimated between 5% and 15% of eligible participants may not have received their pre-invitation letter or kit due to incorrect address details or migration into the area.

- Planned regular updates from PHO data to update NHI information and ensure eligible people moving into WDHB are offered bowel screening have not occurred. When PHO uploads occur directly to the Register, it updates only the GP/participant match and not participants' contact details.
- The success of the active follow-up phone calls by CAR workers is constrained as the BSP Register does not contain phone numbers. CAR workers try to find phone numbers via the White Pages, WDHB's iPIMs, and contacting general practice which is time consuming.

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<sup>47</sup> It was intended that the NHI numbers would be supplemented by PHO enrolment data but due to logistical reasons this did not occur.

<sup>48</sup> <http://www.health.govt.nz/our-work/health-identity/national-health-index/national-health-index-overview>

<sup>49</sup> Includes iFOBT kits that were resent due to spoilt or expired kits.

<sup>50</sup> Refer section 3.6 table 9 for quarterly distribution tables.

<sup>51</sup> Discussions with the BSP Coordination Centre highlighted that 136,575 pre-invitations were mailed out from 1 January 2012 and 1 January 2014. For the months of May – December 2013, 1,954 pre-invitation letters were returned as not at this address; an average of 61 a week, which is equivalent to 6,344 returned mail over two years.

<sup>52</sup> There were no statistical differences in those who had not received a letter or kit by ethnicity.

## Data quality

- A few coding issues have been identified with a small number of laboratory results due to mismatched codes. The BSP Coordination Centre is aware of the issue and is monitoring to ensure appropriate corrective action.

Histopathology and treatment data are only now being entered manually on to the Register. Before late 2013, WDHB Clinical Director maintained a spreadsheet of all cancers identified and treated. The WDHB Clinical Director would provide this to the Ministry of Health for analysis and reporting purposes. Some types of polyps could not be entered (e.g. serrated polyps) as there was no field for this in the Register. Following updates to the Register in late 2013, these data can now be entered.

Other issues noted with histopathology and treatment data are:

- The histopathology details the most significant findings from the colonoscopy/CTC but not all the findings (e.g. if 20 polyps are found, only the most important are listed).
  - There is no field on the Register to record the date when the histology letter is sent out so it is not possible to monitor the timeliness of results being sent to the participant and their GP. This letter is generated from the WDHB transcription system because it is a letter which needs to be modified for each participant. It is labour intensive to access this data as it is a manual process.
- The inflexibility of some of the iFOBT pathology result fields are frustrating for LabPLUS. The Register only allows the entry of a result or an error code. In some cases there can be an error (i.e. a completed expired test kit) and a result as the kit was tested. In this case, LabPLUS wants to note the error and the result but cannot.
  - Validation or auditing of data on to the Register at WDHB and the Ministry of Health were not consistently undertaken due to limited workforce capacity.

## Lack of data and IT resource

- Understanding of the Register sits with a small number of people in WDHB and Ministry of Health, and some of the assumptions underpinning the definition of variables are not known. There is documentation about the Register at the Ministry and WDHB, although there are incomplete areas.
- Not enough dedicated data and IT resources at WDHB<sup>53</sup> and the Ministry of Health which contributed to a lack of timely updates to the Register resulting in challenges ensuring data quality.

In October 2013, a new full time data manager was employed at the BSP Coordination Centre which may help to address these issues. The Ministry of Health now has access to SAS to manipulate the Register data.

## Conclusions and recommendations

Data quality and completeness of Register data are essential to ensure the effectiveness of the BSP processes and to enable appropriate monitoring and evaluation. Given the noted limitations of the Register, a comprehensive review is strongly recommended together with the implementation of a robust data-quality-assurance programme.

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<sup>53</sup> Before September 2013, there was 0.5 FTE Data Manager at WDHB. From September 2012, there was 1 FTE Data Manager.

Key improvements required to enhance the Register's effectiveness are:

- developing a strategy to enhance accuracy of participant contact details and to identify eligible participants moving into WDHB
- ensuring the knowledge management system and data dictionary on the Register is complete and clearly specifies variable definitions and assumptions underpinning data generated
- ensuring the Register has all the data fields necessary to meet quality and other reporting requirements, particularly with regard to histopathology, treatment data and adverse events
- reviewing the process, frequency and responsibilities for data quality of the Register at WDHB and the Ministry of Health
- ensuring adequate IT support at the Ministry of Health to undertake updates and refinements to the Register as needed.

### 3.3 Acceptability to the target population

#### Evaluation objective addressed in section

*Acceptability to the target population* - To pilot provision of information and support to the target population to facilitate informed participation and evaluate the knowledge, attitudes and satisfaction of groups of participants (defined by sex, age, ethnicity, socioeconomic status and geographical residence) in the screening pilot, including identifying factors associated with non-participation.

This section addresses the evaluation objective on the acceptability of the BSP amongst the eligible population. The evaluative findings draw on the quantitative and qualitative research with the eligible BSP population living in WDHB (Litmus 2012, 2013 and 2014a).

The key evaluation findings against the objective are presented first followed by a summary of supporting evidence.

#### Key evaluation findings

The acceptability of the BSP (defined by awareness, attitudes and knowledge) varies amongst the eligible population reflecting it is not a homogenous group. Acceptability of the BSP is higher amongst the eligible Other ethnic group<sup>54</sup>, and lower amongst eligible Māori and Pacific people.

Since the launch of the BSP, awareness of the BSP has significantly increased amongst the eligible Other ethnic group. Knowledge about bowel cancer risk factors, symptoms and bowel cancer tests has also increased. Perceptions of the iFOBT have also become more positive with significant increases in disagreement that the iFOBT is painful, embarrassing, inconvenient, messy and inaccurate.

Compared to the Other ethnic group, Māori and Pacific people have lower awareness of bowel cancer risk factors, symptoms and bowel cancer tests including the iFOBT which may reflect their lower levels of participation. Other barriers to participation include a dislike of bowel screening, a preference for seeing their doctor, not being concerned, a fatalistic attitude of 'what will be will be' or not wanting to know, and not wanting to do the test at home. Pacific people also perceive the iFOBT as messy.

BSP participants' experience of the BSP is mainly positive. Pākehā, Māori and Pacific BSP participants interviewed consistently described their experience of the BSP as convenient, the iFOBT as easy to do with timely results and progression along the pathway. For those with a positive iFOBT, the communication about their results was reassuring, and their colonoscopy experience was timely and respectful.

#### Awareness, knowledge and attitudes

The following insights were identified from two surveys of the eligible BSP population living in WDHB (Litmus 2012 and 2014a).

**Increasing but continuing variance in awareness of bowel cancer symptoms and risk factors:** The perceived risk of getting bowel cancer continues to be low (9% feel they are quite/ very likely to get bowel cancer in 2011 and 2013 surveys).

<sup>54</sup> The Other ethnic group is defined as non-Māori, non-Pacific, and non-Asian and is predominantly made up of New Zealand European/ Pākehā.

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 (52% confident/ very confident in 2013 compared to 44% in 2011). In particular there have been increases in unprompted awareness of:

- blood in bowel motions (83% aware in 2013 compared to 72% in 2011)
- a change in toilet habits (56% aware in 2013 compared to 46% in 2011).

Confusion continues about whether the bowel not completely emptying is a symptom of bowel cancer (4% unprompted and 56% prompted in 2013).

Between 2011 and 2013 surveys, there was a statistically significant increase in recognition that the following are risk factors for bowel cancer:

- a diet low in fibre (72% strongly/ somewhat agreed in 2013)
- a family history of bowel cancer (73% strongly/ somewhat agreed).

The influence of exercise, red meat and a diet containing sufficient fruit and vegetables continues to be less well recognised as risk factors for bowel cancer, 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 and improved perceptions of iFOBT:** Reflecting the BSP launch and distribution of BSP letters and kits, there is a statistically significant increase in awareness of the WDHB iFOBT from 49% in 2011 to 90% in 2013.

Since 2011, perceptions of the iFOBT have changed with a statistically significant increase in disagreement that the iFOBT is:

- painful (94% strongly/ somewhat disagree up from 86% in 2011)
- embarrassing (84% strongly/ somewhat disagree up from 77% in 2011)
- inconvenient (79% strongly/ somewhat disagree up from 65% in 2011)
- messy (65% strongly/ somewhat disagree up from 46% in 2011)
- inaccurate (53% strongly/ somewhat disagree in 2013 up from 33% in 2011).

At an individual level, there is a marked shift in more favourable attitudes towards the iFOBT. Some respondents however continue to be unsure about the accuracy of the iFOBT, and those who have not returned the BSP iFOBT kit are more likely to find them embarrassing.

In contrast, people are less likely in 2013 to consider colonoscopies to be inaccurate (72% strongly/ somewhat disagree up from 66% in 2011), but more likely to view them as:

- messy (54% strongly/ somewhat disagree)
- embarrassing (51% strongly/ somewhat disagree)
- painful (44% strongly/ somewhat disagree)
- inconvenient (49% strongly/ somewhat disagree).

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:

- early treatment of bowel cancer increases the odds of survival (97% strongly/ somewhat agree in 2013 up from 94%)
- testing is important even when there are no symptoms (87% strongly/ somewhat agree up from 77% in 2011)
- testing is important even when there is no family history of bowel cancer (84% strongly/ somewhat agree up from 68% in 2011).

Greater acceptance of the iFOBT is noted with rejection that the test is 'more trouble than it's worth' (84% strongly/ somewhat disagree up from 75% in 2011).

**Increased awareness of the BSP:** Awareness of the BSP is high (88%). 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 survey respondents stated they had received the BSP letter and kit (71%), while 21% had received neither<sup>55</sup>. 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 (refer section 3.2).

Of those who had received a BSP kit, three quarters (73%) 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 52% respondents participating in the BSP, similar to the BSP Register participation rate at the time of the survey. 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 (64%). Those not wanting to take part cite a preference for seeing their doctor, a lack of concern, a fatalistic attitude of 'what will be will be' and that they do other bowel tests.

Variation in responses by Māori and Pacific respondents were noted and offer insight into possible reasons underlying their lower levels of participation in the BSP<sup>56</sup>.

### **Māori responses**

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 (28% unprompted mentioned by Māori compared to 60% Other ethnicity in 2013).

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<sup>55</sup> There was no statistically significant difference noted between Māori, Pacific and the Other ethnic group on whether or not they had received a kit.

<sup>56</sup> Appendix 3 provides an overview of the comparative results for Māori and Pacific respondents in the 2013 eligible WDHB population survey (Litmus 2014a)

Although awareness of bowel cancer tests including the iFOBT and colonoscopies has increased since 2011, it remains lower than the Other ethnic group. Likewise awareness of the BSP has increased (75% aware in 2013 up from 18% in 2011) but is also comparatively low (90% of Other ethnicity in 2013).

Māori are the least likely to have their doctor suggest a bowel cancer test. Māori who have not participated cite a preference for seeing their doctor, not being concerned, a fatalistic attitude of 'what will be will be' or not wanting to know and not wanting to do the test at home.

The survey suggests that, for Māori, low awareness and knowledge are likely drivers to lower participation. For Māori, these patterns could be a reflection of the lower levels of health literacy amongst this group.<sup>57</sup>

### **Pacific people's responses**

Pacific people<sup>58</sup> are less aware of the risk factors for bowel cancer, in particular, having a close family relative with bowel cancer (48% strongly/ somewhat agreed compared to 76% Other ethnicity) and a diet high in fibre (41% compared to 74% Other ethnicity); although they are more aware than others of the risks associated with being overweight. One third do not know any bowel cancer symptoms (35%), although this has decreased from half before the introduction of the BSP (55%).

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

Pacific people have a low level of awareness of bowel cancer tests including iFOBT (37% aware of any tests compared to 76% of Other ethnicity). Further, when told about bowel cancer tests they are more likely to perceive an iFOBT as inconvenient, embarrassing, inaccurate and painful, and colonoscopies as inaccurate, messy and painful. Pacific people are less likely to have ever done an iFOBT (31% have done a test compared to 51% Other ethnicity).

Compared to 2011, there is a 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 than the Other ethnicity (72% compared to 90% Other ethnicity), although it has increased since 2011 (21%). 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 by Māori as well as perceiving the kit as messy.

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<sup>57</sup> <http://www.healthliteracy.org.nz/about-health-literacy/health-literacy-statistics/> accessed 27 February 2012.

<sup>58</sup> Differences between specific Pacific ethnicities cannot be determined from the survey.

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.

### **People living in most deprived areas**

As noted in section 3.1, low participation is evident amongst people living in the most derived areas and more disease was found in this population group. In the population survey, 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, and less likely to mention the WDHB BSP test.

### **Participant experience**

The qualitative research with BSP participants (Litmus 2013 and 2014c) and the customer research undertaken by WDHB (WDHB 2013) shows that BSP participants' experience of the BSP is mainly positive. In the WDHB BSP participant survey 90% rate their treatment overall in the endoscopy unit as very good, 8% as good and 2% average (WDHB 2013).

Pākehā, Māori and Pacific BSP participants interviewed (Litmus 2013 and 2014c) consistently described their experience of the BSP as convenient, the iFOBT as easy to do with timely results and progression along the pathway. For those with a positive iFOBT, the communication about their results was reassuring, and their colonoscopy was timely and undertaken respectfully.

Three key factors underpinned the completion and return of the iFOBT by BSP participants interviewed:

- Primed – they had a pre-disposition towards bowel screening due to concerns about cancer, wanting to check their bowel health, undertaking other non-symptomatic health checks, and wanting to be around for their family/ whānau long-term.
- Prompted – they were reminded to act thereby overcoming the perceived unpleasantness of the test and the other pressing priorities in their lives.
- Proficient – they were able to read the material received and had the ability to complete and return the iFOBT kit.

Across BSP participants interviewed (Litmus 2013) there was a lack of understanding about what happens next in relation to bowel screening. BSP participants interviewed who are exiting the BSP into surveillance were also unclear about their next steps.

### **Reasons for not taking part**

In December 2012 qualitative research was undertaken with six Māori and six Pacific people who had received a pre-invitation, invitation and reminder letter between April and September 2012, had not returned a completed kit, and had not contacted the Coordination Centre to opt out of the BSP (non-responders). Due to small sample sizes and the diversity of Māori and Pacific populations, the findings presented below are indicative only. However they do offer insight into non-participation reasons which are consistent with the findings from the quantitative surveys (Litmus 2012 and 2014a).

## Eligible Māori non-responders

For Māori non-responders interviewed, the overarching reason for not taking part in the BSP was they had an aversion to the concept of bowel screening per se, were opposed to doing faecal sampling in their home and/ or did not want to post a faecal sample as others would have to handle their sample<sup>59</sup>.

For some Māori non-responders interviewed, the overall concept of bowel screening is abhorrent and therefore it is unlikely they can be supported or encouraged to take part. Other Māori non-responders interviewed appreciated the benefits of bowel screening but found the idea embarrassing, in particular they are strongly against mailing a faecal sample. With a more appropriate approach to create understanding and action, these non-responders may consider participating in the BSP. Māori non-responders interviewed suggested dropping samples off at a lab, hospital or their general practice.

While aversion barriers to participating in the BSP are forefront, Māori non-responders interviewed also noted other barriers to taking part, including:

- more pressing health issues (e.g. cancer or heart disease)
- previous negative experience of the health system in relation to issues to do with their bowels; other health experiences as well as negative health outcomes for whānau with cancer also created significant barriers to participating in the BSP
- misinterpretation of their eligibility to take part due to the content of the pre-invitation.

## Eligible Pacific non-responders

Across Pacific non-responders interviewed, there was evidence of difficulty in understanding the BSP invitation letters<sup>60</sup>. When the BSP was verbally explained, Pacific non-responders supported the idea of screening and acknowledged the benefit of knowing their health status to ensure they can support their families long-term.

A range of inter-linking barriers to participation were identified amongst the Pacific non-responders interviewed, specifically:

- opposition to bowel screening and the BSP, in particular undertaking the test at home and mailing a sample of their faeces. Some suggested being able to do the test in a clinic setting and dropping samples off at a lab, hospital or their general practice.
- environmental barriers, relating to not receiving the kit which appeared to be due to misplacing the kit in their home or through the use of a PO Box
- literacy and language barriers which impede understanding of the letters, BSP purpose, and the actions required
- other pressing health priorities (e.g. cancer).

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<sup>59</sup> Māori view all tissue and body fluids as taonga (to be treated as a treasure). However, body fluids and tissues are also regarded as tapu (sacred, and therefore need to be treated with caution) rather than noa (neutral). This distinction is important, since biological specimens must be treated with great care (Sporle and Koea 2004). Further, faecal matter and the buttocks area in particular is viewed as damaging tapu (for example a person should not sit on a pillow – the pillow is a resting place for a person's head, which is very sacred). Interviews with Māori non-responders highlighted that the request for a sample of bowel motion and the processes to manage this sample create significant cultural barriers and whakamā (embarrassment) to participate in the BSP.

<sup>60</sup> The interviews were undertaken before the revision of the BSP communication collateral.

### **Consistency of findings with wider literature**

The findings for participation and non-participation of particular population groups are in the main consistent with the international literature. As highlighted by Weller et al (2009), Senore et al (2010) and Reeder (2011), multiple factors influence screening participation, including cancer characteristics, screening test characteristics, individual factors, and the health system context. While international research offers evidence on which factors influence participation, to date the relative weight of these are not known in achieving or improving participation in bowel screening (Senore et al 2010).

Reviews undertaken by Senore et al (2010), Power et al (2009) and Christou et al (2010) identified a number of determinants and barriers to participation in bowel screening, summarised in Table 7 below, and are reflective of the feedback from BSP participants interviewed.

**Table 7: Summary of enablers and barriers to participation (from the literature)**

Level	Factors that increase participation
Individual	Perceived benefits of screening
	Perceived risk of bowel cancer
	Previous participation in screening
	Health motivation in practising health promoting behaviours or by avoiding unhealthy lifestyles
	Having a partner who encourages and supports healthy behaviours
System	Support from health care providers/ GP, particularly for those with low levels of literacy and less likely to read information provided
	Letter sent from GP
	Advance notification of screening (may increase participation)
	Reminders to take part (with telephone being the most effective and costly)
	Involvement of community workers in kit distribution and collection following some general training.
Level	Factors that decrease participation
Individual	Limited knowledge and awareness of bowel cancer and screening
	Lack of confidence in screening effectiveness
	Anxiety about test, results, fatalistic attitude
	Perceived low risk
	Low levels of literacy, health literacy and/ or self-efficacy
	Cultural beliefs – faecal taboos
	Embarrassment
	Presence of co-morbidities
System	Lack of culturally appropriate health promotion material
	Low general exposure to health media exposure/ bowel cancer media exposure
	Distrust of the health system
	Discomfort/ poor experience with health system
	No fixed residence/ frequent change of address
	Lack of coordination of the screening service
	Cost to see general practice including transport; Perceived cost for screening and treatment

Sources: Senore et al 2010, Power et al 2010, Christou et al 2010, Brynum et al 2012.

Of the BSP participants interviewed, their reasons for taking part in the BSP are also consistent with the health belief model developed to promote health screening behaviours in public health (Strecher Rosenstock 1997; in Causey and Greenwald 2010), specifically:

- perceived susceptibility (the belief that they are vulnerable to the disease)
- perceived severity (the belief there are consequences to having the disease)
- perceived benefit (the efficacy of the recommendations to reduce the seriousness of the disease)

- perceived barriers (the cost to participate in screening)
- cues to action (strategies to promote readiness to take part)
- self-efficacy (the confidence to take the recommended action).

International literature highlights low levels of participation by certain ethnic and minority groups in other countries' implementation of bowel screening programmes. Lower participation is also noted among the less educated, lower income groups and those from non-English speaking backgrounds. Studies controlling for income and other factors show that ethnicity is an independent predictor of screening participation (Christou et al 2010).

Christou et al (2010) identified a range of barriers to participation, also relevant to the New Zealand context. Specifically, low awareness of cancer and screening services, low levels of literacy and health literacy, low priority of screening and presence of other co-morbidities, distrust of mainstream providers, and a lack of culturally relevant educational resources.

Drawing from the wider literature, Christou et al (2010) put forward a range of strategies to improve access and participation for indigenous Australians, including:

- alternate means of distributing and returning test kits
- use of general practice to promote bowel screening
- improved health promotion and availability of cultural relevant educational materials
- more community-based research into indigenous understandings and perceptions of bowel cancer.

The participation rate in bowel screening is a critical determinant of the magnitude of the screening impact on bowel cancer incidence and mortality (Senore et al 2010). Recent literature raises concerns about the potential conflict between promoting high participation rates and the need to enable people to make an informed choice about whether or not they want to be screened. Strategies to promote participation need to be balanced with information on the risks and benefits of screening (Weller et al 2009).

## **Conclusions and recommendations**

Awareness, knowledge and attitudes to bowel cancer and bowel cancer screening have increased since the launch of the BSP. However, eligible Māori and Pacific people have lower levels of awareness and knowledge about bowel cancer and bowel screening, and dislike the at-home test and the idea of posting faecal samples. Further, little is known about the reasons for non-participation by people living in the most deprived areas.

In the future, consideration should be given to:

- Identifying culturally appropriate health promotion and community awareness raising activities to further enhance Māori participation. For Māori non-responders, a key strategy to address cultural dislike to the BSP is *kanohi-ki-te-kanohi* (face-to-face). Quality face-to-face or phone engagement with a Māori health promoter can enable sensitive discussions about bowel screening to empower and support Māori to act. It is acknowledged that not all Māori will need this intensive level of engagement. Focus could therefore be placed on targeting Māori living in high deprivation areas so support and encouragement is offered to those more likely to also have other participation barriers (e.g. those who have difficulty understanding the BSP invitation).

- Identifying health promotion and community awareness raising activities that will increase Pacific people's awareness, understanding and engagement with the BSP and enable them to make an informed choice about whether or not to take part. Given the diversity of Pacific non-responders, a multi-faceted consistent engagement and empowerment strategy is required to support Pacific people to take part in the BSP, for example:
  - facilitative conversations with Pacific health promoters to offer a more personalised engagement process of face-to-face, one-on-one discussions
  - use of Pacific languages and design in pamphlets and other forms of communication
  - use of Pacific networks, churches and matai to promote the importance of BSP.
- Reviewing the process of sample delivery and determining whether it would be feasible for participants to drop samples off at a lab, hospital or their general practice, or being able to do the test in a clinical setting.
- Undertaking qualitative research with eligible people living in the most deprived areas who have and have not participated to understand their barriers and enablers to taking part in the BSP.



### 3.4 Fair access for all New Zealanders

#### Evaluation objective addressed in section

*Fair access for all New Zealanders* - To determine whether a bowel screening programme can be delivered in a way that provides fair access for all New Zealanders. In particular, to evaluate the process of adopting a focus in leadership, decision making processes and implementation of the pilot to provide fair access to all eligible people.

This section addresses the evaluation objective on ensuring fair access to all New Zealanders, particularly focusing on leadership and decision-making processes in the implementation of the BSP. The evaluative findings in this section draw on the two immersion reports (Litmus 2013a and 2014).

The key evaluation findings against the objective are presented first followed by a summary of supporting evidence.

#### Key evaluation findings

The current design and implementation of the BSP is not resulting in fair access to the eligible BSP population in WDHB. Eligible Māori, Pacific people and those living in the most deprived areas are less likely to take part in the BSP (refer section 3.1). Reasons for non-participation appear to reflect issues of both fair access and acceptability.

The Ministry of Health and WDHB, in both the design and implementation stages of BSP, have endeavoured to identify and implement strategies to try and ensure the BSP is delivered in a way that enables access for all with a particular focus on eligible Māori and Pacific people. However, feedback highlights that Māori and Pacific leaders could have been more involved in decision-making during the design and implementation of the BSP.

Feedback from eligible Māori and Pacific people who received a kit and did not respond suggest the current design of distributing kits and collecting samples via mail is not effective for all due to literacy, language and environmental barriers (not receiving or opening the letter). Further, research highlighted that the initial BSP letters, kit instruction and consent form were not easy to understand. In 2013 the pre-invitation letter, kit instructions and consent form were revised to be more accessible to a wider range of literacy levels. These revised documents were introduced in the second screening round beginning in January 2014.

In screening round one, CAR and communication activities were the key mechanisms employed to raise awareness and increase acceptance and completion of the iFOBT amongst Māori, Pacific and Asian populations. CAR and communication activities were not defined in the BSP programme design. Consequently, the BSP Coordination Centre and the CAR team used a range of tactics to increase awareness and participation.

Awareness of the BSP has increased for eligible Māori and Pacific people since the launch of the BSP, although not to the same level as the 'Other' ethnic group (Litmus 2014a). The later suggests that the communication strategies are having an effect. Anecdotal evidence suggests that face-to-face engagement is beneficial in supporting and prompting Māori and Pacific people to act. The evaluation is unable to assess the effectiveness of CAR strategies used. However, it is acknowledged that without them uptake by Māori and Pacific people is likely to have been lower.

## Design

### Focus on equity

From the outset, the BSP design was guided by the fundamental principle of not increasing existing health inequities. The Ministry of Health identified Māori and Pacific populations as priority populations for the BSP; those living in the most deprived areas were not identified as a priority population.

In 2005 an Equity Impact Assessment of bowel cancer screening recommended ways a programme could be designed and monitored to achieve a reduction in inequalities in bowel cancer outcomes, as well as improving population health (Shaw 2005).

In 2010 the Ministry of Health undertook a literature review of the interventions that optimise participation of Māori and Pacific people entering and continuing through the bowel screening pathway (Ministry of Health 2010). The report made a number of recommendations focused on structural, organisational, behavioural and other strategies to optimise participation of Māori and Pacific people entering and continuing through the screening pathway. A number of these recommendations were incorporated into the design of the BSP.

### Involvement of Māori in the Ministry of Health design process

In 2010, the Ministry of Health held an Equity Focused Workshop to inform the equity and health promotion requirements for the BSP.

The Māori Expert Advisory Group (MEAG)<sup>61</sup> was set up and was the key mechanism by which the Ministry of Health received advice on BSP's appropriateness and effectiveness for Māori. The Group had access to working papers and participated in the tender process to select the pilot providers. In addition to the MEAG, a member of Te Kete Hauora (the Māori Health Business Unit at the Ministry of Health) was invited to attend all bowel screening team meetings and the bowel screening team were able to seek the advice of Te Kete Hauora as needed.

The MEAG had a valuable role in ensuring an equity lens was applied to the design of the BSP. MEAG stakeholders reported they provided specific advice on a Māori screening pathway. The Ministry of Health reports that feedback from the MEAG was incorporated in the BSP screening pathway.

With the establishment of the national Bowel Cancer working group, the Bowel Cancer Taskforce<sup>62</sup> and the MEAG were disestablished. To ensure consistency and transfer of knowledge, a member of the MEAG is on the national Bowel Cancer working group.

In implementing the BSP, the responsibility for maintaining systems and processes to ensure programme effectiveness for both Māori and Pacific populations lies predominantly with WDHB. If needed, the Ministry of Health seeks advice from Te Kete Hauora and ex-MEAG members.

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<sup>61</sup> Membership of the group included those with an understanding of DHB service provision, barriers to Māori accessing screening programmes, epidemiology, health promotion and education, and experience in implementing programmes that were successful at increasing participation rates of Māori.

<sup>62</sup> In August 2008 a Bowel Cancer Taskforce was established to provide advice and recommendations on the implementation of a national bowel screening programme. Members had relevant experience in diagnostic and treatment services for bowel cancer.

## **Involvement of Pacific in Ministry of Health design process**

No Pacific Expert Advisory Group was established to advise the Ministry of Health on programme effectiveness for Pacific populations. Establishment of a Pacific advisory group was discussed. However, senior Pacific staff at the Ministry of Health advised that, as long as Pacific people were involved in the programme design and roll-out, a separate Pacific advisory group was not required. Advice from Pacific staff at the Ministry of Health was sought through the development of the BSP.

## **Early implementation (first 12 months)**

### **Involvement of Māori and Pacific in the WDHB implementation process**

From the outset, WDHB acknowledged that Māori and Pacific populations were BSP priority populations. At a WDHB level, Māori and Pacific stakeholders were involved in programme design through the following mechanisms:

- consultation with the WDHB Māori and Pacific Health Planning and Funding Managers
- Māori representation on the WDHB BSP Steering Group, and through the Northern Cancer Network
- Māori and Pacific representation on the Project Management Group
- meetings with Māori and Pacific stakeholders to inform particular aspects of BSP delivery (e.g. community awareness raising)
- health equity workshops.

### **Leadership and governance that focus on equity**

Two core groups were tasked with advising and monitoring the implementation of the BSP with regard to equity:

- The BSP Steering Group<sup>63</sup> has responsibility (amongst other things) for reviewing and monitoring BSP data and recommending actions to ensure equity of access (and safety needs).
- The Community Awareness Raising (CAR) Group<sup>64</sup> was established to raise awareness, establish acceptance and operate within an equity framework.

### **Development of the CAR approach, structures and resources**

In seeking to encourage participation in the BSP, WDHB established (from the outset of the pilot) a BSP CAR team within the BSP Coordination Centre. The pilot design for the BSP did not specify how CAR would operate within the screening pathway or the level of monitoring required.

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<sup>63</sup> This group meets monthly as a minimum. Membership comprises WDHB Chief Planning and Funding Officer, WDHB Public Health Medicine Specialist, WDHB General Manager Surgical and Ambulatory Services, WDHB BSP Clinical Director, Ministry of Health, National BSP Programme Manager and National BSP Clinical Director, Clinical Director Waitemata PHO, and Inequalities Advisor from the Northern District Cancer Network. The BSP Programme Manager also attends.

<sup>64</sup> This group meets quarterly. Membership comprises of WDHB Planning and Funding, Māori and Pacific Managers, Inequalities Advisor from the Northern District Cancer Network, WDHB community engagement coordinator, WDHB Māori representative, a representative of West Fono, consumer representatives and PHO representatives.

In the first nine months of the pilot two CAR delivery models were being used:

- Internal delivery of CAR by Māori, Chinese and Korean CAR Coordinators employed by BSP and located at the Coordination Centre.
- External delivery of CAR by West Fono and Pacific Integrated Health. The rationale for contracting West Fono and Pacific Integrated Health was to reach a greater diversity of Pacific people. Both providers are 'By Pacific For Pacific' community health organisations. Their workforce is predominantly Pacific, providing existing relationships and credibility.

In the first 12 months of the pilot, there were four core components to ongoing CAR work:

- Community engagement through community events, resource distribution and local communications.
- Active kit follow-up where Māori, Pacific and Asian people were followed up by CAR personnel after two weeks; everyone else is sent a reminder letter from the Coordination Centre after four weeks. The purpose of active follow-up was to encourage and enable people to complete their test kit.

The BSP Register does not have phone numbers. Active follow-up phone calls were therefore dependent on Coordinators being able to identify phone numbers via the White Pages or WDHB iPIMS. Coordinators also followed up with a home visit if requested.

- Spoilt kit follow-up<sup>65</sup> where CAR Coordinators and West Fono receive a list of people who have returned spoilt kits. The first time Māori, Pacific, Chinese and Korean participants return a spoilt kit the CAR Coordinators phone and advise on how to complete the kit correctly. They are then sent a replacement kit. If CAR Coordinators are unable to contact Māori, Pacific, Chinese and Korean participants by phone, a letter is sent with a second kit.
- Colonoscopy support for Pacific people which involves contacting those who are having a colonoscopy, explaining the procedure to them, ensuring they understand what preparation they need to do, answering any questions they might have and, if needed, providing transport to WHEU.

CAR resources were also developed and distributed. These included presentations and translation of presentations into Samoan, Tongan, Niuean, and Tuvaluan, and basic information brochures in Māori, Samoan, Tongan, Korean, Chinese and English using community 'heroes'.

### **Communication strategy**

In April 2012, WDHB finalised the Strategic Communications Plan for the BSP (WDHB, 2012d). The overall communication goal is to make the general public more aware of bowel cancer and the BSP, and to encourage participation in the programme.

Four primary target audiences receive regular communications about the BSP: eligible participants and influencers who interact with them; primary care providers and health professionals; community groups, NGOs, and local health organisations; and WDHB staff and partners.

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<sup>65</sup> Other populations who have returned a spoilt kit receive a second test kit and a letter explaining the error. If they send in a second spoilt kit, the CAR coordinator phones and advises on how to complete the kit correctly.

Key communication channels include: media including local media placement, advertising including print advertising in local newspapers, internal and external newsletters, public relations, stakeholder collateral, Bowel Screening Waitemata website (<http://www.bowelscreeningwaitemata.co.nz/>), other websites and other internal WDHB communications channels.

### **Immersion visit findings**

Review of the BSP implementation in 2012 (Litmus 2013a) highlighted a number of areas where the implementation process could be strengthened to ensure a sustained equity approach, specifically:

- Investigating ways to increase Māori and Pacific involvement in decision-making in the BSP at leadership and operational levels.
- Revising the BSP communications material so those with low literacy and/or English as another language can make an informed decision on whether to take part.
- Determining whether the current screening pathway for the BSP needs to be revised to be more appropriate for eligible Māori and Pacific people, e.g. offering clinic-based test locations and sample drop-off choices.
- Building on existing CAR strategies for example, ‘kanohi ki te kanohi’ (a face-to-face approach) may be effective in seeking to overcome cultural opposition to bowel screening for some Māori. A range of strategies were put forward for Pacific people reflecting their diversity, however it is not known which are the most effective (Litmus 2013).

### **Implementation (12–18 months)**

Recognising the ongoing lower participation in the BSP by eligible Māori and Pacific people, the BSP Coordination Centre took action in 2013 to review and revise their leadership structures and processes, including (Litmus 2014):

- establishing WDHB’s Kaitiaki Roopu to address the lack of robust Māori participation and partnership in the overall direction, design and governance of the BSP. The purpose of the Kaitiaki Roopu is to provide a Treaty of Waitangi based partnership and participation oversight to the WDHB BSP. Kaitiaki Roopu also provides guidance, support, advice and links into the Māori community serviced by the WDHB to ensure Māori make informed decisions about the BSP.
- having representatives from two Pacific providers continue to offer advice to the BSP Coordination Centre via the CAR group. The DHB’s Manager, Pacific Health also attends CAR meetings from time to time and is available for ad hoc advice.
- undertaking research to review communication collateral (Phoenix 2013) and revising the pre-invitation letter, kit instructions and consent form to be more accessible to all literacy levels. These revised documents were introduced in the second screening round beginning January 2014.
- revising CAR processes to encourage completion of the iFOBT and to ensure kits are completed correctly. Key changes included:
  - focusing on active follow-up by Pacific, Māori, Korean and Chinese CAR coordinators by phoning non-responders within two weeks of sending the iFOBT kit. A lack of up-to-date phone numbers continues to be an issue.

- employing a Samoan male CAR coordinator from August 2013 to focus on active follow-up with primarily Samoan and also other Pacific nations where appropriate. The Samoan CAR coordinator has also supported West Fono in community awareness presentations.
- establishing, following a review, a dedicated 0.5 full time equivalent (FTE) position with the Pacific provider West Fono to ensure contractual agreements such as follow-up (spoilt kit and active follow-up), group education sessions (and follow-up from these sessions), home visits and leadership/coordination were completed.
- employing a new Māori female CAR Coordinator in July 2013 to follow up Māori who do not participate and those who have incorrectly completed a kit. The Māori CAR Coordinator also undertakes other activities.
- developing a DVD to encourage Māori participation. A randomised control trial commenced in January 2012 to assess the extent to which the DVD supports higher participation levels<sup>66</sup>. Pacific advisors indicated the DVD is also acceptable to use within the Pacific community.
- developing a DVD offering a step-by-step process to complete the bowel screening test using the iFOBT was posted on YouTube and WDHB's Bowel Screening website<sup>67</sup>. The DVD was fronted by Mr Ily Delasau, a Fijian surgical registrar at WDHB. The YouTube video was posted on 7 October 2013 and by 13 February 2014 had received 123 hits.

In 2012, feedback from Māori and Pacific people indicated some disliked doing the test in their home and posting faecal samples (Litmus 2013). In 2013, no action was taken to modify the screening pathway in this regard, although CAR coordinators will pick up samples if requested.

Monitoring Pacific people and Māori participation through 2014 will contribute to determining the effectiveness of these initiatives.

### ***Those living in the most deprived areas***

To date there have been no strategies developed that seek to address the low participation by those living in the most deprived areas. This reflects that this population has only been identified as having low participation rates in the epidemiological analysis presented in this report.

### ***Conclusions and recommendations***

The current design and implementation of the BSP is not resulting in fair access to the eligible BSP population in WDHB. Currently, the Ministry of Health and WDHB are seeking to strengthen Māori and Pacific leadership in the BSP. Working with Māori and Pacific leaders, they are seeking to agree a strategy to develop more evidence-based CAR activities to target eligible Māori and Pacific peoples, ensure their systematic use and to monitor their effect on participation over the remainder of the pilot.

In the future, consideration should be given to:

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<sup>66</sup> Half of the reminder letters sent to eligible Pacific people and Māori contains the DVD.

<sup>67</sup> <http://www.youtube.com/watch?v=J-Qz0XOMldo> and [http://www.bowelscreeningwaitemata.co.nz/Home.aspx#video\\_box](http://www.bowelscreeningwaitemata.co.nz/Home.aspx#video_box) accessed 6 December 2013

- The need to revise the design of the current BSP screening pathway to offer more flexibility to eligible Māori and Pacific people, e.g. more face-to-face interactions to overcome barriers to participation linked to the distribution of the kit, offering clinic-based test locations and sample drop-off choices.
- The strategies to increase participation of those living in the most deprived areas.

### 3.5 Acceptability to providers

#### Evaluation objective addressed in section

*Acceptability to providers* - To evaluate the knowledge and attitudes and acceptability to health professionals and health care providers based in community, primary care and hospital settings.

This section addresses the evaluation objective on the acceptability of the BSP to providers. The evaluative findings draw on the quantitative and qualitative research with providers including staff in the BSP Coordination Centre, endoscopy nurses, Gastroenterologists (GE), surgeons, radiology staff, laboratory staff, oncology staff and general practice including GPs, practice nurses and practice managers. The findings presented below are drawn from two provider survey reports (Litmus 2012a and 2014b), two immersion visit reports (Litmus 2013a and 2014) and the report on the role of general practice (Litmus 2014c).

For a description of providers' roles refer to section 2.3.

The key evaluation findings against the objective are presented first followed by a summary of supporting evidence.

#### **Key evaluation finding**

The acceptability of the BSP (defined by awareness, attitudes and knowledge) and its design is high amongst providers in the community, primary care and hospital setting. There is support for the BSP to be rolled out as a national screening programme, although there is recognition that further work will be required to ensure equity of participation, adequate workforce capacity particularly colonoscopy capacity, and that bowel screening does not impact on symptomatic services (refer section 3.6).

#### **Awareness, knowledge and attitudes**

##### **Overview**

Findings from the follow-up provider survey provide indicative and useful information about awareness, knowledge and attitudes to the BSP amongst general practice staff, endoscopy staff and radiology staff (Litmus 2014b). Key findings from the follow-up provider survey include:

- high levels of awareness of the BSP across WDHB GPs (100%), practice nurses (99%), endoscopy (100%) and radiology staff (100%).
- a significant increase in the extent providers feel informed about the BSP since 2011. However between 8% and 32% of each of these groups still agree that they are not well informed about the BSP, with radiology staff the least informed and GPs the most informed.
- all health providers surveyed view New Zealand's bowel cancer death rate as a significant health concern (ranges from 95% to 100% agree/ strongly agree).
- near universal support among health providers for the BSP in WDHB (ranging from 79% to 89% for strongly support and from 96% to 100% for support and strongly support combined).



- strong support for use of the iFOBT amongst GPs (93% agree/strongly agree with use), practice nurses (92%) and endoscopy staff (82%). Radiology staff indicate less support for its use (50%).
- support is also very high for a national bowel screening programme (ranges from 67% to 82% for strongly support and from 95% to 100% for support and strongly support combined).
- awareness of the New Zealand Familial Gastrointestinal Cancer Registry<sup>68</sup> remains relatively low despite improvements in awareness amongst some provider groups.

### General practice

Overall, GPs and practice nurses are aware of the different roles of general practice in the BSP. Positively, there have been significant improvements in the awareness of each of the roles that were identified as less certain in the 2011 baseline provider survey. Of particular note is the strong agreement that it is the role of GPs to inform BSP participants of positive iFOBT results; although 7% continue to disagree this is their role.

Following the launch of the BSP and associated promotions to general practice, there has been a significant increase in general practices' awareness of the BSP, support for the iFOBT, BSP and the potential national roll-out, and general practices' confidence in explaining the BSP. Since launch, the WDHB BSP Clinical Director and BSP Project Manager have promoted the BSP to PHOs and general practice and sought to build understanding of their role.

General practices' awareness and performance could be enhanced in the following BSP activities:

- notifying patients who receive a positive iFOBT, as not all are aware of this role
- liaising with the BSP Coordination Centre when unable to contact patients with a positive iFOBT.

There is a need for ongoing promotion of the New Zealand Familial Gastrointestinal Cancer Registry to general practice. While GP awareness has increased from 59% in 2011 to 71%, only half of GPs rate their performance of referring to the Registry as good/ very good (50%).

These knowledge gaps highlight the importance of ongoing BSP promotion and information provision to general practice. As indicated from the qualitative feedback from general practices there is interest in refreshers about the BSP process as well as learning how the pilot is progressing with regard to uptake and identification of cancers.

### Endoscopy staff

Reflecting their core role, endoscopy staff are aware of the BSP and agree that they have an important role. There is also near universal support for the BSP and for the possible national roll-out of a bowel screening programme. Most endoscopy staff are confident explaining the BSP to their patients and feel well-informed about the BSP.

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<sup>68</sup> A service that offers assessment, diagnosis and surveillance of inherited gastrointestinal cancer syndromes.

In the main, endoscopy staff continue to have good awareness of 'core endoscopy functions', such as undertaking pre-assessments, providing high quality colonoscopies and providing results to GPs. Positively, there has been increased understanding of notifying patients who receive a positive iFOBT (if they do not have a GP or have not been notified by general practice) and referring patients for a CTC (if a colonoscopy is not suitable for them).

### **Radiology staff**

Compared to 2011, awareness, knowledge and understanding of the BSP has increased among radiology staff at Waitakere Hospital and North Shore Hospital; although awareness tends to be lower than general practice and endoscopy staff.

### **Perceptions of the BSP**

All stakeholders interviewed in the 2013 immersion visit<sup>69</sup> hold very positive perceptions of the BSP, how it is being implemented and achievements to date (Litmus 2014). Compared to 12 months ago, there was recognition that the implementation of the BSP has moved to business-as-usual and is running more smoothly. This has been achieved through greater clarification of roles and processes and actions taken to address issues identified through quality monitoring and the evaluation findings.

The following strengths were identified with the BSP:

- integrated with the Ministry of Health's Bowel Cancer Programme
- participants' positive experience through the BSP screening pathway
- high functioning multi-disciplinary team working effectively across the screening pathway, linked together via a range of networked meetings and led by respected and motivated clinical leaders at national and regional levels
- quality improvement process embedded into the BSP through the monitoring and review of quality standards and auditing processes.

While provider perceptions across the screening pathway are in the main positive about the BSP, there are areas where service delivery could be strengthened (see section 3.6).

### **Conclusions and recommendations**

The 2013 provider survey indicates increased levels of awareness, knowledge and support for the BSP among general practice, endoscopy and radiology staff. Key areas of focus for screening round two are:

- ensuring all GPs are aware of their role to inform BSP participants of positive iFOBT results
- building awareness of the New Zealand Familial Gastrointestinal Cancer Registry amongst BSP providers and their role in referrals.

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<sup>69</sup> Includes staff from Ministry of Health and BSP Coordination Centre, endoscopy nurses, GEs, surgeons, radiology staff delivering CTC, laboratory staff and oncology staff.

### 3.6 Service delivery and workforce capacity

#### Evaluation objective addressed in section

*Service delivery and workforce capacity* - To monitor the effect, including resource implications of screening activities, on primary care, community health services, laboratory, and secondary and tertiary services and the implications of this for a national programme.

This section addresses the evaluation objective on service delivery and workforce capacity by summarising the resource allocations, highlighting pressure points, and identifying areas of changes or challenges in the service delivery model.

As noted in the evaluation plan (Litmus 2011), the evaluation does not include quantitative analysis of waiting times or impact on workforce capacity and normal service delivery.

The evaluative findings draw on the quantitative and qualitative research with providers including BSP Coordination Centre staff, endoscopy nurses, GE, surgeons, radiology staff, laboratory staff, oncology staff and general practice including GPs, practice nurses and other practice staff. The findings presented below are drawn from the following reports: the provider report (Litmus 2014b), two immersion reports (Litmus 2013a and 2014), the eligible population survey (Litmus 2014a) and the report on the role of general practice (Litmus 2014c).

The key evaluation findings against the objective are presented first followed by a summary of supporting evidence for each component of the screening pathway.

#### Key evaluation findings

As evidenced in the immersion visit reports (Litmus 2013a and 2104), the BSP screening pathway is being implemented as intended (refer overview of pathway below). Feedback from BSP participants also indicates a mainly positive screening experience (Litmus 2013 and WDHB 2013).

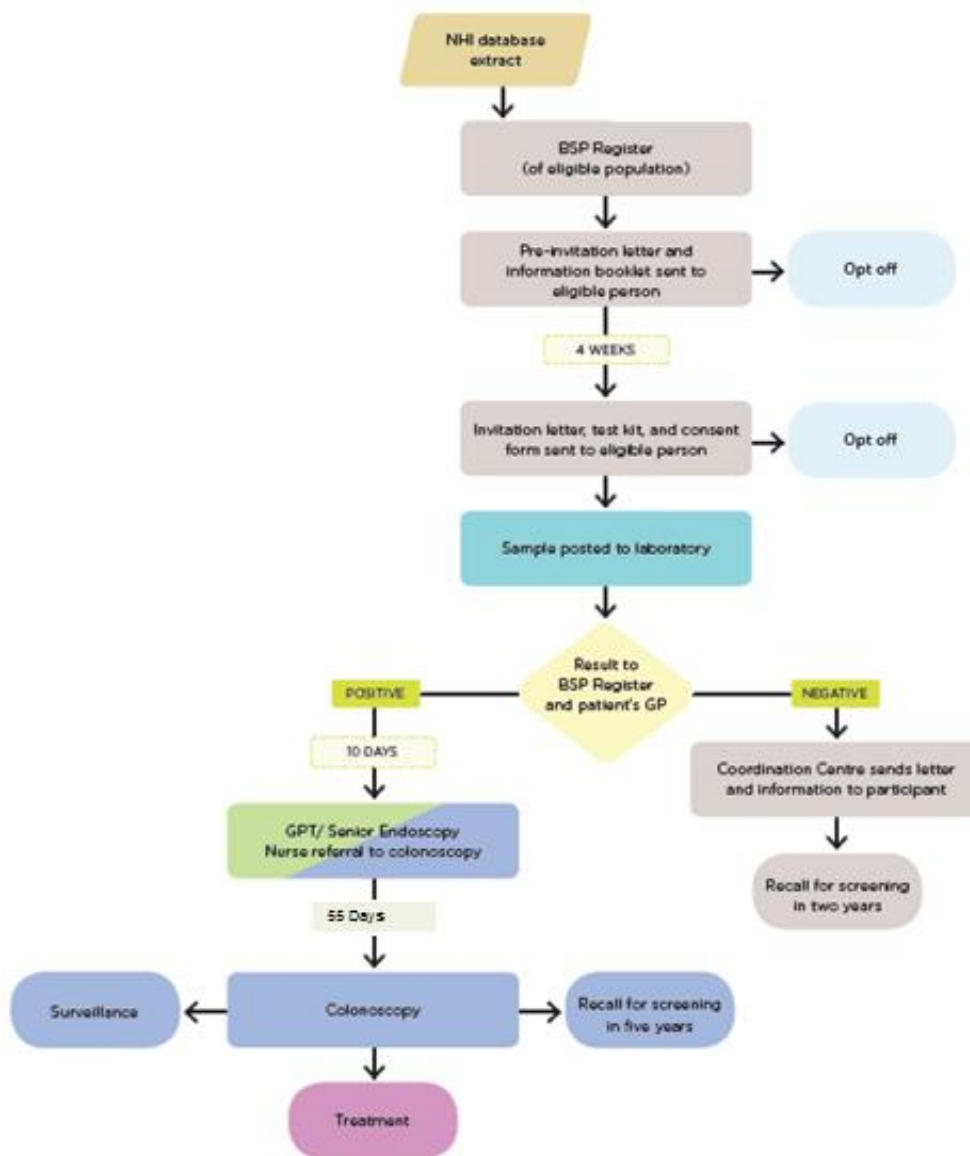
Across the screening pathway there are a number of critical pressure points on workforce capacity that if not effectively managed, could have an adverse impact on BSP service delivery, specifically:

- Colonoscopist capacity: ensuring there is adequate colonoscopist capacity to meet BSP quality standards continues to be a critical resource challenge for the BSP. For the period January 2012 to 31 December 2013, 91% of participants with a positive iFOBT received the first offer of colonoscopy within 55 working days compared to the expected quality standard of 95%. However, only 4% had a first offer of colonoscopy within 25 working days compared to the standard of 50%.
- Impact on treatment services: the increase in the number of cancer patients identified by the BSP is putting pressure on treatment services due to no additional resource being allocated to this service. As the BSP moves into screening round two, the pressure on surgery and oncology is likely to dissipate over time as fewer BSP participants will be identified with late stage cancers.
- Impact of BSP surveillance colonoscopies on symptomatic services: the high level of polyps detected via BSP colonoscopies will, over time, add significantly to the symptomatic colonoscopy lists. The accumulative effect of the surveillance colonoscopies have not yet impacted on the symptomatic list. Monitoring is required to

ensure that BSP participants requiring surveillance colonoscopies at one year and later receive timely appointments.

The value added by general practice informing participants they have a positive iFOBT result rather than the screening unit is not clear. Most BSP participants do not have a strong preference on who informs them about a positive iFOBT result so long as their results are timely, convenient, given in a reassuring manner, their GP is kept informed, and the transition to colonoscopy is well explained, timely and streamlined. The exception is BSP participants who are highly anxious, have other health conditions, or are reluctant to have a colonoscopy who feel they benefit from a consultation with their GP about their positive iFOBT result. Māori BSP participants cited a preference of hearing about their positive iFOBT result from the screening unit (Litmus 2014a).

Figure 14: Overview of screening pathway (WDHB 2012c)



## **Resource and activity overview**

Over the last 12 months of screening round one, monitoring of service demand has led to refined resource allocation at WDHB for the BSP. Summarised below is the reallocation of resources:

### **Endoscopy unit**

- An additional Registered Nurse
- Additional WDHB colonoscopists.

### **BSP Coordination Centre**

- Following resignation of the 0.5 FTE Programme Manager in 2012, the Project Manager took on this role as a 1.0 FTE.
- The Quality Lead position was vacant from October 2012 to May 2013, and dropped to 0.5 FTE from May 2013.
- The Data Manager FTE increased from 0.5 to 1.0 FTE from September 2013.
- The information phone line FTE was reduced by 0.6 FTE to increase administrative capacity at the endoscopy unit by 0.6 FTE to address the larger than expected administrative workload.
- The Māori CAR Coordinator role's was reduced to 0.6 FTE to enable the employment of a Samoan CAR Coordinator with the 0.4 FTE balance.

### **Ministry of Health**

- An additional senior advisor.

Tables 8 and 9 summarise the FTEs allocated to the BSP in screening round one and the volumes of activity across the screening pathway.

**Table 8: FTEs allocated to the BSP in screening round one**

Areas	Roles	2012 FTEs	2013 FTEs
<b>BSP Coordination Centre</b>	BSP Clinical Director	0.2	0.2
	Project Manager	1	–
	Programme manager	0.5	1
	Quality Assurance	1	0.5
	Data Manager	0.5	1
	Information phone line	3	2.4
	CAR manager	1	1
	Asian CAR workers	1	1
	Māori CAR worker	1	0.6
	Pacific CAR worker	0 <sup>70</sup>	0.4
<b>Endoscopy unit</b>	Clinical nurse specialist (CNS)	2	2
	Lead endoscopist	0.2	0.2
	Endoscopy nurses	4	5
	Administrator	0.8	1.4
	Colonoscopists (DHB)	0.269	0.482
	Colonoscopists (contractors)	0.304	0.324
	Colonoscopists (outsourced)	0.04	0.145

Source: BSP Coordination Centre, June 2014

Notes:

- **Colonoscopists (contractors)** are private providers who were contracted on a sessional basis to undertake colonoscopy sessions. Each session tends to involve between four and five colonoscopies depending on the experience of the colonoscopist.
- **Colonoscopists (outsourced)** were a one-off event to ensure participants with a positive iFOBT received a colonoscopy within the 55 days as stated in the quality standard. With the agreement of the Ministry of Health, the BSP covered the costs of symptomatic services outsourcing colonoscopies to the private sector to free WDHB colonoscopists to cover the BSP colonoscopy lists at WHEU.

<sup>70</sup> Contracted out to West Fono in 2012 and 2013.

**Table 9: Summary of pilot activity data, 2012/13**

Stage of pathway	Volume indicator	2012 Jan-June	2012 July-Dec	2013 Jan-June	2013 July-Dec	Total Jan 2012 – Dec 2013
<b>Obtain the samples</b>	Number of pre-notification letters sent	31,843	32,248	41,332	31,152	136,575
	Number of iFOBT kits sent (includes resends)	28,286	34,792	40,844	39,715	143,637
	Number of reminder letters sent at 4 weeks *	14,251	20,531	24,435	24,281	83,498
<b>Test the samples</b>	Number of samples received at laboratory	13,462	17,984	22,900	20,499	74,845
	Number of positive result	765	1,187	1,395	1,423	4770
	Letters sent to patients with a negative result	9,931	14,397	18,355	16,253	58,936
<b>Conduct colonoscopies</b>	Number of pre-assessments completed	712	1,176	1,337	1,438	4663
	Colonoscopies completed (DHB staff)	172	450	523	359	1504
	Colonoscopies completed (contractors)	297	425	368	682	1772
	Colonoscopies completed ('temporary increased capacity')	0	86	279	64	429
	Colonoscopy under general anaesthetic *	3 <i>estimate</i>	4	2	3 <i>estimate</i>	12
	CTC instead of colonoscopy	7 <i>estimate</i>	11	23	12	53
<b>Histology</b>	Histology conducted as a result of colonoscopy	368	763	855	949	2953

Data sourced from: WDHB, BSP Biannual Reports to Ministry of Health. (Items annotated with \* are supplementary data provided to Sapere directly from the pilot).

Table 9 is based on dynamic time based volumes therefore the numbers do not add sequentially.

### ***Identification, pre-invitation and invitation***

In the first 18 months, the BSP Coordination Centre undertook the distribution of the pre-invitation and invitation letters. Review of the internal mail out process found it inefficient due to the lack of appropriate printers, collation and mail out equipment and the physical layout of the BSP Coordination Centre (Litmus 2013a).

In 2013, the BSP Coordination Centre is trialling the outsourcing of the pre-invitation letter mail out. If this outsourcing is assessed as working well, the kit, reminder letters and negative result letter will also be outsourced to gain efficiencies in administrative processes.

### ***iFOBT test results – incorrectly completed kits and expired kits***

In 2012 and 2013, the receipt of incorrectly completed kits and completed kits after their expired date were identified as issues.

#### **Managing incorrectly completed iFOBT kits**

In 2013, an estimated 17% of iFOBT kits were not completed correctly the first time they were returned (Read et al 2014), mainly due to supporting paperwork being incorrectly completed (Litmus 2013a and 2014). Most of these people went on to complete a kit correctly, once another kit was sent to them together with a letter explaining the error. Māori, Pacific and Korean participants received a phone call to discuss the error before the kit was sent.

Simplified and more pictorial kit instructions and revisions to the consent form were introduced in late 2013 to increase the number of kits completed correctly first time. The impact of the revised documents on correct completion will not be known until late 2014.

#### **Management of completed samples using an expired iFOBT kit**

By 10 December 2013, 72 completed iFOBT kits were received that had been completed after the printed expiry date (which is about 0.1% of completed kits). The Ministry, WDHB, LabPLUS and the supplier worked together to agree the appropriate response to this issue. Currently, expired kits are identified after they are tested. While this is not failsafe due to the potential for human error, there are fewer risks identifying at this stage than before testing.

At present, participants with positive expired iFOBTs are referred for a colonoscopy, and those with a negative result using an expired iFOBT are asked to repeat the test. Supply arrangements have been changed to ensure the maximum possible time before expiry, and participant brochures and pamphlets have been updated to encourage prompt completion.

### ***iFOBT test results – laboratory***

WDHB has a Service Level Agreement with LabPLUS (which is an ADHB service). LabPLUS is based in Grafton, central Auckland. The LabPLUS BSP team comprises personnel from the following four areas:

- Administration: Business Development Manager, Quality Manager, IT.
- Automation and Laboratory Support Services (ALSS): This team looks after receipt of iFOBTs and histology samples, iFOBT registration and checking. About 20 people are involved in receipt, registration and checking of iFOBTs (on a roster basis).



- Specialist Chemical Pathology: This team is responsible for iFOBT testing and results reporting. About 20 people are trained to do iFOBT testing (two people undertake this role on a day-to-day basis).
- Histology: This team looks after registration and testing of histology samples, and histology reporting. Two pathologists, 13 scientists and technicians are involved in the BSP work.

### **Service delivery**

The processing of iFOBT tests by LabPLUS is seen as quick and timely. iFOBTs are generally processed within a day; 95% are processed within six hours (Litmus 2013a).

### **Implications for a potential national roll out**

Feedback from LabPLUS highlights that adequate resources, time and priority will need to be given to the development of an IT interface between the national bowel screening information system and laboratory information systems.

### ***iFOBT test results – general practice***

The role of general practice in informing BSP participants of a positive iFOBT is a unique element of the BSP. The intention is that GPs discuss a positive iFOBT result with their patient and refer for colonoscopy to BSP via the Booking and Scheduling department at WDHB within ten days. Internationally, general practice involvement in bowel screening has been shown to have a positive impact on iFOBT screening participants, although this is subject to high variability (Federici et al 2006, Koo et al 2010, Power et al 2009).

General practices in WDHB have high levels of awareness, knowledge and support of the BSP, and in the main they are undertaking their role in the BSP as intended (Litmus 2014b). To a large extent the BSP has moved to business-as-usual across many general practices as evidenced by three quarters of BSP participants hearing about their positive iFOBT result from their general practice (Litmus 2014c).

- For the first 18 months of the pilot, 74% of BSP participants at pre-assessment have been informed of their positive iFOBT result by their general practice (Ministry of Health Register dated 29 January 2014). The remaining 26% were informed via the Endoscopy Unit's CNS. For those BSP participants who did not hear about their positive iFOBT result via their general practice, this can reflect their personal choice and circumstances (i.e. not wanting their GP informed, not having a nominated GP in their practice, or not being contactable within ten days) or incorrect consent form completion<sup>71</sup> (Litmus 2014c).

In 2013 the WDHB eligible population survey (Litmus 2014a) found that<sup>72</sup>:

- 23 people (out of the 324 people who had received a BSP kit) had a positive iFOBT result.

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<sup>71</sup> The revised consent form introduced in 2014 seeks to address this confusion.

<sup>72</sup> Data presented is based on the weighted data.

- Of the 23 people with a positive iFOBT, 16 received the news of their results from general practice (70% similar to the Register data), three stated they were called by someone from the Endoscopy Unit, one received a letter from the Endoscopy Unit and three did not know<sup>73</sup>).

The BSP screening pathway does not stipulate the process of how general practice informs participants about their positive results, simply that the referral is made within ten days. This flexibility was offered to enable the BSP to fit into existing general practice processes. Interviews with general practice highlighted that informing participants about their positive iFOBT result varies from a face-to-face consultation with a GP to a phone discussion with a practice nurse or GP.

Feedback from the endoscopy unit staff indicates that most referrals sent from general practice follow the agreed pathway, although a few are sent to symptomatic or surgical services. Endoscopy staff also note variation in the quality and completeness of general practice referral information to endoscopy. Some provide the required information, while others simply refer with little relevant information. The introduction of e-referrals in 2013 has standardised information received and improved the quality of referrals. However, not all general practices use e-referrals.

Promotion of the BSP by general practice is opportunistic. Currently practices are unaware of the non-responders in their practice as there is no system to inform general practice who has received an iFOBT kit and not returned it. A potential enhancement to general practice's role is following up non-responders, in particular Māori and Pacific non-responders, but only if this information is provided to them by the BSP Coordination Centre in a streamlined and timely fashion.

### Perceptions of workforce capacity

The majority of general practice staff reported their workload increased due to the BSP, although the impact is lower than expected before the pilot commenced in 2012 (Litmus 2014b).

- Six-in-ten GPs and practice nurses felt that the BSP *increased* or *significantly increased* the workload in their general practice (60% and 56% respectively), with the large majority of the remainder indicating that there had been *no change* in the workload (40% and 36% respectively). This was significantly different to the expected impacts reported in the 2011 baseline provider survey (100% *increase* or *significantly increase* for GPs, and 93% *increase* or *significantly increase* for practice nurses).

Compared to 2011, GPs are less concerned about the capacity of other services to meet the needs of the BSP, in particular, colonoscopy, CTC and secondary care services, although there continues to be high levels of 'don't know' responses for CTC and secondary care (Litmus 2014b)<sup>74</sup>.

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<sup>73</sup> Both the qualitative interviews and the quantitative survey highlighted that some BSP participants do not recall how they received the news of their results.

<sup>74</sup> GPs may not be able to accurately comment on capacity of other providers therefore the findings presented are perceptions and need to be considered in this context.

Ongoing concerns about the effect of the BSP on symptomatic colonoscopy capacity continue amongst GPs. Qualitative survey comments and interviews with general practice staff highlight a particular concern that the BSP is reducing available services for symptomatic patients particularly with regard to colonoscopy wait times for symptomatic patients (Litmus 2014b & c).

### **Participants perceptions**

Most BSP participants do not have a strong preference about who informs them about a positive iFOBT result so long as their positive iFOBT results are timely, free and convenient, given in a reassuring manner, their GP is kept informed, and the transition to colonoscopy is well explained, timely and streamlined.

Two new attitudinal questions were asked in the 2013 survey to identify whether respondents had a preference about who tells them their iFOBT result. The findings highlight that both options (general practice and BSP Coordination Centre) 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 iFOBT test result. Similarly, 76% are happy to be contacted by someone else from the BSP to tell them about a positive iFOBT 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 (Litmus 2014a).

Māori and Pacific BSP participants interviewed who had received their results from the Endoscopy Unit perceived this approach as more convenient, potentially cheaper (as no need to take time of work or incur transport costs), timely and aligned with the next step of having a colonoscopy rather than from their general practice. For these participants it is critical that their GP is aware of their iFOBT result (Litmus 2014c).

BSP participants interviewed who were anxious, had other health conditions or were reluctant to have a colonoscopy, gained benefit from a consultation with their GP about their positive result (Litmus 2014c).

### **Implications for a potential national roll out**

There are mixed perceptions during the first screening round about general practice informing participants about their positive iFOBT results. In considering the role of general practice in a potential national roll out, the possible consequences of their not being involved needs to be considered, in particular:

- The impact on the continuity of care for participants diagnosed with bowel cancer. It is assumed the impact would be minimal provided GPs are informed about their patients' results.
- The impact on general practice's promotion of the BSP and willingness to follow up non-responders if they no longer have a key role in the pathway. This comment reflects that day-to-day general practice deals with many competing priorities so there is a risk that without this role the BSP may not be top of mind. Currently there is a need to identify strategies to increase participation by eligible Māori and Pacific people. General practice could have a role in encouraging non-responders (if made aware of whom they are) to take part in the BSP – it is unknown whether or not general practice involvement will increase participation by Māori and Pacific people.
- The impact and cost of the Endoscopy Unit's CNS undertaking this role for all participants with a positive iFOBT result and if not the CNS the acceptability of other BSP staff to participants.

## **Pre-assessment**

The pre-assessment phone call with BSP participants, while very resource-intensive on CNS time, contributes to checking the appropriateness of colonoscopy versus alternative procedures, reducing DNA rates<sup>75</sup> and ensuring good bowel preparation. Due to the time needed to undertake the pre-assessment, the CNSs are no longer also calling participants the day before their colonoscopy to ensure the bowel preparation is proceeding as intended.

Use of translators for people with English as another language was identified as important to ensure participants understand information given both at the pre-assessment phone call and when having their colonoscopy.

## **Colonoscopy**

### **Ensuring adequate workforce capacity**

Pre-BSP research highlights a significant gap between colonoscopy demand and provision, and that population screening would require a significant increase in colonoscopy capacity (Yeoman and Parry 2007). In 2012, Green et al concluded that colonoscopy requirements of an iFOBT based population screening for bowel cancer are high to deliver the initial confirmatory procedure and subsequent surveillance procedures in a timely manner. They note significant expansion of colonoscopy services is required to meet the screening requirements including surveillance whilst maintaining symptomatic services.

In 2012, reflecting this research and following the launch of the BSP, having adequate colonoscopy capacity to meet BSP quality standards was identified as a key challenge. While this challenge remains in 2013, 91% of BSP participants with a positive iFOBT had their colonoscopy within the quality standard of 55 days in screening round one (January 2012 to 31 December 2013). In contrast, only 4% of participants had their colonoscopy within 25 working days compared to the standard of 50%.

To remain within the quality standards, 50 colonoscopies per week must be completed, based on the current participation and iFOBT positivity result rates.

To achieve this, the BSP programme manager, the WDHB BSP Clinical Director and the two CNSs work continuously to encourage and support endoscopists from WDHB, other DHBs and private consultants to undertake the lists available. Some of the identified pressures on the availability of endoscopists are:

- Not enough endoscopists within WDHB to cover the BSP lists. A new endoscopy room was opened at Waitakere Hospital for symptomatic lists in late 2013. As a result the availability of endoscopists has declined. The BSP Coordination Centre seeks to ensure that their actions do not affect the availability of endoscopists for the symptomatic list.

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<sup>75</sup> The DNA rate for BSP colonoscopy is 0.0028% (Griffith, Turner and Williams 2013).

- Staff turnover and need to increase staff. New staff, both a surgeon and Gastroenterology Fellow, commenced work in January 2014, which may alleviate some of the pressure to find endoscopists to get lists completed within quality standards. The surgeon will contribute to both the BSP colonoscopies and treatment.

A resizing of some senior clinician roles has resulted in the confirmation of three additional lists per week for the BSP from October 2013 onwards.

- Competing priorities affect the availability of endoscopists from other DHBs.

Key stakeholders highlight the need for experienced endoscopists for bowel screening, given the complexity of the colonoscopies and the additional risks of asymptomatic participants.

### Perceptions of workforce capacity

All endoscopy staff (100%) reported that the BSP had increased their workload, with 65% stating that the workload had *significantly increased* (Litmus 2014b).

Other provider perceptions of the current capacity of WHEU colonoscopy services were mixed (Litmus 2014b)<sup>76</sup>.

- Just over half of GPs (52%) indicated that capacity is *about right* or *more than enough* for colonoscopy services, via the WHEU, for the BSP. This was a significant increase from 8% reported in the 2011 baseline provider survey. A third (37%) said there is *not enough capacity* and 11% *don't know*.
- One-third of practice nurses (34%) indicated that capacity is *about right* or *more than enough*, whereas 27% (significantly lower than 43% in the 2011 baseline provider survey) felt that there is *not enough capacity* and 40% reported they *don't know*.
- Seventy-one percent of endoscopy staff thought that capacity for colonoscopy services for the BSP was *about right* or *more than enough*.
- Most radiology staff (59%) reported they *don't know* what the current capacity is for colonoscopy services. Only 9% indicated that capacity is *about right*, significantly lower than 27% in the 2011 baseline provider survey.

### Other issues noted

Other issues noted in interviews with endoscopy staff (Litmus 2014):

- **The need for regular reminders on the quality standards.** While there is awareness of the quality indicators for colonoscopy, awareness of the detailed BSP quality standards is variable amongst endoscopists.
- **Clear processes for the management of incomplete colonoscopies.** Endoscopists are aware that it is critical that BSP participants who have incomplete colonoscopies are rescheduled quickly. However, the process to transfer and the responsibility for ensuring these BSP participants are seen promptly via the symptomatic list is not clear to all, and feedback indicates the process is not seamless. Action has been taken to address this issue through the establishment of a monthly general anaesthetic colonoscopy list at Waitakere Hospital.

<sup>76</sup> Other provider groups may not be able to accurately comment on capacity therefore the findings presented are perceptions and need to be considered in this context.

## Histopathology

### Perceptions of workforce capacity

Reflecting the high polyp detection rate, LabPLUS are processing more polyps than they originally expected and planned for. As a result, LabPLUS instigated a review of workforce to ensure quality standards relating to timeliness of results were adhered to.

LabPLUS is required to provide histopathology results within ten working days. LabPLUS reports histopathology results directly into Concerto (the WDHB patient record system) using a standardised reporting template. In screening round one (January 2012 – December 2013), the standard of 95% of specimens submitted from colonoscopy being reported and relayed to the referring endoscopist with ten working days of receipt by the laboratory was met with the exception of two months in 2012.

**Table 10: BSP Histology Samples Indicators for January 2012 – December 2013**

	No. of cases Arrived (in Histology)	> 10 Days No. of Overdues last month	> 10 Days No. of Overdues this month	Max Turn Around Time (Days)	Average Turn Around Time (Days)	Percentile Rank	Avg. no. of pots received per case	No. of cases with missing information
Jan 12	4	0	0	9	8.5	100	1.3	0
Feb 12	13	0	0	8	6.4	100	1.3	2
Mar 12	77	0	0	10	6.7	97	3.2	24
Apr 12	84	0	3	11	5.9	95	2.8	8
May 12	76	3	2	14	5.5	97	2.4	9
June 12	88	2	9	13	7.3	84	3.4	11
July 12	114	9	10	12	6.5	86	3.7	26
Aug 12	133	10	0	10	5.1	100	3.9	3
Sep 12	89	0	0	8	5.1	100	2.9	11
Oct 12	125	0	0	10	5.1	100	2.7	1
Nov 12	167	0	1	11	4.7	99	3.1	13
Dec-12	135	1	0	10	3.8	99	3.8	7
Jan-13	128	0	0	10	3.9	100	3.4	14
Feb-13	135	0	1	11	4.4	99	3.6	17
Mar-13	152	1	1	11	3.80	98	3.0	14
Apr-13	135	1	0	7	4.0	100	3.0	7
May-13	173	0	0	9	4.0	100	3.0	0
June-13	132	0	0	9	3.4	100	4.3	0
Jul-13	185	0	0	8	4.1	100	3.1	0
Aug-13	170	0	1	11	4.2	99	3.1	0
Sept-13	128	1	0	9	4.6	100	2.9	0
Oct 13	135	0	0	8	3.0	100	3.1	0
Nov 13	136	0	0	9	3.4	100	2.9	0
Dec 13	110	0	0	8	4.3	100	3.4	0

Source: LabPLUS June 2014

Histology staff that process tissue samples receive monthly reports detailing indicator results which they note are actively monitored and any outliers are investigated. Turnaround times are received on a bi-monthly basis as due to the high workload there is potential for the timelines to slip. Strategies are used to minimise the timeframe from receipt to reporting. For example, the samples go directly to the pathologist, and are not reviewed by a Registrar.

## Focused on quality

As expected for an International Accreditation New Zealand (IANZ) accredited lab, LabPLUS has a strong focus on monitoring quality indicators as defined in the BSP Quality Standards<sup>77</sup>.

Key stakeholders commented that there is an effective working relationship between LabPLUS histopathology, BSP endoscopy unit and the BSP Coordination Centre. LabPLUS are seen as having quality processes in place, being timely in their delivery and connected and engaged with the wider BSP screening pathway.

Feedback from endoscopists highlights support for the processes and procedures that enable quality histopathology.

Over the last 12 months, the faxing of tracking sheets of biopsies received by LabPLUS to the BSP Endoscopy Unit commenced. The tracking sheets allow the BSP Endoscopy Unit to audit whether all pots are received and to manage any labelling errors (which LabPLUS noted there are very few).

Feedback from LabPLUS suggests that they receive the majority of information required about BSP colonoscopy biopsies. Very occasionally, information is missing such as date of the specimen, or there is a lack of specification on the location of where the polyp was taken.

## Changing role of the CNS

From 2013, the CNS has been reviewing the colonoscopy reports and the histopathology results and advises the BSP administrator the correct letters to send out to participants, their GP, and WDHB notes. The CNS prepares a spreadsheet of actions taken which is reviewed by the WDHB BSP Clinical Director or WDHB BSP Lead Endoscopist. Where there is any concern or uncertainty, the CNS discusses the results with the BSP Clinical Director or Lead Endoscopist. A formal policy has been developed (*Histology Results Management*) which sets out parameters within which the CNS may make decisions.

Review of histology results by the CNS is seen to have a number of key benefits, specifically ensuring consistency of review, timeliness of referrals, and freeing up the WDHB BSP Clinical Director and WDHB BSP Lead Endoscopist<sup>78</sup>. Endoscopists interviewed were comfortable with the CNS reviewing the results.

## Alternative investigation – CTC

BSP participants assessed as unfit for colonoscopy or with an incomplete colonoscopy are offered a CTC investigation. Occasionally when a colonoscopy fails, the person may proceed to have a colonoscopy under general anaesthetic (estimated at 53 in screening round one, Artus et al 2014).

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<sup>77</sup> LabPLUS is accredited annually by International Accreditation New Zealand (IANZ) to ensure the quality of results released meets the New Zealand Standard NZS/ISO15189, 'Medical Laboratories – Particular requirements for quality and competence'.

<sup>78</sup> In symptomatic services histology results are normally reviewed by the endoscopist who performed the colonoscopy. To ensure continuity and timeliness, this was not feasible for a screening programme.

## Perceptions of workforce capacity

Stakeholders interacting with CTC are in the main positive about their communication and ability to see BSP participants who have had a failed colonoscopy that day or the next to avoid participants having to repeat their bowel preparation. There is acknowledgement that it took time to set up appropriate processes and that there are further areas for improvement.

Qualitative feedback from radiology staff highlights that the BSP has had minimal impact on their workload. It is estimated that from July 2012 to October 2013:<sup>79</sup>

- In Waitakere Hospital – 34 BSP CTCs have been performed out of a total 492 CTC (7% of CTC undertaken were from the BSP)
- In North Shore Hospital - 13 BSP CTCs have been performed out of a total 456 CTC (3% of CTCs undertaken were from the BSP)
- In total across the two hospitals - 47 BSP CTCs have been performed out of a total 948 CTC (5% of CTC undertaken were from the BSP).

In contrast, three-quarters of radiology staff (74%) reported that the BSP had increased the workload at the North Shore Hospital radiology unit (70% *increase*), whereas less than half (48%) reported that the BSP had increased the workload at the Waitakere Hospital radiology unit.

This was significantly different to the expected impacts reported in the 2011 baseline provider survey of 96% *increase* or *significantly increase* at the North Shore Hospital radiology unit, and 90% *increase* or *significantly increase* at the Waitakere Hospital radiology unit. It is noted, however, that the difference is largely accounted for in the increase in radiology staff particularly at Waitakere Hospital reporting that they *don't know* what impact there has been on the workload.

Other provider perceptions regarding the current capacity of CTC services for the BSP tended to vary by type of provider<sup>80</sup>. GPs, practice nurses and endoscopy staff each had large proportions of providers that reported they *don't know* the capacity.

- One-third of GPs (35%) indicated that there is currently *not enough* CTC capacity for the BSP, although this was a significant reduction from 67% in the 2011 baseline provider survey. In addition, 44% did not know.
- Twenty-eight percent of practice nurses indicated that there is *not enough* CTC capacity, while 57% did not know.
- All endoscopy staff either thought capacity was *about right* (47%), or felt they did not know about capacity of CTC services (53%).
- Radiology staff were divided in their opinions, in that 50% reported the capacity was *about right*, and 50% reported that there was currently *not enough* capacity of CTC services.

<sup>79</sup> Personal communication from John Greenwood dated 22 October 2013.

<sup>80</sup> Other provider groups may not be able to accurately comment on capacity therefore the findings presented are perceptions and need to be considered in this context.



### Other service delivery issues noted for CTCs

- **Inconsistent coding of BSP participants.** BSP participants coming into CTC should be given a unique code to identify them as coming from the BSP. The coding of BSP participants does not appear to be occurring consistently. For BSP participants seen on the day or day after their failed colonoscopy, this does not create any pathway issues. However for those added to CTC's general list, this can create potential delays (refer below). Review is required to identify if all BSP participants who have had a CTC are noted in the BSP Register.
- **Lack of adherence to BSP referral and wait standards.** BSP participants deemed unfit for a colonoscopy and fit for CTC are added to the pool of patients referred for a CTC. BSP participants are treated the same as other CTC patients. The quality standards of CTC for referral and wait times differ from BSP quality standards. The Radiology Department is confident that BSP participants are seen within 30 days (their standard) and not BSP's standard of 20 days.

CTC send letters to all referred patients inviting them to call and make an appointment. Consequently, if patients do not respond promptly to the letter there will be a delay.

Radiology staff are confident that they deliver against the other BSP quality standards, although they are not actively monitored by the Radiology Department. The Department relies on the BSP Coordination Centre or WDHB BSP Clinical Director to inform them if they are at risk of breaching the quality standards.

- **Ensuring BSP participants are clear about next steps.** Calls to the BSP Coordination Centre have indicated that following a CTC, some BSP participants are not receiving the correct information about what happens next. This reinforces the need to be able to identify BSP participants and to ensure Radiology staff are aware of the next steps for BSP participants.

### Surveillance

Stakeholders interviewed recognised that the high level of polyps detected via BSP colonoscopies will, over time, add significantly to the symptomatic colonoscopy lists. Green et al (2012) found that in the first few years of a screening programme the main colonoscopy requirement is for the initial referral after a positive iFOBT. By year seven, surveillance colonoscopies will have built up and account for 40% of the total colonoscopies.

While the accumulative effect of the surveillance colonoscopies have not yet impacted on the symptomatic list, there is some qualitative feedback that BSP participants requiring surveillance colonoscopies at one year are not receiving timely appointments (Litmus 2014). Monitoring is required to ensure that BSP participants requiring surveillance colonoscopies at one year and later are receiving timely appointments.

Planning has been undertaken to quantify known issues with symptomatic colonoscopy lists and to assess the impact of BSP participants being referred for surveillance colonoscopies. A business case to the WDHB has resulted in additional resources to address the needs of symptomatic patients as well as to accommodate the flow on effect of BSP surveillance colonoscopies. The impact of the BSP on symptomatic services needs to be monitored (Litmus 2014).

Concerns about having adequate colonoscopy capacity to meet the demands of both a screening programme and people with symptoms have been highlighted in other countries including Ireland and England (Green et al 2012).

## **Treatment**

106 participants had cancer detected through the BSP<sup>81</sup> (Read et al 2014).

### **Perceptions of workforce capacity**

WDHB commenced the pilot with five FTE colorectal surgeons. In 2013, a workforce analysis conducted in WDHB found there are now three FTE colorectal surgeons, and the support of a surgeon seeking to retire. Recruitment of replacement surgeons has been slow. The decreased number of colorectal surgeons and the historically low number of surgeons per head of population at WDHB has meant that the number of participants diagnosed with cancer via the BSP has placed significant pressure on these limited resources.

The availability of theatre space is also highlighted as creating a barrier to ensuring timely surgical intervention. As explained by a surgeon, the general rule is that a patient with colorectal cancer can require the equivalent to half a day of operating time.

The lack of surgical resource is perceived to be adversely impacting on the time to surgery for BSP participants diagnosed with cancer (Litmus 2014).

Further, feedback suggests that benign colorectal issues are not being addressed due to the impact of the BSP and the lack of surgical capacity.

Like surgical services, the increase in the number of cancer patients identified by the BSP is starting to put pressure on oncology services due to no additional resource being allocated to this service. As the BSP moves into screening round two, the pressure on surgery and oncology is likely to dissipate over time as fewer BSP participants will be identified with late stage cancers.

Other providers' perceptions about the capacity for secondary care services varied. High proportions of respondents also said they did not know about current capacity of secondary care services for bowel cancer.

- Forty-two percent of GPs indicated that capacity is about right or more than enough for secondary care services, a significant increase from 17% reported in the 2011 baseline provider survey.

In contrast, the other provider groups<sup>82</sup> had larger proportions that reported there is *not enough* current capacity of secondary care services for bowel cancer:

- Twenty-nine percent of practice nurses indicated that there is *not enough* current capacity, while 49% did not know.

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<sup>81</sup> 11 out of the 106 participants with cancer were in the self-selected population.

<sup>82</sup> Other provider groups may not be able to accurately comment on capacity therefore the findings presented are perceptions and need to be considered in this context.

- Forty-seven percent of endoscopy staff said that there is *not enough* current capacity (significantly higher than 25% in the 2011 baseline provider survey), while 35% did not know.
- Twenty-seven percent of radiology staff indicated that the capacity of secondary care services is *not enough*, 50% did not know.

### **BSP multi-disciplinary meetings**

BSP multi-disciplinary meetings (MDMs) are in the main well attended and all BSP participants are discussed as per the guidelines. The challenging areas for attendance are histopathology and oncology representation due to the need to travel from Auckland. Histopathology attendance is irregular due to clashing MDM commitments in their DHB. Action is being taken to address this issue (Litmus 2014).

## **Conclusions**

The implementation of the BSP is consistent with the design of the screening pathway.

The following aspects on the pathway require refinement or review:

- Ensure there is adequate colonoscopist capacity to meet BSP quality standards for initial referrals and for surveillance procedures, while not impacting on symptomatic services.
- Review the management and clarity of processes for incomplete colonoscopies.
- Ensure BSP participants are correctly coded in CTC and receive the appropriate discharge information.
- Determine whether the revised and more pictorial iFOBT completion instructions and consent form decreases the number of incorrectly completed kits received.
- Assess the efficiency gains from outsourcing the pre-invitation mail out.

In screening round one, challenges in ensuring adequate workforce capacity were particularly noted for having enough endoscopists to meet BSP quality standards. The following are considerations for service design and workforce capacity in the context of a potential national roll out for bowel screening:

- Agree the role of primary care in the screening pathway.
- Ensure colonoscopy capacity and quality meets bowel screening standards across New Zealand.
- Allow for a realistic implementation planning period at the end of which providers demonstrate their ability to meet the bowel screening quality standards. Providers will need a considerable amount of time to find space for the bowel screening programme, ready their endoscopy units, recruit and train staff and set up quality and reporting systems, etc.
- Review the histopathology workforce in New Zealand as there are suggestions there may not be enough histology technicians and scientists to service the high volume of specimens.
- Ensure adequate workforce and service capacity for both bowel screening and symptomatic colonoscopy services.

### 3.7 Quality monitoring

#### Evaluation objective addressed in section

*Quality* - To pilot the agreed quality standards and monitoring requirements along the Screening Pathway and assess the implications for a national programme; in particular to pilot the acceptability and safety of the standards and screening to providers and for different population groups.

This section addresses the evaluation objective on quality. As noted in the evaluation plan (Litmus 2011), the evaluation does not systematically audit service delivery but uses data from WDHB and Ministry of Health reporting to monitor quality standards along the Screening Pathway.

The evaluative findings draw on the quality monitoring section in the 2013 immersion visit report (Litmus 2014) and WDHB's Biannual Reports (WDHB 2013c). This section describes the quality standards and processes Ministry of Health and WDHB use to monitor the quality of the BSP. The findings of the 2013 review of the BSP quality standards are presented followed by an overview of 2013 quality activities, adherence to BSP quality standards and issues and risks identified.

The key evaluation findings against the objective are presented first, followed by a summary of supporting evidence.

#### Key evaluation findings

The review of quality monitoring confirms that BSP has a range of quality standards and processes in place that align with international best practice. Quality standards, risks and issues are actively monitored, reported, discussed and actions taken to address risks of breaching quality standards, and mitigated risks emerging.

While WDHB note that reporting against all quality standards is now possible (with exception of the timeliness of the histology result letter), data was not sighted by the evaluation team for all quality standards.

In November 2012, a review of the BSP interim quality standards (Ministry of Health 2012a) was jointly undertaken by Ministry of Health, WDHB and LabPLUS. Overall, no substantive issues were identified with the existing quality standards, although refinements and clarifications were made to the interim quality standards (Ministry of Health 2013c).

One area where the BSP is not operating within the quality standard is the first offer of colonoscopy within 25 working days which is 4% compared to the standard of 50% for the period January 2012 to 31 December 2013. However, 91% received the first offer of colonoscopy within 55 working days just under the standard of 95%.

Discussions with key stakeholders highlighted potential risks to adhering to quality standards, including:

- not having enough endoscopist capacity to remain within agreed wait times to colonoscopy
- variable awareness of all the BSP quality standards for colonoscopy procedures amongst endoscopists. While endoscopists are aware of the indicators for quality colonoscopy, there is variable awareness of the full range of quality standards for BSP

- a lack of awareness of the BSP quality standards for CTC amongst radiology staff and BSP participants not being appropriately coded
- duplication and potential confusion due to the number of Ministry of Health quality documents for the BSP
- a lack of clarity in the link between the Global Rating Scale (GRS) being used to improve the quality of endoscopy in New Zealand and the BSP's quality standards.

### **Overview of BSP quality standards and processes**

The BSP is a population-based pilot, the design of which draws on the European Guidelines for Quality Assurance in Colorectal Cancer Screening and Diagnosis (Segnan et al 2010). The European Guidelines were also used as a guide for the development of the BSP quality standards. Where no standard exists, the Ministry of Health working with the Bowel Cancer Taskforce, Māori Equity Advisory Group and the Bowel Screening Advisory Group reached a consensus decision based on consultation with experts involved in pilots undertaken in Scotland, England, Wales and Australia, and a review of existing evidence.

Five key quality documents were developed for the BSP. These documents are interim reflecting that they are 'living' documents.

1. BSP Final Service Delivery Model (Ministry of Health 2013d): This document details the final Service Delivery Model and outlines the screening pathway for the eligible population in the BSP site at WDHB.
2. Policy and Operational Procedures for the BSP (BPOP) (Ministry of Health 2011): This document is intended to provide an overview of business practices and processes for the whole bowel screening process, including the population database, invitations, informing general practice, communications, setting up screening tests and quality standards for iFOBT. The BPOP, which will inform the national programme (should it proceed), will be progressively developed as the BSP is implemented.
3. BSP Interim Quality Standards (Ministry of Health 2012a and 2013c): This working document sets out the monitoring, draft quality standards, clinical audit, risk management, and monitoring indicators. These Standards were reviewed by the Bowel Cancer Taskforce, the Colonoscopy Quality Working Group and the BSP Quality Assurance Group. The Standards are monitored within the BSP and continually reviewed by the BSP Quality Assurance Group during the pilot's four year period. The interim BSP Quality Standards have been collated based on the English, Welsh and Scottish bowel cancer screening programmes. These UK Standards are based on the outcome of the English and Scottish BSP evaluations.
4. BSP iFOBT Draft Performance Quality Standards (Ministry of Health 2011a): This document identifies requirements for manufacture of the test kit and requirements for laboratory testing. Ministry of Health and LabPLUS jointly developed the document.

5. Standards for Endoscopy (colonoscopy) Facilities BSP (Ministry of Health 2011b)<sup>83</sup>: This document covers service management, quality assurance, participant care, infection control, equipment and participant sedation. The standards were developed by the Bowel Cancer Colonoscopy Nurses Quality Working Group based on the *Endoscopic Facilities and Services Guidelines*; Gastroenterological Society of Australia, 3<sup>rd</sup> Edition 2006, and recommendations from the Australian Quality Working Group report *Improving Colonoscopy Services in Australia* (2009).

Other relevant documentation to guide quality in the BSP are the New Zealand Guidelines Group's:

- Suspected cancer in primary care: guidelines for investigation, referral and reducing ethnic disparities (2009)
- Surveillance and management of groups at increased risk of colorectal cancer (2004).

The leadership, governance and management structures relating to quality standards are:

- BSP Quality Assurance Group which meets quarterly to review relevant standards, guidelines, and monitor performance/compliance of the BSP against appropriate standards and guidelines.
- BSP Steering Group which meets monthly and to which any issues relating to BSP quality monitoring and their mitigation strategies are referred. The BSP Steering Group maintains a Risk Register which is reviewed and updated each month.
- BSP Clinical Governance Group which meets quarterly and is focused on the clinical subset of the BSP quality standards.
- Bowel Screening Advisory Group which meets quarterly and from which quality issues arising may be referred for a wider sector opinion.
- Endoscopy Review Group which meets fortnightly to review all issues relating to endoscopy services including readmissions, incidents and clinical performance data.

From January 2013, Ministry of Health has been publishing on a quarterly basis results for 15 key monitoring indicators (refer Appendix 4).

From January to around August 2012, Ministry of Health and WDHB focused on agreeing the quality standards for the BSP. From August to October 2012 the focus shifted to monitoring and reporting and resolving any issues arising relating to definitions and data formulas.

With the Quality Lead reappointed in May 2013<sup>84</sup> there was an increased focus on using the data from the monitoring of quality standards and wider data to drive quality improvement initiatives for BSP. Examples of quality improvement initiatives include<sup>85</sup>:

- review of bowel preparation for colonoscopy which resulted in revised afternoon and morning information sheets accompanied by a low fibre diet sheet
- review of readmission data which resulted in further training for endoscopists about polyp removal and the removal of hot biopsies forceps
- review of anticoagulant policy

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<sup>83</sup> The standards referring to the quality assurance of the colonoscopy procedure are outlined in the BSP Interim Quality Standards.

<sup>84</sup> The Quality Lead position was vacant from October 2012 to May 2013.

<sup>85</sup> Other quality initiatives may have been undertaken that are not listed here.

- BSP participant survey findings being used to identify further improvement areas to enhance participant experience.

Having a Quality Lead dedicated to focusing on quality through reviewing data and trends and identifying areas where quality can be enhanced is noted by stakeholders as a particular strength of the BSP (Litmus 2014).

### **Review of BSP quality standards**

In November 2012, a review of the BSP interim quality standards (Ministry of Health 2012a) was jointly undertaken by Ministry of Health, WDHB and LabPLUS. A line-by-line analysis was undertaken and any issues were noted with suggested recommended changes. Overall, no substantive issues were identified with the existing quality standards, although refinements and clarifications were made.

On 30 March 2013, an updated version of the BSP interim quality standards was released (Ministry of Health 2013c).

In summary, key changes made as a result of the review of the interim BSP quality standards were:

- from 2014, the New Zealand Familial Gastrointestinal Service questionnaire will be completed where there is evidence of a family history of bowel cancer for participants undergoing colonoscopy.
- a five day increase in the timeframe for a participant to have a colonoscopy following a positive iFOBT result (from 50% having a first offer of colonoscopy at 20 working days to 25 working days and 95% at 55 working days instead of 50 working days).
- all adverse events and hospital admissions within 30 days following a colonoscopy within the BSP are documented and reviewed.
- changes to polyp and adenoma detection rates.
- participants who had an incomplete colonoscopy and underwent polypectomy will not have an immediate CTC but will have one between 30 and 50 working days.

### **Quality monitoring results**

#### **Reporting on quality standards**

For the first six months of the BSP implementation, WDHB were required to report monthly to Ministry of Health on the quality standards. At six months into the BSP implementation, WDHB prepared a summary report for Ministry of Health followed by bi-annual reports (WDHB, 2012a&b and 2013 a, b & c).

#### **Quality monitoring activities**

Between July 2012 and June 2013, the following quality monitoring activities were completed:

July - December 2012

- All policies identified by Ministry of Health were in place.

- An audit of time taken to transport histology samples from Waitakere Hospital to LabPLUS.
- Readmission data was reviewed at the fortnightly Endoscopy Unit meetings.
- The first BSP participant satisfaction survey on the Endoscopy service was conducted (Bowel Screening 2012).
- Informed consent audit.
- Endoscopist performance data audit.
- Access to the Register for reporting purposes were established which highlighted the need to clarify the data required and work on data definitions.
- Three compliments were received about Endoscopy Unit services. One complaint was received from a GP who claimed not to be informed about the BSP.

#### January - June 2013

- A second BSP participant satisfaction survey on the Endoscopy service was conducted (WDHB 2013).
- A postal time audit of the test kit time in transit which showed that the time is well within requirements and confirmed the importance of emphasising not to mail samples on Friday or over the weekend.
- Second informed consent audit.
- Many compliments and one complaint were received.

#### July - December 2013

- WDHB able to report against all quality standards required in six monthly reports to Ministry of Health.
- The Register was modified to allow all treatment data to be entered. Treatment data for the period January 2012 to December 2013 was captured on a spreadsheet and will be entered into the Register retrospectively. Data relating to treatment occurring from January 2014 onwards will be entered directly.
- Developed and published policy on *Endoscopy Anti-coagulation and Anti-platelet Guidelines*.
- Reviewed and revised the policy on *Anti-coagulant Management for Outpatients having an Endoscopy Procedure* to incorporate the symptomatic service.
- Completing the final review of the *Histology Transport policy* relating to the transport of BSP histology samples directly from Waitakere Hospital to LabPLUS
- An audit of two general practices on the time taken to refer:
  - One general practice had an average of 6.2 days between the advice of a positive result and date of referral. Four out of the 38 referrals were made outside the ten day standard.
  - The second general practice had an average of 5.3 days between advice and referral. Two out of 17 referrals did not meet the ten day standard.
- Two complaints were received; one was classified as serious and investigated by WDHB Quality Department with the involvement of relevant members of the BSP team.



## **Adherence with quality standard targets**

Using the summary of quality standards listed in BSP interim quality standards (Ministry of Health 2013), an analysis was undertaken to identify the level of adherence with the standards at June 2013 (Litmus 2014 refer Appendix 5). The analysis highlighted the need for further data from the Register and other sources to assess adherence with the quality standards, particularly with regard to timeframes along the BSP pathway. Undertaking this analysis is beyond the scope of this quality review.

## **Risks identified on the Risk Register**

At 31 December 2013, 31 risks had been identified since the commencement of the BSP: 21 have been resolved or merged and ten remain active. Of the ten active risks, two have a high likelihood and high impact status (WDHB 2013b).

## **Issues log**

Review of the four bi-annual WDHB reports demonstrates a declining trend in issues:

- 75 from January to June 2012
- 26 from July to December 2012
- 18 from January to June 2013
- 14 from July to December 2013.

The decline in issues may reflect the growing maturity of the pilot as well as clearer definitions of what constitutes issues/ incidents that require recording.

During the early implementation period, issues related to GPs coming to understand their role within the BSP were most frequently mentioned. The WDHB BSP Clinical Director and WDHB BSP Programme Manager followed up directly with practices that were not following BSP procedures. Over time, mention of primary care on the issues log has declined.

From January to June 2013, data issues had the most frequent listing with four mentions (i.e. kits registered at LabPLUS and consent form received by BSP Coordination Centre but no results on Register).

Between July and December 2013 positive results on expired kits was the most frequent listing (three mentions).

In summary, the BSP has a range of quality standards in place that align with international best practice. Quality standards, risks and issues are actively monitored, reported, discussed and actions taken to address risks of breaching quality standards and mitigated risks emerging. While WDHB note that reporting against all quality standards is now possible (with exception of the timeliness of the histology result letter), data has not been sighted by the evaluation team for all quality standards (refer Appendix 5).

## **Reflections on quality standards monitoring**

Providers interviewed commented that the monitoring of quality standards is a strength of the BSP enabling the identification of quality improvement initiatives. Quality standards and their monitoring are described as integrated into the process and systems of the BSP (Litmus 2014).

Review of the quality monitoring indicators and feedback from stakeholders interviewed indicate potential risk areas to adhering with the BSP quality standards including:

- Not having enough endoscopist capacity to remain within agreed wait times to colonoscopy.
- Variable awareness of all the BSP quality standards for colonoscopy procedures amongst endoscopists. While endoscopists are aware of the indicators for quality colonoscopy, there is variable awareness of the full range of quality standards for BSP.
- A lack of awareness of the BSP quality standards for CTC amongst radiology staff and BSP participants not being appropriately coded.

Other challenges noted about the BSP quality monitoring are:

- Awareness of quality standards is varied. Some stakeholders on the BSP screening pathway have a detailed understanding of the quality standards which tend to reflect their roles and reporting lines. In contrast, others tend to be aware at a broad level there are quality standards but have little appreciation of the detail. Whether this is of concern is not clear as quality standards appear to be embedded in the BSP systems.
- Beyond referral times, primary care has no quality standards for their role in the BSP. Primary care has the flexibility to manage informing BSP participants about a positive iFOBT and referral to endoscopy within their standard practice.
- Duplication and potential confusion due to the number of Ministry of Health quality documents for the BSP. Stakeholders questioned whether the quality documents could be rationalised into one so it is clear that this is the guiding document. LabPLUS also wants quality standards for bowel screening to be based on International Accreditation New Zealand (IANZ) standards.
- Clarifying the link between the GRS and the BSP quality standards. In 2013, work was undertaken to strengthen the implementation of the GRS within WDHB's endoscopy unit. In 2013 the GRS team undertook a one-off review. The review process for the GRS highlighted confusion about how the BSP quality standards and the GRS fit together. The GRS is not cited within the BSP quality standards.

## Conclusions

The review of quality monitoring confirms that BSP has a range of quality standards in place that align with international best practice. Quality standards, risks and issues are actively monitored, reported, discussed and actions taken to address risks of breaching quality standards and mitigated risks emerging.

Key areas to strengthen quality monitoring and assurance are:

- ensure the completeness and accuracy of data on the Register (refer Litmus 2014, Appendix 5)
- increase awareness of BSP quality standards for colonoscopy procedures amongst endoscopists
- increase awareness of BSP quality standards for CTC amongst radiology staff and ensure BSP participants are appropriately coded
- clarify the link between the GRS being used to improve quality of endoscopy in New Zealand and the BSP's quality standards.

The following are considerations for the BSP quality standards and monitoring within the context of a potential national roll-out for bowel screening:

- The importance of having a Quality Lead in the programme to ensure quality data collection, review of monitoring data and trends and to facilitate processes to review issues arising and to undertake quality improvement initiatives.
- The Register must collect quality data to inform the quality standards. Data audit and logic checks need to be part of the ongoing maintenance of the Register as well as having capacity and capability to run reports of the Register to inform the review of the quality standards.
- Consider aligning BSP quality standards with quality standards for laboratories (IANZ) to avoid unnecessary duplication, and to enable their inclusion in the IANZ annual audit.
- Consider how to align the BSP quality standards with the GRS.

### 3.8 Costing analysis

#### Evaluation objective addressed in section

*Costing analysis* - To explore the nature and quantum of costs associated with the design, implementation and operation of the pilot during the first screening round. A full cost effectiveness analysis will be completed at the conclusion of the second screening round.

This section presents the results of the report entitled **Interim costing analysis – costs of the first screening round (2012-2013) undertaken by Sapere Research Group 2014** (Artus, Love, Blick and Poynton, 2014). A full copy of the Sapere report is in [Appendix 2](#).

#### Introduction

The results from the costing analysis are presented as follows:

- An analysis of the nature and quantum of costs associated with the design, implementation and operation of the pilot to date (including some detailed analysis related to specific aspects of the screening pathway and a forecast of estimated total cost of the BSP for two full screening rounds); and
- An extrapolation of high-level estimates of the potential 'steady state' cost of operating a bowel screening programme on a national basis (excluding development/start-up costs and the on basis of some broad brush assumptions).

It is essential that two key caveats in relation to the results are acknowledged and that extreme care is taken to ensure that results are not placed out of this context:

- Firstly, it is important to emphasise that this costing analysis is not an incremental analysis but rather takes a 'snap-shot' perspective of costs incurred to design and run the pilot in the first two years, with some assumption-based extrapolation to inform understanding of potential future costs. As such, it does not account, for example, for the fact that some cancers detected as a result of pilot screening, may have been detected symptomatically anyway.
- Secondly, in extrapolating high-level estimates for the operating cost of bowel screening on a national basis, in the absence of key policy decisions about the configuration and implementation approach, we have based our analysis on some broad-brush assumptions about the way a national bowel screening programme may run in 'steady state'. Also, as stated above, the figures quoted relate to operating costs only.

#### Method

The analytical approach, the methodology (including the modelling approach, definitions of key terms, data sources and assumptions) and results obtained for key input parameters are provided in full at Appendix 2.

In broad terms, two primary costing approaches are applied:

- Assessment of the cost of the pilot is based on a detailed bottom-up costing model of the screening pathway that determines unit costs for all key programme inputs and applies actual volumes of activity undertaken. Primary data sources for this component are:
  - **Cost data:** two detailed six month samples of actual cost data from the pilot; and cost data from the Ministry of Health.

- **Volumes data:** information reported by the BSP to the Ministry of Health on a bi-annual basis, identifying activity volumes for key parameters for the full two-year screening round; and data from the Ministry of Health published BSP monitoring indicators for the period to December 2013.
- Estimates of costs associated with treatment of bowel cancers detected as a result of the pilot are based on estimates of average NZ lifetime costs of treating bowel cancer diagnosed at different stages. Primary data sources for this component are:
  - A data-extract from Ministry of Health national data-sets identifying all publically funded health care activity for each New Zealander occurring from July 2006 - June 2011 with national pricing applied; and
  - An extract from the New Zealand Cancer Registry (NZCR) from 2011 restricted to relevant ICD codes, to assess the distribution of bowel cancers diagnosed at each stage in New Zealand, prior to the introduction of the BSP.

\$ figures presented in this analysis are rounded to the nearest \$1000 and quoted exclusive of GST.

### Pilot development costs

The costs incurred to develop the pilot are estimated at \$3.148 million. The main elements of this estimate are: the contract with WDHB to plan for the implementation of the pilot during 2011 (\$1.346 million); and the design and build of the pilot register (\$1.608 million). The estimate of development costs also includes expenditure incurred by the Ministry of Health in the development of promotional materials (\$164,000). It does not include the cost of Ministry of Health staff time to produce the business case for the pilot.

### Pilot operating costs

From the sample cost data we estimated that the total operating cost for the twelve-month period financial year 2012/13 was \$5.580 million. The total annual operating costs were extrapolated for the preceding and following six months, as illustrated in Figure 15.

**Figure 15: Estimated operating cost of the pilot – four six-month periods**

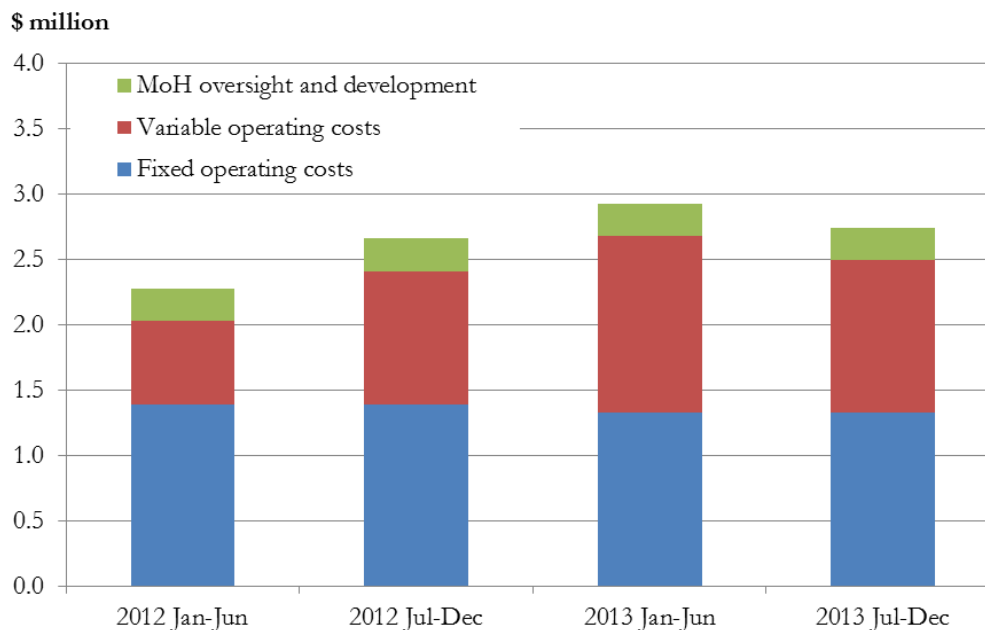


Table 11 below provides a summary of all costs for the development and implementation of the first screening round, during 2012 and 2013. This excludes treatment costs.

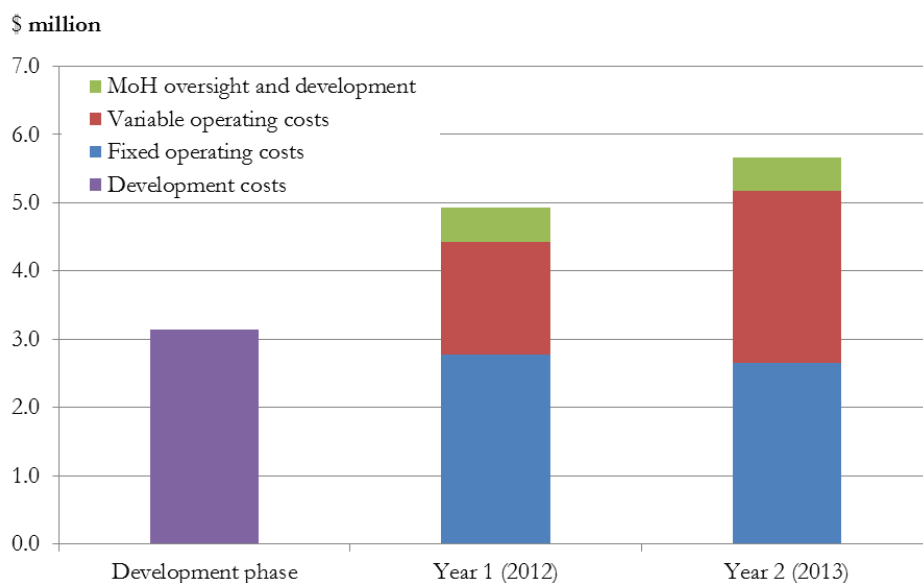
**Table 11: Summary of costs for the first screening round**

	Development phase	Year 1 (2012)	Year 2 (2013)
<b>Development costs</b>	<b>\$3,148,000</b>		
<b>Operating costs</b>			
<b>Fixed</b>		\$2,780,000	\$2,651,000
<b>Variable</b>		\$1,653,000	\$2,520,000
<b>Sub total</b>		<b>\$4,433,000</b>	<b>\$5,172,000</b>
<b>Additional Ministry of Health</b>			
<b>Ministry oversight <sup>86</sup></b>		\$495,000	\$495,000
<b>Total</b>		<b>\$4,927,000</b>	<b>\$5,666,000</b>

<sup>86</sup> This is an estimate of the proportion of Ministry of Health staff time spent per year on the BSP, including contract management, monitoring and development of policy advice.

In Figure 16 below, the estimated development cost of \$3.148 million is presented alongside operating costs of \$10.594 million. The combination of all these costs gives a total of \$13.742 million incurred in developing and operating the first two years of the Pilot (excluding the costs of treating cancers diagnosed).

**Figure 16: Estimated cost of Pilot – development phase and Year 1 and Year 2**



### Cost of treating cancers detected through the BSP

Table 12 below provides an estimate of the lifetime cost of treating cancers that have been detected through the screening programme.

It is important again to emphasise that this estimate of treatment costs is not a fully developed incremental analysis. If the pilot had not been in place, some of the early stage cancers may not have been detected during this time period and thus the cost of treatment is higher than may otherwise have been incurred. However, the whole point of screening is to change the stage distribution of cancer; without a full incremental analysis, we are not able to fully understand the financial off-set of detecting these cancers earlier (rather than diagnosing them symptomatically at stage III later in the person's life).

On the basis of current information from the pilot, we do not have the ability to fully understand and adjust for this impact.

**Table 12: Estimated lifetime cost of treating bowel cancer detected during the first screening round**

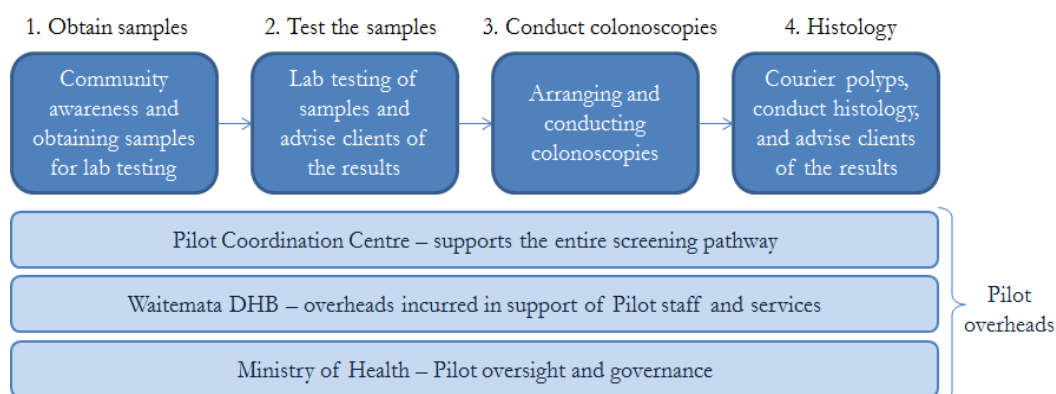
Stage of diagnosis	Stage distribution (Jan 2012- Dec 2013)	Estimate of cancers detected by stage	Estimate NZ ave. lifetime cost of bowel cancer by stage (\$NZ2011)	Total cost (\$NZ2011, millions)
I	44.4%	57	\$33,000	\$1,881,000
II	24.1%	31	\$53,000	\$1,643,000
III	22.3%	29	\$70,000	\$2,030,000
IV	9.3%	12	\$52,000	\$624,000
<b>Total (actuals)</b>		<b>129</b>		<b>\$6,178,000</b>

## Drilling down into the data (years 1-2)

### Relative cost of screening pathway stages

As shown in Figure 17, the screening pathway can be viewed as having four discrete phases. Looking at the pilot operating costs through this lens can help to determine where the bulk of the costs are incurred and where the costs-per-outcome are highest.

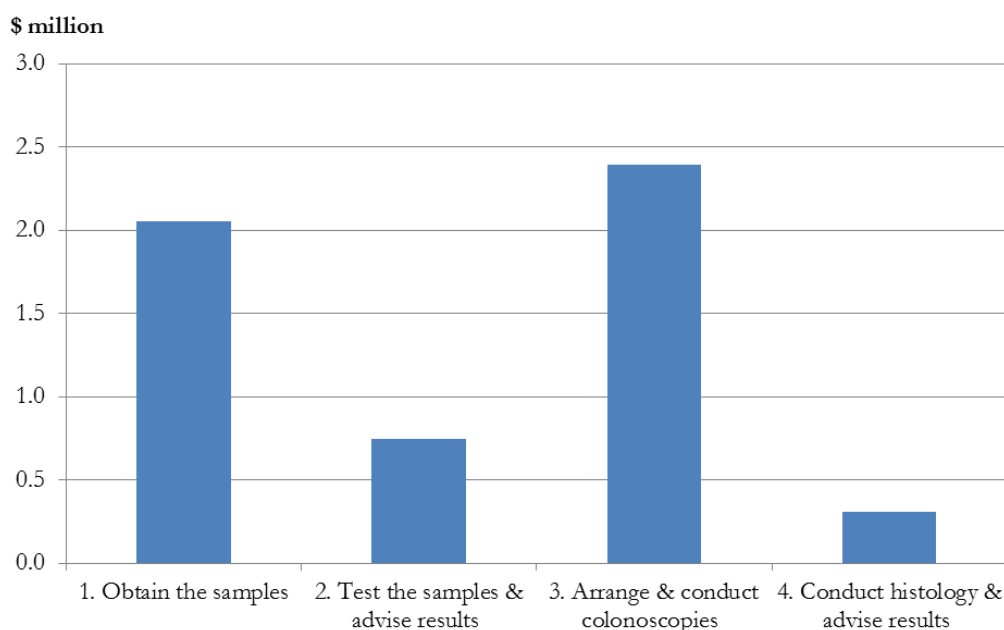
**Figure 17: Four high-level stages of the screening pathway and associated overheads**



The high-level results of this stage-by-stage cost analysis (estimates of annual cost based on the 2012 and 2013 samples of cost data) are shown in Figure 18. It illustrates that stages 1 and 3 of the pathway consume the largest relative proportion of resources by far (37% and 43%, respectively). This may not be surprising when it is considered that the initial laboratory testing is largely automated and that the histology component deals with relatively small volumes (i.e. the positivity rate from initial testing is generally 7-8% and around 75% of those who receive a colonoscopy as a result then have samples being sent for histology).



**Figure 18: Stages of the screening pathway – relative costs**



#### **Average cost per 'process outcome' for each stage**

The cost of the four stages of the pathway can also be examined on a cost-per-outcome basis. These unit costs have been developed by dividing the annual operating cost for each stage by a key process outcome measure, as shown in Table 13:

- The cost incurred for each person who returns a sample to the laboratory is relatively low (\$64 per person) due to high volumes at this stage of the pathway (based on a figure of 32,129 people between July 2012 and June 2013). Stage one can also be subdivided into two categories – promotion, outreach and targeted support to potential participants (44% of stage one costs) and mail-outs and sample collection activities (56%). Using this split, \$28 per person of the stage one unit cost relates to promotion, outreach and targeted support efforts and \$36 per person to mail-outs and sample collection activities.
- Similarly, the laboratory testing of the samples and the advising of the results has a relatively low unit cost (\$18) due to a combination of high volumes (based on a figure of 40,884 kit tests being conducted between July 2012 and June 2013) and the role that automation plays in the testing process.
- In contrast, the cost of a colonoscopy per person is relatively more costly (\$1,107 per person on average). This high unit cost is not unexpected given that the procedure is carried out in a clinical environment and involves skilled labour.
- Histology being conducted as a result of a colonoscopy has the second highest unit costs (\$190 per person), likely due to the cost of the trained and skilled labour inputs involved even though the volumes are smaller at this stage of the screening pathway (based on a figure of 1,618 tests being conducted between July 2012 and June 2013).

**Table 13: Unit cost for process outcomes at each stage of the screening pathway**

	1. Obtain the samples	2. Test the samples	3. Conduct colonoscopies	4. Histology
<b>Total cost (A)</b>	\$2,054,000	\$748,000	\$2,397,000	\$307,000
<b>Process outcome measure</b>	Person returning a sample	Samples tested at laboratory	Person receiving a colonoscopy	Histology conducted
<b>Volume of units of outcome (B)</b>	32,129	40,884	2,165	1,618
<b>Cost per unit of outcome (A/B)</b>	\$63.92	\$18.30	\$1,107.03	\$189.75

We combined the operating costs for stages one and two and divide by the number of people returning a kit for testing to derive a cost per participant screened of \$87.21.

We also derive a cost per participant receiving investigation of \$1,268.76 by combining the operating costs for stages 3 & 4 and dividing by the number of colonoscopies conducted (acknowledging that most of these participants go on to have histology).

The unit costs used for the variable cost components are shown in Table 14 below.

**Table 14: Unit cost of variable cost components, by stage of pathway**

Process step	Components	Unit cost
<b>Stage 1: Obtain samples</b>		
Pre-invitation letter sent	Letterhead, Letter printing, Brochure "All About Bowel Screening", DLE envelope, Postage	\$1.20
iFOBT kit sent (includes re-sends)	Sample bottles, Sample collection sheet, Plastic zip lock bags, Collation and packaging of test kits, Letterhead, Overprinting of letterhead, Letter printing, C5 envelope, C5 envelope postage, Pamphlet "Quick Reference Guide"	\$5.62
Standard follow-up at four weeks (reminder letter)	Letterhead, Letter printing, DLE envelope, Postage	\$1.13
iFOBT kit returned to NZ Post mail centre	Sample return envelope (production), Sample return postage	\$2.33
iFOBT kit couriered to LabPLUS	Courier trips of iFOBT kits from Mail Centre to LabPLUS; return of consent forms to Coordination Centre	\$41.68
<b>Stage 2: Test the samples</b>		
iFOBT kit read at laboratory	LabPLUS processing cost, Lab orders of reagents	\$7.07
Negative result	Letterhead, Letter printing, Pamphlet "All Clear", DLE envelope, Postage	\$1.20
GP informs patient of positive result	GP payment for managing positive iFOBT	\$60.00
<b>Stage 3: Conduct colonoscopies</b>		
Colonoscopy preparation (following telephone assessment)	Letter printing, Pamphlet "Further Investigation", Bowel preparation instruction sheet, Colonoscopy Information Sheet, Glycoprep, Bisercodyl, Bisercodyl bottling/labelling, Courier pack	\$19.66
Colonoscopy - under local anaesthetic	In-house salaried colonoscopists	\$123.08
	In-house - private contractor	\$350.00
	"Temporary increase" capacity	\$1,000.00
	Clinical supplies for in-house procedure	\$117.85
Colonoscopy - under general anaesthetic	In-house service	\$1,001.50
Colonoscopy - ProVation reports	Report (paper), Report (printing - colour), DLE Envelope, Postage	\$0.68
Alternative investigation	Participant receives CT colonoscopy	\$427.75
<b>Stage 4: Histology</b>		
Histology	Analysis per participant, Laboratory handling fee, Specimen courier, Histology results letter (paper), Histology results letter (printing), Envelope, Postage	\$151.38

### **Average cost for key screening outcomes**

The cost per cancer and per lesion detected is a useful measure of the cost of the pilot in terms of key screening outcomes, given that at this stage in the evaluation full cost effectiveness analysis is not yet feasible.

Screening for colorectal cancer includes removing premalignant lesions (adenomas) during the colonoscopy. These adenomas thus never present as cancers, meaning that the incidence of colorectal cancer declines with screening. For this reason, it is important to present the cost of screening per lesion (adenoma and cancer) detected as well as per cancer.

### **Cost per cancer detected**

Table 15 below presents the numbers cancers detected during the first two years of the pilot (129) alongside the operating cost over the same period (\$10,593,900). This gives an operating cost per cancer detected of \$82,100.

**Table 15: Estimated operating cost per cancer detected during first two years**

Indicator	Total
Number of cancers detected	129
Operating costs	\$10,593,900
Operating cost per cancer detected	\$82,100

i. Figures rounded to nearest \$100.

### **Cost per lesion detected**

Table 16, below, presents the number of lesions (cancers or adenomas) detected during the first two years of the pilot (1,896) alongside the operating cost (as before). The cost per lesion detected is \$5,600.

**Table 16: Estimated operating cost per lesion detected**

Indicator	Total
Number of lesions detected	1,896
Operating costs	\$10,593,900
Operating cost per lesion detected	\$5,600

ii. Figures rounded to nearest \$100.

## Costs of specific types of activity

Further analysis was completed to drill down into the cost of specific types of activity that takes place within the four phases of the screening pathway, to enable us to build our understanding of key cost drivers.

### *Improving participation of under-screened populations*

The pilot undertakes a number of activities aimed at improving the participation of population groups that may be more likely to encounter barriers to access due to language or cultural reasons. Four sizeable populations receive additional focus aimed at improving their rates of participation – Māori and Pacific peoples, as well as the relatively large Chinese and Korean-speaking populations that reside within WDHB.

The pilot has employed coordinators with relevant language and cultural expertise to undertake community outreach activities, such as presentations about the pilot to a range of ethnic specific community groups and churches (for example, there were than 100 such presentations in 2012/13 year). The coordinators also assist in the development of information resources (i.e. posters, translations of resources) and by recording radio advertisements and appearing on community radio and television shows. The team also takes responsibility for follow-up calls to people within these populations who have not responded to the pre-invitation letter and to people who have returned a test kit which cannot be tested (e.g. due to errors in the accompanying documentation) in order to explain the error and to send out a second kit.

Some of the direct costs involved in the provision of these services are straightforward to measure. The pilot employs a Māori coordinator, a Samoan coordinator, a Chinese coordinator and a Korean coordinator with bilingual language abilities and cultural knowledge. The coordinators are contracted to work between 0.4 and 0.6 of a full-time equivalent. In addition, there are two contracts with community providers that work with Pacific peoples.

The direct cost of all of these services is estimated at an average of \$187,000 per year in Year 1 and Year 2. As a proportion of the direct annual operating cost of the pilot for those years, these costs equate to an average of 3.5%.

As well as the potential limitation of this analysis (in that all costs may not be captured) it is not straightforward to calculate the unit cost of these outreach activities in the absence of detailed activity and outcome data. Within the course of day, a coordinator may need to search out contact numbers and make a variety of approaches to a particular individual; ultimately, the outcome may result in agreement to provide a sample, a decline or no response. For the period of time under consideration for this analysis, the pilot did not hold information on outcomes to this level, though subsequently systems have been established to collect this.

### **Cost of colonoscopy**

As noted earlier, the pilot has purchased colonoscopies in different ways, although all pilot volumes are delivered at Waitakere Hospital. Table 17 below presents a breakdown of the estimated unit prices for each type of lead colonoscopist arrangement, along with the volumes delivered in Year 1 (2012) and Year 2 (2013) and the associated cost in those years.

The overall cost of colonoscopies – including the nursing team, clinical supplies, equipment, and facility costs – is estimated at \$1,042 million in Year 1 and \$1,550 million in Year 2.

This increase is driven by the higher volumes being delivered in Year 2 and by the more expensive cost of volumes provided through the temporary arrangement described above.

**Table 17: Colonoscopy volumes and colonoscopist costs in year 1 and 2**

	WDHB salaried colonoscopist	WDHB contracted colonoscopist	Temporary increased capacity
Unit price for lead colonoscopist (estimate)	\$123	\$350	\$1,000
Volumes - Year 1	622	722	86
Volumes - Year 2	882	1,050	343
Colonoscopist costs - Year 1	\$105,600	\$252,700	\$86,000
Colonoscopist costs - Year 2	\$132,400	\$367,500	\$343,000

**Note:** these costs do not include a range of other costs associated with colonoscopy delivery, including patient preparation, nursing team, clinical supplies and the equipment and clinical space at the endoscopy unity at Waitakere Hospital.

### **Mix of colonoscopy providers**

Colonoscopies are a relatively expensive stage in the screening pathway and the cost per output has been dependent on the provider used. We therefore examine the pilot's colonoscopy volumes to test the extent to which they determine the differences in the direct annual operating cost incurred in Year 1 (2012) and Year 2 (2013). We hold the volume of colonoscopies conducted in Year 1 constant, while scaling the mix of providers to that used in Year 2. This means that the share of colonoscopy volumes decreases for salaried DHB staff (44% to 39%) and private contractors (50% to 46%) while 'temporary increased capacity' increases (6% to 15%).

Under this scenario, the direct annual operating cost of the Pilot in Year 1 (2012) would be \$4.552 million, which is \$119,000 or 2.7% higher than the base case of \$4.433 million. This accounts for approximately 16% of the difference in the direct annual operating cost between Year 1 (2012) and Year 2 (2013). This suggests that the difference in volumes – e.g. the number kits returned for testing was 28% higher in Year 2 – is the more important factor in explaining the difference between the annual operating cost in Year 1 and Year 2 than the mix of colonoscopy providers.

### **Cost of involving Primary Health Teams**

General practitioners are contracted to inform and advise their patients who have submitted a kit that is found to have a positive result. The payment for advising of a positive kit is made on a fee-for service basis and was set at \$60 for each referral.

The total amount for this service is estimated at \$119,000 in Year 1 (based on 1,952 positive results) and \$169,000 in Year 2 (2,818 positive results). These estimates may be

slightly above the actual costs incurred, given anecdotal evidence that a small number of general practices were, initially, not claiming this fee. Furthermore, some patients did not have a general practitioner. These caveats are not considered to be substantial enough to warrant an adjustment to these estimated figures.

### Cost of spoiled kits

Spoiled kits accounted for 14% of all kits returned by participants to the laboratory for testing on average in Year 1 and Year 2. The average cost per year of testing spoiled kits is estimated at \$78,000 in direct costs which equates to 1.6%, on average, of the direct annual operating cost of the pilot.

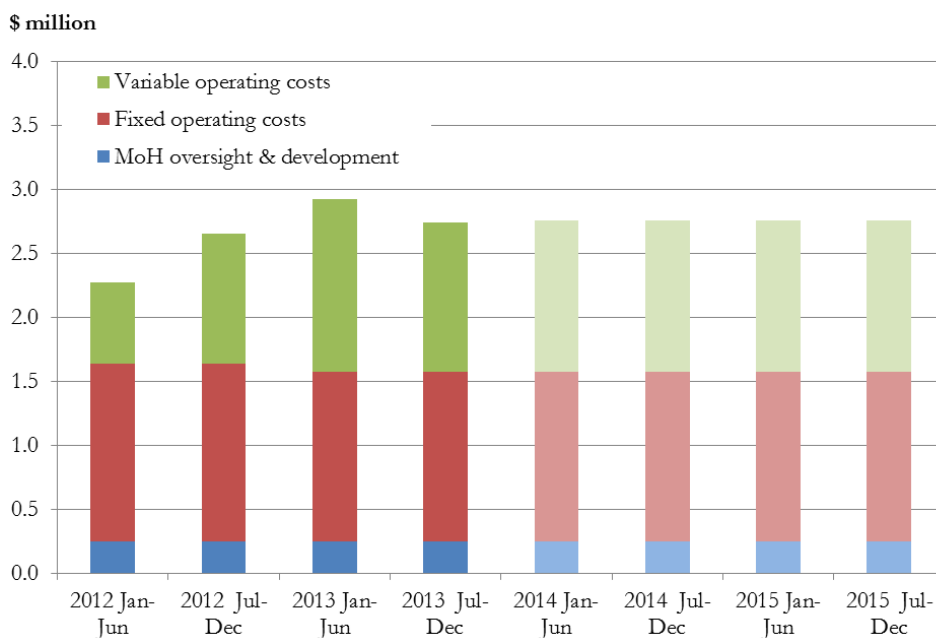
This estimate includes the cost of the spoiled kit itself, the initial postage and packaging, the postage for the sample being returned, and the testing of the sample at the laboratory. It does not include the pre-invitation letter and the follow-up letter at four weeks, as these items form part of the initial contact that would be incurred only once. Also excluded are cost items that are relatively fixed and insensitive to the volume of spoiled kits, such as the follow up with priority populations, daily courier trips of the kits from the mail centre to the laboratory, and WDHB corporate overheads.

### Forecast total cost of the pilot (Years 1-4)

#### Operating costs

The forecast operating cost estimates for Year 3 (2014) and Year 4 (2015) of the pilot are shown below in Figure 19. The forecast operating cost is \$2.753 million for each of the six-month periods, which combined give a forecast operating cost of \$5.505 million per year for year 3 and year 4 of the Pilot (excluding development costs but including Ministry of Health oversight). These forecasts are slightly lower than the estimated operating cost for Year 2 (\$5.666 million), which was relatively high due to the temporary increased capacity for colonoscopy procedures.

**Figure 19: Pilot operating cost – forecasting years 3 and 4**



### Summary of total cost for delivery of the pilot

As shown in Table 18, the total cost for delivery of the pilot over the four years (including full absorption of all pilot development costs) is forecast to be **\$24.753 million**.

**Table 18: Summary Pilot cost – estimates and forecast**

		Year 1 (2012)	Year 2 (2013)	Year 3 (2014)	Year 4 (2015)	Total
Development cost	\$3.148m					\$3.148m
Operating cost (including Ministry of Health oversight costs)		\$4.927m	\$5.666m	\$5.505m	\$5.505m	\$21.604m
<b>Total cost</b>						<b>\$24.753 million</b>

### Estimating the ‘steady state’ cost of a national programme

#### Estimated annual ‘steady state’ operating cost for base case

##### National view

The main result metric is the annual operating cost of a national screening programme in steady state – this excludes development costs and Ministry of Health oversight. The annual operating cost of a national programme is estimated at \$39.073 million – or 7.8 times higher than our estimate of the annual operating cost of \$5.010 million for the pilot in Year 4.

To a large extent, this result reflects a scaling up for the national population aged 50-74 years, which is approximately 8 times larger than the equivalent population at WDHB. Whereas the fixed costs for national programme are assumed to be 8.0 times those of the pilot, differences in the age profile and ethnic groups within the national population contribute to the variable costs being slightly less than 8 times those incurred in the pilot.

##### Regional view

The national programme is also considered on a regional basis and the results are shown alongside the national view in Table 19. The results for each region largely reflect their population share but slight differences in participation rates matter too. As noted earlier, the regional approach also factors in differences in participation rates for each five-year age group and four ethnic groups of Māori, Pacific, Asian and Other, which are applied to the mix of age and ethnic groups among the four regional populations.

As a result, the Northern Region, which has higher proportions of groups that tend to have lower participation rates (i.e. Māori, Pacific and younger age groups), has a slightly lower participation rate (54%) than the Southern Region (58%), which has an older age profile. The rates for the Midland and Central Regions match that derived for the national model (56%).



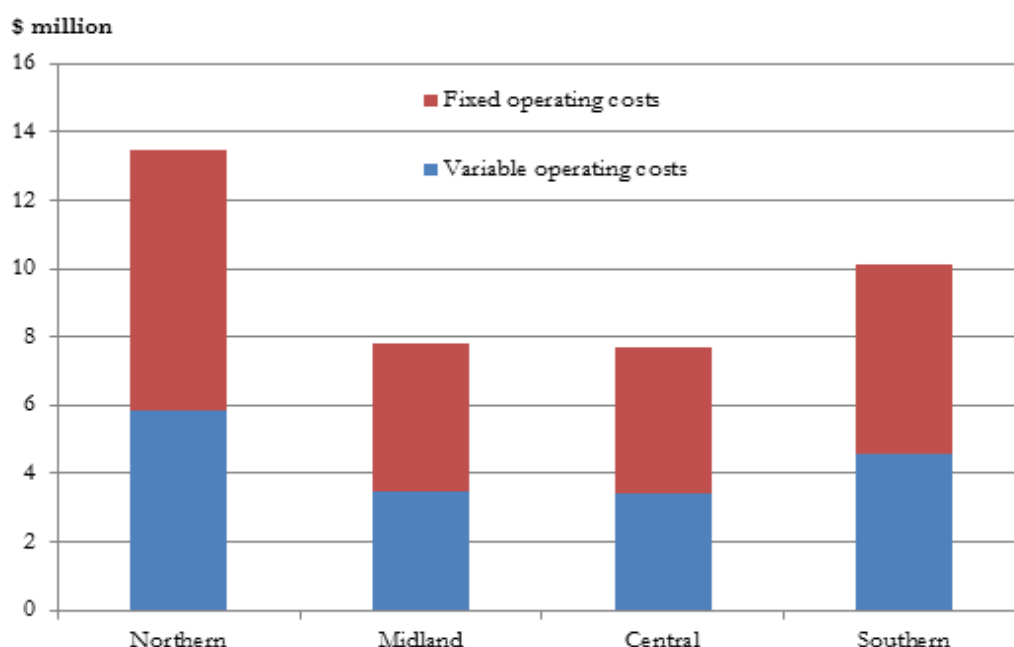
**Table 19: National model - estimated annual operating cost in steady state, by region**

	Northern	Midland	Central	Southern	Total
<b>Regional costs (\$ million)</b>					
Variable operating cost	\$5.862	\$3.483	\$3.435	\$4.568	\$17.348
Fixed operating cost	\$7.592	\$4.311	\$4.250	\$5.572	\$21.724
<b>Annual operating cost</b>	<b>\$13.454</b>	<b>\$7.794</b>	<b>\$7.686</b>	<b>\$10.139</b>	<b>\$39.073</b>
<b>Regional shares (%)</b>					
Share of national population (50-74 years)	34.9%	19.8%	19.6%	25.6%	100.0%
Share of total operating costs	34.4%	19.9%	19.7%	25.9%	100.0%

Figure 20 shows that the Northern Region is modelled as having the highest share of total annual operating costs, at \$13.454 million or 34.4% of national model costs. This is consistent with the region having the largest share of the national population aged 50-74 years (34.9%).

Whereas the variable costs are determined by the size of each region's population, adjusted for age and ethnic group differences in participation rates, the fixed costs are those derived for the national model and allocated on a population share basis.

**Figure 20: Annual operating costs under the national model by region**



## High and low estimates from sensitivity analysis

The results of sensitivity testing undertaken suggest a plausible range for the annual operating cost of a national screening programme in steady state as being between \$26.531 million and \$50.623 million (with the base case estimate at \$39.073 million).

These low and high estimates are scenarios that have been constructed by combining the results of separate sensitivity tests of key elements among the fixed and variable costs, namely:

- varying the scale-up factor for the fixed costs of the coordination centre to explore the potential impact of economies of scale;
- varying the participation rate, which has a flow-on impact to the rest of the screening pathway and associated variable costs; and
- varying the positivity rate, which also has a flow-on impact to later stages of the screening pathway, namely the variable costs of colonoscopies and histology.

The individual results of these sensitivity tests are reported below.

### ***Fixed costs and potential economies of scale***

Varying the scale-up factors use for the fixed cost components provides a plausible range for the annual operating cost of a national screening programme of between \$29.736 million and \$44.504 million.

The results in Table 20 show how we have varied these scaling assumptions for these fixed cost elements to produce these 'low' and 'high' scenarios.

Departing from the base case scaling assumption of 8.0 – which is based on the eligible national population being approximately eight times larger than the Waitemata population – we test the assumption of community awareness activities and the coordination centre functions being four times as large as the pilot. This scalar of 4.0 allows for an increase in outreach activities on a national scale while also implying that there will be some economies of scale in that the larger volumes will not increase workload by an equivalent amount (e.g. programme management, clinical oversight, quality management, data management and analysis). This assumption reduces the annual fixed costs in the base case by \$9.337 million.

The high scenario tests a scaling factor of 10.0 as an upper bound. The rationale for this is that the larger national programme may involve an extra level of complexity that outweighs any economies of scale from higher volumes, for example additional layers of programme management and coordination, quality control for national standards and auditing etc. This assumption increases the annual fixed costs in the base case by \$5.431 million.

**Table 20: National model - estimated annual operating cost in steady state**

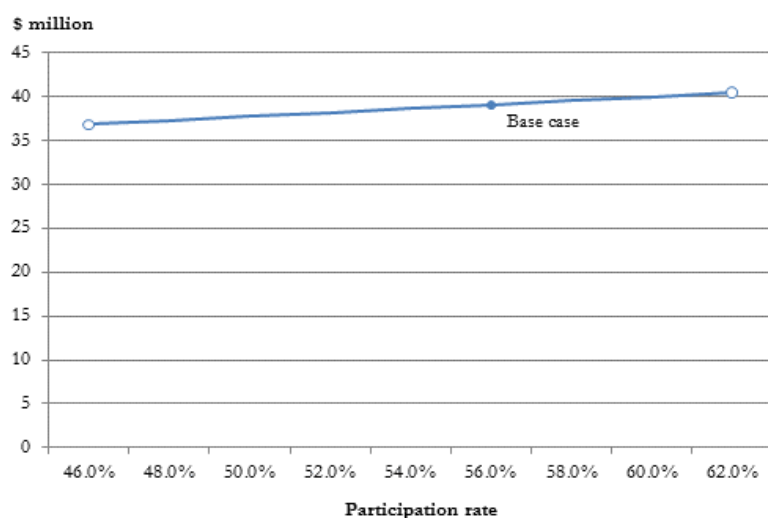
	Low scenario	Base case	High scenario
<b>Scaling assumptions</b>			
Community awareness and outreach	4.0	8.0	10.0
Coordination Centre functions	4.0	8.0	10.0
<b>Results (\$ million)</b>			
Annual variable costs	\$17.348	\$17.348	\$17.348
Annual fixed costs	\$12.387	\$21.724	\$27.156
<b>Annual operating cost</b>	<b>\$29.736</b>	<b>\$39.073</b>	<b>\$44.504</b>

### Varying the participation rate

The operating costs are sensitive to the participation rate – i.e. the proportion of clients who were sent a kit and then return it to the laboratory for testing. In our base case, the participation rate of 56% was determined by applying age/ethnic group-specific rates from the pilot to the national population.

Figure 21 shows how different assumptions about the participation rate impact on the estimated annual operating cost of a national screening programme in steady state. If the participation rate is assumed to be 46% – approximately 10 percentage points lower than the base case assumption of 56% – then the annual operating cost would be \$36.820 million, or \$2.252 million lower (-5.8%) than the base case of \$39.073 million. Under the “high” scenario, where the participation rate is 62%, the annual operating cost would be \$1.352 (+3.5%) million higher than the base case, at \$40.425 million.

**Figure 21: Sensitivity of the annual operating cost (steady state) to changes in the participation rate**

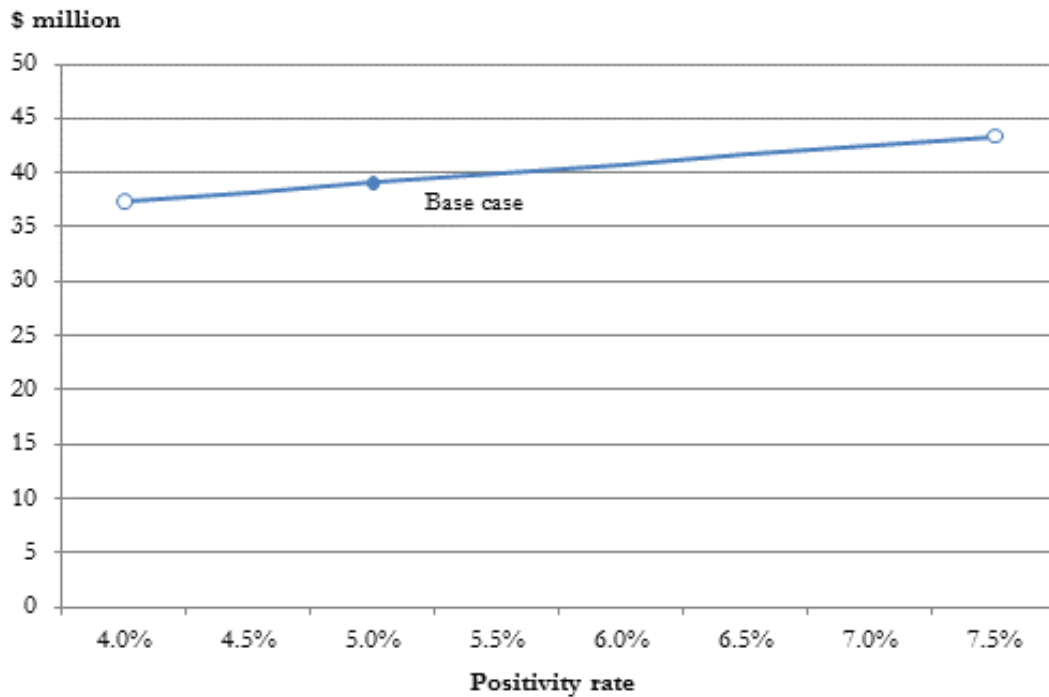


### Varying the positivity rate of iFOBT

The annual operating costs are fairly sensitive to small changes in the positivity rate (i.e. the proportion of positive results among clients who return a kit), as shown by adjustments of our base case assumption of 5.0%. It should be noted that this base case assumption is somewhat lower than the average of the positivity rates for the first two years of the pilot, as reported in the Biannual Reports (i.e. approximately 7.5% across 2012 and 2013), as it was determined to be a more appropriate 'steady state' figure, following consultation with the Ministry of Health.

Figure 22 shows that the impact of varying the positivity rate assumption at intervals of half a percentage point. If the positivity rate is assumed to be 4.0%, rather than the base case assumption of 5.0%, then the annual operating cost falls by \$1.723 million (or -4.4%) to \$37.350 million. Conversely, if the positivity rate is assumed to be higher, at 7.5%, the annual operating cost is \$4.307 million higher (or +11.0%) at \$43.380 million.

**Figure 22: Sensitivity of the annual operating cost in steady state to changes in the positivity rate**



### Combined impact of sensitivity testing

The next step is to combine the sensitivity tests conducted on the fixed cost and variable cost components. Table 21 combines the low and high assumptions from the three tests into low and high scenarios. The combined impact of varying both of the scaling factors for the fixed costs and values for participation and positivity rates is to provide a range of \$26.531 million to \$50.623 million. Table 21 also displays these combined low and high scenarios.

**Table 21: National model - estimated annual operating cost with combined scenarios**

	Low scenario	Base case	High scenario
<b>Sensitivity tests</b>			
Fixed costs scaling assumptions	4.0	8.0	10.0
Participation rate	46.0%	56.0%	62.0%
Positivity rate	4.0%	5.0%	7.5%
<b>Results (\$ million)</b>			
Annual variable costs	\$14.144	\$17.348	\$23.467
Annual fixed costs	\$12.387	\$21.724	\$27.156
<b>Annual operating cost</b>	<b>\$26.531</b>	<b>\$39.073</b>	<b>\$50.623</b>

### Exploring the impact of variation in colonoscopy provision

The model of the national bowel screening programme was tested for sensitivity to changes in the mix of colonoscopy provision. The mix of lead colonoscopists used in the base case reflects the average mix observed across the first two years of the pilot, namely, in-house DHB staff providing 40%, contractors providing 50%, and a level of ‘temporary increased capacity’ accounting for 10% of colonoscopy volumes delivered.

Arguably, a national programme in steady state might have more capacity in-house and rely less on contracted and temporary increased capacity. Such a scenario might offer greater certainty around capacity and at a lower cost. To that end, we model a “low” scenario where two-thirds (67%) of the volumes are delivered in-house by salaried DHB staff and one-third (33%) is delivered by private contractors working in-house. Under this scenario, the annual operating cost of the national programme would be \$37.345 million, which is \$1.728 million or 4.4% lower than the base case of \$39.073 million.

We also model a “high” scenario where approximately one-third (34%) of the volumes are delivered in-house by salaried DHB staff, one-third (33%) by private contractors working in-house, and one-third (33%) via temporary increased capacity. Under this scenario, the annual operating cost of the national programme would be \$41.392 million, which is \$2.319 million or 5.9% higher than the base case.

## Conclusions

Stepping back from the detail of analysis, this costing exercise has confirmed several features of the pilot screening pathway.

The volume of clients involved steadily decreases as the pathway stages progress – from initial contact via letter to the testing of the kits, through to the colonoscopies and histology being undertaken. Accordingly, the costs in the early stages of the pathway tend to be driven by higher volumes at relatively low unit costs, whereas the latter stages, which are more investigative and diagnostic in nature, are characterised by lower volumes and high unit costs.

The arranging and conducting of colonoscopies, which we have defined as ‘stage 3’ of the screening pathway, is the most expensive phase – on a per-unit basis and in terms of aggregate costs. Our modelling suggests that small movements in either the volume (i.e. the combination of client participation and positivity rates) or the unit cost of colonoscopies has the potential to materially affect the cost of the pilot. This stage probably represents the key risk in terms of annual operating costs of the screening pathway, both for the next two years of the pilot, and for any future national roll-out.

It is also worth noting that the pilot has managed an increase in volumes as it has ramped up activity during Round 1. While these higher volumes have added to the variable costs, the fixed costs have remained constant, or in some cases, declined, as internal systems have matured. The fixed costs generally relate to community awareness and sending out kits to clients as well as to general planning and oversight, clinical governance, and analysis and reporting. Many of these fixed cost elements offer scope for economies of scale if screening volumes increase.

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## 5. Glossary

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

- ADHB – Auckland DHB
- BPOP – Policy and Operational Procedures for the Bowel Screening Pilot
- BSP – Bowel Screening Pilot
- CAR – community awareness raising
- CATI – computer-assisted telephone interviewing
- CPHR – Centre for Public Health Research
- CNS – clinical nurse specialists
- CTC – Computerised Tomographic Colonography
- DHB – District Health Board
- DNA – did not attend
- FTE – full time equivalent
- IANZ – International Accreditation New Zealand is the accreditation body of the Testing Laboratory Registration Council in New Zealand
- iPIMs – WDHB’s Intelligent Patient Information Systems
- iFOBT – immunochemical faecal occult blood test<sup>87</sup>. A single sample iFOBT test is being used in the BSP. The test is known as OC-Sensor.
- General practice – refers generically to the differing systems and models in which primary care is delivered
- GE – Gastroenterologists
- GP – General Practitioner
- GRS – Global Rating Scale
- MDM – multi-disciplinary meeting
- NHI – National Health Index
- Non-responders – people who have received a pre-invitation, invitation and reminder letter, have not returned a completed kit, and have not contacted the Coordination Centre to opt out of the BSP
- PHO – Primary Health Organisation
- Spoilt kits – refers to iFOBT kits where the test has not been performed or labelled correctly. Most spoilt kits are due to date and label issues
- TAT – Turnaround time
- The pilot – the Bowel Screening Pilot/BSP
- UK – United Kingdom
- WDHB - Waitemata District Health Board

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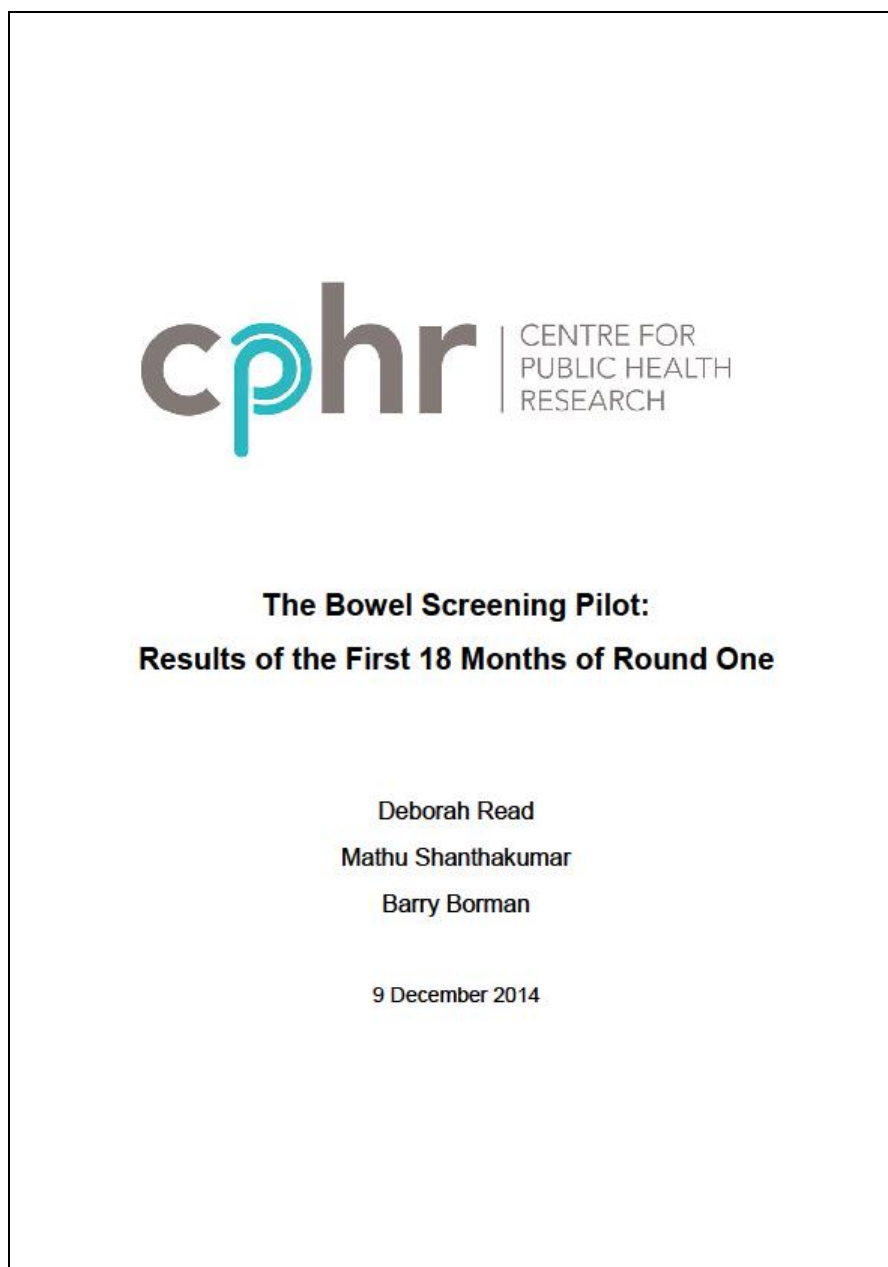
<sup>87</sup> Referred to internationally as Faecal Immunochemical Test for Haemoglobin (FIT)

- WHEU - Waitakere Hospital Endoscopy Unit
- The Register – BSP information system

## Appendices

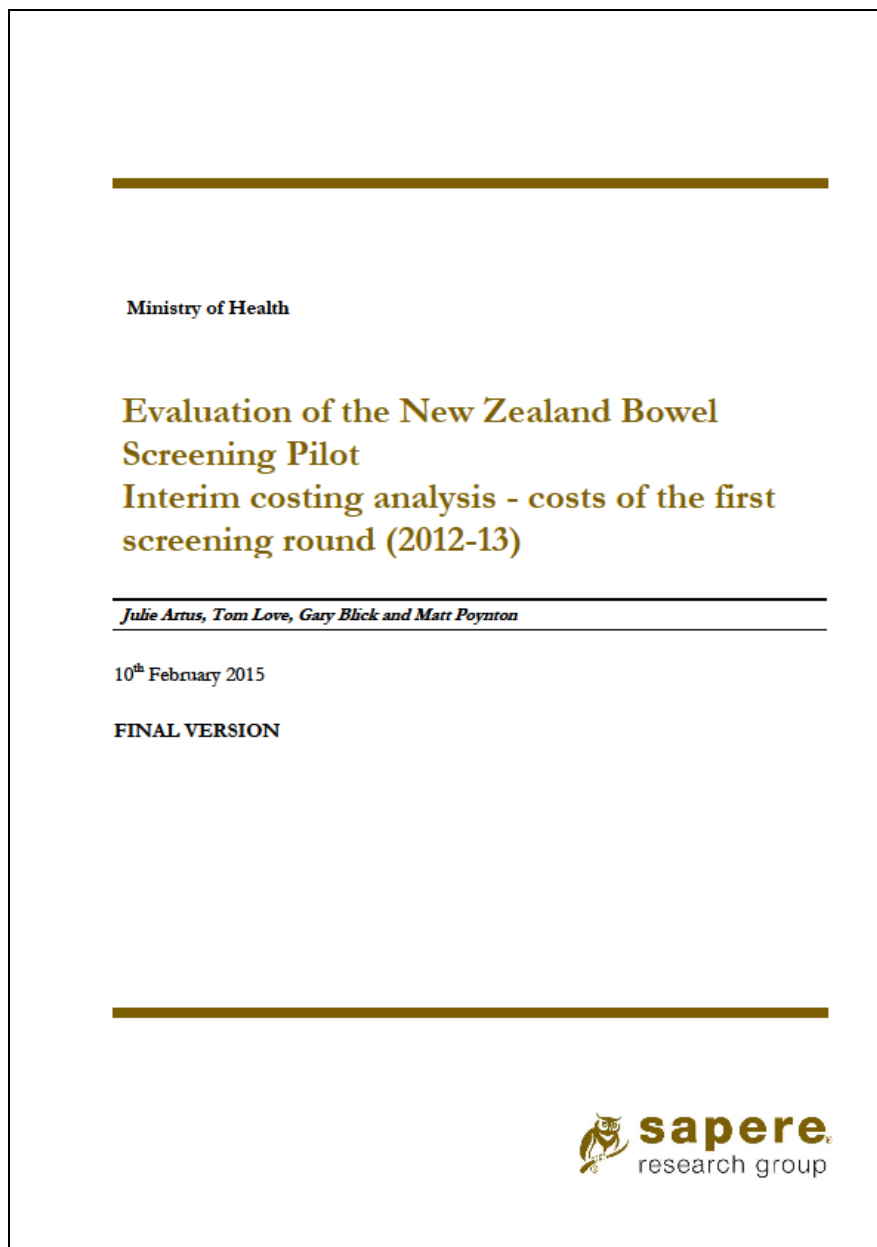
### Appendix 1: Epidemiology Report (Read et al. 2014)

Double click on the [page](#) below to access the complete epidemiology report: Read D, Shanthakumar M, Borman B. 2014. *Results of the First Round of the Bowel Screening Pilot*. Prepared for the Ministry of Health. Wellington, New Zealand: Centre for Public Health Research, Massey University.



## Appendix 2: Interim costing analysis (Sapere Research Group, 2014)

Double click on the page below to access the complete interim costing analysis report: Artus J, Love T, Blick G and Poynton. 2014. *Interim costing analysis – costs of the first screening round (2012-13)*. Prepared for the Ministry of Health. Wellington, New Zealand: Sapere Research Group.





## Appendix 3: Overview of Māori and Pacific respondent survey results

The following is a summary of the statistically significant differences in the responses by Māori and Pacific respondents in the 2013 eligible WDHB population survey (Litmus 2014a).

### **Māori responses**

#### **Eligible Māori respondents: lower awareness of prevalence and risks factors**

- Lower awareness of bowel cancer prevalence compared to Other ethnicity
  - Second most common cancer in men: 31% of Māori are aware compared to 39% Other ethnicity
  - Second most common cancer in women: 10% of Māori are aware compared to 21% Other ethnicity in 2013
- Less well informed about the risk factors for bowel cancer than Other ethnicity
  - Less agreement: a close relative with bowel cancer is a risk factor (45% of Māori strongly/ somewhat agree compared to 76% Other ethnicity)
  - Less agreement: having a diet low in fibre can increase chance of developing bowel cancer (49% of Māori strongly/ somewhat agree compared to 74% Other ethnicity)
  - More likely to disagree: eating fewer than five servings of fruit and vegetables a day can increase a person's chance of developing bowel cancer (61% of Māori strongly/ somewhat agree compared to 34% Other ethnicity).

#### **Eligible Māori population: lower awareness symptoms and tests**

- Lower unprompted awareness of symptoms of bowel cancer
  - 69% of Māori mention unprompted blood in bowel motions (85% Other ethnicity)
  - 28% of Māori mention unprompted change in toilet habits (60% Other ethnicity)
- Increasing but lower awareness of bowel cancer tests
  - 51% of Māori are aware of any test up from 32% in 2011; 76% other in 2013
  - 84% of Māori have a prompted awareness of iFOBT increased from 51% (similar to Other ethnicity 91%)
  - 81% of Māori have a prompted awareness of colonoscopy lower the Other ethnicity 92%
- Less likely to have their doctor suggest a bowel cancer test (18% compared to 28% Other ethnicity)
- Increasing but comparatively lower awareness of BSP (75% in 2013 up from 18% in 2011; 90% Other in 2013)
- Māori (87%) are more likely to agree than the Other ethnic group (75%) that they are happy for the screening unit to contact them.

## **Pacific responses**

### **Eligible Pacific respondents – Lower awareness of risk factors**

- Pacific respondents are more aware that being overweight is a risk factor for bowel cancer (70% of Pacific strongly/ somewhat agree compared to 57% Other ethnicity)
- But less aware of other risk factors than Other ethnicity:
  - less agreement: close relative with bowel cancer is a risk factor (48% of Pacific strongly/ somewhat agree compared to 76% Other ethnicity)
  - less agreement: diet low in fibre can increase a person's chance of developing bowel cancer (41% of Pacific strongly/ somewhat agree compared to 74% Other ethnicity)
  - more likely to disagree: eating fewer fruit and vegetables can increase a person's chance (54% of Pacific strongly/ somewhat disagree compared to 34% of Other ethnicity).

### **Eligible Pacific population – Lower awareness symptoms**

- Pacific respondents have lower awareness of bowel cancer symptoms and some Pacific respondents disagree changes are related to bowel cancer
  - 35% of Pacific respondents know no symptoms; decline from 55% in 2011 (unprompted)
  - 56% of Pacific respondents mention unprompted blood in bowel motions (85% Other ethnicity)
    - when prompted 65% of Pacific respondents are aware compared to 87% Other ethnicity
    - 27% of Pacific respondents say this is not a symptom of bowel cancer
  - 31% of Pacific respondents mention unprompted change in toilet habits (60% Other ethnicity)
    - when prompted 58% of Pacific respondents are aware compared to 78% Māori
    - 29% of Pacific respondents say this is not a symptom of bowel cancer.
- Pacific respondents are not or not at all confident they can identify bowel cancer symptoms (34% compared to 23% other), but more likely to feel they may develop bowel cancer (22% Pacific respondents compared to 9% Other say they are very or quite likely to develop bowel cancer)
- Less likely to report of family history of bowel cancer (9% Pacific respondents compared to 24% Other).

### **Eligible Pacific population – Lower awareness tests**

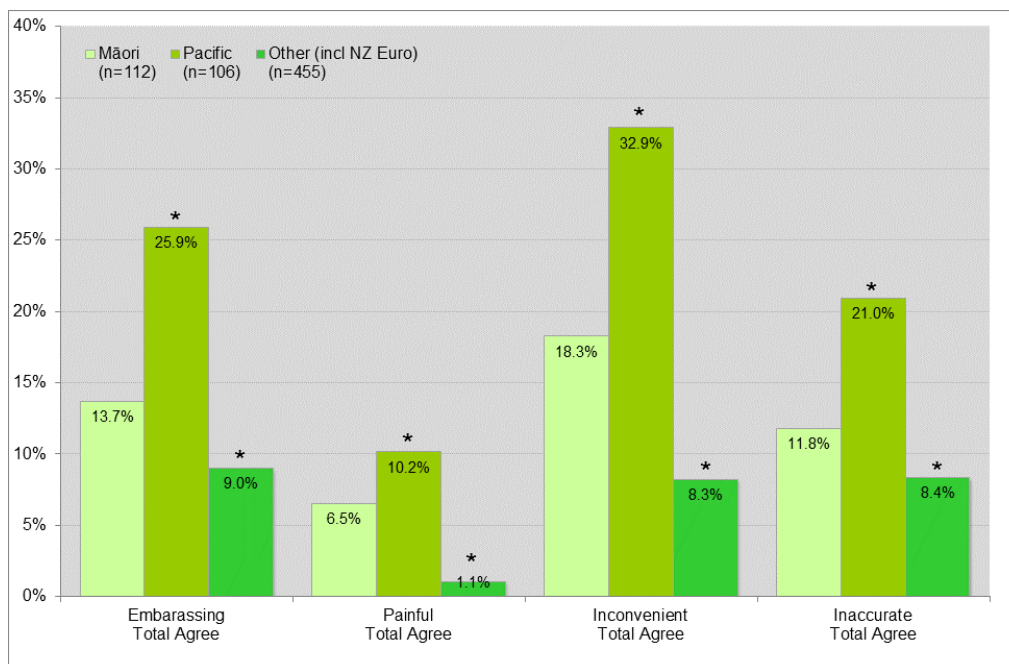
- Lower awareness bowel cancer tests
  - 37% of Pacific respondents are aware of any tests compared to 76% Other ethnicity

- 21% of Pacific respondents mentioned unprompted the iFOBT compared to 39% Other ethnicity
- when prompted 77% of Pacific respondents are aware of iFOBT, an increase from 40% in 2011 but lower than Other ethnicity (91%)
- 20% Pacific respondents mentioned unprompted colonoscopy compared to 44% Other ethnicity
- when prompted 62% of Pacific respondents are aware of colonoscopy compared to 93% Other ethnicity
- Pacific respondents are less likely to have ever done iFOBT (31% compared to 51% Other ethnicity)
- Pacific respondents are more likely to see iFOBT as inconvenient, embarrassing, inaccurate and painful (see Figure A3.1 below)
- 28% of Pacific respondents somewhat or strongly agree iFOBTs are more trouble than they are worth (compared to 8% other)
- Pacific respondents are more likely to agree colonoscopies are painful (40%), inaccurate (34%), and messy (36%) (see Figure A3.2 below)

#### Eligible Pacific population – lower awareness BSP

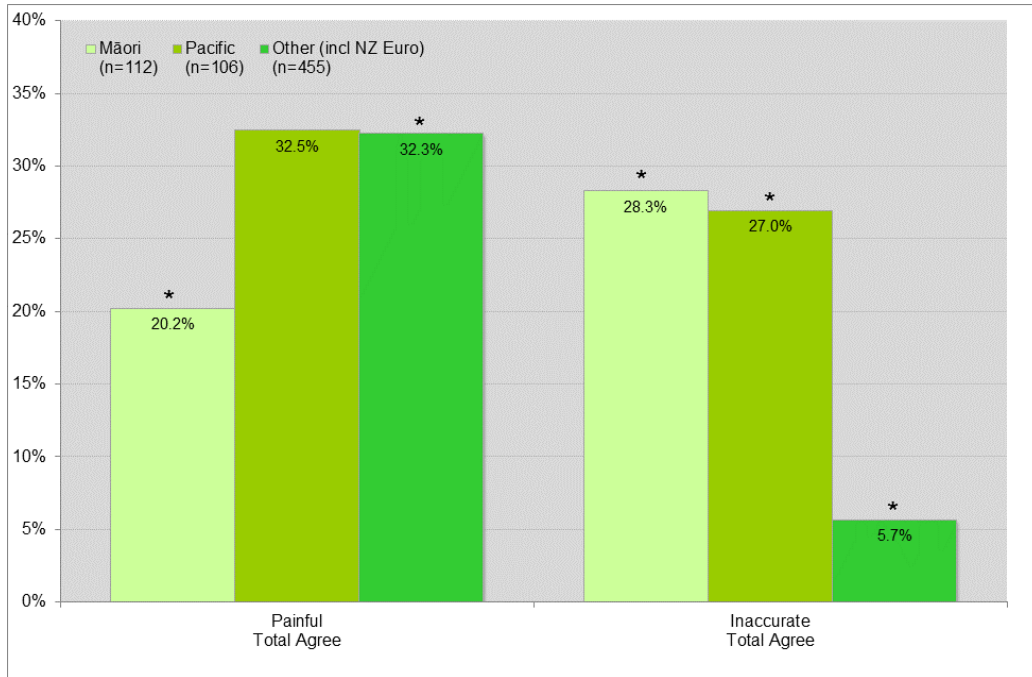
- Pacific respondents have an increasing but comparatively lower awareness of BSP
  - 72% of Pacific respondents are aware of the BSP in 2013 compared to 21% in 2011; (90% other in 2013)
- There is an increase in doctors suggesting to Pacific respondents they do a bowel cancer test (44% mentioned in 2013 compared to 14% in 2011).

**Figure A3.1: Agreement on statements about the iFOBT by ethnicity, WDHB, 2013**



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

**Figure A3.2: Agreement about colonoscopies by ethnicity, WDHB, 2013**



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

## Appendix 4: BSP monitoring indicators

The Ministry of Health developed a detailed set of monitoring indicators (the Indicators) which have been drawn up to monitor and evaluate the progress of the BSP. Not all of the Indicators can be calculated at present, as some can only be completed at a later stage in the pilot.

**Table A4.1: New Zealand BSP Monitoring Indicators 1 January 2012 to 31 December 2013**

Indicator number	Indicator description	Evidence	Target	Value (1 January 2012 to 31 December 2013)
1	Overall participation	This is the % of people with a final iFOBT result (positive or negative) out of all those invited by the programme (adjusted for undelivered kits and letters, those meeting exclusion criteria) for the first and subsequent screening round.	60% first screen	53.8%
2	Coverage	This is the % of eligible people in WDHB who were invited to participate during the first screening round.	>95%	To be advised
3	Time to colonoscopy as at 30 September 2013.	This is the % of people whose time between the laboratory receiving a positive iFOBT to having a colonoscopy carried out was within a specified target (excludes persons who decline colonoscopy).	95% <11 weeks*	91.3%
			50% < 5 weeks *	3.6%
4	Proportion of individuals with a positive screening test undergoing colonoscopy	This is the % of screened people with a positive iFOBT result who undergo a colonoscopy or CTC through the programme.	>90% undergo colonoscopy	91.0%
5	Colonoscopy completion rate	This is the % of completed colonoscopies (reaching the caecum).	Acceptable >90% Desirable > 95% completion to the caecum	97.4%
6	Colonoscopy complication rate for perforation or bleeding	This is the number of people requiring admission to hospital for an intermediate or serious adverse event related to perforation or bleeding occurring within 30 days of colonoscopy, per 1000 of those who had a colonoscopy during the first and subsequent screening round.	<10 per 1000 colonoscopies **	3.9 per 1000
7	Colonoscopy complication rate for events other than perforation or bleeding	This is the number of people requiring admission to hospital for other intermediate or serious adverse events not related to perforation or bleeding occurring within 30 days of colonoscopy, per 1000 of those who had a colonoscopy during the first and subsequent screening round.	No agreed international standard	3.9 per 1000
8	Positivity rate	This is the % of people with a positive iFOBT during the first and subsequent screening round.	6-8% first screen	7.5%
9	Colorectal Cancer (CRC) detection rate	This is the number of people diagnosed with any CRC per 1000 screened with an iFOBT result available for the first and subsequent screening round.	First screen 1.8-9.5 per 1000 (Range from population screening programmes with iFOBT)	Approximately 2.4 per 1000
			Second screen 1.3 per 1000	N/A
10	Colorectal Cancer	This is the TNM staging for CRC detected		Stage 1: 44.4%

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Indicator number	Indicator description	Evidence	Target	Value (1 January 2012 to 31 December 2013)
	(CRC) Stage at diagnosis (including polyp cancers)	at the first and subsequent screening round. In cases where more than one staging was given for an individual only the most serious staging result is included.		Stage 2: 24.1% Stage 3: 22.3% Stage 4: 9.3%
11	Advanced Adenoma detection rate	This is the number of people diagnosed with any advanced adenoma (villous or tubulovillous or, high grade dysplasia or, greater than or equal to 10 mm in size) per 1000 screened with an iFOBT result available for the first and subsequent screening round.	No agreed international standard	Approximately 19.4 per 1000
12	Adenoma detection rate	This is the number of people diagnosed with any adenoma per 1000 screened with an iFOBT result available for the first and subsequent screening round.	13.3-22.3 per 1000 (Range from population screening programmes with iFOBT)	Approximately 35.5 per 1000
13	Positive predictive value of iFOBT for cancer	This is the % of people with a malignant outcome in those having a colonoscopy for the first and subsequent screening round.	PPV Cancer first screen 4.5%-8.6%	Approximately 3.8%
14	Positive predictive value of iFOBT for advanced adenoma	This is the % of people with any advanced adenoma in those having a colonoscopy for the first and subsequent screening round.	No agreed international standard	Approximately 30.2%
15	Positive predictive value of iFOBT for adenoma	This is the % of people with any adenoma in those having a colonoscopy for the first and subsequent screening round.	PPV adenoma first screen 9.6 – 40.3%	Approximately 55.2%

Unless otherwise stated the Indicators were developed using recommendations and standards set out in the European Guidelines for quality assurance in colorectal cancer screening and diagnosis.

\* These timeframes have been extended by one week to allow adequate time for GPs to contact their patients who have a positive iFOBT result.

\*\* This number was calculated on the expected number adverse event rates reported in the UK Bowel Cancer Screening Programme Quality Assurance Guidelines for Colonoscopy and based on the fact that 70% of pilot participants proceeding to colonoscopy are identified to have had a lesion.

## Appendix 5: Adherence to BSP quality standards

To inform the quality monitoring review, analysis was undertaken to identify 1) whether data was available against each of the quality standards and 2) any variance from targets set.

**Table A5.1: Adherence to BSP quality standards dated 30 June 2013**

Number	Section	Requirement	Results
1	Uptake QS 1, 2	<ul style="list-style-type: none"> <li>Bowel Screening is offered to the target population within the BSP.</li> <li>60% of all eligible people will participate (completed an iFOBT test) in the screening programme after 2 years.</li> </ul>	<ul style="list-style-type: none"> <li>55% participation: <ul style="list-style-type: none"> <li>– 25% Pacific people</li> <li>– 43% Māori</li> <li>– 53% Asian</li> <li>– 58% Other group</li> </ul> </li> </ul>
2	Call/Recall QS 3	<ul style="list-style-type: none"> <li>95% of eligible participants are sent their first invitation for screening, through a pre-notification letter, within 2 years of commencement of the BSP.</li> <li>95% of eligible participants are recalled for screening every 2 years (within 27 months) of their previous invitation for screening.</li> </ul>	<ul style="list-style-type: none"> <li>Calculated at the end of the first screening round</li> <li>Calculated at the end of the second screening round. The system automatically returns all participants with a negative result to two year recall.</li> </ul>
3	Informed Choice/ Consent QS 3, 4	<ul style="list-style-type: none"> <li>95% of bowel screening participants surveyed report that they were appropriately informed about the process involved prior to participating in BSP.</li> <li>90% of bowel screening participants receive appropriate information in a format that meets the needs of the individual.</li> <li>95% of participants return an iFOBT consent form with their completed iFOBT sample.</li> <li>95% of participants surveyed report telephone contact was respectful, informative and culturally appropriate.</li> </ul>	<ul style="list-style-type: none"> <li>Not measured.</li> <li>Not measured.</li> <li>This data can be accessed from a manual count but it cannot be reported off the Register. LabPLUS advise the BSP Coordination Centre each time a kit is received without a consent form. The BSP Coordination Centre arranges for a replacement kit to be sent with advice to the participant on including the consent form. It is not a reporting requirement at the moment.</li> <li>100% of the survey participants said that the information line had met their needs.</li> </ul>
4	Failsafe QS 3	<ul style="list-style-type: none"> <li>100% of bowel screening participants with a negative screening result are returned to 2 yearly recall.</li> <li>100% of bowel screening participants with a positive iFOBT result are followed up by the BSP Endoscopy Unit and/or their GP.</li> </ul>	<ul style="list-style-type: none"> <li>The BSP system automatically moves participants to two yearly recall and there is no reason to suspect that this is not happening as it should.</li> <li>100% – the system sends tasks to the Endoscopy Unit if the timeframe within which the referral should be received has not been met and the CNSs assume responsibility for contacting the participant. There is a formal process in place for when a participant is unable to be contacted at all.</li> </ul>

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Number	Section	Requirement	Results
5	FIT Kit QS 4, 5	<ul style="list-style-type: none"> <li>100% of iFOBT logged within 1 working day of receipt in laboratory.</li> <li>100% of correctly completed iFOBTs received by the screening laboratory are tested and results released within 2 working days of receipt in the laboratory.</li> <li>95% of individuals returning a correctly completed iFOBT are advised of their results by the GP or endoscopy unit within 10 working days of receipt of the test result from the laboratory.</li> <li>100% of laboratory staff performing iFOBT testing must be appropriately qualified and receive relevant training before undertaking unsupervised work.</li> </ul>	<ul style="list-style-type: none"> <li>100% - LabPLUS provide BSP Coordination Centre with a quarterly report and this standard has been met consistently for the period to 30 June 2013. This is not a Ministry of Health reporting requirement but is a requirement for LabPLUS to report to the BSP under the terms of the Agreement with WDHB to provide BSP lab services.</li> <li>100% - as above.</li> <li>Difficult to measure as it is not known whether the date of advice is the same as the date of referral. The Register records only the date of referral. The standard is certainly met by the Endoscopy Unit (when the person does not want their GP involved) – dependent on whether the participant is able to be contacted. This standard will be subject to review in 2014. The BSP Coordination Centre has recently conducted 'audits' within specific general practices and if these practices are typical then the standard is being met.</li> <li>100% - IANZ accreditation requirement.</li> </ul>



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Number	Section	Requirement	Results
6	Pre-Assessment QS 6	<ul style="list-style-type: none"> <li>The time interval following a positive result being entered into the BSP IT system and date of initial contact, for colonoscopy is within 15 working days for at least 95% of individuals.</li> <li>100% of participants are documented to have received a pre -assessment interview.</li> <li>100% of participants deemed fit for colonoscopy are appropriately referred for colonoscopy.</li> <li>For all participants with a positive iFOBT result who do not proceed for colonoscopy there is documentation that appropriate pathways were followed and action taken.</li> <li>95% of participants responding to patient satisfaction surveys report that they received appropriate information relating to colonoscopy and bowel preparation for the procedure.</li> <li>95% of participants responding to patient satisfaction surveys report that timely and appropriate advice regarding colonoscopy and bowel preparation was available.</li> <li>For 90% of participants proceeding to colonoscopy there is evidence that a participant has completed the questionnaire relating to family history of bowel cancer. The questionnaire (yet to be finalised) is designed to facilitate on-referral to the New Zealand Familial Gastrointestinal Service, if appropriate.</li> </ul>	<ul style="list-style-type: none"> <li>Not reported to the Ministry of Health but data can be accessed. Difficult to measure as the date of initial contact depends on the ability to contact the participant (i.e. it is not always within the BSP control to meet this standard).</li> <li>100% of participants having a colonoscopy within the Pilot.</li> <li>89.1% - note this result reflects participant behaviour and choices, e.g. the denominator includes participants who decide to have their colonoscopy in the private sector.</li> <li>Yes, documented on the system.</li> <li>97% rated very good or good 'provide clear information to prepare you for your colonoscopy'.</li> <li>Covered above.</li> <li>Commences in 2014.</li> </ul>
7	Colonoscopy QS 7	<ul style="list-style-type: none"> <li>In at least 95% of cases, the interval between the pre-assessment appointment and the first date offered for colonoscopy is within 15 working days.</li> <li>In at least 50% of cases, the interval between the notification (of the positive screening result and the date colonoscopy is completed is within 25 working days (5 weeks). In at least 95% of cases, the interval between the notification of the positive screening result and the date colonoscopy is completed is within 55 working days (11 weeks).</li> <li>100% of screening colonoscopy outcomes site are reported in the BSP IT system.</li> <li>100% of screening colonoscopy results (excluding histopathology) are reported within 5 working days after the procedure to the participants nominated GP and to the CC.</li> <li>100% of participants will receive the results of all colonoscopy investigations (including histopathology) within 20 working days of the final procedure.</li> </ul>	<ul style="list-style-type: none"> <li>100% - There is no interval because the date is offered at the time of the pre-assessment.</li> <li>44.2% at 5 weeks.</li> <li>97.8% at 11 weeks.</li> <li>100%.</li> <li>100% - Participant receives the procedure report to take home on the day and also on the same day it is put in the mail to the GP.</li> <li>Difficult to calculate as result letter not generated from BSP system. Estimated at 98%.</li> </ul>

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8	Colonoscopy Procedure QS 7	<ul style="list-style-type: none"> <li>All colonoscopists working in the BSP are approved to work in the programme by the BSP Endoscopy Lead.</li> <li>The minimum standards for performance of colonoscopy are met and reviewed three monthly by the Lead Endoscopist. These records are available for external audit as de-identified data. Minimum Standards for performance of colonoscopy are: <ul style="list-style-type: none"> <li>The caecal intubation rate for each proceduralist is 95% or greater for screening patients.</li> <li>The mean colonoscope withdrawal time from the caecum is 6 minutes or greater for procedures where no polypectomy performed.</li> <li>The polyp detection rate for each proceduralist is in line with the average polyp detection rate being documented in participants proceeding to colonoscopy within the WDHB BSP.</li> </ul> </li> <li>The Adenoma detection rate for each proceduralist performing colonoscopy within the BSP should be <math>\geq</math> than 35% of screening colonoscopies.</li> <li>The rate of polyp recovery for pathological examination for each proceduralist is more than 95% for polyps &gt; 5mm.</li> <li>All colonoscopists working in BSP receive performance feedback from the BSP Endoscopy Lead and these records are available for external audit as de-identified data.</li> <li>100% of screening colonoscopy results are reported in the BSP IT system.</li> <li>100% of screening colonoscopy results are reported within 5 working days after the procedure to the participant's nominated GP and the BSP IT system.</li> <li>All adverse events and hospital admissions within 30 days following performance of colonoscopy within the BSP are documented and appropriately reviewed at a minimum of monthly intervals. The severity categorisation, root cause analysis and information to be recorded as per the United Kingdom NHS Quality Assurance Guidelines for Colonoscopy.</li> <li>These records are available for external audit as de-identified data.</li> <li>The rate of intermediate or serious colonoscopic complications relating to perforation or bleeding requiring hospital admission within 30 days of performance of colonoscopy within the BSP shall be &lt;10:1000 colonoscopies ( this number is based on the fact that 70% of participants proceeding to colonoscopy in the WDHB Pilot have a lesion detected).</li> </ul>	<ul style="list-style-type: none"> <li>Yes.</li> <li>Yes – noted by all relevant stakeholders.</li> <li>97.2%.</li> <li>7.2 minutes.</li> <li>The number of polyps detected is recorded on the register within the participant's record, and the name of the proceduralist is not captured. An aggregated polyp detection rate number is therefore used for the proceduralists as a group.</li> <li>Standard is met on the aggregated data.</li> <li>Standard is met on the aggregated data.</li> <li>Yes – noted by all relevant stakeholders interviewed.</li> <li>100%.</li> <li>100%.</li> <li>Yes - The BSP adheres to the National Policy for the Management of Healthcare Incidents. All incidents are entered onto the RiskPro system and managed, recorded and reported according to a standardised process.</li> <li>All hospital admissions reported to the Ministry of Health in de-identified form. A record of participant readmission review is retained at endoscopy unit. Adverse events reviews, subsequent reports and other actions are undertaken in accordance with Ministry of Health requirements of DHBs for management and reporting of adverse events.</li> <li>Perforation or bleeding 5.7 per 1000</li> <li>Other than perforation or bleeding 0.4 per 1000</li> </ul>

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Number	Section	Requirement	Results
9	Alternative Investigation QS 7	<ul style="list-style-type: none"> <li>95% of participants requiring a CTC are given a date for the procedure on the day they are deemed unfit for colonoscopy or within 5 working days if pre-assessment is carried out by telephone.</li> <li>95% of participants requiring CTC receive the examination within 20 working days (4 weeks) from the day they are deemed unfit for colonoscopy/pre-assessment.</li> <li>95% of radiological reports will be sent to GPs within 7 working days from completion of the examination.</li> <li>A date for CTC is offered within 5 working days of the incomplete colonoscopy.</li> <li>90% of participants will be notified of their results of all final investigations within 7 working days.</li> <li>100% of providers of CTC comply with the CTC Standards as endorsed by the Royal Australian and New Zealand College of Radiologists.</li> </ul>	<ul style="list-style-type: none"> <li>No data, but the process is that when the CNS pre-assesses and is of the view that the participant may be unsuitable for colonoscopy the Lead Colonoscopist will make a decision within 5 days and refer for CTC. Data is not kept on whether the Radiology Department contacts the participant with an appointment within 5 days.</li> <li>No data kept on this – the date of the CTC appointment is not captured on the system.</li> <li>No data kept on this – letters not generated by the system therefore unable to report.</li> <li>In most instances the person receives the CTC on the same day or the next day. This is not able to happen for people from a Friday afternoon list who are referred for an appointment – again. The date of the appointment is not captured on the BSP system.</li> <li>As above – letters not generated from BSP system so unable to report.</li> <li>100%.</li> </ul>
10	Histopathology QS 8	<ul style="list-style-type: none"> <li>100% of BSP pathology specimens obtained during BSP colonoscopy or surgery are reported using BSP standardised/synoptic reports.</li> <li>95% of specimens submitted from colonoscopy are reported and relayed to the referring endoscopist/surgeon within 10 working days of receipt of the specimen in the laboratory.</li> </ul>	<ul style="list-style-type: none"> <li>100% – this is the only report used by LabPLUS for the BSP.</li> <li>This standard is reported by LabPLUS to BSP as part of their quarterly contract report and has been consistently met for the period to 30 June.</li> </ul>
11	Referral Pathways QS 9	<ul style="list-style-type: none"> <li>95% of BSP participants requiring clinical follow-up have been referred and seen by an appropriate consultant within 10 working days of diagnosis (2 weeks).</li> <li>95% of BSP participants diagnosed with cancer are referred to the appropriate consultant for presentation at an MDM within 20 working days from diagnosis (4 weeks).</li> </ul>	<ul style="list-style-type: none"> <li>This data can now be reported from the system due to recent system upgrade<sup>88</sup>. The standard is also subject to a review because in effect the 'seen by an appropriate consultant' occurs at the time of cancer identification at the time of the colonoscopy.</li> <li>Can now report this from the system – but have yet to do so.</li> </ul>

<sup>88</sup> Currently data is being transferred from a spreadsheet into the Register. On completion these data points will be calculated.