Evaluation of the Bowel Screening Pilot – Findings from 2012 Immersion Visit

Ministry of Health

Manatū Hauora

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Level 9, iCentre Building
50 Manners Street
PO Box 24181
Wellington 6142
TEL +64 4 473 3885
FAX +64 4 473 3884
www.litmus.co.nz

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Preface

This report has been prepared for the Ministry of Health by Liz Smith and Kiri Milne from Litmus Limited, with contributions from Michele Grigg (Litmus Limited), Lisa Davies (Kaipuke Consulting), and Catherine Poutasi (Integrity Professionals Limited).

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- staff in the Bowel Screening Pilot teams at the Ministry of Health and the Waitemata District Health Board for supporting the Bowel Screening Pilot Evaluation.

Please contact Liz Smith (liz@litmus.co.nz) if you have any questions about this report.

1. Executive summary

1.1 Background

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

In the first nine months, 38,725 people in the appropriate age range (50-74 years) were invited to take part in the BSP. Of these, 20,919 returned a Faecal Immunochemical Test for Haemoglobin (iFOBT) kit to be tested by the laboratory[1]. This represents an average participation rate of 54%, which is higher than the internationally defined minimum participation rate to have an effective bowel screening programme. Based on the first nine months of the Pilot, Pacific people and Māori appear to be emerging as under-screened populations.

In September 2012, an immersion visit was undertaken to gain a detailed understanding of the early implementation of the BSP, from those who are 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.

1.2 Methodology

Evaluators from Litmus, Kaipuke Consulting and Integrity Professionals visited WDHB and undertook 62 face-to-face, phone interviews and group discussions with providers across the screening pathway (including representatives from the Ministry of Health, Waitemata District Health Board, LabPLUS, New Zealand Post, Orangebox, Primary Health Organisations and general practices). Fieldwork was undertaken between September and October 2012. All interviews followed an informed consent process.

The findings from the immersion visit offer a record of the early implementation of the BSP and useful insights into implementation successes and challenges. It is acknowledged that the findings are limited by the relatively small number of general practices that participated in an interview. Reflecting the early implementation of the BSP, less focus was placed on the investigation, surveillance and treatment stages of the screening pathway. This will be explored in more detail in the 2013 and 2015 immersion visits.

1.3 Key findings

Overall, the implementation of the BSP, (while intensive and not without its challenges), has progressed relatively smoothly, demonstrated in the overall participation rate. The factors that have positively contributed to the BSP's implementation are:

[1] A single sample immunochemical faecal occult blood test (iFOBT) is being in the BSP. The test, known as OC-Sensor, is an iFOBT widely used in screening programmes internationally.

- **Widespread sector support for a bowel screening programme.** The design and implementation of the BSP was based on development work undertaken over the last ten years, which draws on the international evidence-base as well as the depth of expertise in the Bowel Cancer Taskforce and now the Bowel Screening Advisory Group.
- **Effective leadership and management.** While both the Ministry and WDHB initially grappled with ensuring clear roles and responsibilities between the funder and provider, the relationships established have enabled implementation issues to be debated and resolved. Effective clinical leadership both nationally and regionally has significantly contributed to the promotion and implementation of the BSP and to ensuring primary and secondary care clinicians' engagement with the BSP.
- **Multi-disciplinary provider involvement in decision making.** Having Coordination Centre, primary care, laboratory and endoscopy staff involved in the decision making structures for the BSP has enhanced their understanding of the wider screening pathway and how it interfaces with their areas of responsibilities. As a result, providers have developed effective working relationships and are committed to working collaboratively to find solutions to issues arising.
- **Use of a population register (the Register).** Having an eligible population database is seen as a key strength of the BSP in enabling the identification and monitoring of the eligible population, and to inform targeted participant follow-up and community awareness raising strategies.
    - A key limitation of the Register, which impacts on follow-up and community awareness raising activities, is inaccuracies in contact details, especially the lack of phone numbers.
- **The BSP screening pathway is being implemented as intended.** Feedback from BSP participants also indicates a mainly positive participant experience.
- **Quality monitoring of the BSP.** Monitoring of the BSP and the mechanisms to discuss quality issues and risks emerging are being appropriately used to maintain quality standards and ensure participant safety.

Key challenges noted in the early implementation of the BSP include:

- **Ensuring fair access for all New Zealanders**. Pacific people (in particular) and Māori are emerging as the under-screened populations for the BSP. Younger men are also emerging as a potential under-screened group. Over time, these participation rates may change and therefore ongoing monitoring of participation by ethnicity, gender, socio-economic and other variables is needed.

  During the design phase, the risk of Māori and Pacific people emerging as the underscreened populations was identified; efforts were made to try and avoid this by:

    - Involving Māori and Pacific health and community leaders to varying degrees in key governance and management structures, nationally and regionally.
    - Identifying screening processes that may be more acceptable to Māori and Pacific people, which were incorporated into the BSP design.
    - Having Māori and Pacific community awareness raising coordinators to identify and implement appropriate and unique strategies to encourage participation.
    - Tailoring communications to eligible Māori and Pacific people.

Research with eligible Māori and Pacific people who did not participate in the BSP suggests for some, there is cultural opposition to bowel screening in general, while others are culturally opposed to specific aspects of the screening process (i.e. undertaking the test at home and posting faecal samples). Eligible Māori and Pacific people also face other barriers to participation including low levels of literacy and self-efficacy – all prerequisites to making an informed decision and being able to take part in the BSP.

Review of the BSP implementation highlighted a number of areas where the implementation process could be strengthened to ensure a sustained equity approach, with a focus on appropriate systems, processes and structures.

- Investigating ways to increase Māori and Pacific involvement and decision making in the BSP at leadership and operational levels so decisions on engaging with Māori and Pacific people are placed into a wider strategic context.
- 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.
- 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. This review is currently taking place.
- Building on the existing community awareness raising strategies and lessons of what is working well. For example, 'kanohi ki te kanohi' (a one-to-one approach) appears to be effective in seeking to overcome cultural opposition to bowel screening for some Māori. Currently, a range of strategies have been put forward for Pacific people reflecting their diversity, however it is not known which are the most effective.

Discussions with the BSP Coordination Centre highlights that particular focus is being placed on supporting Pacific people and Māori to take part in the BSP in 2013. In seeking to increase bowel screening participation by Pacific people and Māori, care is needed to balance promotional strategies with informed consent on whether or not they want to be screened.

- **Managing the variability in general practices' role in the screening pathway.** General practitioners (GPs) and practice nurses interviewed are generally supportive of the BSP, encourage their participants to take part, and note that participants appreciate the opportunity to discuss their positive iFOBT result before referral. They indicate that the ten day notification timeframe is acceptable and achievable. Feedback from the BSP Coordination Centre indicates that most general practices appear to be following the prescribed screening pathway of informing and consulting with participants with a positive iFOBT before referring to the BSP Endoscopy Unit within the ten day period. However, variation in BSP processes and practices across general practice was found, including:
  - Different internal processes and practices are being used to inform participants of a positive result. Variation also exits in the consultation and referral processes used (e.g. who is responsible for noting positive results, whether the participant is informed by the practice nurse or GP, etc.) Currently, the flexibility offered is appreciated by general practice as it enables the BSP process to be fitted into their business-as-usual systems.
  - A small number of participants are not being informed of positive results and/or not being referred. Consequently, this triggers the safety net of the BSP Endoscopy Unit contacting these participants.
  - Referrals to the BSP Endoscopy Unit range from excellent to very basic with important information missing.

The BSP Coordination Centre has placed significant effort on developing effective relationships with primary care. In instances where the screening pathway is not working as intended the general practice is promptly contacted by the BSP Clinical Director or the BSP Programme Manager to discuss the issue and rectify for future participants. Primary Health Organisations (PHOs) are also informed of issues arising.

Given the unique role of general practice in the BSP screening pathway, consideration is needed on whether this level of variation is acceptable. Internationally, GP involvement in bowel screening has been shown to have a positive impact on iFOBT screening participants, although it is noted that like New Zealand this is subject to high variability (Federici et al 2006, Koo et al 2010, Power et al 2009). In this context and acknowledging the limited focus on general practice in this immersion visit, this is an area for further investigation.

- **Ensuring adequate workforce capacity.** Having adequate colonoscopy capacity to meet quality standards was the challenge identified most frequently in relation to the BSP. At one stage, concerns were raised that there were not enough endoscopists to undertake the ten lists per week needed to ensure BSP participants with a positive iFOBT have their colonoscopy within 50 working days. Through a range of strategies, BSP management was able to recruit enough endoscopists to fill all ten lists, and the 50 day quality standard was not breached.

  Limited endoscopy capacity is a New Zealand–wide issue. GPs are concerned that resource dedicated to bowel screening may be being diverted from symptomatic lists resulting in longer wait times for symptomatic patients.

- **Managing incorrectly completed iFOBT kits.** An estimated 15% of iFOBT kits are not completed correctly the first time they are returned; mainly due to supporting paperwork being incorrectly completed. These are known as 'spoilt kits'. Over a three-month period, this reduces to 3% with participants being asked to complete another kit and/or receiving advice and guidance on using the kit. The likelihood of a person returning a spoilt a kit increases with age, and some ethnic groups are more likely to send in incorrectly completed kits. At the time of this report, instructions for the kit were only printed in English (supported by diagrams). This may contribute to the higher rate of spoilt kits in some ethnic groups. Currently, work is underway to simplify the kit instructions with a view to reducing the number of spoilt kits.

1.4 Quality monitoring

The review of quality monitoring confirms that the BSP has a range of quality standards in place that align with international best practice. Quality standards are being actively monitored and processes to address risks of breaching quality standards have been tested on one or two occasions.

This review found that quality issues arising have been identified by the BSP Coordination Centre, and responsibility lines are clear and the quality resolution loops are closed. Further, no complaints have been received from BSP participants about their experience. While quality monitoring processes are in place and appear effective, it is acknowledged that it is relatively early days for the BSP. The review identified some considerations for the BSP to enhance quality monitoring:

- ensure quality monitoring adopts an equity focus
- link and share information between the New Zealand Global Rating Scale's Endoscopy User Group and the BSP Quality Assurance group

- clarify specifications for Register data and ensure other IT systems inform quality monitoring, and have the capacity to analyse data
- streamline quality standard documentation.

1.5 Considerations for a possible national bowel screening programme

At this early stage of the BSP implementation and evaluation, it is not yet known 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.* Early evidence and participation suggests strong provider acceptance and a level of acceptability amongst some populations. While further evidence is needed to address the overarching evaluation goals, detailed below are the early implementation lessons that could inform a national bowel screening programme – should it proceed.

Programme design - leadership and governance

- Ensure effective governance and leadership structures for a national programme at a national and regional level, with clear roles and lines of responsibilities and accountability.
- Ensure strategic and operational involvement of Māori, Pacific and any other population groups identified as under-screened in the BSP, at all levels and in all programme phases. This will increase the likelihood of the programme being effective for priority populations.
- Ensure transfer of knowledge between the BSP and a national programme through active knowledge management and advice from those involved in the BSP.

Fair access for all New Zealanders

- Identify from the BSP which sub-groups are more likely to not participate in bowel screening.
- Collate learnings from the BSP to ensure Māori and Pacific people and other under-screened are appropriately engaged with bowel screening.

Service delivery and workforce capacity

- 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 can demonstrate their ability to meet bowel screening quality standards.
- Review the histopathology workforce in New Zealand as there are suggestions that current capacity of histology technicians and scientists is insufficient to service the high volume of specimens generated through a national programme.
- Ensure adequate workforce and service capacity for both bowel screening and symptomatic colonoscopy services.

1.6 Evaluative activities in 2013

In late 2013 another immersion visit will be undertaken to assess how implementation is progressing. This visit will focus on understanding the impact of the BSP on symptomatic services, including radiology, surveillance and treatment. It is suggested that further discussions be held with general practice and other providers and stakeholders about the value and benefits of the role of general practice in the BSP screening pathway.

Ongoing monitoring of quality processes and responses will also be undertaken.

2. Introduction

2.1 Background

The Ministry of Health ('the Ministry') has funded Waitemata District Health Board (WDHB) to run a Bowel Screening Pilot (BSP) over four years from 2012–16.[2] The BSP began with a 'soft launch' in late 2011, with full operation of the Pilot starting in January 2012. Litmus and Sapere Research Group have been funded by the Ministry to undertake an evaluation of the BSP, including a cost-effectiveness analysis. The evaluation will inform a decision about 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. 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?

A number of activities are planned for the evaluation of the BSP.[3] Included in these are three immersion visits, whereby the Litmus evaluation team interviews providers and stakeholders are involved in all aspects of BSP implementation. The immersion visits inform a number of evaluation questions.[4] This report presents findings from the first immersion visit undertaken in September – October 2012; nine months after the BSP was launched. Follow-up immersion visits will be undertaken in 2013 and 2015.

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

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2 WDHB was named as the pilot bowel screening site in December 2010 http://beehive.govt.nz/release/waitemata-named-bowel-screening-pilot-site Accessed 22 February 2012.

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

4 Refer Section 2.4 of the *Evaluation Plan for the Bowel Screening Pilot 2011–2016* (Litmus Limited 2011) for the full list of evaluation questions.

2.2 Immersion visit purpose

The purpose of the immersion visit was to gather insights about the implementation of the BSP from those who are 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.

2.3 Results from the first nine months of the BSP

The results from the first nine months of the BSP are presented below to provide a context for the findings of the immersion visit. The results have been sourced from the Ministry of Health website[5]. Appendix 1 contains the complete list of the BSP's monitoring indicator results from January to September 2012 (Ministry of Health 2012e).

Participation in the BSP

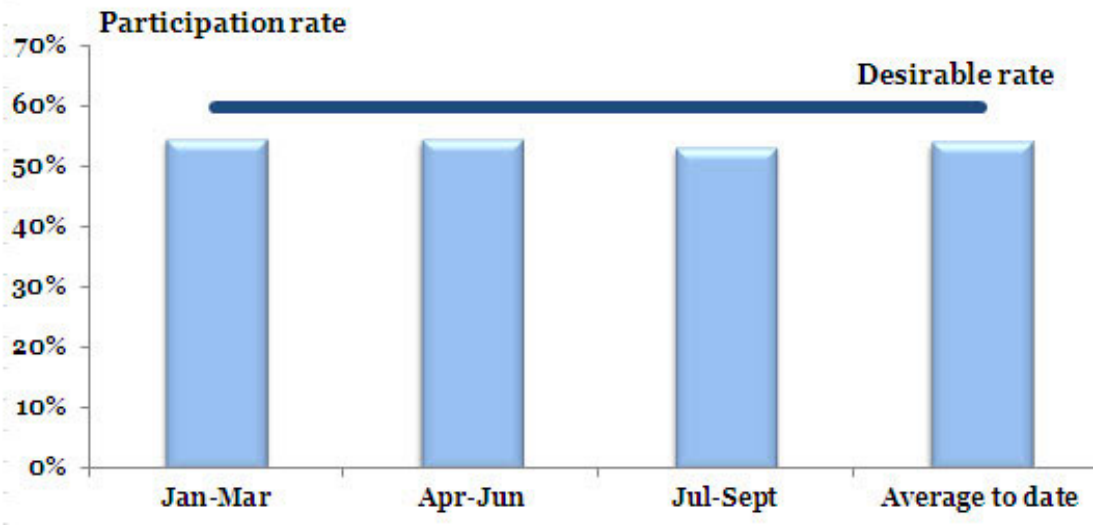
Between January and September 2012, 38,725 people in the appropriate age range (50-74 years) were invited to take part in the BSP. Of these, 20,919 returned an iFOBT kit to be tested by the laboratory. A single sample iFOBT test is being used in the BSP. The test, known as OC-Sensor, is an iFOBT widely used in screening programmes internationally.

Over this time, the **average participation rate was 54%**. 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% (Faivre et al 1991; Zorzi et al 2008). A randomised controlled trial (RCT) of faecal-occult-blood screening for colorectal cancer demonstrated a mortality reduction with 60% participation (Hardcastle et al 1996). Reflecting the European Guidelines and the RCT findings, the Ministry has set the desirable participation rate at 60%.

[5] http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/bowel-cancer-programme/bowel-screening-pilot/bowel-screening-pilot-results/bowel-screening-pilot-january-september-2012-results accessed 13 May 2013. The interim report, due in late 2014, will contain the detailed epidemiological analysis.

Figure 1: Participation rate for the Bowel Screening Pilot, January to September 2012



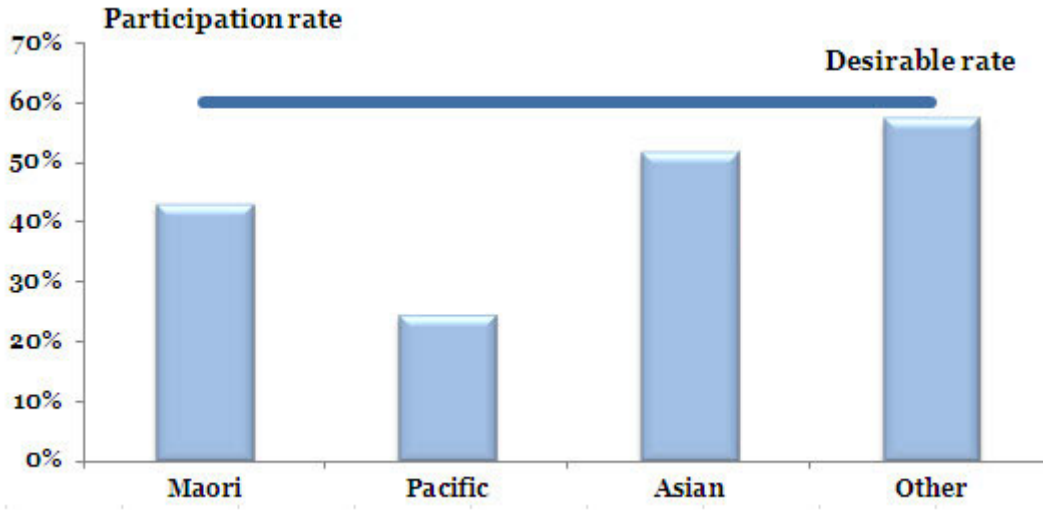
Source: The New Zealand Bowel Screening Pilot IT system

Based on the first nine months of operation, not all population groups are participating in the Pilot in equal measure. **Pacific people have a much lower participation than other groups, and Māori participation is lower than Asian and the Other population group.**

Between January and September 2012, the average participation rate for:

- Pacific people was 24%
- Māori was 43%
- Asian was 52%
- Other population group was 57%.

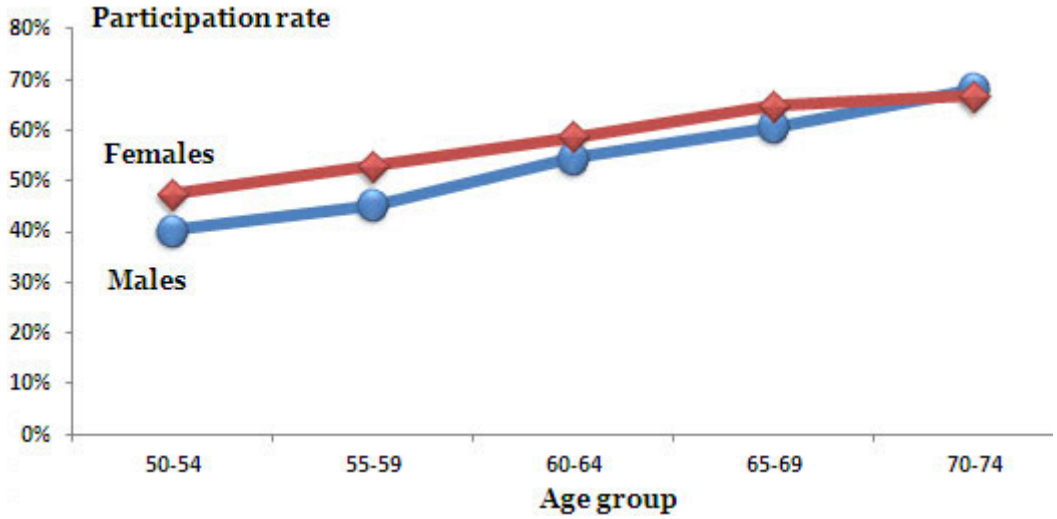
Figure 2: Participation rate for the Bowel Screening Pilot by ethnic group, January to September 2012



Source: The New Zealand Bowel Screening Pilot IT system

Those in the younger age ranges are less likely to participate than those who are older, and women are more likely to take part than men.

Figure 3: Participation rate for the Bowel Screening Pilot by sex and age group, January to September 2012



Source: The New Zealand Bowel Screening Pilot IT system

Positive iFOBTs

About 7% of all participants who correctly complete their iFOBT kit show a positive result[6]. This is within the expected range when compared with other international bowel screening pilots (Colorectal Cancer Screening Advisory Group 2006; Segnan et al 2010).

Between January and September 2012, 1,545 people were identified as having an abnormal result.

Number of colonoscopies performed

Between January and September 2012, **886 people attended a colonoscopy** on the BSP. As required in the screening pathway, participants in this period were being offered a colonoscopy within ten weeks of the laboratory identifying that their test was positive.

Number of cancers found

As at 30 September 2102, **31 people had been diagnosed with cancer through the BSP**. This number is within the expected range when compared with international bowel screening programmes (Segnan et al 2010). When a cancer is diagnosed, the participant is referred on for appropriate treatment and care.

In addition to finding cancers, the Pilot is also finding that many participants have non-cancerous polyps called adenomas. These polyps are removed at colonoscopy. These participants will require regular bowel checks by colonoscopy (i.e. surveillance) in the future.

[6] Refer Appendix 1 for the detailed set of BSP monitoring indicators.

Complications following colonoscopies

Between January and September 2012, **28 BSP participants were admitted to hospital within 14 days after undergoing a colonoscopy to have further treatment or monitoring**. Most of these admissions were for complications that were not considered to be serious[7] and involved a short stay in hospital for observation.

2.4 Glossary of terms

For clarification, in this report the following terms have been used as follows:

- ADHB – Auckland DHB
- ALSS – Automation and Laboratory Support Services
- BPOP – Policy and Operational Procedures for the Bowel Screening Pilot
- BSP – Bowel Screening Pilot
- CAR – community awareness raising
- CCNZ – Cancer Control New Zealand
- CMDHB – Counties Manukau DHB
- CNS – clinical nurse specialists
- CTC – Computerised Tomographic Colonography
- DHB – District Health Board
- DNA – did not attend
- FTE – Full-time equivalent
- iFOBT – immunochemical faecal occult blood test[8]. 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
- gFOBT - guaiac-based faecal occult blood test
- GP – General Practitioner
- GRS – Global Rating Scale
- MDM – multi-disciplinary meeting
- MEAG – Māori Equity Advisory Group
- The Ministry – Ministry of Health
- MoH – Ministry of Health
- NGOs – non-government organisations
- NHI – National Health Index

[7] Serious adverse events include bowel perforation or major bleeding after colonoscopy and are more likely to be associated with an intervention such as removal of bowel polyps. Serious (major) adverse events are as defined in the UK NHS BSCP Quality Assurance Guidelines for Colonoscopy (Chilton and Rutter 2011).

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

- Non-responders – people who have received a pre-invitation, invitation and reminder letter between April to September 2012, had not returned a completed kit, and had not contacted the Coordination Centre to opt out of the BSP
- NZ GRS – New Zealand Global Rating Scale
- The Pilot – the Bowel Screening Pilot/BSP
- PHO – Primary Health Organisation
- Spoilt kits – refers to iFOBT kits where the test has not been performed or labeled correctly. Most spoilt kits are dues to date and label issues
- WDHB - Waitemata District Health Board
- The Register – BSP information system
- Under-screened populations – no definition was agreed on what constitutes an 'under-screened' sub-group therefore the focus was placed on those sub-groups with the lowest level of participation.

3. Immersion visit methodology

This section outlines the method used to undertake the immersion visit. It details the sample frame, recruitment and interviewing approach, analysis and research limitations.

3.1 Sample

Litmus worked with the Ministry and WDHB to develop a sample frame that ensured participation of providers who are involved or engaged in the implementation and delivery of the BSP across the ten implementation areas (refer Table 1 below).

Table 1: Sample frame across the ten implementation areas

Ten implementation areas
Leadership, governance and management
District coordination
Register
Screening Pathway 1: iFOBT kit sent
Screening Pathway 2: iFOBT result – Laboratory and Coordination Centre management of iFOBT kits and results
Screening Pathway 3: Pre-assessment
Screening Pathway 4: Colonoscopy
Screening Pathway 5: Alternative investigation
Surveillance
Treatment

In total, 62 providers participated in an interview or group discussion across the ten implementation areas. Table 2 details the interviews undertaken by provider type.

Table 2: Sample achieved by provider type

Provider type	Number
Ministry of Health	9
Waitemata DHB - management	2
Clinicians	7
Coordination Centre	9
Community awareness raising providers	5
Primary care	12
Laboratory	9
Endoscopy unit	6
Other services	3
Total	**62**

3.2 Fieldwork

Evaluators from Litmus, Kaipuke Consulting and Integrity Professionals visited WDHB to undertake face-to-face interviews and group discussions with providers across the screening pathway. Interviews were also undertaken by phone to offer greater timing convenience to providers.

Fieldwork was undertaken between September and October 2012. All interviews were audio-recorded and notes were taken during the interview. All interviews followed an informed consent process.

3.3 Research questions

The BSP immersion visit informed ten of the 13 implementation areas identified in the Evaluation Plan, specifically:

- Leadership, governance and management
- District coordination
- Register
- Screening Pathway 1: iFOBT kit sent – Invitation to participate in iFOBT screening
- Screening Pathway 2: iFOBT result – Laboratory and Coordination Centre management of iFOBT kits and results
- Screening Pathway 3: Pre-assessment
- Screening Pathway 4: Colonoscopy
- Screening Pathway 5: Alternative investigation
- Surveillance
- Treatment.

Across each area focus was placed on describing the actual implementation of the BSP, what was working well and not so well and identifying key process improvements to enhance the BSP implementation. Consideration was also given to identifying lessons to inform a national roll-out of a bowel screening programme, should it proceed.

Refer Appendix 2 for the information sheet, consent form and discussion guide.

3.4 Analysis

The immersion visit in 2012 focused on understanding the early implementation of the BSP, its effectiveness and how well the interfaces are working for participant referral across providers. Critical consideration was given to the strategies being used to address the identified under-screened population likely to be Māori and Pacific people.

A grounded theory approach was applied to the analysis of the data from the immersion visits, whereby qualitative interview data was coded and grouped into concepts and categories.

3.5 Limitations

Litmus is confident that the report accurately represents the views and perceptions of providers who contributed to the evaluation. In considering the findings of the 2012 immersion visit, a number of limitations are acknowledged:

- The perspective of primary care on the BSP is limited to the participants from six general practices from Waitemata Primary Health Organisation (PHO) and Procare.

  WDHB, working with the Waitemata and Procare PHOs, identified general practices to approach. In selecting the list of general practices to approach care was taken to include those who were perceived as more and less engaged in the BSP, as well as differing size and location.

  Recruiting general practices to participate was variable due to a perceived lack of relevance of the research and the need to interview within busy general practice workloads.

- Less focus was placed on the investigation, surveillance and treatment stages of the BSP screening pathway. This will be explored in more detail in the 2013 and 2015 immersion visits.

4. Development of the bowel screening programme

This section provides an overview of the BSP development phase, including key aspects of the Ministry and WDHB development processes, and involvement of Māori and Pacific in these processes. Success factors and challenges in the development phase of the BSP are identified, followed by a summary of key lessons to inform a national roll-out of a bowel screening programme, should it proceed.

4.1 Background to the development of the BSP

The following is a chronological summary of bowel screening advice and decisions in New Zealand (Ministry of Health 2011):

- In 1998 the first New Zealand specific report, from the National Health Committee, did not recommend a population-based bowel screening programme based on the evidence available at that time (Working Party on Screening for Colorectal Cancer 1998).
- In 2003 the National Screening Unit appointed a Colorectal Cancer Screening Advisory Group to provide independent strategic advice and recommendations on a possible bowel screening programme in New Zealand.
- In 2003 and 2005 investigating options for cancer screening programmes was identified as a priority in the New Zealand Cancer Control Strategy (Minister of Health 2003) and the accompanying Action Plan (Cancer Control Taskforce 2005).
- In 2005 an Equity Impact Assessment of bowel cancer screening was commissioned by the National Screening Unit. The Assessment considered the impact of a screening programme on inequalities in screening participation and health outcomes. The report 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 2006 a consumer acceptability research report made a number of recommendations for maximising consumer acceptability of bowel cancer screening in New Zealand (Campbell, King, Pipi et al 2006).
- On 30 May 2008, the previous Minister of Health announced that the Government was committed to the development of a national Bowel screening programme in New Zealand.
- In August 2008 a Bowel Cancer Taskforce (the 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.
- From August 2008 to June 2011 planning for bowel screening implementation was undertaken.
- On 5 May 2010, the Minister of Health announced the implementation of a Bowel Screening Pilot to commence October 2011 within one or two geographic regions with an eligible population aged 50–74 years.

4.2 Ministry development process

Bowel screening team

A core team of four Ministry staff worked on the initial development of the BSP. The team included a programme manager, a project manager for development of programme quality standards, a project manager to lead development of the information system, and an analyst who worked on the programme information system. Once WDHB had been selected to deliver the BSP, a contract manager was brought in to assist with setting up contracts, and a communications manager was brought in to work with WDHB on programme communications.

Bowel screening which is overseen by the bowel cancer programme manager and clinical director is part of the wider bowel cancer programme. The team was (and continues to be) situated within the cancer programme overseen by the National Programme Manager for Cancer (now the Group Manager, Personal Health Services Improvement). A decision was made early on to situate development of the Bowel Screening Programme within the Cancer Team rather than within the National Screening Unit.

The BSP information system

A built-for-purpose information system 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. Several factors influenced the final decision to build a bespoke system:

- The inflexibility of existing screening information systems and the cost associated with modifying them.
- Using an existing system would have required that the business rules were 'locked in' before the commencement of the system design.
- The requirement that the bowel screening information system function as a programme register, including maintenance of an eligible population list, able to issue participant invitations, and able to track participant progress on BSP pathway.
- The lack of final and stable design requirements for the bowel screening system. When system development commenced, service design was still very high level, as the provider and invitation process had not yet been finalised.

The BSP information system ('the Register') was built with a Rapid Application Development approach. This iterative approach was fast and allowed incremental system builds that could be tested with user groups at regular points in the development process. There were nine iterations of the information system in the development and implementation phases.

National Health Index (NHI) numbers were selected as the primary source of eligible participant information for the Register[9]. 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).[10] NHI information provides a comprehensive, population-based dataset from which eligible participants can be identified and subsequently invited to take part in the BSP.

Quality standards

Quality standards were developed. Five key quality documents were developed for the BSP:

1. BSP Final Service Delivery Model (Ministry of Health 2011c)
2. Policy and Operational Procedures for the Bowel Screening Pilot (BPOP) (Ministry of Health 2011)
3. BSP Interim Quality Standards (Ministry of Health 2012a)
4. BSP iFOBT Draft Performance Quality Standards (Ministry of Health 2011a)
5. Standards for Endoscopy (colonoscopy) facilities BSP (Ministry of Health 2011b)[11].

The quality documents are intended to be **living documents**. Some changes to quality documents can be agreed between the Ministry and WDHB, while more significant changes go through the Bowel Screening Advisory Group. WDHB, as the selected programme provider, was tasked with developing **standard operational procedures**. Refer to section 8 on quality monitoring for more detail on these documents.

A review of existing standards identified a need for service improvement on aspects of the existing endoscopy service. In 2010, the Ministry funded two sector-based clinical leads: the National Clinical Lead, Gastrointestinal Endoscopy and National Endoscopy Service Improvement Lead (National Endoscopy Leads). In 2010/2011, a stocktake of endoscopy practice across New Zealand highlighted the need for a planned approach to the development and implementation of quality standards using patient experience of endoscopy as the outcome measure (Theobald and Masters 2011). Literature reviews of research into endoscopy training and models of care/scopes of practice identified the Global Rating Scale (GRS) as a potential quality improvement tool to Pilot in New Zealand (O'Brien and Russell 2010a and b). Following modification, the New Zealand GRS (NZ GRS) was trialled from 31 August 2011 to 31 August 2012 in four DHBs: Waitemata, Lakes, Wairarapa and Canterbury DHBs. It is intended that NZ GRS[12] will be incrementally rolled out nationwide.

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9 It was intended that the NHI numbers would be supplemented by Primary Health Organisation (PHO) enrolment data due to logistical reasons this did not occur (refer section 6.2).

10 http://www.health.govt.nz/our-work/health-identity/national-health-index/national-health-index-overview

11 The standards referring to the quality assurance of the colonoscopy procedure are outlined in the BSP Interim Quality Standards.

12 http://www.hqsc.govt.nz/our-programmes/other-topics/news-and-events/news/522/. The NZ GRS is a web-based tool that allows endoscopy units to self-assess against 12 patient-centred standards focused around clinical quality, quality of the patient experience, workforce and training.

Defining priority audiences

From the outset the BSP design was guided by the fundamental principle of not increasing existing health inequities. **The Ministry identified Māori and Pacific populations as priority populations for the BSP**.

Inequities in bowel cancer between Māori and non-Māori exist within New Zealand (Ministry of Health 2010: 7). Māori currently have a lower incidence of bowel cancer but have similar mortality rates to non-Māori/non-Pacific people (Blakely et al 2009 cited in Ministry of Health 2010). Sarfati et al (2010) note that while Māori currently have lower rates of colorectal adenoma and cancer, these are increasing rapidly and are likely to converge with European rates in the near future. The early detection of colorectal cancer through the BSP offers particular benefit to Māori patients, who are currently more likely to have their cancer diagnosed at a later stage (Robson et al 2006).

Māori in New Zealand experience unequal access to, and through, the health care system (Westbrooke et al 2001; Cormack et al 2005; Jefferys et al 2005; Davis et al 2006 cited in Ministry of Health 2010). Evidence exists that issues of unequal access to health care services are also present for Pacific people in New Zealand (Barwick 2000 cited in Ministry of Health 2010). This inequity of access by ethnicity is seen in existing cancer screening programmes in New Zealand (Cormack et al 2005; Shaw et al 2008 cited in Ministry of Health 2010). A key risk for the BSP was that it may unintentionally increase health inequities through the under-screening of eligible Māori and Pacific people as occurred for indigenous Australians (Christou, Katzenellenbogen and Thompson 2010). Further, the introduction of a bowel screening programme has the potential to either reduce or increase ethnic disparities in colorectal cancer survival depending on the accompanying investment in management of colon cancer (Sarfati 2010).

Involvement of Māori in the Ministry development process

In 2010, the Ministry undertook a series of consultation workshops to inform the development of the BSP. An Equity Focused Workshop was held to inform the equity and health promotion requirements for the BSP.

The Māori Expert Advisory Group (MEAG) was the key mechanism by which the Ministry received advice on programme appropriateness and effectiveness for Māori. The remit of this group was to provide advice and recommendations with a focus on equity to the Ministry on the development and implementation of the BSP. 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. 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) 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. However, it appears that there were differing interpretations of the role of the MEAG. On one hand the MEAG sought to offer strategic and high level advice on the development of the BSP through key principles for ensuring equity in the BSP and on how to enhance the effectiveness of the pathway for Māori. In contrast, the Ministry was also seeking more operationally focused advice on how to increase Māori participation in the BSP. These differing perceptions are not unique and are evident in other programmes that have used a similar group to inform a health equity approach (Litmus 2012a). The tension highlights the need for a shared definition of health equity – one that is grounded in the appreciation that a health equity approach focuses on changing the structures, systems and processes which perpetuate inequities and seeks levers for systemic change, rather than more narrowly on community awareness raising (CAR) or engagement strategies.

MEAG stakeholders reported they provided specific advice on a Māori screening pathway. The Ministry reports that feedback from the MEAG was incorporated in the BSP screening pathway.

With the establishment of the national Bowel Cancer working group, the Taskforce 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.

With the shift to implementation, the responsibility for maintaining systems and processes to ensure programme effectiveness for both Māori and Pacific populations now lies predominantly with WDHB. If needed, the Ministry seeks advice from Te Kete Hauora and ex-MEAG members.

Involvement of Pacific in the Ministry development process

No Pacific Expert Advisory Group was established to advise the Ministry on programme effectiveness for Pacific populations. Establishment of a Pacific advisory group was discussed. However, senior Pacific staff at the Ministry 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 was sought through the development of the BSP.

Optimising participation of Māori and Pacific people

In 2010, the Ministry 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 review highlighted that the most successful programmes for Māori and Pacific people are systematic, intensive, multi-faceted and/or multi-disciplinary.

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. Specifically, these included targeted resourcing, commitment to equity in the programme at leadership and provider levels, community engagement and education with Māori and Pacific populations before mailing out the invite, a systematic reminder system, monitoring, and use of participant navigation. A number of these recommendations have been incorporated into the BSP.

4.3 WDHB development process

Overview of the WDHB bid for the BSP

In December 2010, WDHB were chosen as part of a selective tendering process to undertake the Pilot. The Waitemata DHB proposal demonstrated (Ministry of Health 2011)[13]:

- an understanding of their current capacity to provide colonoscopies and a clear plan to provide the additional capacity required for the Pilot
- the capacity to treat participants who have a diagnosis of cancer
- a thorough understanding of the entire screening pathway
- the ability to use their expertise and experience in running their regional breast screening programme
- evidence of support from primary care providers in the region.

WDHB clinicians, planning and funding personnel worked with primary care representatives to develop the WDHB bid. WDHB saw the BSP as an opportunity to improve symptomatic services, particularly endoscopy, as well as a chance to offer a bowel screening programme to the WDHB population. The bid was supported by the two other Auckland DHBs through a process led by the Northern Cancer Network. Auckland DHB (ADHB) offered to contribute its laboratory (LabPLUS) and endoscopist capacity to the BSP. Counties Manukau DHB (CMDHB) also offered endoscopist capacity, although to date no CMDHB endoscopists have worked on the BSP.

The WDHB bid, including how the programme would be resourced, was modelled on the breast screening programme. The breast screening model was seen to work well and to offer structures and processes that the bowel screening programme could draw on (e.g. an existing call centre, programme and data management, effective outreach processes for Māori and Pacific populations). Breast screening sat under Surgery so bowel screening was also positioned within Surgery. This allowed the two programmes to have the same reporting lines.

Role of primary care

Primary care played a key role in the development of the WDHB bid and in the final BSP service model. In WDHB primary care stakeholders perceived that breast and cervical screening had been imposed on them without primary care having a significant role. The team working on the WDHB bid were keen to ensure that this was not the case for bowel screening.

> *"Doctors wanted to manage positive results, wanted to protect relationships with their patients ... Tried very hard to avoid leaving GPs out of bowel screening after breast screening experience."* (PHO)

[13] http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/bowel-cancer-programme/bowel-screening-pilot accessed 15 December 2011.

From a health systems perspective, WDHB wished to avoid multiple systems and increase the chance of programme sustainability through ensuring the bowel screening programme was integrated with primary care. Consequently, general practices were given responsibility for notifying their participants of positive iFOBT results, and actively referring them to the BSP endoscopy service for colonoscopy.

Involvement of Māori and Pacific in the WDHB development process

From the outset, WDHB acknowledged that Māori and Pacific populations were BSP priority populations, as their engagement and completion of bowel screening was likely to be lower than other population groups.

At a WDHB level, Māori and Pacific stakeholders were involved in programme design and set-up 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 programme delivery (e.g. community awareness raising)
- health equity workshops.

Ensuring equitable participation by Māori and Pacific populations was a key focus of discussions with Māori and Pacific advisors.

BSP commencement

In October 2011, a soft launch of the BSP commenced to test the BSP screening pathway before the main launch in January 2012. A sample of 500 eligible participants was drawn from two general practices. A letter was sent from their GP telling them that they had been selected to participate in the soft launch and that the GP supported their participation. This letter from the GP was unique to the soft launch and was used to ensure a high response rate to test the BSP systems. Following the soft launch, GP endorsement only appears generically in the pre-invitation letter (i.e. the GP is not named).

After the GP letter, the first batch of 500 pre-invitation letters was sent out. The distribution of test kits quickly followed. The test kits were distributed in less than the usual four weeks to ensure participants with positive iFOBT results were able to progress to colonoscopy before Christmas.

4.4 Success factors in the development phase

Several factors appear to have been important to the successful development and subsequent roll-out of the BSP. These are detailed below.

- **Widespread sector support** for a bowel screening programme.

  > *"[The BSP was] well supported by the sector on the whole ... we didn't get push back from any particular group."* (Ministry of Health)

- **The Bowel Cancer Taskforce** was seen to provide an important source of support and guidance during the programme development phase.

> *"Right set of people around the table providing the right advice at the right time. I don't think we'd have a safe, effective bowel cancer screening programme without them."* (Ministry of Health)

- **A committed and skilled bowel screening project team**.

> *"Had great people while building the system. Very dedicated team of people doing it."* (Ministry of Health)

- **Using an iterative approach to develop the Register**. The Rapid Application Development approach allowed the project team to user-test different iterations of the system as programme and system requirements continued to be refined. The incremental build was also key to ensuring the information system – albeit an early version – was ready for programme launch. The build took seven to eight months.

> *"For a national programme, would really recommend an incremental build as such a great way of making sure we get a system that delivers the outcomes that users and businesses are expecting. This was invaluable."* (Ministry of Health)

> *"Wouldn't have been able to deliver in any other way in the timeframe. We allowed for 20% change, think it was about 50% change in the end. That's why we had two releases - Release 1 allowed invitations to go out, Release 2 was able to accept lab results and move participants through the pathway – Release 2 was a wash up of all the changes that couldn't be done in time for Release 1."* (Ministry of Health)

- **Situating the development of the bowel screening programme within the Cancer Team** rather than the National Screening Unit. This decision was seen to offer a number of benefits, including positioning the programme within the wider cancer continuum and supporting BSP integration with primary care.

> *"A decision was made (don't know why) to place us in the Cancer programme – helpful to widen the perspective across the whole cancer continuum."* (Ministry of Health)

4.5 Challenges in the development phase

Several elements of the development phase were challenging for the Ministry and WDHB teams working on the design and final development of the BSP. These are detailed below.

- **Colonoscopy capacity and quality**. The availability of skilled endoscopists and endoscopy nurses, capable of undertaking screening-standard colonoscopies, is the challenge identified most frequently in relation to all aspects of the BSP.

  The initial scoping work for introducing the BSP revealed long wait lists for colonoscopies, considerable variation in DHBs' referral processes, inadequate triage, prioritisation and quality monitoring systems for colonoscopy, and a lack of training or accreditation for endoscopists across New Zealand. WDHB endoscopy services also faced these challenges. The identified quality and capacity issues reinforced the decision to pilot bowel screening before proceeding to a national screening programme. It also highlighted the potential risk that participants in the BSP may receive faster and higher quality services than symptomatic patients.

As noted, the NZ GRS is a key tool in the response to endoscopy capacity and quality issues. Stakeholders view the NZ GRS as the pre-implementation quality improvement mechanism for ensuring endoscopy units are ready to implement a national bowel screening programme. In WDHB, stakeholders note that the NZ GRS project did not develop the traction needed within a timeframe that was useful for the BSP. The development of quality policies and processes for the BSP therefore went ahead of the NZ GRS.

> *"The key issue for the ongoing Pilot is to ensure you have ongoing colonoscopy capacity and quality. Quality colonoscopy relies on capacity."* (Ministry of Health)
>
> *"It's all about colonoscopy capacity."* (WDHB)
>
> *"The two would have to go hand in hand. You couldn't not have looked at the GRS component and say we are going to have a national roll-out. You needed the GRS to see if you could actually get sites ready." (Ministry of Health)*

- **Agreeing the role of primary care in the screening pathway**. There was much debate and negotiations between the Ministry and WDHB over general practices' role in the notification of iFOBT results. These debates reflected differing perspectives about the role of primary care in screening per se, and concerns about general practices' ability to meet notification and referral timelines required by the BSP quality standards.

  The decision to include primary care reflected the shift to greater primary care integration in the health system, and the positive results noted in overseas programmes where primary care had a leading role[14]. The perceived ability of general practice to encourage Māori and Pacific people, and their wider patients to take part in the BSP strengthened the rationale for their inclusion in the BSP model.

  WDHB successfully negotiated with the Ministry for general practice to have a wider role in the BSP, as well as a longer timeframe in which to communicate iFOBT results to their participants (ten days instead of the original five days).

  The enhanced role of general practice in results notification required significant modifications to the BSP information system. For the lab to send electronic iFOBT results to participants' GPs, the system had to collect general practice information for each participant (usually this is known as lab tests are requested by individual doctors). Matching BSP participants to individual GPs is challenging when not all participants have an identified GP, people change their GPs and some participants belong to a general practice but do not have an assigned GP within that practice.

  > *"Always a tension between it being a public health programme, nationally-run, nationally-based versus a primary care component. The underlying ethos of screening is that it is run nationally ...If you're a purist in screening programmes then GPs don't have the level of involvement that they do in our programme."* (Ministry of Health)
  >
  > *"Was difficult, mostly internally in the team, where people had different perspectives. Biggest concern was that 'it's not a population health programme'. Some were also concerned about the delays with getting positive results to people."* (Ministry of Health)

[14] GP involvement in bowel screening has been shown to have a positive impact on FOBT screening participants, although this is subject to high variability (Federici et al 2006, Koo et al 2010, Power et al 2009)

- **Developing the Register without clearly defined specifications based on a final service delivery model**. The iterative development approach to the Register enabled continual development of the system as details of the service model were being finalised. However, the lack of certainty regarding how systems were going to work and the large number of changes required was challenging for the system developers.

  Ideally, the service delivery model, the roles and responsibilities of different providers, and the overall business process, would be decided before system development commenced. Consequently, a stable set of system requirements would be agreed against which the system could be built.

  > *"A key challenge was the changing decisions, or sometimes lack of decisions being made between Ministry and WDHB regarding how the systems were going to work - who was responsible for notification, how the invitation process would work etc."* (Ministry of Health)

4.6 Lessons for a potential national roll-out

The following lessons have been identified as useful to inform a national roll-out of a bowel screening programme, should it proceed:

- **Prioritise colonoscopy capacity and quality**. The availability of skilled endoscopists and endoscopy nurses is critical to both the BSP and to a national roll-out of a bowel screening programme, should it proceed. The NZ GRS will be an important mechanism for ensuring endoscopy units can meet the high quality standards required in bowel screening. Other activities designed to support improved capacity and quality of endoscopy services (e.g. colonoscopy standards, referral, triage and prioritisation standards, consideration of an expanded role for endoscopy nurses) will also be important.
- **Finalise the bowel screening service model** before beginning the information system build. The BSP should inform clear decisions about the delivery model, roles and responsibilities and business processes for a national programme. Clear agreement on the model will provide a stable set of requirements for developing the information system. In a national information system, consideration will need to be given to which (if any) aspects of the system can be tailored to local provider information systems.
- **Ensure strategic and operational involvement of Māori and Pacific clinical and community leaders** at all levels and in all programme phases and from the outset of the programme development. This will increase the likelihood of the programme being effective for priority populations. Involvement needs to sustained, challenging of underlying assumptions and strength-based focused on addressing inequities and barriers created in policies, systems and processes barriers.
- **Ensure transfer of knowledge between BSP and a national programme** through knowledge management and advice from those involved in the BSP.

  > *"Critical for continuity of knowledge when transitioning from small to large. No amount of documentation can replace the value of people involved who have been involved throughout. The things that are not documented are why things weren't done a certain way." (Ministry of Health)*

- **Allow for a realistic implementation planning period** for providers to demonstrate their ability to meet 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, set up quality and reporting systems, etc.

"One of the tensions is how quickly you will be able to roll-out a programme. The reality, and our knowledge and experience from overseas projects, is that careful slow progression is the best option. You would probably do it in a systematised way – you would only roll it out when you are satisfied the provider has met the core standards and that they had the infrastructure to support the screening programme." (Ministry of Health)

"DHBs would need to be funded for an implementation planning phase of an agreed period. And the Ministry would determine when a DHB was ready to roll-out." (WDHB)

5. Leadership, governance and management

This section of the report provides an overview of current BSP leadership, governance and management structures. Aspects of these structures that work well ('strengths') and aspects that do not work so well ('challenges') are identified. The section concludes by identifying suggested areas of change for enhancing the ongoing delivery of the BSP, and lessons to inform a national roll-out of a bowel screening programme, should it proceed.

5.1 Overview of leadership, governance and management structures

Advisory groups

The BSP is currently overseen by six core advisory groups at a national and regional level:[15]

National level advisory groups to the Ministry

1. **Bowel Screening Advisory Group** to the Ministry: The role of this group is to:
   - provide strategic guidance on the direction, approach and development of the BSP
   - provide ongoing monitoring of the BSP
   - advise on the technical aspects of the BSP and review performance of the iFOBT
   - advise on a possible national bowel screening programme in New Zealand.

   This group, which meets a minimum of every three months, was convened by the Ministry. Members have relevant experience in diagnostic and treatment services for bowel cancer. The Bowel Screening Advisory Group is a sub-group of the National Bowel Cancer Working Group which was set up following the disestablishment of the Bowel Cancer Taskforce and retains some Taskforce members.

2. **BSP Evaluation Advisory Group**: The role of this group is to:
   - oversee and monitor the independent evaluation of the BSP
   - provide strategic guidance on the direction and approach of the evaluation including approval of the Evaluation Plan
   - peer review annual evaluation reports and other publicly released reports
   - advise on and approve any subsequent substantive changes to the Evaluation Plan
   - provide independent advice or comment on any aspect of the evaluation (if requested) by the Ministry.

[15] Refer to the *Reporting Framework for Bowel Screening Programme* (Ministry of Health 2012).

This group meets bi-annually as a minimum. Membership comprises people with professional expertise in bowel screening, cancer epidemiology, evaluation (including formative evaluation), statistical analysis with expertise in modelling, health services research and evaluation, health economics, Public Health, screening, kaupapa Māori and research/evaluation with other minority groups, consumer, and diagnosis and management of bowel cancer in the New Zealand setting. The group also has representative/s of Cancer Control New Zealand (CCNZ).

WDHB level advisory groups

3. **BSP Steering Group**: The role of this group is to:
   - review and monitor BSP data and recommend actions to ensure equity of access (and safety needs)
   - monitor the capacity and capability of the BSP to deliver services along the screening pathway in accordance with the BSP quality standards
   - review the BSP risk register on a regular basis
   - identify barriers (and gaps) to successful delivery of the BSP and advise on mitigating strategies and action.

   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.

4. **BSP Clinical Governance Group:** The role of this group is to:
   - advise on the development and review of key clinical performance indicators
   - advise on the clinical impact of policies and related implementation issues
   - monitor the capacity and capability of clinical services along the screening pathway in accordance with the BSP quality standards
   - advise on areas for audit or investigation arising from results of monitoring clinical activities.

   This group meets quarterly as a minimum. Membership comprises Ministry of Health National BSP Clinical Director, WDHB BSP Clinical Director, WDHB BSP Lead Endoscopist, WDHB BSP Quality Lead, WDHB BSP Endoscopy Clinical Nurse Specialist (CNS), and LabPLUS Chemical Pathologist and Anatomical Pathologist.

5. **BSP Quality Assurance Group**: This group was formerly the **Quality Working Group**, and its role is to:
   - review relevant standards, guidelines and other documentation to support the BSP
   - monitor performance/compliance of the BSP against appropriate standards and guidelines
   - identify quality improvement initiatives for the BSP
   - provide a mechanism for formal sign-off of quality related documentation
   - risk monitoring and management.

This group meets monthly as a minimum. Membership comprises WDHB BSP Quality Lead, WDHB BSP Clinical Director, WDHB BSP Lead Endoscopist, WDHB BSP Programme Manager, WDHB BSP Endoscopy CNS, LabPLUS Quality Manager, Ministry of Health BSP Senior Quality Advisor and a GP.

6. **The Community Awareness Raising (CAR) Group**. The role of the Group is to raise awareness, establish acceptance and operate within an equity framework. The CAR Group:
   - advises on the identification and development of culturally appropriate key messages and resources
   - provides guidance and support to BSP that takes advantage of existing leadership structures, local champions, known community links and resources and the leveraging off these to raise BSP awareness
   - assists with the review of feedback, data and reports to develop specific community awareness raising action plans for Māori and Pacific populations.

   This group meets quarterly. Membership comprises of WDHB Planning and Funding Māori and Pacific Managers, Inequalities Advisor from the Northern District Cancer Network[16], WDHB community engagement coordinator, WDHB Māori representative, a representative of West Fono, consumer representatives and PHO representatives.

Management groups

In addition to the six advisory groups for the BSP, the WDHB has three management groups:

- **Endoscopy Review Group** – This group meets fortnightly to ensure the colonoscopy service is running smoothly and reviews readmissions, performance against endoscopy standards, etc. The group comprises the WDHB BSP Clinical Director, the WDHB BSP Lead Endoscopist, the WDHB BSP Endoscopy CNS, the WDHB BSP Programme Manager, and the WDHB BSP Quality Lead.
- **Project Management Group** – This group was established to support planning of implementation. Its membership currently includes the WDHB BSP Programme Manager, senior Coordination Centre personnel, LabPLUS personnel, and PHO representatives. In its early form membership also included the Charge Nurse at Waitakere Surgical Unit, the Operations Manager for Theatres and Anaesthesia, a WDHB IT person, the WDHB Planning and Funding Māori and Pacific Managers, and the WDHB Community Engagement Coordinator. These stakeholders no longer attend regularly as this group now focuses on review and monitoring of results and any issues arising. The group currently meets monthly however, there is a plan to reduce the frequency of these meetings to quarterly.
- **A weekly programme meeting** – This group comprises the WDHB BSP Programme Manager, Clinical Director, Data Manager, Communications Advisor, CAR Coordinator and Coordination Centre Office Manager. This meeting focuses on operations, ensuring everyone is aware of what is going on. An issues register is maintained and reviewed at all meetings.

[16] These stakeholders no longer attend regularly as the group now focuses on strategic planning rather than BSP implementation.

Accountabilities

Accountability for the BSP within the Ministry sits with the Group Manager, Personal Health Services Improvement (formerly the National Programme Manager for Cancer). The focus of this role (in regard to the BSP) is on ensuring the Pilot is supported to be successful and strategic inter-linkages are developed in preparation for a possible national roll-out. These linkages include, for example, conversations with the National Screening Unit, the National Health Committee and financial personnel.

The National BSP Clinical Director and the National BSP Programme Manager report to the Group Manager, Personal Health Services Improvement. The National Programme Manager provides a formal monthly report to the Group Manager and they have weekly meetings.

In WDHB, accountability for planning for roll-out (the first year of the BSP contract) sat with the Chief Planning and Funding Officer. The Project Manager reported to this role and the Programme Manager reported to the General Manager Surgical and Ambulatory Services.

WDHB Planning and Funding now contracts to the WDHB provider arm for provision of BSP services. Accountability for BSP operations has therefore transferred to Surgical and Ambulatory Services. In this context, the Project Manager and Programme Manager (currently the same person) report to the General Manager Surgical and Ambulatory Services, with a less formal reporting line to the Chief Planning and Funding Officer. The Clinical Director reports to the General Manager Surgical and Ambulatory Services.

Reporting and communications

In the pre-launch stage, WDHB programme management personnel had a weekly teleconference with the Ministry team. Once the programme went live, key WDHB personnel (including programme management and LabPLUS) had daily 'go live' teleconferences with the Ministry team. The frequency of these teleconferences reduced to weekly, then to 'as required', and then stopped altogether in June 2012. The WDHB BSP Programme Manager and the National Programme Manager also spoke daily in the pre-launch and go live phases.

Formal reporting from the WDHB to the Ministry is via the following mechanisms:

- Annual Coordination Plan
- monthly progress reports during the period January – June 2011
- quarterly progress reports for the period July 2011 – December 2015
- biannual coordination reports for the period July 2011 – December 2015
- biannual business review meetings involving senior people from the WDHB and the Ministry
- final report August 2016.

5.2 Strengths of leadership, governance and management structures

Strengths in the BSP leadership, governance and management structures as described in Section 5.1 are detailed below.

- **Bowel Screening Advisory Group**. In the same way that the Taskforce played a valuable advisory role during the development phase, the Bowel Screening Advisory Group is seen to provide valuable leadership and advice for BSP implementation.

  > *"Having the Advisory Group was key - critical that the Taskforce expertise carried through." (Ministry of Health)*

- **Effective clinical leadership**, from both the Ministry and WDHB. The Ministry had a period of months when the National Clinical Director position was vacant; this proved a significant challenge and highlighted the importance of this role.

  The WDHB BSP Clinical Director has a particularly strong and effective leadership role in the BSP. WDHB stakeholders highlighted the importance of having clinical leaders who are accessible and engaged.

  WDHB stakeholders noted the strong lead taken by the WDHB BSP Clinical Director on building relationships, particularly with primary care. The Clinical Director has played a key role in promoting the BSP to primary and secondary care clinicians, as well as liaising with GPs and endoscopists regarding BSP operations. Non-clinical stakeholders emphasised the value of having a senior clinician liaising directly with other clinicians.

  > *"[The WDHB BSP Clinical Director and Lead Endoscopist] are both very engaged and very approachable - both out at Waitakere every week doing lists." (WDHB Endoscopy)*

  > *"Strong clinical director leadership - really crucial in terms of having a clinician to clinician relationship with GPs. Any issue with a participant or GP involvement, [the WDHB BSP Clinical Director] has simply picked up the phone to discuss - GPs have really appreciated that - senior person, very competent, ringing and discussing." (WDHB)*

- **Effective relationship-based programme and project management in WDHB**. Having a core programme team that represents key components of the BSP (clinical leadership, programme management, quality and endoscopy) and works effectively together is a significant strength for the ongoing implementation of the BSP. Having a highly experienced, skilled and competent Programme Manager, particularly one with screening experience and links to primary care, has also been very important. The Programme Manager has played a key role in building and maintaining good relationships with LabPLUS and primary care.

- **BSP provider representation in leadership, governance and management structures has enabled BSP implementation.**
  - Primary care is represented on the Steering Group, the Quality Assurance Group and the Project Management Group.
  - LabPLUS is involved in the Clinical Governance Group, the Quality Assurance Group and the Project Management Group.
  - Endoscopy is involved in the Clinical Governance Group, the Quality Assurance Group and all three WDHB management groups.

Feedback from stakeholders highlights that having providers from across the screening pathway involved in decision making structures helped build support for the programme, and assisted with a smooth implementation process. Being involved in design and implementation decision making enabled providers to understand the wider challenges of implementation across the screening pathway and the interfaces with their areas of responsibilities, and as a result, providers were committed to working collaboratively to find solutions to issues arising.

> *"Because volumes are difficult to predict, lots of things have to be planned and funded based on assumptions - you need everyone on the pathway to demonstrate some goodwill and flexibility. For example, funding of the lab is based on assumptions regarding numbers. Uptake has been higher, histology has been higher - we've needed to work together on how we're going to manage that demand. It's very unhelpful if providers refuse to offer more - because Lab has been 'in the tent', they're part of finding solutions." (WDHB)*

5.3 Challenges associated with leadership, governance and management structures

Some challenges and areas for strengthening the BSP leadership, governance and management structures are detailed below.

- **Establishing effective governance structures between the Ministry and WDHB**. Work was undertaken early in the development to clarify and agree effective governance and advisory structures and their roles and responsibilities, and associated reporting requirements.

  > *"Nobody knew what data would come to what [group], so there has been a lot of work that we have been doing with the previous data paths and we have been looking at the components of the quality standards and which parts would need to go to which committees – day-to-day monitoring, or strategic meeting, and actually plot the reporting mechanisms really." (Ministry of Health)*

- **Ensuring clear roles and responsibilities and accountability between the Ministry and WDHB**. An ongoing tension has been negotiating the accountability lines between the Ministry and WDHB. At times, the Ministry is perceived as stepping over the role of funder and seeking to have greater say and control in operational matters. The strong, collaborative and trusting relationship between the Ministry National Programme Manager and the WDHB BSP Programme Manager, and their shared understanding of their organisations' different roles has facilitated the negotiations around these tensions.

  > *"The other difficulty is figuring out who is responsible for what. What is the Ministry's responsibility – monitoring and oversight - versus the WDHB responsibility – charged with implementing the Pilot?... We (the Ministry) need to let them (WDHB) get on and do it, and if mistakes are made then they need to learn from that … That's been the most difficult challenge, not so much the governance arrangements but sorting out responsibilities.' (Ministry of Health)*

  > *"Challenge between WDHB and the Ministry has been with boundaries - what's a WDHB and what's a Ministry accountability/decision?" (WDHB)*

- **Reporting and accountability lines within WDHB**. Although WDHB accountability lines are reasonably clear (the Programme Manager and the Clinical Director report to the General Manager Surgical and Ambulatory Services), the Service Level Agreement formalising the Surgical and Ambulatory Services contract to provide the BSP has been drafted but not signed. The Programme Manager (who is also currently the Project Manager) continues to report informally to the Chief Funding and Planning Officer. This contributes to a perception that no single senior WDHB manager 'owns' the BSP.

  Feedback from WDHB stakeholders highlighted debate about where bowel screening best fits within DHB structures and systems, who is accountable for programme delivery and where the reporting lines lie. There is considerable support among WDHB personnel for the BSP sitting in Gastroenterology, within Medicine, rather than in Surgery.

  > *"It would be good to have more DHB General Manager involvement - one was involved in negotiations but peripherally involved now." (Ministry of Health)*

- **Limited Māori and Pacific representation in leadership and governance structures.** There is a Māori representative (from Northern District Cancer Network) on the Steering Group. Māori and Pacific General Managers were on the Project Management Group, and continue to be regularly consulted with, particularly on community awareness raising in Māori and Pacific communities. There is no Māori or Pacific representation on other leadership, management or governance groups, with the exception of Māori representation on the BSP EAG, the National Bowel Cancer Working Group and Bowel Screening Advisory Group.

  To maximise outcomes for Māori and Pacific from the BSP, a strategic approach needs to be taken to the design, deliver and monitor participation. If equitable outcomes for Māori and Pacific are to be achieved, it is critical to seek expert advice from Māori and Pacific at all programme levels, from decision making to operations, and at all phases of the programme, from development to implementation.

  > *"Disappointed we don't have Pacific participation at that [Steering Group] level." (WDHB)*

  > *"Probably a gap, but difficult to know what to have at governance and what to have at ops. Someone to provide advice would be good. Someone who could look at programme design and comment on the effectiveness of it for Māori and Pacific." (WDHB)*

- **Inadequate resource and support for WDHB programme management and clinical leadership roles**. Resourcing of the BSP was based on the breast screening model and as a result there appears to have been an under-estimation of the work involved for key management and leadership roles. The resourcing challenge is further complicated by the heavy existing demand on BSP clinical leadership from symptomatic services, making it hard to ring-fence hours meant to be spent on BSP.

  > *"A key challenge has arisen out of well-intentioned, under-estimation of the size and complexity of the exercise. Resourcing was based on what was needed for breast screening - this was a huge under-estimation, particularly for development of the programme and then for the initial roll-out." (WDHB)*

  > *"Clinical Director and Endo Lead is a challenge, working such small hours. CNS needs to talk clinically with them and their availability is minimal." (WDHB)*

  > *"Coordination Centre Programme Manager – too much work to be a 0.5 position." (PHO)*

5.4 Considerations for enhancing the BSP

Some of the challenges identified in Section 5.3 can be addressed in the short to medium-term, with potential benefit to the BSP and its ability to achieve its intended goal and objectives. Considerations are listed below.

- Review the purpose of the BSP Steering Group, particularly with regard to whether it should fulfil an enhanced clinical governance function, and review Group membership to ensure it is fit-for-purpose. *Note: Already actioned by WDHB.*
- Continue to review and reinforce boundaries between the different roles and responsibilities of the Ministry, as funder, and WDHB, as provider of the BSP.
- Strengthen Māori representation on BSP governance and advisory groups. Investigate ways to increase Māori involvement and decision making in the BSP at leadership and operational levels.
- Gain Pacific representation on BSP governance and advisory groups. Investigate ways to increase Pacific involvement and decision making in the BSP at leadership and operational levels. To achieve this may require looking for this expertise outside of WDHB.
- Review the scope of the WDHB BSP Programme Manager role and clinical leadership roles and consider additional resource to increase capacity.

5.5 Lessons for a potential national roll-out

The following lessons about leadership, governance and management structures have been identified as useful to inform a national roll-out of a bowel screening programme, should it proceed:

- Ensure clarity in the roles and responsibilities of the Ministry versus providers.
- Strong clinical and non-clinical leadership and management structures. Leadership needs to include people with previous experience of screening programmes.
- Early and ongoing representation of Māori at strategic and operational levels to facilitate the identification of strategies to ensure participation by this population.
- Early and ongoing representation of Pacific at strategic and operational levels to facilitate the identification of strategies to ensure participation by this population.
- Early and ongoing involvement of key providers (endoscopy, primary care, laboratory) in leadership, governance and management structures.
- At a provider level, ensure clear management and accountability structures and effective resourcing of key clinical and non-clinical roles.

> *"The importance of identifying key leaders. Good knowledge of bowel screening, people who are passionate for the concept but understand its limitations." (Ministry of Health)*

> *"Identify people who are competent to manage a programme - there have been plenty of screening programmes going on in New Zealand, need to involve people with some experience in screening." (WDHB)*

"A good screening programme relies on good collaborative relationships …Trying to make sure that you maintain good working relationships between all the groups. Communication across the programme is really important." (Ministry of Health)

"[Provider] programme manager needs to have good relationships with their equivalent in the Ministry. Ability to pick up the phone, take a collaborative approach, expect that they are 'rolling it out together'." (WDHB)

6. BSP Waitemata district coordination

This section provides an overview of BSP Waitemata district coordination functions before presenting detailed information on: the BSP Register, the information line, kit collation and postage, communications strategy and community awareness raising. For each area, successes and challenges are noted followed by potential enhancements to the ongoing delivery of the BSP and considerations to inform a future national roll-out, should it proceed.

6.1 Overview of BSP coordination functions

Programme management and clinical leadership

In February 2011, a full-time equivalent (FTE) Project Manager was contracted for 12 months to support the planning and implementation phase of the BSP. In February 2012, the Project Manager's contract was extended for a further year to continue to support the Programme Manager given their significant workload.

The Programme Manager is a 0.5 FTE role, based at the BSP Coordination Centre in Takapuna, Auckland. The Programme Manager role was originally held by the Breast Screening Programme Manager, who was 0.5 FTE on BSP and 0.5 FTE on Breast Screening. Since June 2012, when the Programme Manager resigned, the BSP Project Manager has also held the Acting Programme Manager role.

The BSP Clinical Director role is held by the Head of the Colorectal Surgery Unit at North Shore Hospital and is a 0.2 FTE role. The focus of this role is clinical oversight of the Pilot and includes oversight of the BSP Endoscopy Unit, regular endoscopy lists, histology sign-off and liaison with primary and secondary care clinicians.

The BSP Register

The BSP Register is owned and overseen by the Ministry of Health. WDHB's work on the Register is based at the Coordination Centre and managed by the BSP Data Manager. The Data Manager, who is 0.5 FTE on BSP and 0.5 FTE on Breast Screening, also manages the BSP information line and data administration teams.

There are two BSP data administration staff (1 FTE each). Their role is to update participant details on the Register (name, address, phone number, GP) based on information provided on consent forms, and to check test results have been uploaded. Data administrators also play a key role in kit collation and postage processes (see below).

Information phone line

The BSP information line is based at the Coordination Centre and is staffed by three people (3 FTE). Their primary role is to answer incoming calls on the information line. They also help out with data entry, a monthly consent form audit, active follow-up of spoilt kits, and filing.

Community awareness raising

The community awareness raising (CAR) team is based at the Coordination Centre and comprises a CAR Team Leader (1 FTE), a Māori CAR Coordinator (1 FTE), a Chinese CAR Coordinator (0.6 FTE) and a Korean CAR Coordination (0.4 FTE). In addition, West Fono and Pacific Integrated Health, Pacific primary health providers, are contracted to undertake CAR work with Pacific populations in the North Shore and West Auckland.

Waitemata PHO and Procare do not have a formal role in CAR for priority populations. However, their health promotion staff are members of the CAR Group.

Kit collation and postage

Three organisations are involved in postage and iFOBT kit collation: Orangebox (a logistics company), the BSP Coordination Centre and NZ Post.

Orangebox is responsible for the storage of test kit instructions and envelopes, and for the collation of the test kit components.

The Coordination Centre Office Manager, who is 0.5 FTE BSP and 0.5 FTE breast screening, manages consumables for the iFOBT kits. This includes ordering and managing the printed material and the test kit components. Data administrators at the Coordination Centre are responsible for:

- collation and mail out of the pre-invitation letter and brochure
- receipt of test kit components
- printing and insertion into test kit envelopes of consent forms and invitation letters
- mail out of test kit envelopes
- stock management and stock storage
- management of spoilt kits
- management of returned mail
- stock management.

NZ Post delivers pre-invitation letters and test kits to eligible participants, and postal and courier delivery of completed test kits to LabPLUS.

Quality assurance

At a district level, quality assurance is led by the WDHB Quality Lead; a full time role based at the Coordination Centre.

In the implementation planning phase, the WDHB Quality Lead worked with the Ministry on development of the key quality documents and establishment of the Quality Working Group (now the Quality Assurance Group). The day-to-day implementation role includes complaint management, incident management, participant surveys, readmission reporting and development and documentation of policies and processes.

There is also a Quality Analyst within the Ministry bowel screening team.

Primary care liaison

The BSP funds primary care liaison within Procare and Waitemata PHOs. The funding is used to support a range of activities to support and enable primary care involvement in the BSP, including practices outside the Waitemata district where Waitemata residents are enrolled. In Waitemata PHO, the BSP funds a dedicated 0.5 BSP primary care liaison person. The role of primary care liaison is to inform and educate general practice teams about the BSP, set up services for claims (e.g. for practices to claim from PHOs for results notification), and set up screening templates.

There is also a PHO representative on the BSP Steering Group. Both PHOs have a representative on the Programme Management Group, and there is a GP on the Quality Assurance Group.

Endoscopy

Colonoscopy for the BSP is provided by a dedicated screening unit (the BSP Endoscopy Unit) at Waitakere Hospital. The Endoscopy Unit comprises one dedicated BSP endoscopy room[17], a Lead Endoscopist, two clinical nurse specialists (CNS), four dedicated endoscopy nurses, and one administrator.

The role of the **BSP Lead Endoscopist** is 0.2 FTE and includes:

- medical management (e.g. management of people for whom colonoscopy is not appropriate, management of people on anti-coagulant drugs)
- results management (dealing with the lab results from colonoscopies, along with the Clinical Director)
- advice regarding the suitability of endoscopists for the BSP
- participation in BSP management
- one endoscopy list per week
- oversight of endoscopists' performance.

The role of the **CNS** is to facilitate colonoscopies, including contacting participants, undertaking phone pre-assessments, arranging appointments and overseeing the BSP rooms. The CNS will sometimes work in the endoscopy room. The CNS role is 1 FTE. A second CNS for the BSP (1 FTE) has recently been appointed. The four endoscopy nurses work across the BSP endoscopy room, the symptomatic endoscopy room (if available and required), and recovery.

The **BSP Endoscopy Administrator** manages all appointment bookings, couriers out information packs, ensures participants have transport and a support person for the day of the procedure, organises interpreters, organises for participant notes to be sent over from Clinical Records, manages distribution of histology reports, sends closed BSP files to the Coordination Centre and monitors the Register for overdue positive results or missing referrals.

[17] There is a second endoscopy room at Waitakere Hospital which is used if available for BSP lists.

BSP colonoscopies are currently undertaken by:

- the BSP WDHB Clinical Director (one list per week)
- the BSP Lead Endoscopist (one list per week)
- the Clinical Director Gastroenterology
- ADHB (one list a week, shared by four colonoscopists) - this contribution is scheduled to end in December 2012
- two private sector, sessional colonoscopists
- three regular WDHB endoscopists.

Dependent on endoscopist availability, the BSP Endoscopy Unit at Waitakere Hospital has capacity to undertake ten BSP colonoscopy lists a week, which equates to around 50 colonoscopies per week.

Lab testing of iFOBTs and histology samples

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.

Further information on the BSP Register, the information line, kit collation and postage, community awareness raising, and quality assurance, is provided in Sections 6.2 to 6.6 below. Endoscopy and laboratory aspects of the BSP are covered in Chapter 7. Management and leadership structures are covered in Chapter 5.

What's working well?

Relationships between programme management/coordination and BSP providers are, in the main, good.

- **The interface with primary care** is perceived positively. Significant engagement has been undertaken by the BSP Clinical Director and BSP Programme Manager to ensure primary care is informed about the BSP and their role in the screening pathway. Any issues arising relating to primary care's role in the BSP have been dealt with promptly by the BSP Clinical Director and BSP Programme Manager.

  > *"Good primary care input. [Programme manager has] included primary care in everything, opportunity to discuss and input - it's been great, wish we could do that with other projects." (PHO)*

Beyond developing positive and effective relationships, key facilitators to achieving primary care buy-in are funding a practice liaison role and PHO-led activities, and reimbursing general practices for the management of positive iFOBT results. In a multi-priority primary care environment, solely relying on goodwill to ensure buy-in and defined behaviour was seen as an ineffective and risky engagement strategy. Recognising the time intensity of the activities required, the BSP paying PHOs offered reassurance that BSP activities in relation to systems and education occurred. Further, paying general practice to offer a consult and make a referral ensured adherence to quality standards relating to management of positive iFOBT results.

> *"It's been crucial to fund people within primary care to work on our behalf - this has meant that [programme management] can control and require things of [practice liaison personnel]. Recognising that what we've needed is time and resource intensive, why would we not expect to purchase that?" (WDHB)*

> *"MOH [Ministry of Health] cannot assume that GPs are going to give patients a free consultation if not funded by the MOH - capitation does not fund it - either the patient or MOH has to pay." (PHO)*

> *"Important to reimburse general practice for their role. Given that we wanted doctors to do more than just make referral (e.g. offer consultation), we felt quite strongly that we couldn't ask GPs to schedule an additional appointment that's free to patients, so the cost is absorbed by general practice - in this instance, someone needs to pay for the GP consultation." (WDHB)*

- **The interface between the Endoscopy Unit and programme management/ coordination** is perceived to be working well with frequent interaction between the Unit and the Coordination Centre. The Clinical Director, Programme Manager and Quality Lead visit the Endoscopy Unit frequently; the Clinical Director, Programme Manager, Quality Lead and CNS work together on BSP management groups; the information line staff are regularly in touch with the endoscopy nursing staff; and the Chinese CAR coordinator is often out at the Unit to support BSP participants.

> *"Between Coordination Centre and Endoscopy Unit - great relationships - tight-knit group that runs the programme - very good team." (WDHB)*

- **Relationships between LabPLUS and programme management/coordination are viewed positively by both parties**.

> *"The relationships with the Lab are really good – they're responsive, willing to fit things in."(WDHB)*

> *"Engagement with the Coordination Centre, [programme manager] and the team is fantastic." (LabPLUS)*

What are the challenges?

- **Having the BSP delivered across three different locations** (Takapuna, Grafton and Henderson) makes it more challenging for the Coordination Centre, the lab and the Endoscopy Unit, to work together as a team. A potential risk exists of documentation or specimens getting lost[18] and timeliness being compromised with the movement of material between the three sites. Internationally, the lab and the coordination centre are co-located in bowel screening programmes.

[18] The Ministry is not aware of any situations were either documents or specimens have gone missing.

"Proximity of services - so everyone feels they're part of the same team. I think it's a shame that our Coordination Centre and endoscopy service are so far apart. This constrains us from having corridor conversations. Everything has to be planned." (WDHB)

"Geographical distances not good for coordination. Would be good for the lab to be on same site as Coordination Centre." (WDHB)

"Having the lab and iFOBT distribution and the Coordination Centre at three different sites is a bit mucky at the moment. It's not efficient having the Waitakere Unit, the North Shore Coordination Centre, and the lab sites at three different places. At the moment forms are going backwards and forwards from the lab to the Coordination Centre, for daily data entry. This creates a risk. It's being well managed at the moment, but it's still there." (Ministry of Health)

- **Inadequate capacity due to key roles being 0.5 FTE.** Feedback suggests that full time roles would enable more efficient management and monitoring of the BSP.
- **Enhancements to communications** from governance and programme management level to operational levels are suggested, although it is acknowledged this is improving.

"The Steering Group works in isolation, little comms down to the quality group. Sharing of minutes would be good." (WDHB)

"Sometimes there will be change in procedures or exclusions but this is not conveyed to front-liners immediately. Recently, we are included in the monthly meeting and the programme manager sends weekly bulletin. This works well." (WDHB)

Considerations for enhancing the BSP

Two opportunities identified for enhancing BSP implementation are:

- full-time BSP Programme Manager and Data Manager
- communication mechanisms to disseminate governance and management decisions in a timely manner to those implementing the BSP at an operational level.

Considerations for a potential national roll-out

Two considerations for a potential national roll-out are:

- defining the benefits of having primary care involved in bowel screening, and if beneficial the levers most effective to ensure quality standards are met (e.g. the use of financial compensation)
- the potential structures in New Zealand that may facilitate co-location of the BSP coordination centre, endoscopy and laboratory functions.

6.2 Register

What's working well?

The BSP Register is generally viewed positively. Having an eligible population database is seen as a key strength of the BSP and one that sets it apart from other screening programmes. In the main, the Register appears to work well.

> *"The Register does a good job."* (WDHB)

> "*One of the things that is different from this screening program from others – use of a population register ... A very rigorous and powerful tool for identification of who you are going to be sending your invitations to as well as identifying who it may not be appropriate to send an invitation to. The population register is working well – it is exceeding expectations, it has helped to identify an accurate idea of the population and the area we are servicing, identifying where the gaps are."* (Ministry of Health)

What are the challenges?

A number of challenges are associated with the BSP Register that need to be considered for a national bowel screening information system.

- **Incorrect participant address details have resulted in perceived high volumes of returned mail[19].** Ideally the quality of NHI information will be considerably improved before being used as a participant data source for a national bowel screening information system. It has been suggested that the new NHI system will have the ability to test whether addresses are valid.

  > *"Need to do a lot of work on NHI data cleansing." (Ministry of Health)*

  > *"Need to ensure better data from NHI, address fields need to be more up to date." (WDHB)*

- **Planned regular updates to the Register from PHO data have not occurred**. The purpose of the PHO updates was to add information about participants' general practice into the Register. It appears that these updates have not been taking place due to the work involved in merging PHO files with the Register, and a lack of clarity around whose role it is to instigate these updates and how often these updates need to occur. Poor participant general practice information presents an increased risk of results not being communicated to participants within the ten day notification period, and the Endoscopy Unit having to communicate a higher percentage of results than planned for.

  > *"Sharing of databases didn't work well. Our database is updated every three months so that needs to be checked against the Coordination Centre register. Should happen every three months in sync with our downloads." (PHO)*

- **Currently understanding of the Register sits with a small number of people**. This presents a risk to the programme if key people leave or are unavailable. For a national bowel screening programme it will be important to ensure a knowledge system is developed for the Register as well as greater number of people having a good understanding of the information system and how it supports the programme.

[19] It is suggested that this perception is quantified to determine the extent of the issue.

"A risk that understanding lies with only a couple of people. For a national programme, there would need to be a bigger group with a comprehensive understanding of how the business is working, and how the system is supporting that business; big picture of how it works end-to-end. A couple of key people is not enough - next layer up needs to have a comprehensive understanding of everything as well." (Ministry of Health)

- Other system limitations highlighted by Register users include:
  - Histology results are not automatically recorded in the Register. Currently, only iFOBT results are automatically collected; results from colonoscopy need to be manually entered.
  - Treatment information is not recorded in the Register. It has to be sought from other DHB information systems and entered manually. The Coordination Centre is currently working on this issue.
  - Some waiting times have to be generated manually. For example, BSP has 20 working days to let participants know their histology result. Currently, there is no place to record the date of advice in the Register, and the letter of advice to the participant is not generated by the Register.

Considerations for enhancing the BSP

Some of the challenges identified above can be addressed in the short- to medium-term, with likely benefit to BSP implementation.

- Develop and implement a project plan for PHO updates to the Register, including a timeline, roles and responsibilities and resource requirements to enhance accuracy of participant addresses. PHO updates will help. However, they have some limitations specifically in relation to the Pacific people having differing names they register under.
- Develop a knowledge management system for the Register to enable succession planning at WDHB and the Ministry.
- Review data and reporting requirements to ensure they can be met by the data collected in the Register, and ensure the Register can flag potential quality standard issues.
- Review usability of the Register.

Lessons for a potential national roll-out

The BSP Register implementation experience provides several considerations for a national bowel screening programme information system, should a national roll-out occur.

- Review options for improving the integrity of address information. Options identified include improved NHI information and accessing address information through NZ Post (see Section 6.4).
- Review options for accessing high-quality participant general practice information.
- Ensure any national information system is set up to allow inter-operability with DHB clinical information systems and laboratory systems. This will require good IT support within DHBs and laboratories to facilitate and support information system linkages.

6.3 Information line

Calls to the information line can be divided into six categories:

1. Calls from people who have heard about the BSP and want to find out how they can register, check that their details on the register are correct, or have received a kit and want guidance on how to complete it. This group comprises the bulk of calls to the information line.

   Most of the callers are WDHB residents, in the eligible age group (50 – 74 years) and 65% are of New Zealand European ethnicity. The information line does, however, receive some calls from people residing outside of Waitemata (e.g. from people who have heard about the programme through Chinese TV) and from younger people. Some younger callers wish to know whether they can register for the BSP. Others are calling on behalf of older relatives.

   People such as pharmacists and practice nurses sometimes call on behalf of people for whom English is another language. The information line team can call on the Chinese and Korean CAR Coordinators, as well as staff in the Coordination Centre who speak Samoan, Filipino, Hindi and Malayalam, if need be.

2. Calls from BSP participants regarding their colonoscopies. This is the second biggest group of incoming calls to the information line. The information line team refers them on to the BSP Endoscopy team.

3. Calls from people who have previously had a colonoscopy and are calling to find out whether they are eligible to participate in the BSP. A key misunderstanding is the belief that people with a family history of bowel cancer are a priority for the BSP. For some people already under surveillance, the BSP appears to offer a free and quick colonoscopy. Most callers who are not eligible for the BSP are happy with the explanation about the BSP eligibility criteria. The information line staff encourage the caller to talk to their GP if they have any concerns.

4. Calls from primary care. The third biggest group of incoming calls is from primary care, ringing to find out what to do with positive iFOBT results, when histology results will be available, or how to make a claim for payment. Calls regarding management of iFOBT results have decreased in recent times. Most calls from general practice now relate to invoicing.

5. Calls from BSP participants who have returned their kit but failed to provide key information (e.g. the date they collected their sample). The information line lets the lab know on the participant's behalf.

6. Calls from BSP participants ringing with positive feedback about the BSP and their colonoscopy experience.

Coordination Centre staff have developed an Access database to track calls to the information line and collect key information about the nature of the calls.

In addition to answering calls, the information line team help out with data entry of consent form details, the monthly consent form audit to check error rates, follow-up calls regarding spoilt kits, and filing of BSP participant notes sent through from the Endoscopy Unit.

What's working well?

Key aspects of the BSP information line that are working well are:

- Interfaces between the information line team, the Endoscopy Unit and LabPLUS. The information line team work closely and constructively with BSP staff in both organisations.
- Having Korean and Chinese speaking CAR Coordinators as well as Coordination Centre staff who speak Samoan, Filipino, Hindi and Malayalam available to take calls.
- Having call centre trained information line staff that have been comprehensively trained on the BSP and questions they may need to answer.

> *"Challenge was multicultural needs – language requirements. Good having a range of people with multiple languages. Good having CAR located alongside for message interpretation and how to understand the instructions." (WDHB)*

> *"It's important to have a call centre background. [We have a] background in handling difficult people and difficult questions, and tailoring our response to them … You need to be good multi-tasker – listening, hearing, typing, talking, analysing, gathering info, etc. Basic data entry skills are important." (WDHB)*

What are the challenges?

Overall, the information line appears to be working well. The key challenge for the information line is determining the number of staff required to manage the call volumes. Currently it appears that the information line may have more staff than needed. However, any additional information line staff capacity is used on other important Coordination Centre tasks.

Lessons for a potential national roll-out

Implementation of the BSP information line highlights two important lessons for a national programme, should it proceed:

- the information line is the public face of the bowel screening programme therefore staff answering the phones need to be well trained
- availability of translators for priority populations' languages.

6.4 Kit collation and postage

Key steps in the kit collation and postage process are outlined below.

Pre-invitation letter

- The Coordination Centre generates personalised pre-invitation letters from the Register and NZ Post delivers these letters. Any incorrectly addressed mail is returned to the Coordination Centre.

Kit collation

- ProHealth delivers kit components (sample tube, sample collection paper, and lined zip-lock bag) to the Coordination Centre.

  - ProHealth is contracted to the Ministry for provision of kit components. The Coordination Centre is contractually required to 'receipt' delivery of components and store prior to collation and dispatch.

- The Coordination Centre sends kit components to Orangebox, along with printed test kit instructions. Two years stock of return and mail-out envelopes is held at Orangebox.
  - Orangebox, a mail processing and fulfillment (pack collation) business, is contracted by GSL Network[20] (under contract to the WDHB BSP) to handle collation of iFOBT test kits.
- Orangebox film wraps the sample tube, the sample collection paper, the ziplock bag, and the test kit instructions, and inserts the film-wrapped components and the return envelope into the mail-out envelope.
  - Orangebox undertakes quarterly BSP fulfillments, with flexibility to undertake additional fulfillments as required (e.g. if the Coordination Centre runs out of packs). Each fulfillment usually involves about 17,000 packs and takes around two weeks.
- Orangebox returns the packed but unsealed mail-out envelopes to the Coordination Centre for insertion of the Quick Reference Guide (a pamphlet), and the personalised invitation letters and consent forms.
  - Data administrators at the Coordination Centre oversee printing of consent forms. Two students are employed eight hours a week to stuff envelopes.

Kit postage

- NZ Post delivers test kits to eligible participants. Any incorrectly addressed mail that is returned goes to the Coordination Centre.
- NZ Post delivers completed test kits to LabPLUS. Test kits are mailed to LabPLUS in a Free Post/Parcel Post envelope, addressed to a dedicated Private Bag. The envelopes are sent from the regional postal centre to a city centre mail centre overnight and delivered by courier to LabPlus by 7.00 a.m. the next morning. Participants are asked to post their kit between Monday and Thursday as postal box collections are less frequent over the weekend.

What's working well?

Overall, the postage aspects of the BSP are working well. There was some concern during programme development that spoilage and spillage might be a problem, however, neither has been a significant issue.

> *"Set up requirements for storage and soaking up any possible spillage, this protects other mail and our own people, no known incidents."* (NZ Post)

What are the challenges?

- **Returned mail.** Incorrect address details result in high volumes of returned mail, and therefore considerable wastage, particularly of test kits as they cannot be sent out again. More importantly, returned mail represents people missing out on the opportunity to take part in the BSP. Early in the implementation phase, data administrators tried to work through all the returned mail and find correct addresses.

[20] GSL is an advertising agency that developed the supporting communication and promotional material for the BSP.

However, they have not been able to continue this approach due to their large workload.

Improving quality of address information ('address integrity') would allow WDHB to access cheaper postage rates.

- **Variable pack sizing**. Some replacement test kit packs are marginally over the size and weight limits because additional material is being inserted (e.g. handwritten notes from CAR coordinators). Ensuring pack sizes remain within agreed limits would reduce unexpected postage charges.
- **Multi-part kit collation process**. Within this collation process the storing of kit components by the Coordination Centre adds no value to the process, although this is a contractual requirement. Consideration is being given to developing a process whereby the kit components can go directly to Orangebox for collation, on a just-in-time basis.
- **Limitations of Coordination Centre space, equipment and systems.** The Coordination Centre is not well set up for the stock management, storage and mail-out requirements of the BSP.
    - Coordination Centre staff have to move considerable volumes of stock between the ground floor and the first floor, where BSP is based.
    - Coordination Centre staff have set up a spreadsheet-based stock management system to manage supply of envelopes, test kit instructions, brochures, letterheads, and test kit components. A key challenge is managing iFOBT test expiry dates. Specialist stock inventory software would be required for a national programme.
    - Consent forms were initially being filed in filing cabinets, which was not sustainable long-term as the cabinets took up too much space. Since late 2012, LabPLUS has held the scanned consent forms, which can be accessed by the Coordination Centre, if required. Participants' BSP endoscopy file now goes to the Patient Record department to be filed in the patient's main file which is a clinically safer process than previously when it was held at the Coordination Centre.

> *"Physically challenging not being on ground floor. 25 boxes per day, through multiple security doors, down the lift, through reception, also an issue for inwards goods. Two trolley loads per day usually. A lot of heavy lifting work." (WDHB)*

> *"Storage capacity – kits take up a lot of room. Lots of storage required. Needs to be visible storage to identify dates of components, need a tracking system of what's sent out in relation to dates. We send out 6000/month but imagine it nationally." (WDHB)*

Considerations for enhancing the BSP

The above review of kit collation and postage processes reveals areas that could be improved on in the short-term. Positively, the Coordination Centre is currently enacting several of them.

- Review processes for kit collation, stock management and storage. The Coordination Centre is currently exploring:
    - outsourcing all aspects of kit collation, including insertion of consent forms and invitation letters
    - delivery of test kit components directly to Orangebox

  - a WDHB contract with Orangebox and not a third party is currently under development.

- Review management of spoilt kits (see also Section 6.6) to ensure size and weight limits are not being breached when replacement kits are sent out with additional explanatory information from CAR coordinators.

Lessons for a potential national roll-out

Kit collation and postage process considerations for a national roll-out, should it proceed, are:

- **Investigate options for improving quality of participant address information**. A revised NHI may provide better address information through an internal validation facility.

  NZ Post databases may also offer a way of cleaning up address data. It will be important to work closely with NZ Post in the development of a national programme, to maximise opportunities provided by NZ Post systems as well as to ensure any national programme takes account of the ongoing evolution of NZ Post systems (e.g. expected changes to rural delivery).

  > *"Could be potential savings if database was cleaned. NZ Post could help with cleaning the data. We have rich databases that tell when people have moved. Also saving if addresses are up to standard – 'WOF for addresses'."* (NZ Post)

  > *"Would like to be involved along the way, so we can feed our evolution into it – we're changing a lot quite regularly. Need to be kept in the loop."* (NZ Post)

- **Outsource kit collation**. Investigate whether the national distribution provider's role can include insertion of personalised printed material. Clearly defined timelines will be key to ensuring reliable supply of kits and associated material. This will be particularly important if one or two national fulfilment providers are delivering goods throughout the country.

  > *"National distribution centre would be preferable, ordering, collation, match to recipient letters, distributed. Whole process leads to mail out process."* (WDHB)

  > *"Suggest look at a specialist mail out company to do it. But work is needed to make sure it happens especially when info comes from a confidential register. Need to maintain both cost effectiveness and confidentiality."* (WDHB)

  > *"Defined timelines - so can ensure ability to process packs in a timely manner; if were to roll-out nationally, would need to have very clear understandings of timings required for different regions."* (Distributor)

- **Contract management.** Ensure contracts for goods and services associated with kit production and collation are held by the bowel screening programme provider who will be using the material.

  > "*Management of test items - ProHealth - in future will need to be done by the provider - risky for the Ministry to be managing provision of something they're not using."* (Ministry of Health)

6.5 Communications strategy

Communication goal and objectives

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.**

The main communications objectives of the BSP are:

- Increase awareness of and change perceptions of bowel cancer among eligible participants, their influencers, and the general WDHB population.
- Change perceptions around participating in a screening programme among eligible participants.
- Increase awareness of and help maximise participation in the BSP among the eligible population and their influencers.
- Increase awareness of and involvement in the BSP among all other stakeholders (i.e. health professionals, community groups, internal staff).

Target audiences

Four primary target audiences exist who receive regular communications about the BSP:

- Eligible participants and influencers who interact with them.
- Primary care providers and health professionals including those who provide health services to eligible participants in the BSP (i.e. PHOs, GPs, Practice Managers, Practice Nurses, screening teams).
- Community groups, NGOs, and local health organisations with direct access to eligible participants and their influencers through community meetings, events, publications, and other channels.
- WDHB staff and partners.

Communications channels

Key communication channels include:

- **Media** including local media placements in the form of newspaper/magazine articles and radio/TV broadcast segments. A media kit was developed and disseminated to media incorporating all relevant BSP information.
- **Advertising** including print advertising in local newspapers and publications to support the messages delivered to eligible participants, their influencers and other stakeholders through other channels.
- **Internal and external newsletters** to disseminate important news and updates about the BSP to various audiences.
- **Public relations** to get the BSP message to the widest audience possible.
- **Collateral** to provide specific information to all stakeholders in a clear and succinct way (e.g. brochures, pamphlets, posters, promotional items, provider handbook (WDHB 2012), information sheets and fact sheets).

- **BowelScreening Waitemata website** (http://www.bowelscreeningwaitemata.co.nz/) which is regularly updated to provide BSP information to all stakeholders.
- **Other websites** including WDHB public website http://www.waitematadhb.govt.nz/), Your Local Doctor website (targeting the Asian population http://www.yourlocaldoctor.co.nz/), Ministry of Health website (http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/bowel-cancer-programme/bowel-screening-pilot).
- **Other internal WDHB communications channels** to keep WDHB staff and partners informed about the BSP.

What's working well?

- Since the launch of the BSP, there has been **significant and consistent communication activity** across the four main target audiences consistent with the communication strategy.
    - For the eligible population and their influencers, there have been monthly insertions of an advertorial alternating with a poster in the five community newspapers. Advertisements/posters/articles have also been published in the Rodney Times, the Village Voice (Wellsford), Maharangi Matters, Hibiscus Matters, Good Neighbour (North Shore and Waitakere).
    - For staff in primary care there have been weekly electronic newsletters sent to each GP by the PHOs, via the monthly Primary Care newsletter sent by the WDHB to all practices, and by ad hoc electronic communications (via the PHOs) for special issues.
    - WDHB staff have been kept informed by coverage in Healthlines (WDHB staff newsletter).
    - The BSP has also received national press coverage via the Radio NZ documentary compiled by Karen Brown in September 2012 which was well received. There was also some television coverage and the Listener ran an article on bowel cancer and screening.

  These activities are to continue to the end of 2013 to ensure consistency of awareness raising activities throughout the first two-year screening cycle. The advertorials are being refreshed and updated, and the posters will include photos of a wider range of ethnicities than have been used to date.

- **While the overall effectiveness of the communication strategy for the eligible population is unknown, there are indicators suggesting a level of success.** Uptake amongst non-Māori and non-Pacific people is relatively high, given the implementation stage of the BSP. Qualitative feedback from Pākehā participants indicate that the communications about the BSP are reaching them and supporting their decision to take participate in the screening (Litmus 2013).

- **Given the unique role of primary care in the BSP, significant effort has been placed on developing effective relationship with the PHOs and general practice**. Both the BSP Programme Manager and the WDHB BSP Clinical Director are very active in engaging and communicating with primary care through presentations at Continuing Medical Education sessions, and conferences.

Where it is noted that general practice is not following the screening pathway, the WDHB BSP Clinical Director will call and discuss the issue, particularly where it relates to a clinical issues. The BSP Programme Manager will also discuss issues arising with the PHOs' Practice Liaison staff. As noted in section 7.2 (refer table 3), the majority of general practices are following the screening pathway as intended.

What are the challenges?

Participation rates suggest that the communication strategy in 2012 has been less successful for eligible Māori and Pacific people. Feedback from qualitative research with Māori and Pacific people (both those participating and non-responders) highlights that the generic communications are not reaching these populations. WDHB has already noted this issue and are instigating a number of strategies to address this, including the development of a DVD for Māori, and radio advertising/interviews for placement on Pacific, Asian and Māori radio stations.

Considerations for enhancing the BSP

The key consideration for enhancing the BSP is ensuring all eligible participants are aware of the BSP and have the information they need to make an informed decision about whether or not they will take part. Seeking to ensure equitable participation in the BSP for Māori and Pacific people is discussed further below.

Lessons for a potential national roll-out

At this stage of the implementation of the BSP, two key considerations for a national roll-out, should it proceed, are:

- ensuring the national communications strategy has reach and relevance for all eligible participants, in particular Māori and Pacific people
- the intensity of engagement required with primary care to ensure a readiness to meet their screening pathway requirements.

6.6 Community awareness raising and engagement

CAR goal

The overall goal of BSP CAR and engagement is to encourage participation in the BSP in the eligible population and within each of the priority population groups. The *CAR and Follow-Up Strategic Plan*[21] identifies Māori, Pacific, Asian and men as the priority populations for CAR activities. These groups were selected based on the evidence that they may be less likely to participate in bowel screening than other population groups. The inclusion of Asian also reflects the population profile of WDHB.

[21] Refer *Community Awareness Raising and Follow-Up Strategic Plan for Bowel Screening Pilot 2012-2015* (WDHB 2012d).

Delivery models

As noted, there are two models of CAR delivery:

- **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 is to reach a greater diversity of Pacific people than could be targeted if the BSP hired one Pacific person to undertake CAR activities. Both providers are 'By Pacific For Pacific' community health organisations. Its workforce is predominantly Pacific, providing existing relationships and credibility. Both providers have a number of Pacific health promoters who speak several different Pacific languages. Had the Coordination Centre decided to employ a Pacific CAR Coordinator, it is likely they would have been limited to employing one person who may have spoken only one Pacific language.

  "Difficult to employ one person to do [CAR] for Pacific, because of the multi-lingual need... the barrier is language." (West Fono)

Development of the CAR approach, structures and resources

This work commenced during the BSP implementation planning phase. Key activities included:

- **Establishment of a CAR Group** with membership of the WDHB Planning and Funding Māori and Pacific Managers, Inequalities Advisor from the Northern District Cancer Network[22], WDHB community engagement coordinator, WDHB Māori representative, a representative of West Fono, consumer representatives and PHO representatives.

  The role of the Group is to raise awareness, establish acceptance and operate within an equity framework. The CAR Group:

  - advises on the identification and development of culturally appropriate key messages and resources
  - provides guidance and support to BSP that takes advantage of existing leadership structures, local champions, known community links and resources and the leveraging off these to raise BSP awareness
  - assists with the review of feedback, data and reports to develop specific community awareness raising action plans for Māori and Pacific populations.

  The CAR Group is expected to assist with the development of culturally appropriate messages and resources, facilitate working groups, and develop specific CAR action plans for priority populations. During the planning phase, the CAR Group also contributed to decision making regarding other aspects of BSP implementation such as the invitation strategy, consultation with consumer groups on the look and feel of the BSP brand (this work was led by GSL) and participation in the development of BSP resources (led by the Ministry).
- **Establishment of an Asian CAR Advisory Group** to support the Chinese and Korean CAR Coordinators by letting them know what events are on, which media to use, who to contact, etc.

[22] These stakeholders no longer attend regularly as the group now focuses on strategic planning rather than BSP implementation.

- **Development of CAR resources** such as presentations and translation of presentations into Samoan, Tongan, Niuean, and Tuvaluan, and basic information brochure into Māori, Samoan, Tongan, Korean, Chinese and English using community 'heroes'.

There are three core components to ongoing CAR work: community engagement (community events, resource distribution and local communications), active and spoilt kit follow-up, and colonoscopy support.

Active and spoilt kit[23] follow-up

Below is a descriptive overview of approaches to active and spoilt kit follow-up.

- **Active kit follow-up**. Māori, Pacific and Asian people are 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 is to encourage and enable people to complete their test kit.

  CAR Coordinators receive a list of people who have been sent a kit but have not responded. They call the person during the day, and then again in the evening if they cannot make contact during the day. They talk to them about the BSP and the test kit, and seek to address any concerns or issues. The success of the active follow-up phone calls is constrained by whether a phone number can be identified via the White Pages or WDHB patient management systems (as the BSP Register does not have phone numbers).

  Coordinators may follow-up with a home visit if requested. Home visits were a key focus of active follow-up in the early implementation period. More recently a decision has been made to focus on phone calls and only undertake home visits if specifically requested.

- **Spoilt kit follow-up.** CAR Coordinators and West Fono receive a list of people who have returned spoilt kits. The first time Māori, a Pacific, Chinese and Korean participant return a spoilt kit the CAR Coordinators phones and advises 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.

  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 phone and advises on how to complete the kit correctly.

Engagement with Māori

Overview

The eligible Māori population in WDHB numbers around 7,000 people. Active and spoilt kit follow-up has been, and continues to be, a key focus of Māori CAR work. Most of the follow-up is via phone calls, with a small number of home visits. Recently there has been an increased emphasis on community engagement activities.

- **Community engagement activities**: The Māori CAR Coordinator undertakes community engagement activities with Māori organisations and Māori stakeholder groups such as kaumātua and kuia groups affiliated to Māori health providers.

[23] Spoilt kits – refers to iFOBT kits where the test has not been performed or labeled correctly.

- **Active kit follow-up**: At the time of interview, the Māori CAR coordinator had undertaken around 800 phone calls to the eligible Māori population who either had not returned a kit or who had returned a spoilt kit.

What's working well?

Between January and September 2012, the average participation rate for Māori is 43%, compared to 57% of other non-Māori, non-Pacific and non-Asian populations. In comparison, participation by Pacific people is 24%. **While Māori participation lags behind the Other population, the participation rate by Māori suggests 'something' is working well in an area that has significant cultural barriers to participation**.

Feedback from the Māori CAR coordinator highlights **the importance of one-to-one discussion to overcome cultural opposition to taking part in the BSP**. Creating a culturally safe environment for this sensitive discussion enables the Māori CAR Coordinator to mitigate literacy issues and attempt to breakdown cultural barriers.

Cultural barriers created by the screening process:

> *"They know what they know and they have heard their old people speak to them and anything to do with the 'back end' is really tapu[24]. Despite the fact that a lot of our people are not fluent in Te Reo Māori, what I find is that they still have that cultural underpinning ...They have the invitation letter in one hand and the test kit in the other and when they start reading, it has something to do with their back end....gone, it's ditched. That's the cultural reality." (WDHB)*

Low literacy levels prevents engagement and test completion.

> *"The reality is that many of our people can't read it. Those who can read have partial comprehension and might take the wrong message from the presentation. They can't comprehend this stuff. Those who can't read will have to look at the pictures and hope for the best." (WDHB)*

> *"The very first person I went to visit in this job out in the Kaipara couldn't read. He said I just took a shot at it and looked at the pictures. But the pictures are still not good enough. …you really have to put yourself into their shoes. Whose boots are we trying to fit? Are we trying to fit Māori boots or someone else's …we are trying to get the right fit for Māori and at the moment we do not have it." (WDHB)*

The Māori CAR Coordinator has found that talking to people over the phone provides him with an opportunity to recognise and acknowledge the concerns of eligible participants and attempt to mitigate them sufficiently for them to reconsider undertaking the test. The Coordinator found engaging with people 'kanohi ki te kanohi' is even more effective as it affords him and the eligible participant a chance to connect and develop a rapport in a way that is not possible over the phone. In turn this makes the conversation about what some feel is a highly offensive proposal easier.

> *"It needs to be upfront and kanohi ki te kanohi in order to have a far greater chance of convincing them to take this test. Kanohi ki te kanohi has a greater chance of convincing Māori." (WDHB)*

[24] Defined in the Māori Dictionary (website) as "to be sacred, prohibited, restricted, set apart, forbidden, under *atua* protection"

> *"My strategy was to phone every participant who had been invited onto the programme. This was one way of partially overcoming the 'one size fits all' approach adopted by the project team. The strategy allowed me to explain and demystify the iFOBT process." (WDHB)*

Research with eligible, invited and non-participating Māori, strongly demonstrates the cultural barriers to the BSP (Litmus 2013). The research also showed that the process of reflective discussion in a culturally safe environment encouraged some Māori non-participants to reconsider their initial rejection of bowel screening. Further, Māori participants interviewed also recalled contact with the BSP Māori Coordinator and found the discussion enabled or prompted them to take part.

What are the challenges?

While Māori were involved in the development of the BSP and in the CAR approach for eligible Māori participants, **there is a perception that greater focus could have been placed on tailoring the BSP implementation for Māori and their unique barriers to bowel screening and the BSP pathway**.

> *"They had all these pie in the sky ideas of getting 300 to each presentation, thinking way up in the clouds. Without really thinking of the realities of what needs to be done in terms of setting the proper foundation to getting it up and running for Māori. That was not done."*

The CAR design was drawn from the learnings of other programmes that have been successful in engaging with Māori, for example, breast screening and the MENZB immunisation programme. However, the evidence base of what works to enable Māori engagement in bowel screening is currently unknown. As a result, it is perceived by some that a standardized approach is being used 'of one size fits all'. For example, the general BSP presentation is the same for all participants which assumes the same messages work across the diversity of participants regardless of their level of literacy and barriers to participation.

Recent directives have placed focus on spoilt kit follow-up[25], which means less time is available to spend on active kit follow-up. Focusing on spoilt kits, (i.e. those people who have already decided to participate), detracts resources from following up those who face the greatest barriers to participation due to literacy, cultural and other barriers. **The strategy to focus on spoilt kits runs the risk of further marginalising Māori participants with the greatest barriers to participation.**

Engagement with the Asian populations.

Overview

- **Engagement with the Chinese population.** The eligible Chinese population in WDHB is around 10,000 people. The Chinese CAR Coordinator role (based in the Coordination Centre) includes CAR activities, active and spoilt kit follow-up, dealing with calls to the information line from Chinese people, and colonoscopy support. The Chinese CAR Coordinator initially worked two days per week but the large workload prompted a shift to three days per week.

[25] This decision reflects the relatively high spoilt kit rate, which through these activities are reduced to the international mean.

  - Community engagement activities: Initially the Chinese CAR Coordinator undertook community engagement activities four to five times a week. However, this has reduced to twice a month with the increase in workload associated with kit follow-up. The Coordinator identifies which activities to undertake – there is no overall organisational plan against which Chinese CAR activities are planned.
  - Active kit follow-up: At the time of interview, the Chinese CAR coordinator had around 250 names on the active kit follow-up list and spent around eight hours a week on this task.
  - Spoilt kit follow-up: There are around 15 spoilt kits per week for the Chinese CAR Coordinator to follow-up. The Coordinator sends a handwritten note with the - replacement kit, explaining how to complete the kit correctly.
  - Colonoscopy support: Chinese BSP participants are perceived as the biggest users of transport to the Endoscopy Unit. The reasons for their higher use of transport compared to other groups is not known.
- **Engagement with the Korean population**. The eligible Korean population in WDHB is around 3,000 people. Like the Chinese CAR role, the Korean role includes community engagement activities, active and spoilt kit follow-up, dealing with calls to the information line, and colonoscopy support.
  - Community engagement activities: Much of these activities are focused around churches. Initially the Korean CAR Coordinator undertook community engagement activities every week; this has reduced to every other week to allow time for active and spoilt kit follow-up. Relationships have been developed with the Korean Society of New Zealand and with Korean-focussed primary care providers. The BSP has been profiled in the Korean Post and the Asian Health Service Directory.
  - Active and spoilt kit follow-up.

What's working well?

- Constructive interface between the CAR team and the BSP Endoscopy Unit. The Endoscopy Unit regularly calls on the CAR Coordinators, particularly the Chinese and Korean Coordinators, to ensure effective communications with participants through their colonoscopy.

What are the challenges?

- **Challenging CAR workload**. As identified above, the CAR workload is demanding and, in the case of the Chinese and Korean CAR Coordinators, requires significant trade-offs. All have ended up doing less community engagement events and more spoilt kit follow-up. All coordinators considered community engagement events to be an important mechanism for raising awareness. Ideally, there would be sufficient resource to maximise efforts in both community engagement events and one-on-one follow-up of spoilt kits.
- **Resource-intensive approach to spoilt kit follow-up**. The CAR Coordinators all have a slightly different approach to following up spoilt kits, including phone calls, home visits, handwritten notes explaining what was done incorrectly on the spoilt kit and what to do differently next time, and post it notes attached to consent forms providing guidance on how to complete different parts of the form.
- **Identifying Korean participants** and in particular up-to-date contact details:
  - Koreans are listed under 'Other Asian' and the only way to identify them is to go through the 'Other Asian' list and identify which names look Korean

- many older Korean people do not have up-to-date phone numbers in their record and many move frequently between different family members' homes.

Engagement with Pacific populations.

Overview

The eligible Pacific population in WDHB is close to 6,000 people; most live in Waitakere. Pacific Integrated Health (which is North Shore based) has only contracted to undertake CAR activities for the BSP. West Fono (which is West Auckland based) has been contracted to undertake 38 education sessions per year, kit follow-up and colonoscopy support.

- **Education sessions**: These sessions are conducted in Samoan, Tongan, Niuean, Fijian, Cook Island Māori and Tuvaluan by West Fono health promoters. The sessions focus on the iFOBT, including demonstrating how to do the test using mashed potato, and key messages about bowel cancer and bowel screening.
- **Kit follow-up**: West Fono receives a list of people to follow-up from the CAR Team Leader. Many of the names do not have phone numbers. Initially West Fono got around this by visiting people at their homes but they found this was too time-consuming and expensive. Now they call those for whom they have phone numbers. West Fono currently does not do any home visits for kit follow-up unless the participant requests this.
- **Colonoscopy support**: This involves contacting Pacific people 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 the Endoscopy Unit in Waitakere. At the time of writing, West Fono had only provided colonoscopy support to a small number of BSP participants. It is important that Endoscopy staff are also culturally competent.

West Fono is represented on the CAR Group and gave feedback on test kit instructions, posters and translations of PowerPoint presentations, as well as providing local Pacific models for the posters. The West Fono phone number is listed on the test kit instructions.

Pacific Integrated Health (based on the North Shore) have also undertaken BSP education sessions with Pacific populations.[26]

What are the challenges?

Currently, eligible and invited Pacific people have the lowest participation in the BSP (i.e. 23% participation compared to 57% for Others, 52% Asian and 43% Māori. In this context, **it would appear that CAR activities for Pacific are not creating awareness and prompting Pacific people to act.** The reasons for this low participation and the overall effectiveness of Pacific CAR activities are not clear. Currently, there is limited evidence on best practice CAR activities to encourage participation in the BSP by Pacific people.

West Fono identified possible barriers to undertaking the screening test amongst Pacific people include:

- Limited awareness of bowel cancer and limited understanding of screening.

[26] *Community Awareness Raising and Follow-Up Strategic Plan for Bowel Screening Pilot 2012-2015* (WDHB 2012).

"Need to educate and teach the community about the importance of screening." (West Fono)

- Fatalistic approach to cancer.

Fatalistic perception view of screening "Often in the Islands cancer equates with death ... so why would you get screened because you are just going to find out that you are dying." (West Fono)

- Lack of engagement – some people may not open the envelope to read about the screening test.
- Lack of confidence in the test because it is not conducted in a clinical setting.

Stakeholders suggestions for improving Pacific participation were:

- **Improve test kit material** (consent form, instructions, graphics – as identified in Section 7.2) – for example translating into Pacific language, increase use of graphics.
  - Target the adult children of eligible Pacific people – this group is likely to have a better understanding of English, a higher literacy level and can be key influencers on health behaviour decision making of older people and will support the elders to do the test.
  - Use Pacific clinicians to promote and explain bowel screening and the BSP via Pacific media.

Given the low participation in the BSP by invited and eligible Pacific people, and the lack of evidence of effective CAR, this is an important area for further investigation.

Other comments on areas working well

- **The use of local BSP 'champions'** and BSP promotion through local media and community forums is perceived to be effective at raising awareness of the BSP among the WDHB population.

"The way we've done it has been pretty good overall. The basic CAR, including the comms, for the generic population has been very good.... CAR people are getting out there, really finding out the comms mechanisms. Finding out what people in WDHB need." (WDHB)

"Having community heroes, as the face of the brand - think that's really important - every community is different." (WDHB)

Other challenges noted included:

- **Lack of definition in how to assess the effectiveness of CAR across the differing priority populations**. Currently, there is no shared agreement about how to assess the effectiveness of CAR activities. Simplistically, effectiveness for CAR could be determined by having a positive influence on the targeted population's participation in the BSP i.e. return a completed kit. However, effectiveness could also be to inform people about the BSP so they make an informed decision on whether or not they take – the outcome is not therefore participating but the actual decision being an informed one regardless of the action. Further, to isolate the influence of CAR activities within a potential participant's decision making process is challenging, given the number of wider variables at play.

- **Challenging CAR workload**. As identified above, the CAR workload is demanding and, in the case of the Māori, Chinese and Korean CAR Coordinators, requires significant trade-offs. All have ended up doing less community engagement activities and more spoilt kit follow-up. All coordinators considered community engagement to be an important mechanism for raising awareness and encouraging participation. Ideally there would be sufficient resource to maximise efforts in both community engagement and follow-up of spoilt kits.
- **Resource-intensive approach to spoilt kit follow-up**. The CAR Coordinators all have a slightly different approach to following up spoilt kits, including phone calls, home visits, handwritten notes explaining what was done incorrectly on the spoilt kit and what to do differently next time, and post-it notes with first language explanations attached to consent forms providing guidance on how to complete different parts of the form.
- **Lack of up-to-date phone numbers for follow-up.** CAR personnel invest considerable time trying to track down phone numbers, and the lack of up-to-date phone numbers limits the ability to actively follow-up those who have not returned kits.

> *"Phone numbers and addresses are often incorrect. Many people have moved on. Many are very transient and moved out of the WDHB, including to Australia." (WDHB)*

Considerations for enhancing the BSP

Particular focus is needed on encouraging and supporting participation by Pacific people as well as further increasing participation by Māori to be at least equivalent to Asian and Other populations. In this context:

- Review the qualitative research with the eligible Māori and Pacific people who did and did not take part to better understand motivators and barriers to participation in the BSP and to gain feedback on BSP processes, and communication material (Litmus 2013 and Phoenix 2012). Recognise that a tailored and multi-layered approach to CAR is needed across the priority populations.
- Informed by the above research and further discussions with Māori and Pacific advisors and CAR Coordinators, review and if appropriate revise current approaches to CAR among Māori and Pacific. Consideration should be given to reviewing:
  - The effectiveness and adequacy of current BSP resources and materials, in particular the FTE of the CAR coordinators to adequately target their ethnic population.
  - The place of spoilt kit follow-up and colonoscopy support in CAR – should these activities be separated out from activities intended to increase initial participation in the BSP?
  - The effectiveness of the range of CAR activities for eligible Māori and Pacific people.

The role of CAR in increasing Pacific participation

- More indepth review is needed to assess the effectiveness of Pacific CAR activities.
- Explore whether PHOs could be involved in increasing awareness and understanding of the BSP amongst their enrolled eligible Māori and Pacific people and consider the use of key performance indicators attached to these activities.

- Review current CAR arrangements for Pacific populations in the North Shore to ensure these populations are not missing out on awareness raising and engagement activities, kit follow-up and colonoscopy support.

Further enhancing Māori participation

- Recognise the success for Māori participation in the one-to-one active follow-up discussions about non-returned kits. Recognising the resource limitation of the internal CAR coordinators, consider ways to build and leverage on this success through the use of other externally contracted Māori providers (i.e. moving to a multi-pronged internal and external CAR strategy).

> *"Once again you are constrained by assumptions that exacerbate the enormity of the task and you actually have to leverage your efforts and do it in a sensible way that makes a difference." (WDHB)*

> *"For me the providers would be the ones taking the test to the people. The navigators themselves and explaining. They would be trained, there would be training for them to explain how to do it. They do it within their own communities. So it is a team". (WDHB)*

Lessons for a potential national roll-out

In addition to the areas that could be improved in the short to medium-term, implementation of CAR provides several lessons for a national roll-out of a bowel screening programme, should it proceed. These are listed below.

- **Need to confirm the under-screened populations**. Pacific people (in particular) and Māori are emerging as the under-screened populations for the BSP. Younger men are also emerging as a potential under-screened group. Over time, these participation rates may change and therefore ongoing monitoring of participation by ethnicity, gender, socio-economic and other variables is needed.
- **Further work needs to be undertaken to fully understand what the barriers are to non-participation by different ethnic groups** (e.g. literacy; cultural barriers) and then ensure that the CAR approach is adequately designed to mitigate or preferably eliminate these barriers.
- **Consider a public awareness-raising campaign to increase community awareness and understanding of the test process and requirements**. Such an approach needs to be supplemented with specific and targeted CAR for Māori and Pacific people, and the appreciation that communications targeting Māori are unlikely to resonate with Pacific people and vice versa. Thus, it is likely a multi-pronged communication and CAR strategy will be needed. The participation rate of the BSP is a critical determinant on the magnitude of the screening impact on bowel cancer incidence and mortality. However, promoting high participation rates needs to be balanced with ensuring people are making an informed choice about whether or not they want to be screened.
- **Ensure a comprehensive programme plan for the CAR work** is developed at the outset, setting out what this strand of work is intended to achieve, who the priority population groups are, what strategies will be employed to achieve goals and objectives, and how achievement will be measured. Development of the programme plan should be informed by a strong evidence-base regarding what factors drive participation in bowel screening and what works in terms of increasing participation in bowel screening. The BSP experience of CAR will provide crucial lessons in this regard.

7. Bowel screening pathway

This section provides an overview of the BSP screening pathway: identification, pre-invitation, invitation and participation, iFOBT test results, diagnostic testing: pre-assessment, colonoscopy; alternative investigation and surveillance, and treatment. It highlights areas of strengths and challenges at this stage of implementation.

Note that most of the **bolded** information about the BSP process is drawn from the BSP resource for health providers (WDHB 2012).

7.1 Identification, pre-invitation, invitation and participation

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 2012).

Participation in the BSP is by invitation only, with the exception of eligible Māori and Pacific people (see below). 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. As described in earlier sections, details on the Register are taken from the NHI, and individuals who self-register.

Pre-invitation

Initial contact with the eligible population is through a pre-invitation letter that is sent by the Coordination Centre. 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 comprehensive 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 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.

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 iFOBT kit
- 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 sessions 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 a health promotion activities of 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 the sample is spoilt or documentation is incomplete, spoilt kit follow-up is triggered. 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.

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 after four weeks; everyone else is sent a reminder letter from the Coordination Centre after four weeks. See Section 6.6 for further information on active follow-up processes.

What's working well?

Providers perceive that the identification of eligible participants, postage of pre-invitation letters, and postage and return of iFOBT kits appears to be working fairly well. Return rates for completed kits have been higher than expected at this stage of implementation. Between January and September 2012, 54% of people invited to take part returned a completed iFOBT kit. The New Zealand participation rate is higher than what is considered internationally to be the minimum participation rate (Ministry of Health 2012d).

As noted in Section 6.4, spillage and spoilage during postage of samples has not been a major issue.

What are the challenges?

Key challenges noted about the invitation and participation stages of the BSP include the following:

- **Low participation by Pacific people** with only 24% of Pacific people who received an iFOBT kit between January and September 2012 completed and returned it. Feedback from the Pacific people indicate a number of barriers to participating in the BSP including cultural opposition to handling faeces, as well as language and literacy barriers (Litmus 2013).

- **Participation by Māori is also lower that the average participation**, with 43% of those invited returning a completed kit. In the qualitative research, five out of the six Māori non-responders interviewed highlighted objections to the BSP based on their cultural beliefs. The strength of cultural opposition ranged from those who found the overall concept of bowel screening culturally abhorrent to those who appreciated the benefits of bowel screening but found the idea embarrassing or whakamā (Litmus 2013).
- **The current distribution of kits may not be effective for Pacific people** due to environment barriers resulting in BSP letters not being received (Litmus 2013). Three Pacific men interviewed did not recall receiving their invite letter. Their busy households suggest that the letters may have got lost in the home environment. Further, Pacific people may be registered under another name at their general practice, and potentially in the NHI.
- **Return mechanisms for the BSP are culturally inappropriate for some Māori and Pacific people**. Research indicates that some Māori and Pacific are culturally opposed to handling faeces in their home and posting faecal matter (Litmus 2013). Some non-participant Pacific people indicated they would be more comfortable undertaking the test at a clinic or hospital setting. Some non-participant Māori indicated a preference to deliver their sample to the lab or to their general practice rather than mailing it.
- **Unknown effectiveness of the opt-in strategies for Māori and Pacific participants.** To inform the design of effective CAR strategies, particularly if a national roll-out occurs, it would be useful to find out how many Māori and Pacific participants are opting in following attending CAR activities/events.
- **Wastage associated with a population-based invitation strategy.** Sending iFOBT kits to all eligible participants who have not opted out results in many unused kits. This wastage is on top of that associated with kits that have been returned because of incorrect addresses (see Sections 6.2 and 6.4). To reduce this wastage, a suggestion was put forward by one stakeholder to explore the use of opt-in strategies for BSP, which would also enable the confirmation of address and general practice information. It is likely that the use of an opt-in strategy could further increase inequities of participant participation amongst Māori and Pacific people.

  "Invite strategy could be looked at, huge wastage with kits coming back, not being used. Opt in instead?" (WDHB)

  "The lab suggested a questionnaire go out with the invitation, build information [from returned questionnaires] into the system (including GP information), then send the kit out with all information already; what's happened instead is that information regarding participation and GP comes back with the test." (LabPLUS)

Other challenges associated with the identification, pre-invitation, invitation and participation stages of the BSP have been discussed in previous sections, including:

- incorrect participant address details, resulting in high volumes of returned mail (Sections 6.2 and 6.4)
- logistical challenges relating to kit collation and stock management (Section 6.4)
- a lack of participant phone numbers making follow-up challenging (Section 6.6)
- a resource-intensive approach to active and spoilt kit follow-up (Section 6.6).

7.2 iFOBT test results

LabPLUS tests iFOBT samples and sends all results (positive, negative or spoilt) 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 the IT system at the end of each day on which participant results have been sent out to GPs.

See below for more detail on LabPLUS processes and systems.

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
- refer their participant to the Endoscopy Unit for a screening colonoscopy.

See below for more details on general practice processes and systems.

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 CNS within 15 working days of a positive result. Extensive efforts are made by the CNS to contact the participant using a range of strategies including:

- phoning at different times of the day and week
- finding other contact numbers such as work number or mobile
- phoning their general practice for up-to-date contact details
- using community support workers or interpreters, if appropriate.

If the Endoscopy Unit is unable to contact a participant with a positive iFOBT, the CNS sends the participant 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 recall system and remains on the BSP Register.

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.

For a spoilt kit, participants are sent a replacement kit. See Section 6.6 for spoilt kit follow-up processes.

LabPLUS processes and systems

iFOBTs are generally processed within a day; 95% are processed within six hours.

Receipt of iFOBTs. iFOBTs are delivered by couriers to LabPLUS in boxes of 50-60, six days a week. They are delivered first thing in the morning. Specimen Services staff unpack the courier packages and check:

- Identification - Staff look for two forms of identification (BSP participant number, NHI number, participant surname). They check identification on the specimen against identification on the consent form.
- Sampling date – Staff first look on the consent form. If there is no sampling date on the consent form, they look on the specimen. If there is no date on the specimen, they look for a date against the participant's signature (this is not specifically requested). Any one of the above dates is acceptable.

Registration of iFOBTs. iFOBTs are registered into Delphic, LabPLUS's IT system, from the barcode. Barcode information, including participant BSP number, NHI, and name, is automatically populated into Delphic. Staff manually delete the GP off 'copy to' if the participant has requested on their consent form that their GP not be informed of their result. If participants note a different GP on their consent form, LabPLUS staff can change the GP details in their system. This is the only change to participant details that LabPLUS can respond to (all others changes, such as new contact details, are dealt with by the Coordination Centre). Consent forms are scanned into Delphic.

Sorting of iFOBTs. Samples are not tested if:

- there is no consent form
- the sample is not labelled with the participant barcode
- the sample is leaking.

These spoilt samples are separated out from the others.

Samples for testing are placed in the fridge, in racks of ten, ready for analysis. Consent forms accompany the samples. Samples are ready for testing by late morning/midday.

Samples without a collection date are still tested. The test is deemed valid if the result is positive. The test is deemed invalid if the result is negative.

Testing of iFOBT samples. LabPLUS has two analyser machines for iFOBTs. These are both started up early each day to allow time to run controls, check the machines are calibrated correctly, and ensure adequate reagents. Testing of samples is split between the two machines. This ensures any issues with either machine is quickly identified and addressed. Tuesdays tend to be the busiest day of the week for iFOBT testing, with up to 300 tests per day. Wednesday through Friday is around 150 to 200 tests per day, and Saturday is much lower at around 40 tests.

Results of iFOBTs. Results are downloaded from the analysers into Delphic. A worksheet is printed, any blanks are addressed, error codes from consent forms are entered, and the worksheet is then reprinted. The reprinted worksheet is verified by a colleague, who checks every error code has been correctly entered.

Results are then authorised and sent to GPs and the BSP Register via Healthlink (usually between 3pm and 5pm). Consent forms are collected and sent back to the Coordination Centre for data entry. Participant details are updated in the Register as needed. Samples are retained for a week by LabPLUS.

General practice processes and systems

Responsibility: Overall, the BSP is ultimately responsible for participants' care, while they are on the bowel screening pathway.

Participant invitation. Originally, it was intended that GPs would be kept informed about which of their patients were going to be invited to take part in the BSP. This step has not been implemented. Feedback from GPs and Practice Nurses highlighted that most do not want to be kept informed due to the significant amounts of information they have to deal with on a daily basis. Some, however, felt that it would be good to know when a patient is invited to take part so they can follow-up if the patient does not do the test.

> *"Practice not aware when invitation goes out – don't need to know. This would just mean more paperwork." (Primary care staff)*

> *"It would be nice if we knew when patients were invited to participate. Then we could follow-up if they didn't do the test." (Primary care staff)*

Receipt of results. GPs receive iFOBT results via the business-as-usual lab results process (HL7 messages through Healthlink). The results document includes specific instructions regarding what a GP has to do – '*This is a negative test, your patient will be contacted again in two years for screening'* or '*This is a positive test, please refer your patient to the Endoscopy Unit within ten days'*.

Notification of results. Different general practices have different approaches to managing positive iFOBT results. In some cases, the GP or Practice Nurse call participants to tell them their iFOBT test result and consult with them over the phone; in other cases, participants are given their result over the phone by the Practice Nurse and invited to come in to discuss the result more fully. This face-to-face consultation might be conducted by the GP or the Practice Nurse. GPs and Practice Nurses usually tell the participant that the consultation will be free.

> *"My preference is do it over the phone. Patients seem to be well-briefed." (Primary care staff)*

Most GPs interviewed do not contact the participant upon receipt of a negative iFOBT result. They simply file the result with patient records, as per usual practice and consistent with BSP expectations.

General practice staff interviewed indicated that participants will usually be contacted about their result within two days of it being received by the practice. Some general practices have established designated roles, responsibilities and processes to ensure positive results are notified and referrals made within the ten day timeframe. For example, sometimes a Practice Nurse takes responsibility for running a regular query within the patient management system to check for positive results. Alternatively, Practice Managers will check results have been processed to progress a claim for payment. Some GPs will set themselves a 'task' to remind them to do a referral within the ten days. Others have incorporated the review of iFOBT results into wider screening and recall protocols.

"Most practices are developing additional systems within their own practices for making sure referral is happening in a timely way." (WDHB)

Referral to the Endoscopy Unit. GPs refer their participants to BSP Endoscopy through their regular referral system – referrals are faxed or emailed to the North Shore Hospital central referral office, marked 'Bowel Screening Waitemata'. BSP referrals are the same as any other referral – that is they include a letter, patient medical history, medications and allergies. Increasingly GPs in WDHB are using e-referrals.

GPs interviewed indicated that, if asked, they will usually encourage their participant to have their colonoscopy through the BSP. Most felt that, currently, there is little advantage in going private (BSP colonoscopies happen quickly, within 50 days). They noted however that, if waiting times on BSP colonoscopies got too long, they would encourage participants to consider private colonoscopy.

"If you can do public, it's better. Because the follow-up is so quick. Often have to wait couple of weeks for private, not necessarily quicker." (Primary care staff)

"Haven't bothered to spend much time discussing option of private colonoscopy. BSP seems to be pretty efficient at getting them done. Private pathway not much faster. If time lag continues for BSP colonoscopies, I might encourage people with health insurance to go private." (Primary care staff)

Histology. Histology results from colonoscopy are sent to the Endoscopy Unit (not to a participant's GP), and management decisions are made by the BSP Clinical Director and Lead Endoscopist (see Section 7.4). Participants receive a letter confirming their management plan and a copy goes to the GP. The BSP Endoscopy Unit calls the patient and advises the GP by phone if a cancerous polyp has been found. GPs are not expected to do anything at this point, although, some participants will want to come in and talk with their GP.

Follow-up. General practice have no formal BSP responsibilities following receipt of negative iFOBT results or histology results. Participants with negative iFOBT results will be recalled for screening in two years time. Participants who have had a colonoscopy will enter the DHB surveillance system (see Section 7.6). Some GPs choose to follow-up with a participant following a colonoscopy, or set up a recall in their own patient management system to remind them to check that participant has been followed up.

"Essentially, once I've sent referral, got an acknowledgement that referral is received, I don't do anything." (Primary care staff)

What's working well?

The following aspects of the iFOBT result stage of the BSP are perceived as going well:

- **Use of the iFOBT as the screening tool**. About 7% of all participants who correctly complete their iFOBT kit are showing a positive result. This is within the expected range when compared with other international bowel screening pilots. This suggests that the faecal blood testing approach and tool is working well. However, as noted, feedback from eligible BSP participants who were invited and did not take part suggests that the iFOBT is culturally inappropriate for some Māori and Pacific people.

  "*Testing - the implementation of this part of the programme has worked very well." (Ministry of Health)*

"Over 70% of positive have polyps or some pathology – appears that the test is being very accurate." (Endoscopy)

- **Quick and timely processing of iFOBT tests by LabPLUS**.

  "LabPLUS great – turnaround times are fantastic; 90% of tests are analysed within four hours." (WDHB)

- **Communications with general practices.** GPs and Practice Nurses interviewed note the key role played by the PHO liaison person and indicate that this is who they go to if they had any questions about the BSP. However, some practices feel that there was not enough information about the BSP at the outset and that general practice information arrived too late (for some practices, once the BSP had already started).

  "Communication has been clear regarding referrals and claims." (Primary care staff)

  "Get the information out to practices early. We didn't receive the information packs until after the screening process had started. Once we got the information it was good." (Primary care staff)

- **Engagement of primary care**. GPs and Practice Nurses interviewed are generally supportive of the BSP, encourage their participants to take part, and increasingly, understand their roles, responsibilities and processes. Feedback from BSP participants in the Participant Pathway study also suggests that GPs are encouraging participation amongst their participants (Litmus 2013).

  Most primary care personnel interviewed strongly believe that general practice should be involved in the BSP. Screening tests and referrals facilitate important GP-patient discussions.

  "Screening tests is part of what GPs do - there's discussion around why that test is important, what the possibilities are, what you're going to do about the follow-up. If you lose that involvement, there's no continuity of care, patients are less keen to do the test if their GP is not involved." (PHO)

  "If a patient has bowel cancer, even if they've got a haemorrhoid, we're the ones who are going to support them through that." (Primary care staff)

  GPs and Practice Nurses note their patients are generally pleased to have the opportunity to receive free bowel screening, impressed by the BSP timeframe and value the opportunity to talk with their GP about the iFOBT and, if needed, the colonoscopy.

  "Opportunity to discuss at no charge has been welcomed. People appreciate having someone to talk to about it." (Primary care staff)

  "Patients have been very impressed with the timeframe – within 48 hours of doing the test, they get the result. Patients expect it to take longer." (Primary care staff)

  Some GPs recognise that primary care involvement is not essential to the BSP, and may even introduce additional risk (e.g. general practice failure to notify, failure to refer). However, the flow-on benefits to their patients are seen to outweigh this potential risk.

  GPs and Practice Nurses interviewed indicate that the ten day notification timeframe is acceptable and achievable. However, some GPs appreciate the importance of having a safety net, whereby the Endoscopy Unit follows up with a participant if the general practice has not done so.

"Although I'm pleased to be involved, I would have to say, is there really an advantage in getting the GP to do the referral?" (Primary care staff)

"Good to have that safety net, that if something hasn't been done, someone else picks it up." (Primary care staff)

Key facilitators to primary care involvement in the BSP are:

- use of business-as-usual systems for iFOBT results and colonoscopy referral. This makes it easier for general practice to be involved in the BSP because they do not need to learn new systems and processes, and use of familiar systems reduces the likelihood of errors
- having flexibility so general practice can determine how they manage positive results, within certain parameters. Allowing General Practice to decide what results management process best suits their practice may be a key facilitator of General Practice support and engagement
- reimbursing general practices for management of positive iFOBT results (see Section 6.1)
- having funded PHO Practice Liaison roles (see Section 6.1).

"Go through usual processes – that's good. Don't want extra systems." (Primary care staff)

What are the challenges?

Aspects of the iFOBT result stage which are not going so well or are proving challenging are detailed below:

- **Spoilt kits** - An estimated 15% of iFOBT kits are not completed correctly the first time they are returned; mainly due to supporting paperwork being incorrectly completed. Over a three month period, this reduces to 3% with participants being asked to complete another kit and/or receiving advice and guidance on using the kit. The likelihood of a person spoiling a kit increases with age, and some ethnic groups are more likely to send in spoilt kits. Instructions are currently only printed in English (supported by the use of diagrams), and this may contribute to the higher rate of spoilt kits seen in some ethnic groups.

  The most common cause of a spoilt kit is no sample collection date. The next most common causes are no barcode on the specimen and no consent form.

  Key issues identified by CAR personnel and data administrators include:

  - Poor placement and visibility of instructions regarding the sample collection date. Feedback to information line staff is that it would help if *"write date sample collected"* were presented in bigger and bolder font.
  - No guidance regarding date format (dd/mm/yyyy). If people write the sample collection date in another format the test is deemed spoilt. Writing the wrong date (e.g. wrong month or year) also results in a spoilt test.
  - Faint signature line on the consent form, resulting in some people missing it and not signing the form.
  - Location of the consent form on the back of the invitation letter. The information line regularly receives calls from people who cannot find the consent form. Some people do not realise it is on the back of the invitation letter and throw away the letter.

- Lack of consistency between written instructions for completing the test kits and diagrams. For example, the instructions say not to write on the sample tube, but the tube has space on the sticker that is clearly intended for writing and the pictures on the sample collection paper show someone writing on the tube; the instructions say to tick the yellow box on the consent form if the participant does not want their GP to receive the test result, the picture shows only the barcodes in yellow.
- Having a peel-off barcode sticker. Some people, particularly older people with arthritis, struggle to peel the barcode sticker off the form.
- Using the sample collection tube - some people struggle with inserting the test-stick into the narrow hole; some people have difficulty opening the bottle.
- The volume and complexity of information. Some people ring the Coordination Centre to ask someone to explain it to them.

"Some participants call the Info Line as they are overwhelmed with the amount of material that they need to read. Some callers say that it's too wordy, letters are small and some say that we should make the letter simpler, easy to read and understand." (WDHB)

As a result of people struggling to understand the kit and written instructions, a few stakeholders feel that participants may not be giving a truly informed consent.

"People are requested to sign without knowing what they are signing. Brochure says they should understand everything before they sign." (WDHB)

A suggestion was made that LabPLUS could be more flexible about which iFOBTs they reject. However, LabPLUS must comply with the quality standards that dictate iFOBT management processes. Traceability (ability to follow a documentation trail that demonstrates how an outcome was arrived at) is a key principle. Introduction of any flexibility has the potential to compromise quality standards for BSP.

"Need to reduce error rate [of spoilt kit] - Lab could do more without risking a positive e.g. date received vs. date recorded on the letter, putting barcode on themselves." (WDHB)

- **Some confusion in participant consenting for GPs to receive iFOBT results.** The consent form states that *'if you do not wish your GP to receive your test results, please mark here*'. However, some people mistakenly think they are meant to tick the box if they do want their GP to be notified, resulting in their GP not being notified.

"Some issues with participants thinking they have indicated they want GP involved but ticked other box (double negative?)." (WDHB)

- **The Register may not have the flexibility to accommodate specific requirements associated with the ways laboratories work**. An example of this is amended reports, whereby labs reissue result reports when an error is found. The Register is set up so that an automatic response is generated when iFOBT results are received (e.g. a letter to a participant). A workaround had to be developed to enable the Register to accommodate reissued result reports.

- **Between January and September 2012, an estimated 52 participants were not informed by their general practice they had a positive iFOBT or were not appropriately referred (table 3).** This represents 3% of the 1,545 BSP participants who had a positive iFOBT during this period. As noted in table 3, the number of general practices not following the correct screening pathway has decreased from 30 to 22. While there are a relatively small number of participants not being appropriately referred, this is an important area for further investigation, given the unique role of general practice in the BSP screening pathway.

Table 3: Overview of GPs not following screening pathway as noted in BSP issues summary table in January–June 2012 and July–September 2012 WDHB reports

Description January – June 2012	Total
Participants with positive result - GP not referring and arranging for gFOBT	11
GP referred patient without advising of result	7
Participant not advised of result and not referred	6
Participant advised of result but no referral received	6
Description - July – September 2012	
Participants with positive result - GP not referring and arranging for gFOBT	1
Participant not advised of result and not referred	18
Participant advised of result but no referral received	3
TOTAL	52

Source: WDHB (2012a and b)

> *"Sometimes the [Endoscopy] nurses are the first to tell people they have a positive iFOBT result. Some haven't had a conversation with their GP or Practice Nurse." (Endoscopy)*
>
> *"GP referral is good. The participants who are rung by the CNS - it comes as quite a shock – people don't expect a positive result." (Endoscopy)*
>
> *"Involvement of Booking and Scheduling is useful because it's the systems that GPs know, so reduces risk of pathway gaps." (Endoscopy)*

- **GPs are concerned about colonoscopy capacity**. They are concerned that symptomatic patients have to wait longer for their colonoscopy than BSP participants. They are concerned that resource dedicated to the BSP is resource not being dedicated to reducing symptomatic wait-times.

> *"The DHB will need to look at how to ensure symptomatic patients are not having to wait longer than BSP participants." (PHO)*
>
> *"One patient was upset that BSP participants might be getting their colonoscopy quicker than non-BSP, or that BSP is slowing the system down for other patients." (Primary care staff)*

- **Some GPs would prefer that histology results are copied to them when they are sent to the Endoscopy Unit.** This is particularly an issue when participants call their GP asking for their colonoscopy results and the GP is not able to provide any information. However, the BSP process, whereby Endoscopy manages all aspects from receipt of colonoscopy referral onwards, removes any uncertainty regarding roles and responsibilities.

  Further, the histology results report is not designed to go via the usual HL7 messaging system (i.e. it is not possible for the lab to transmit the report electronically). General practices who have signed up to the regional results repository can look them up. However, this is not encouraged.

"Think doctors should get histology report from lab as well. Easy for lab to cc doctors." (Primary care staff)

- **Speeding up informing participants of their results by the CNS**. A policy is currently being developed to support the CNS review of histology results, and to offer early advice on the results to the participant by phone, which is then followed up by the letter, for all of the 'standard' results.

Considerations for enhancing the BSP

The above review of the iFOBT result stage of the BSP has highlighted a number of actions for the short to medium-term, to achieve improvements in BSP implementation and outcomes.

- **Conduct a review of the causes of spoilt kits** (error codes) and work with labs to agree what is and is not acceptable in terms of accepted and rejected tests.
- **Review the invitation letter including iFOBT-kit material.** Participant testing is currently being undertaken and focused on priority audiences to review the consent form and the alignment between test kit instructions and graphics on test kit components. This review will consider ease of comprehension (particularly for low literacy levels and English as another language). However, it will not assess ease of use (particularly for people who struggle with dexterity).

  "Consent form is the worry - it is a lot of information, it's quite medical - think this is a large barrier." (WDHB)

  "Error rate still 14%; doubt it will get much better than 12% with the current consent form." (WDHB)

- **Determine the extent to which general practices are facilitating the screening pathway as intended, and the value they add for participants and the process.**

Lessons for a potential national roll-out

The above review has also highlighted several considerations for a national bowel screening programme roll-out, should it proceed. These include:

- **The need to test participant information is critical**, particularly the kit instructions including the consent form with priority audiences. Literacy and self-efficacy are required to take part in the BSP. Those who receive BSP invitations must be able to understand the information, to decide whether they want to take part and they need the confidence that they can undertake the test in their own home.
- **Ensure adequate resource, time and priority is given to the IT interface between the national bowel screening information system and lab information systems**. It will be important to ensure careful planning takes place with contracted labs to ensure the labs' IT systems can link into the national system.

  "Labs might need to do quite a lot of information system development. Don't underestimate the amount of time it takes to do the IT." (LabPLUS)

  "What we have in LabPLUS works for us because we had input throughout [to the development process). If they were to roll-out nationally, most labs use slightly different systems." (LabPLUS)

- **Determine the benefits of general practice being involved in the BSP screening pathway for participants and enabling the bowel screening.** Consideration is needed on the diversity of primary care across New Zealand and its ongoing evolution in relation to wider policies (e.g. the Better Sooner More Convenient Initiatives). If this investigation demonstrates the added value of general practice, it will be important to:
    - Ensure early and ongoing involvement of primary care in leadership, governance and management structures for a national roll-out.
    - Assess whether it is more beneficial for the screening pathway to be more defined within general practice (i.e. in stating who is responsible for checking for positive results, who contacts the participant, whether the consultation is by phone or face-to-face, who is responsible for ensuring the referral occurs), or whether the current level of flexibility is more efficient as the BSP process fits with existing general practice processes.
    - Investigate ways to improve participant-GP information. Sending iFOBT results to GPs when the test has not been requested by a GP is not usual practice for LabPLUS and requires additional work to confirm GP details. As noted in Section 6.2, better use of PHO registers may help address the challenge of poor quality GP information. Roll-out of a national programme will also need to consider how to accommodate participants who belong to a general practice but are not assigned to a particular GP.

  Internationally, GP involvement in bowel screening has been shown to have a positive impact on iFOBT screening participants, although it is noted that like New Zealand this is subject to high variability (Federici et al 2006, Koo et al 2010, Power et al 2009).
- **Ensuring adequate workforce and service capacity for both bowel screening and symptomatic colonoscopy services.** Discussions with primary care have highlighted how important it is to reassure the health sector, as well as the general public, that processes are in place to ensure adequate colonoscopy capacity for a national screening programme (without detrimentally or inequitably affecting symptomatic services).

7.3 Diagnostic testing: pre-assessment

All participants with positive iFOBT results are referred for a colonoscopy pre-assessment. BSP participants come into the Endoscopy Unit via three ways: a general practice referral (as discussed in Section 7.3), an alert on the BSP information system that a referral for a positive result is overdue, or from the Register if there is no general practice involvement. In the latter two situations, a CNS contacts the participant to notify them that they have had a positive result and to subsequently undertake a pre-assessment for colonoscopy.

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. Telephone pre-assessments are conducted 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 50 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, Computerised Tomographic Colonography (CTC).

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 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
- information about bowel preparation and instructions
- information about the procedure
- details of culturally appropriate support to attend, if required
- information on links to local support services.

Participants with positive iFOBT results should have their colonoscopy pre-assessment within 15 working days of iFOBT testing. This information is recorded on the BSP Register and is monitored by the Coordination Centre and the Endoscopy Unit.

What's working well?

There are several aspects of the pre-assessment process that appear to work well:

- **Mechanisms to ensure BSP participants understand what is involved for their colonoscopy** and have opportunity to ask questions:
  - use of an interpreter service, in a three-way conversation, to assist with pre-assessment conversations
  - use of interpreters and CAR personnel to contact people one week before their colonoscopy to check they have understood the procedure and the bowel preparation requirements
  - provision of endoscopy contact phone number so that people can call if they have any questions or need to confirm or change their appointment time
  - a call from the BSP administrator to confirm the participant has received their information pack, they have transport, and someone to look after them after the procedure

- a call from an endoscopy nurse the night before the procedure to confirm that the person knows where to come to, what time to come and to chat about the bowel preparation and any other concerns.

"Biggest challenges with getting bowel prep right are with the Samoan community. [Endoscopy] is using West Fono a lot more in this area. Great having that support from CAR roles." (Endoscopy)

- **Mechanisms to support participant compliance**, including good bowel preparation, and few failures to attend scheduled appointments. By September 2012, there had been one 'did-not-attend' or 'DNA' out of around 886 colonoscopies. The number of colonoscopies that could not proceed due to participant non-compliance with the bowel preparation is not known.

What does not work so well?

There are also several aspects of the pre-assessment process that are not working so well or are challenging:

- **Getting hold of participants when contact details are incorrect**. As for other parts of the BSP, the lack of working phone number information creates extra work for Endoscopy nurses. Often they will call participant's GP to try and get up-to-date contact details.

"Most difficult thing for the CNS is contact details of patients. Waste a lot of time trying to get phone numbers." (Endoscopy)

- **Variable quality of general practice referrals to the Endoscopy Unit**. Some are excellent, some are very simple and some do not include key information (e.g. a participant is on Warfarin). Endoscopy nurses manage the risk associated with limited referral information by accessing WDHB's Concerto system, which records hospital admissions, medications and lab tests. Although this is not a fail-safe way of ensuring all high-risk situations are picked up, as not all BSP participants will have come into contact with the hospital, it does provide one mechanism by which Endoscopy can double check relevant medical information is considered in pre-assessment.
- **The volume and complexity of information participants receive regarding their colonoscopy and bowel preparation**. Endoscopy nurses believe there is opportunity to condense and streamline the information, to make it more accessible to participants. They also note that the information is only available in English.

"Amount of written information people receive – could be condensed. It's too much." (Endoscopy)

"Occasional language and understanding issues. Even when English is a first language, people get [bowel preparation] wrong." (Endoscopy)

- **Discovering people are not eligible to participate in the BSP during pre-assessment** e.g. people who have a residential property in the WDHB but do not actually live in the area, people who have a condition that excludes them, or people who have recently had a colonoscopy. Situations of participant ineligibility are referred to the CNS, and the policy relating to the management of people who present for pre-assessment and are not eligible is applied.

There are also cases where the endoscopist discovers during a pre-colonoscopy conversation that a person should not have taken part in the BSP (e.g. the person talks about bright haemorrhoidal bleeding). There is a suggestion that the general practice role in identifying exclusions (people who should not be taking part in the BSP) could be enhanced.

> *"Exclusions require more input from GPs, instead of relying on individuals to report. Probably a lot of people don't require screening."* (PHO)

- **Recent lengthening of time to colonoscopy from the participant completing the iFOBT**. To meet quality standards, colonoscopy should take place within 50 working days. In September 2012, it was recognised that the BSP may not be able to continue to meet this quality standard because of the escalating volume of referrals. The issue was escalated to the Steering Group and strategies agreed to mitigate the risk. The Ministry and WDHB continue to monitor this quality standard closely.

Considerations for enhancing the BSP

Areas relating to pre-assessment that might be addressed in the short-term include:

- **Clarify expectations of general practice regarding referral content and not sending referrals before notifying a participant of their positive iFOBT result**. An electronic referrals template is being developed, which has to be completed before the referral can be sent, is expected to address this issue.
- **Investigate and quantify the number of ineligible people progressing to colonoscopy pre-assessment**. If numbers are significant, investigate ways to reduce the number of ineligible participants, such as increased general practice involvement in confirming eligibility.
- **Participant-test colonoscopy information** to maximise its accessibility to participants. Investigate translation of key colonoscopy material into priority audience languages.

Lessons for a potential national roll-out

The above review of the pre-assessment stage of the BSP has highlighted some important considerations for a national bowel screening programme, should it proceed:

- Ensure multiple, culturally appropriate mechanisms for ensuring participants understand the colonoscopy procedure and required bowel preparation. These mechanisms appear to reduce the likelihood of people not showing up for their appointment and improve the quality of bowel preparation.
- At the end of the BSP, investigate and quantify the number of people who have progressed to colonoscopy pre-assessment but are not eligible for the BSP. Develop strategies for minimising the number of ineligible people who complete the iFOBT test and for managing presentation of ineligible people at pre-assessment.
- As noted previously, investigate ways to improve quality of participant contact information.

7.4 Diagnostic testing: colonoscopy

BSP colonoscopies are undertaken at the Endoscopy Unit at Waitakere Hospital. The procedure is as follows:

- BSP participants arrive at the hospital and are admitted.
- An endoscopy nurse goes through the pre-procedure checklist with the participant - much of the information collected in this discussion has been collected during pre-assessment, but the pre-procedure checklist provides opportunity to check again; if language issues were noted at pre-assessment, an interpreter will have been organised for this pre-procedure discussion.
- 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 themself, 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 results; the endoscopist will always meet with a participant if the result is abnormal.
- The participant's nurse reiterates the results and talks with the participant about post-procedure risks and what they need to do in the immediate post-procedure period.

Specimens from colonoscopy are sent to LabPLUS. Specimens are couriered first to the Waitakere Hospital lab, then to the North Shore Hospital lab, and then to LabPLUS. It can take up to three working days for a specimen to arrive at LabPLUS. When specimens arrive at LabPLUS, they are received by Specimen Services for registration, then sent to Histology for specimen preparation and pathology review. The whole process takes between one and three days, depending on the time of day that specimens arrive. From February 2013, the specimens will go directly from the Endoscopy Unit to LabPlus, bypassing the North Shore Hospital lab. This will reduce the transport time considerably.

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.

Histopathology results are reviewed by the BSP Clinical Director and Lead Endoscopist and a report is prepared that outlines a management/treatment plan. A copy of the histology report goes to the participant, WDHB participant notes, and the referring GP. After this report has been sent out, BSP participant records are entered manually at the Endoscopy Unit into the Register. The BSP Endoscopy Unit calls a GP directly if a cancerous polyp has been found.

Colonoscopy outcomes:

- Participants with normal colonoscopies do not need to undergo another iFOBT screening episode for five years and are referred back to their GP.
- Participants diagnosed with bowel cancer or high-risk polyps are referred for treatment with surgical services. Participants' GPs are notified and these participants are considered to have exited the BSP.

- Participants diagnosed with polyps or other bowel disease requiring ongoing surveillance, have their care handed over to the gastroenterology service. Participants' GPs are notified and these participants are considered to have exited the BSP.
- Participants who have a failed colonoscopy are scheduled for a repeat colonoscopy if the failure is due to inadequate bowel preparation; otherwise they are referred for an alternative diagnostic investigation: computed tomographic colonography (CTC), or colonoscopy under a general anaesthetic.

What's working well?

There are several aspects of the colonoscopy part of the BSP that are working well. These are detailed below.

- **Low DNA rates for colonoscopy appointments**. As noted in Section 7.3, the overall pre-assessment process (interpreters, support from CAR personnel, pre-assessment conversation with an endoscopy nurse) appears to contribute to the very low DNA rates. Negotiated appointment times are also likely to be a factor. In symptomatic services, patients are sent a letter telling them what time and date their colonoscopy will be; for the BSP, participants are able to indicate what time and dates suits them and they can call back and change the appointment time, if needed.

  "Offering the patient the day that suits them, rather than getting a letter in the post with appointment date and time." (Endoscopy)

  Endoscopy personnel also believe that BSP participants are less likely than other patients to not show up for their appointment because they have made an informed decision to take part in the BSP.

- **BSP participants appear very positive about the overall pre-assessment and colonoscopy experience.** This was evident in very positive feedback received from a participant survey conducted by the Coordination Centre in June 2012, and the Participant Pathway research (Litmus 2013). Information line team also get calls from participants to express their gratitude for the BSP and the process.

  The perception of BSP management and senior clinicians is that the Endoscopy Unit is running well, particularly for a new unit with new staff.

  "Patients are quite positive; slightly anxious; a lot immediately assume they have bowel cancer." (Endoscopy)

  "Endoscopy Unit is running well - really positive feedback from patients – this is a real credit to the team." (WDHB)

  "Think they're doing a great job for a new unit and new staff." (Sessional endoscopist)

- **LabPLUS are processing specimens quickly and within the required timeframe**. The process for receipt, registration, preparation and analysis of specimens is largely business-as-usual practice for LabPLUS. The key difference is that the specimens take slightly longer to arrive at the lab because they go via two hospital labs first.

  "Histology turnover time seems to be good." (WDHB)

- **Interfaces between LabPLUS and BSP programme management and Endoscopy are very good** (as noted in Section 6.1), and recently the histology team has become more involved in these relationships. For example, the BSP Programme Manager recently presented to the histology team on where histopathology fits within the BSP. This engagement has been welcomed by the histology team and has provided a useful platform for ensuring discussions regarding histology capacity and transport of specimens.

What does not work so well or is challenging?

There are also several aspects of the colonoscopy component of the BSP that are not working well or are challenging:

- **Limited availability of endoscopists**. As discussed in Section 4.5, the availability of skilled endoscopists was the challenge identified most frequently in relation to the BSP. At the time of interviewing, the BSP Endoscopy Unit was running around six lists per week due to a lack of endoscopists. Since then, BSP management have managed to recruit enough endoscopists to fill all ten lists.

There are a number of factors contributing to the endoscopy capacity issue –

- New Zealand does not have a large endoscopist workforce.
- Introduction of Government colonoscopy targets has meant that ADHB and CMDHB have had to prioritise use of their endoscopists for their own symptomatic lists. Furthermore, in 2012, after the commencement of the BSP, it was identified that the WDHB symptomatic list was larger than was originally thought.
- The travel required (to Waitakere) and the small number of colonoscopies per BSP list (five compared to eight for many endoscopists)[27] are barriers to private sector endoscopists working on the BSP.

"Availability of colonoscopists and experienced colonoscopy nurses - both in short supply and hard to recruit." (WDHB)

- **Impact of BSP on symptomatic services**. As noted in Section 7.2, GPs in particular are concerned about the impact that the BSP will have on symptomatic list wait-times. To date, stakeholders perceive the BSP to have had a minimal impact on symptomatic services as the BSP has a dedicated resource and only a small number of BSP participants have transitioned into the wider DHB system for surveillance or treatment. As BSP implementation progresses, the impact of the BSP on symptomatic services will increase as more participants requiring treatment or surveillance are picked up through the BSP.

"It's not just what you do now, it's what it leads to down the track - people with polyps need follow-up colonoscopies ...Implications down the track in terms of needing colonoscopists and facilities, yet most centres are already under stress." (Endoscopy)

[27] Note: the comment on the smaller numbers of colonoscopies per list may have been expressed before it was appreciated that most colonoscopies performed after a positive iFOBT test will involve endoscopic removal of a number of polyps and therefore require longer procedure times.

- **Tensions between symptomatic endoscopy services resource and BSP resource**. The dedicated BSP Endoscopy Unit is situated within the Waitakere Hospital Surgical Unit and is one of two endoscopy rooms. There has been some tension around the ring-fenced 'new' BSP resources and a sense that BSP endoscopy nurses should work across the service, not just on BSP. To date, BSP nurses have worked in both endoscopy rooms, however, this may not be feasible now that there are ten BSP lists a week.

  "Also competing demands for endo services, and here comes BSP with resources and flash standards! This could also be an issue in other DHBs." (WDHB)

- **BSP colonoscopies are more technically challenging than anticipated**, due to the higher number of polyps per participant, including a higher number of polyps that are challenging to remove. This has an impact on how long it takes to do a single colonoscopy, how long it takes to do a colonoscopy list, and participant wait-times on the day.
- **Using Provation (WDHB software)** is challenging and time consuming for sessional endoscopists who are not familiar with it. This is likely to be addressed through training and increasing familiarity with use.

  "Provation is the worst part of it – no manual, no help with using it. I use it by trial and error ... the computer system is terrible. Half our time is spent on data entry at [the BSP Endoscopy Unit]." (Sessional endoscopist)

- **Long participant wait-times on the day.** The single most common complaint from participants is how long they have to wait on the day for their procedure. This was identified through the participant satisfaction survey conducted by the Coordination Centre. As noted above, BSP procedures taking longer than anticipated is one of the likely causes of long wait-times. There are also aspects of the admission and pre-procedure process that could potentially be streamlined. For example: sometimes there are admission delays; sometimes participants are not ready at the time the endoscopy session is scheduled to start; the nurse could get participant consent as part of the pre-procedure preparation process.

  The Endoscopy Unit has sought to reduce some of these wait-time issues by staggering the times that participants come into the Unit for their procedure.

  "A good informed nurse who is good with patient rapport can get informed consent, then take the patient through to the suite to the doctor. They don't have to necessarily see the doctor beforehand. That would speed things up." (Sessional endoscopist)

- **Larger than expected administration workload** resulting in 1.0 FTE being insufficent resource for both the CNS and the BSP Administrator roles. An additional CNS has recently been appointed and an administrator from the North Shore Hospital bureau has been engaged part-time to increase capacity and cover for leave.
- **Higher than estimated specimen volumes.** Modelling for the BSP estimated that samples would be taken from approximately 40% of colonoscopy participants and there would be one to two polyps per participant. LabPLUS budgeted on 100 specimens per month; in recent months, LabPLUS has been dealing with more than 400 specimens per month.

These figures have resource implications for LabPLUS (histopathologist and technician capacity) and the BSP service itself. In particular, there is a risk that turnaround times will increase, contravening the quality standard that requires LabPLUS to deliver histopathology results within ten days. Currently the timeframe is being met, despite the increased volumes, because LabPLUS is using additional staff to help manage the workload. LabPLUS has no extra capacity available if specimen volumes continue to increase.

- **The length of time for specimens to be delivered to LabPLUS** is longer than necessary due to the specimens' circuitous route. From February 2013 the specimens will go directly from the Endoscopy Unit to LabPLUS, bypassing the North Shore Hospital lab reducing the transport time.
- **Pro-forma reporting for histopathology results** is specific to BSP reporting and new to LabPLUS. Histopathologists are finding the reporting requirements reasonably demanding to meet and time consuming.
- **Larger than anticipated histopathology review workload** due the higher number of specimens being tested. Currently, the BSP Clinical Director and Lead Endoscopist are reviewing all the histopathlogy reports and instructing the Administrator as to which standardised letter should be sent to the participant and their GP. The Endoscopy Unit is moving towards having the CNS review the more simple histopathology reports, phone the participant and then send out the letter once it has been reviewed. As a result, the workload for the Clinical Director and Lead Endoscopist should reduce as well as speed up the process for getting result letters out.

  Other BSP endoscopists, (excluding the Lead Endoscopist and the Clinical Director), do not see the lab results, are not involved in the histology review and do not receive a copy of the histology report. Some endoscopists would like to be more involved in the review of results and subsequent management decisions. However, having only a small number of people doing the histology enhances decision making consistency, and the timeliness of results (as some of the other endoscopists only do one session (or less) per week.

  > *"Not ideal for a professional for someone to do the procedure and then not know the histo or follow-up, all of that is out of our hands. Would like to be more involved in the results of it." (Sessional endoscopist)*
  >
  > *"Fewer people doing the histology, the better - better having one or two people who agree the follow-up parameters." (Endoscopy)*

Considerations for enhancing the BSP

The above review of BSP colonoscopy has highlighted several areas that could be addressed in the short to medium-term to enhance BSP implementation and outcomes. These are listed below.

- Continue to monitor time taken for individual BSP colonoscopies and BSP colonoscopy lists. Strategies such as additional BSP colonoscopy lists may need to be considered if the number of colonoscopies, combined with longer and more complex colonoscopies, continues to put pressure on time frame quality standards.
- Explore ways to reduce long participant wait-times on the day.
- Continue to monitor specimen volumes. If volumes remain high, or increase, consideration may need to be given to increasing LabPLUS capacity to manage the workload.

- Review the scope of the BSP Endoscopy Administrator role and consider whether additional resource is required. The recent increase in endoscopy lists may make the need for additional BSP administration resource even greater.
- Investigate factors that motivate and deter private sector endoscopists contributing to BSP lists and consider whether these factors might be modified to encourage greater involvement (e.g. increased payment, greater administration support for endoscopists who are not familiar with WDHB systems).
- Investigate whether endoscopists might be sent copies of histology reports for their participants.
- Investigate ways to ensure staff in the Waitakere Surgical Unit feel involved in, and a degree of ownership, over the BSP. This might involve, for example, in-services to update staff and training/upskilling opportunities.

  "Existing staff needed more information, in-services; people felt a bit excluded; BSP got new equipment, room." (Endoscopy)

  "Importance of communications for all services. Need to do this to work within existing services – can't work in isolation from those other services." (WDHB)
- Monitor the potential impact of the BSP on symptomatic services including colonoscopies and pathology.

Lessons for a potential national roll-out

The above review has also highlighted several considerations for a national bowel screening programme roll-out, should it proceed. These include:

- **Endoscopist workforce**. This is a critical issue for a national screening programme and there are no easy or quick solutions. Some solutions put forward for exploration include training nurses to do endoscopy, or using private colonoscopy lists (although the implications for quality management were noted).

  "More I look at it, the less I think we have endoscopy capacity in NZ to run a programme in the form of the Pilot." (WDHB)

  "The step increase to build up colonoscopy capacity is huge - that's going to make or break this programme." (WDHB)
- **Histopathologist workforce capacity**. There is a concern that New Zealand may not have enough histology technicians and scientists to service the high volume of specimens seen for the BSP. Consideration of workforce requirements for a national bowel screening programme will need to include consideration of the pathologist workforce, as well as the endoscopist workforce.
- **Transport of specimens from endoscopy units** will be an important consideration for a national bowel screening programme, particularly with specimens needing to be transported from across the country to what may only be a small number of labs. The BSP provides a useful opportunity to determine effective processes for transporting specimens.
- **Review histopathology reporting requirements** and investigate ways of reducing the time it takes to generate the reports. Reduced time spent on reporting will free up histopathologist time for the high volume of specimens that need to be analysed.

- **Managing volumes.** Stakeholder suggestions to manage BSP volumes include:
  - Consider whether all polyps need to be removed or whether smaller polyps (at least half of all polyps) could be left and only large polyps (greater than 5mm diameter) removed and analysed. This review would need to be informed by evidence on what smaller polyps do over a long timeframe – do they become malignant or remain benign?
  - Consider whether, in the context of a screening programme as opposed to a diagnostic programme, all polyps need to be analysed.
  - Reduce the age range for which people are eligible to participate in the BSP. A national programme could start with a narrower age range and increase as endoscopy capacity and other systems are built up.
  - Adjust the sensitivity of the iFOBT test to give a higher threshold for positivity.
- **Separate versus integrated bowel screening service**. This will be a key consideration for a national bowel screening programme. Running bowel screening endoscopy as a standalone unit would remove some of the tensions and challenges associated with fitting a bowel screening programme into an existing service. However, separating bowel screening out from symptomatic services removes the opportunity for bowel screening standards to filter through to symptomatic services. Further, standalone units would probably not be feasible in smaller DHBs; there are a lot of efficiencies in having a bowel screening unit within an existing unit, including shared staffing.
- **Ensure representation of senior endoscopy nursing** in bowel screening leadership structures. This person will need to champion bowel screening quality standards, policies, procedures and training requirements.

> *"Need an experienced Endo nurse - someone who owns this component - this is fundamental. Particularly with smaller DHBs, may not have such a visible BSP Endo Unit, might be doing a much smaller number of bowel screening colonoscopies within a smaller symptomatic, gastro service. Need a person owning the quality standards, policies and procedures, training that are required by BSP - someone needs to hold the line - got to be an experienced senior Endo nurse." (WDHB)*

> *"Very difficult to have standards and requirements for the BSP that are not necessarily shared by the wider Endo service. But wouldn't staff this room exclusively as that's not cost effective. Would expect some crossover. So need committed senior role to ensure all nurses functioning at highest required level." (WDHB)*

7.5 Diagnostic testing: alternative investigation

Participants assessed as unfit for colonoscopy or with an incomplete colonoscopy, are offered a CTC investigation. Both colonoscopy and CTC assess the large bowel. Colonoscopy offers the opportunity to biopsy; it is therefore more appropriate where there is a high probability of finding cancer and ability to biopsy is likely to be required. Occasionally when a colonoscopy fails, the person may proceed to a General Anaesthetic.

Participants are referred to the Radiology Department by the Endoscopy CNS. Referral is via WDHB's usual referral system. If the referral is for a failed colonoscopy, Radiology will try and do the CTC on the same day (at Waitakere) so that the person does not have to go through bowel preparation twice. Most CTCs for failed colonoscopies can be performed on the same day.

Referrals for BSP participants 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. The shorter turnaround time and the unique identifier number on the referral are the only aspects of the process that are different for BSP participants. Once BSP participants are booked they get treated like any other CTC patient.

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

Early review of alternative investigation

Overall, the BSP has had a negligible impact on Radiology to date. At the time of interview, the Radiology Department had dealt with less than ten BSP participants. These low numbers are not expected to change greatly.

> *"Under current BSP model, don't expect significant increase in CTCs for alternative investigation." (Radiology)*

The most significant impact of BSP in the future is likely to be an increased requirement for cancer staging CTCs, as the BSP picks up cancers that might otherwise have gone undetected.

> *"Regardless of how cancer detected, it will come to Radiology for a 'staging CTC' - not really figured out how BSP will impact on Radiology services in this respect." (Radiology)*

Two aspects of alternative investigation components of BSP that are working well are:

- using business-as-usual systems for referral from Endoscopy to Radiology and communicating results from Radiology back to Endoscopy
- as for colonoscopy appointments, DNAs have not been an issue for BSP CTCs.

> *"DNA rate for BSP probably quite low - people are less likely to DNA when signed up to the Pilot."* (Radiology)

The key challenge relating to use of CTC as an alternative investigation is that, if the CTC identifies anything abnormal (polyps for example), the participant will need to go back to Endoscopy for a colonoscopy under sedation. There is a suggestion that the BSP Endoscopy Unit should have the ability to provide colonoscopy under anaesthesia.

> *"People who are not medically fit for a colonoscopy - all very well until you find something - some come back and have a colonoscopy under general anaesthetic - expensive but probably the best thing."* (Endoscopy)

Future considerations

- Continue to monitor the number of BSP CTCs as alternative to colonoscopy, and number of BSP staging CTCs, to gauge the impact of bowel screening on Radiology services.
- Include radiology in 2013 and 2015 evaluation immersion visits to ensure the impact of the BSP on radiology is assessed as the impact of BSP on symptomatic services starts to flow through.

7.6 Diagnostic testing: surveillance

Participants requiring ongoing surveillance are exited from the BSP, referred to a surveillance programme, and not recalled for subsequent screening. Participants requiring surveillance colonoscopy within one year are placed on the WDHB Endoscopy Service wait-list (this is a symptomatic list). Those requiring surveillance colonoscopy over longer timeframes are discharged to their GP with a request to refer to the WDHB Endoscopy Service at the appropriate time.

The BSP Endoscopy Unit is responsible for advising participants they have been referred for surveillance and notifying participants' GPs of surveillance management requirements. The Unit records surveillance management requirements on the BSP Register and removes the participant from the screening pathway. 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*).

Early review of surveillance

It is too early to gauge the impact of the BSP on the WDHB surveillance programme. The small numbers of participants that have been referred for surveillance provides limited information on how well surveillance notification and referral systems and interfaces are working.

The following considerations for surveillance emerged during interviews for this report:

- Referral to surveillance and surveillance of BSP participants is via the WDHB's usual referral system. As for other aspects of the programme, use of business-as-usual systems is expected to reduce errors and gaps in the pathway.
- General practice may not yet have a good understanding of the surveillance pathway for BSP participants and the role of general practice. Some interviewed for this report believed that they had no role in the BSP once they had referred a participant for colonoscopy; others set up recalls in their patient management systems on receipt of histology reports.
    - In the BSP participant pathway research (Litmus 2013), the two participants under surveillance were also uncertain about the next steps, although they felt something would happen.

- The BSP is expected to place a significant demand on WDHB's surveillance programme as implementation progresses and BSP detected cancers and abnormalities generate increased surveillance requirements. The high numbers of polyps in BSP participants is expected to place a particular demand on surveillance services. One endoscopist estimated that BSP participants requiring surveillance colonoscopies at six months and one year would make up around 20% of surveillance requirements; surveillance colonoscopies at three and five years would make up the other 80%. Thus, the real impact of the BSP on WDHB surveillance services can be expected to be in felt in three to five years.
    - In the review of the Evaluation Plan for the BSP, Professor Scott Ramsay the international peer reviewer, noted that consideration needs to be given to evaluating the system impact of surveillance procedures for patients who are found to have polyps.

Future considerations

- Continue to monitor the number and requirements of BSP participants who are exited from the programme and referred to surveillance, and plan accordingly. The BSP Endoscopy Unit already keeps WDHB Endoscopy Services abreast of BSP participants referred to surveillance to assist the Service to plan for future demand. This interface is crucial.
- Ensure consideration of the surveillance component of the screening pathway in 2013 and 2015 immersion visits as the impact of BSP on other services starts to filter through. It will be particularly important to explore surveillance interfaces between general practice and the BSP Endoscopy Unit.

7.7 Treatment

The BSP screening pathway ends when a participant is returned to routine screening, or referred for surveillance, surgery or oncology treatment. Treatment data is collected for BSP monitoring and evaluation purposes.

Participants diagnosed with cancer are referred to a colorectal Multi-Disciplinary Meeting (MDM) by the BSP Clinical Director/Lead Endoscopist. Referrals are made using a standardised regional bowel cancer MDM form. MDMs are held weekly 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 ADHB. ADHB is the regional provider of oncology services for the WDHB population.

Participants diagnosed with cancer are not recalled for screening. The Endoscopy CNS enters treatment outcomes into the BSP Register.

Early review of treatment

It is too early in the BSP to gauge the impact of the BSP on WDHB cancer treatment services. Further, the small numbers of BSP participants that have progressed to cancer treatment provides limited information on how well referral systems and interfaces are working. At 30 September 2102, 31 people had been diagnosed with cancer on the BSP.

The following treatment considerations emerged during interviews for this report:

- Overall, it appears that progression from BSP to cancer treatment is working well. BSP processes have, in the main, interfaced well with existing systems.
- The BSP is expected to place an additional demand on cancer treatment services as cases flow through. Estimates of the impact vary (e.g. WDHB will operate on 50 more cancers than last year) however the impact is expected to be significant.

> *"It's a bit like a tsunami - gradually growing in size and speed." (Endoscopy)*

Future considerations

As for the radiology and surveillance services, the impact of the BSP on cancer treatment services will need to be monitored over the coming years, and BSP interfaces with treatment services will need to be explored in future immersion visits.

8. Quality monitoring

This section describes the **process the Ministry and WDHB use to monitor the quality** of the BSP. It summarises the key quality documents for the BSP, and the structures and processes to monitor BSP quality standards. It highlights quality monitoring challenges and lessons for the BSP going forward, and insights to inform a national roll-out.

8.1 Overview of BSP quality standards

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 working with the BSAG reached a consensus decision based on consultation with experts from those involved in the BSPs undertaken in Scotland, England, Wales and Australia, as well as undertaking a review of existing evidence.

Five key quality documents were developed for the BSP:

1. **BSP Final Service Delivery Model** (Ministry of Health 2011c): This document details the final Service Delivery Model (SDM) 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): This working document sets out the monitoring, draft quality standards, clinical audit, risk management, and monitoring indicators. These Standards have been reviewed by the Bowel Cancer Taskforce, the Colonoscopy Quality Working Group (CQWG) and the BSP Quality Assurance Group. The Standards identified in this document will be 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 bowel screening pilot 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. The Ministry and LabPLUS jointly developed the document.

5. **Standards for Endoscopy (colonoscopy) facilities BSP** (Ministry of Health 2011b)[28]: This document covers service management, quality assurance, participant care, infection control, equipment and participant sedation. The standards have been developed by the Bowel Cancer Colonoscopy Nurses Quality Working Group based on the *Endoscopic Facilities and Services Guidelines*; Gastroenterological Society of Australia, 3rd Edition 2006, and the recommendations from the Australian Quality Working Group report *Improving Colonoscopy Services in Australia* (2009).

These documents are interim reflecting that they are 'living' and cover the screening pathway.

Other relevant documentation to guide quality in the BSP are 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).

As noted in section 5.1, the leadership, governance and management structures relating to quality standards are:

- **BSP Quality Assurance Group** which meets monthly 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. At 31 September 2012, 31 risks had been identified since the commencement of the BSP: 22 are resolved and nine remain active. Four have a high likehood and high impact status (WDHB 2012b).
- **BSP Clinical Governance Group** which meets quarterly and is focused on clinical subset of the BSP quality standards.
- **Bowel Screening Advisory Group** with meets quarterly and to which quality issues arising may be referred for a wider sector opinion.

From January to around August 2012, the Ministry and WDHB have been focused on agreeing the quality standards for the BSP. From August 2012, the focus has shifted to monitoring and reporting and resolving any issues arising relating to definitions and data formulas. Over time, it would be expected the focus on monitoring quality standards would again shift to using the monitoring to drive quality improvement initiatives for BSP.

From January 2013, the Ministry will be publishing on a quarterly basis the result of 16 key monitoring indicators (refer Appendix 1).

[28] The standards referring to the quality assurance of the colonoscopy procedure are outlined in the BSP Interim Quality Standards.

8.2 Quality monitoring and review processes

For the first six months of the implementation of the BSP, WDHB were required to report monthly to the Ministry on the quality standards. At six months into the BSP implementation, WDHB prepared a summary report for the Ministry. Subsequently, reporting has been quarterly.

Other WDHB activities to monitor quality and wider processes include:

- **Audit Plan and programme** which includes the participant satisfaction survey (BowelScreening 2012).
- **Audit of consented endoscopy** which identified issues with consent for tissue return and documenting risks. As a result of the audit, a letter was sent by the WDHB BSP Clinical Director to endoscopists reminding them of the need for full documentation, and a re-audit is scheduled.
- **Monitoring all re-admissions to hospitals within 14 days of having a colonoscopy**. The process to review re-admission for BSP is seen by WDHB as an example of best practice. WDHB BSP Quality Lead, WDHB BSP Clinical Director, WDHB BSP Programme Manager, and WDHB BSP Endoscopy CNS all receive electronic notification of any re-admissions which are reviewed at the fortnightly Endoscopy Review meeting and reported to the Ministry each month. Re-admissions are documented on a spreadsheet which is reviewed by the WDHB BSP Clinical Director and the Endoscopy Lead. The outcome from each re-admission and its review is documented on a template.
- **The Endoscopy Unit's Issues Register** details any issues arising and is reviewed weekly by the WDHB BSP Clinical Director, WDHB BSP Programme Manager, WDHB BSP Endoscopy CNS, WDHB Data, CAR, Communications Manager and Office Manager at the team meeting. The Issues Register clearly documents the issue, who is responsible for the issue, the outcomes and when the issue is closed.
- **WDHB Hospital RiskPro** also details incidents and issues arising from the BSP. Whether an issue is put on WDHB RiskPro is determined by the severity of the issue. For example, issues with booking and scheduling were initially listed but this was then determined not appropriate. These issues continued to be noted in the Endoscopy Unit's Issues Register.

  The BSP adheres to the National Policy for the Management of Healthcare Incidents. Between 1 July and 31 September 2012, two incidents were recorded on the WDHB RiskPro system and have been managed according to requirements.
- **WDHB BSP Programme Manager reports monthly to the BSP Steering Group** and escalates any potential breaches of the quality standards as well as any wider programme risks. The WDHB BSP Programme Manager operates on the basis of transparency and provides early warning of any potential issues relating to BSP quality standards to senior management. If a potential breach to quality standards is noted, the following process is instigated:
  - discussion in the BSP team of the potential risks and actions that can be taken to ensure the quality standards are not breached
  - if not able to address the potential breach, the risk is escalated to the BSP Steering Group and the Ministry (dependent on issue) together with suggested mitigation strategies.

For example, in October 2012 quality monitoring indicated that based on existing capacity, the quality standard requiring BSP participants with a positive iFOBT to have a colonoscopy within 50 working days might be breached. The risk was escalated to the BSP Steering Group and the Ministry with suggested options to mitigate the risk (i.e. slowing the invite process or maintaining the status quo). Neither option was accepted. WDHB adopted an alternative approach to increase endoscopy capacity.

8.3 Quality monitoring findings

For the first six months of the implementation of the BSP, WDHB were required to report monthly to the Ministry on the quality standards.

At six months into the BSP implementation, WDHB prepared a summary report for the Ministry. This report was presented to the Bowel Screening Advisory Group. Table 4 summarises the issues identified and their status, highlighting that most had been addressed. The report noted that, as reflective of early implementation, issues declined over the period due to a multi-disciplinary approach to issues (i.e. the Coordination Centre, WDHB BSP Clinical Director, and PHO working together to address them).

Table 4: BSP issues summary January – June 2012

Description	Open	Closed	Total
System generated ‘ immediate contact’ work task however participant wanted GP involvement		12	12
Participants with positive result - GP not referring and arranging for gFOBT	1	10	11
GP referred patient without advising of result		7	7
Participant not advised of result and not referred		6	6
Participant advised of result but no referral received		6	6
Faxed referral received at Coordination Centre		6	6
Incorrectly addressed electronic referral		2	2
GP referred but not received at NSH		3	3
GP seeking earlier access to histology results	3		3
GP invoice for result management sent to Coordination Centre		2	2
GP charged patient for management of result		2	2
Referral made to surgical services		2	2
Two specimens with same BSP number received		2	2
GP charging for Clexane bridging	2	0	2
Other ‘one off’ issues	1	7	8
TOTAL	**8**	**67**	**75**

Source: WDHB (2012a)

In the quarterly report, 1 July to 31 September 2012, issues with general practices’ role in the BSP screening pathway continue (refer table 5). As noted in the report, the issue is occurring mostly amongst practices outside the WDHB area where only a very small number of positive results are received. The PHO practice liaison team has been notified of the issues, and continues educational activities with primary care. The BSP proactively follows up each general practice to explain the error and confirm the correct process.

Table 5: Incident/Issues summary 1 July – 31 September 2012

Description	Open	Closed	Total
Participants with positive result - GP not referring and arranging for gFOBT		1	1
Participant not advised of result and not referred		18	18
Participant advised of result but no referral received		3	3
GP did not refer due to medical condition		1	1
Faxed referral received at Coordination Centre		2	2
Incorrectly addressed electronic referral		1	1
Participant with a positive result moved out of area		1	1
Participant was sent x2 iFOBTs in kit and provided both samples to LabPlus		1	1
Damaged kits received at LabPlus		5	5
GP charged for management of the positive result		2	2
Histology sample not labelled		1	1
Participant with two NHIs sent two kits and completed both		1	1
Participant sent two consent forms in kit		1	1
GP referral to BSP for participant with +guaiac		2	2
Participant fell from bed in endoscopy room after being given sedation		1	1
GP did not receive the positive result		1	1
TOTAL		**42**	**42**

Source: WDHB (2012b)

8.4 Review of BSP quality standards

In November 2012, a review of the BSP quality standards was jointly undertaken by the Ministry, 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 some refinement of the quality standards occurred. Refinements tended to reflect the inability of WDHB to report on a particular quality standard due to data collection limitations.

LabPLUS also raised issues in relation to iFOBT.

8.5 Quality monitoring challenges

Key challenges for BSP quality standards and monitoring were identified:

- **Operationalising quality standards.** Much of the initial quality documentation was developed by the Ministry, before the selection of WDHB as the pilot site. When it came time to further develop and implement quality standards in the WDHB setting, there were some challenges regarding how the standards would translate into operational procedures. Some of the standards were seen as vague and open to interpretation. Further, the need to avoid a two tier system resulted in a desire to use existing DHB policies and processes where possible. However, these did not always meet the rigorous standards required of a bowel screening programme (e.g. clearly identified roles and responsibilities and timelines). Knowing the pilot site earlier in the quality standard development process would have avoided some of these challenges.

> *"We were developing a lot of quality documentation in the Ministry, and had working groups set up, then we tried to implement quality documents for the pilot site ... knowing the pilot site earlier would have provided opportunities to address some of the implementation challenges."* (Ministry)

- **Duplication and potential confusion due to the number of quality documents for the BSP.** Having multiple quality documents raises the potential risk of inconsistency or use of differing definitions. In seeking to revise quality standards in one document therefore results in the need to review all documents to maintain cohesion for the BSP. For example, internationally the iFOBT is now being referred to as to Faecal Immunochemical Test for Haemoglobin (FIT). To make this revision requires all documents to be updated. Stakeholders questioned whether the quality documents could be rationalised into one so it is clear that this is the guiding document.
- **Developing monitoring indicators after the quality standards created uncertainties** for WDHB as it was unclear what data was required (or could be collected) to effectively monitor the quality standards.
- **Balancing the reporting requirements of the Ministry and WDHB** (e.g. re-admissions are being monitored by both the Ministry and WDHB).
- **Initial uncertainty about incident reporting requirements of the Ministry** due to a lack of definition of what constitutes an 'incident' versus a 'serious incident' (e.g. is bleeding after a colonoscopy an incident as this is an expected risk of the procedure?)
- **Uncertainty regarding appropriate quality standards for primary care's role,** and the contingency processes if quality measures are not met. Some stakeholders question whether general practice can perform its role to the high standards required of a screening programme.
- **While monitoring BSP quality standards is critical, over the last year there has been increased recognition that one of the roles of the pilot is to review and determine whether quality standards set are realistic in the New Zealand context**. Some stakeholders note that this realisation is fostering discussions at the BSP Quality Assurance Group and Steering Group about the appropriateness of standards set.
- **An initial lack of clarity on the process to modify BSP quality standards**, which has now been clarified. Although further streamlining of this process is suggested.

> *"There is now a formal process in place for modifying quality standards. All quality standards cannot even be looked at unless this [process] is completed. It has to have real evidence behind it ...Where there is a need for immediate change then those decisions are made immediately between the Clinical Directors of both programmes. If they are unable to reach a solution it gets escalated to make a decision and inform the Ministry." (Ministry of Health)*

- **Challenges of the Register and other IT system providing the data to inform the monitoring of the quality standards.** Systems have been set up to report on mortality and re-admissions.
- **The amount of reporting required of BSP** is questioned by some Ministry stakeholders. Suggestions are raised about whether there is a better and more informative way to report on the BSP.
- **Little evidence that quality monitoring has adopted an equity focus.**

8.6 Considerations for BSP going forward

The review of quality monitoring has highlighted that the BSP has a range of quality standards in place that align with international best practice. Quality standards are being actively monitored and processes to address risk of breaching quality standards have been tested on one or two occasions. Evidence exists that quality issues arising have been noted, responsibility lines are clear and the quality loops are closed. Further, no complaints to date have been received from participants on their experience of the BSP. While the indications in relation to quality monitoring are relatively positive, it is acknowledged that it is relatively early days for the BSP and that a number of challenges in quality monitoring have been identified above.

The review has also identified some considerations for the BSP to enhance quality monitoring:

- ensure quality monitoring adopts an equity focus
- link and share information between the GRS's Endoscopy User Group and the BSP Quality Assurance group
- register data specification and the need to ensure other IT systems inform quality monitoring, and capacity to analyse data
- streamline quality standard documentation.

8.7 Lessons for a potential national roll-out

Key quality considerations to inform a national bowel screening programme, should it proceed, include:

- having experienced quality management expertise and adequate resource for development and implementation of quality monitoring mechanisms
- developing BSP quality frameworks and associated standards for primary care, if they have a role in a national bowel screening programme
- reviewing the quality standards to ensure they reflect service delivery across New Zealand, and that there is consistency of wording and definitions across the standards
- consider the linkages and consistency between programme and DHB required quality standards and processes and the link to GRS
- ensuring quality standards can be adapted to measure technological advances in cancer treatment
- having clearly defined processes, and roles and responsibilities for modifications to quality standards.

> *"Need a lot of support in quality, and developing the quality framework. You would need a lot of expertise in this area. Having a robust quality group would be important – two to three in a quality team. That is an area to work on." (Ministry of Health)*

9. Future directions

Drawing across the report findings, this section presents key process improvements for the BSP to achieve its goal and objectives. It also summaries the key lessons from the early implementation of the BSP to inform a national roll-out, should it proceed. An overview of evaluative activities for 2013 is presented together with suggested areas for further research.

In reviewing this section it is acknowledged that participation in the BSP to date is already higher than what is considered internationally to be the minimum participation rate. As shown through this report, the BSP has in the main a clearly defined pathway, systems and processes, and quality monitoring. The BSP's multi-disciplinary team both nationally and regionally appears to be working effectively at governance, leadership and operational levels. Inter-sectoral relationships and open and frank discussions of providers across the screening pathway are facilitating the implementation of the BSP.

9.1 Key process improvements to achieve Pilot goal and objectives

Detailed below are the key process improvements to facilitate the process to achieve the BSP goal. The improvements have been sorted into the key objective areas for the BSP. While a number of improvements are listed, the critical areas of focus are:

- ensuring adequate colonoscopy capacity to meet quality standards
- increasing participation by Pacific people
- increasing participation by Māori
- defining the value of the role of primary care.

Programme design - leadership and governance

- Continue to review and reinforce boundaries between the different roles and responsibilities of the Ministry, as funder, and WDHB, as provider of the BSP.
- Strengthen Māori representation on BSP governance and advisory groups, in particular, the Steering Group. Investigate ways to increase Māori involvement and decision making in BSP at leadership and operational levels so operational decisions on engaging with Māori is placed into a wider strategic approach.
- Strengthen Pacific representation on BSP governance and advisory groups, in particular, the Steering Group. Investigate ways to increase Pacific involvement and decision making in BSP at leadership and operational levels so operational decisions on engaging with Pacific is placed into a wider strategic approach.
- Review the scope of the WDHB BSP Programme Manager and Project Manager roles and clinical leadership roles and consider additional resource to increase their capacity.

Fair access for all New Zealanders

- Increase Māori participation:
  - Increase the evidence-base on the strategies that are most effective on engaging with and supporting Māori to take part. A one-to-one approach appears to be effective in seeking to overcome cultural opposition to bowel screening.
  - Implement effective multi-tiered CAR and 'prompts and to action' strategies to support Māori to take part.
- Increase Pacific participation.
  - Increase the evidence-base on the strategies that are most effective on engaging with and supporting Pacific people to take part. Currently, a range of strategies has been put forward, however it is not known which are the most effective.
  - Implement effective multi-tiered CAR and 'prompts to action' strategies to supporting Pacific people to decide whether or not they want to take part.

Service delivery and workforce capacity

- Seek further enhancement to the Register, specifically:
  - develop a plan for PHO updates to the Register to enhance accuracy of participant contact details
  - review data specifications to meet quality and other reporting requirements, and ensure the Register can flag potential quality standard issues
  - review usability of the Register
  - ensure adequate workforce capacity to undertake the analysis needed to monitor the BSP.
- Review distribution of and management of kits, specifically:
  - review kit collation, storage and stock management process
  - review spoilt kit management with a view to systematising
  - review delivery of specimens.
- Defining the value of the role of primary care:
  - determine the extent to which general practice are facilitating the screening pathway as intended, and the value they add for participants and the process.
  - assess whether it is more beneficial for the screening pathway to be more defined within general practice, or whether the current level of flexibility is more efficient as the BSP process fits with existing general practice processes.
- Ensuring adequate colonoscopy capacity to meet quality standards:
  - continue to monitor colonoscopy capacity, lengths, specimen volumes with a view to managing colonoscopy and lab capacity.

Quality

- Ensure quality monitoring adopts an equity focus.
- Register data specification and the need to ensure other IT systems inform quality monitoring, and capacity to analyse data.

9.2 Key lessons for a possible national bowel screening programme

At this stage of the implementation of the BSP and its evaluation it is not known 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.* Early evidence and participation suggests strong provider acceptance and a level of acceptability amongst some populations, but not all. While further evidence is needed to address the overarching evaluation goals, this section focuses on presenting the early implementation lessons that can inform a national bowel screening programme – should it proceed.

The findings are presented as appropriate against the evaluation objectives. As with the lessons for the BSP, emphasis is placed on colonoscopy capacity, inclusion of all New Zealanders to avoid increasing health inequities, and the role of primary care. Running throughout is the need to ensure robust systems and processes along the screening pathway together with effective quality monitoring.

Programme design - leadership and governance

- Ensure effective governance and leadership structures for a national programme at a national and regional level and have clear roles and lines of responsibilities and accountabilities.
- Ensure strategic and operational involvement of Māori, Pacific and any other population groups identified as under-screened in the BSP, at all levels and in all programme phases. This will increase the likelihood of the programme being effective for priority populations.
- Ensure transfer of knowledge between BSP and national programme through knowledge management and advice from those involved in the BSP.

Fair access for all New Zealanders

- Identify from the BSP which sub-groups are more likely to not participate in bowel screening.
- Gather the learnings from the BSP to ensure Māori and Pacific people engagement in bowel screening.

Service delivery and workforce capacity

- Agree the role of primary care in the screening pathway.
- Ensure colonoscopy capacity and quality meets bowel screening standards across New Zealand.
- Finalise the bowel screening service model and ensure it is streamlined.
- Allow for a realistic implementation planning period at the end of which providers demonstrate their ability to meet 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, 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.

Areas for further exploration are:

- Explore whether structures in New Zealand will facilitate co-location of the BSP coordination centre, endoscopy and laboratory functions. Separate versus integrated bowel screening service will be a key consideration for a national bowel screening programme.
- Transport of specimens from endoscopy units will be an important consideration for a national bowel screening programme, particularly with specimens needing to be transported from across the country to what may only be a small number of labs.

Quality

- Having experienced quality management expertise and adequate resource for development and implementation of quality monitoring mechanisms.
- Reviewing the quality standards to ensure they reflect service delivery across New Zealand, and that there is consistency of wording and definitions across the standards.
- Consider the linkages and consistency between programme and DHB required quality standards and processes and the link to NZ GRS.
- Ensuring quality standards can be adapted to measure technological advances in cancer treatment.
- Having clearly defined processes, and roles and responsibilities for modifications to quality standards.

9.3 Evaluative activities in 2013

In late 2013 another immersion visit will be undertaken to assess how implementation is progressing. During this visit greater focus will be placed on understanding the impact of BSP on symptomatic service, including radiology, surveillance and treatment. Further discussions will also be held with primary care and other providers and stakeholders about the value and benefits of the role of general practice in the BSP screening pathway. Given the need for greater understanding on the role of general practice, it may be appropriate to undertake research to focus solely on eliciting the pros and cons of primary care involvement, and having more clarity on the screening pathway within the primary care setting.

Participation by Pacific people is low, and the strategies to support participation in the BSP are as yet unproved. Following review of the participant pathway and under-screened research (Litmus 2013), and the participant testing currently underway (Phoenix Research), it will be clearer whether further research needs to be conducted with the under-screened populations.

Ongoing monitoring of quality process and responses will also be undertaken.

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Appendices

Appendix 1: BSP monitoring indicators

The Ministry developed a detailed set of monitoring indicators (the Indicators) 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.

The Indicators were developed using recommendations and standards set out in the European Guidelines for quality assurance in colorectal cancer screening and diagnosis.

The monitoring indicator results for between January and September 2012 are summarised below (Ministry of Health 2012e).

Indicator Number	Indicator Description	Evidence	Target	Value (January to September 2012)
1	Overall participation	This is the % of people with a final FIT result (+ve or –ve) 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	54 %
2	Coverage	This is the % of eligible people in Waitemata DHB who were invited to participate during the first screening round.	>95%	Calculated at end of pilot
3	Time to colonoscopy	This is the % of people who are offered a colonoscopy within 10 weeks of the laboratory identifying a positive FIT result (excludes persons who decline colonoscopy).	>95% within 10 weeks	88.7%
		This is the % of people who are offered a colonoscopy within 4 weeks of the laboratory identifying a positive FIT result (excludes persons who decline colonoscopy).	>50% within 4 weeks	13.9%
4	Proportion of individuals with a positive screening test undergoing colonoscopy	This is the % of screened people with a positive FIT result who undergo a colonoscopy.	>90% undergo colonoscopy	92.7%
5	Colonoscopy completion rate	This is the % of completed colonoscopies (reaching the caecum).	Acceptable >90% Desirable > 95% completion to the caecum	98.6%
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 14 days	<10 per 1000 colonoscopies *	5.6 per 1000

Indicator Number	Indicator Description	Evidence	Target	Value (January to September 2012)
		of colonoscopy, per 1000 of those who had a colonoscopy during the first and subsequent screening round.		
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 14 days of colonoscopy, per 1000 of those who had a colonoscopy during the first and subsequent screening round.	No agreed international standard	3.4 per 1000
8	Positivity rate	This is the % of people with a positive FIT during the first and subsequent screening round.	6-8% first screen	7.40%
9	Colorectal Cancer (CRC) detection rate	This is the number of people diagnosed with any CRC per 1000 screened with a FIT result available for the first and subsequent screening round.	First screen 1.8-9.5 per 1000	Approximately 2.8 per 1000
			(Range from population screening programmes with FIT)	
			Second screen 1.3 per 1000	N/A
10	Colorectal Cancer (CRC) Stage at diagnosis (including polyp cancers)	This is the TNM staging for CRC detected 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 1: 43.3% Stage 2: 26.6% Stage 3: 25.3% Stage 4: 6.7%
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 a FIT result available for the first and subsequent screening round.	No agreed international standard	Approximately 20.8 per 1000
12	Adenoma detection rate	This is the number of people diagnosed with any adenoma per 1000 screened with a FIT result available for the first and subsequent screening round.	13.3-22.3 per 1000 (Range from population screening programmes with FIT)	Approximately 38.7 per 1000
13	Positive predictive value of FIT for cancer	This is the % of people with a malignant outcome in those with a positive FIT who went on to colonoscopy for the first and subsequent screening round.	PPV Cancer first screen 4.5%-8.6%	Approximately 3.8%
14	Positive predictive value of FIT for advanced	This is the % of people with any advanced adenoma in those with a positive FIT who went on to colonoscopy for the first and	No agreed international standard	Approximately 30.5 %

Indicator Number	Indicator Description	Evidence	Target	Value (January to September 2012)
	adenoma	subsequent screening round.		
15	Positive predictive value of FIT for adenoma	This is the % of people with any adenoma in those with a positive FIT who went on to colonoscopy for the first and subsequent screening round.	PPV adenoma first screen 9.6 – 40.3%	Approximately 57.6%
16	Time to FSA	This is the length of time taken for a participant referred urgently with a high-suspicion of cancer to have their first specialist assessment. For Pilot participants the colonoscopy date is used as the referral date.	Within 14 days	Data will be available from mid-2013
17	Time from decision-to-treat to first treatment	This is the length of time taken for a participant with a confirmed diagnosis of cancer to receive their first cancer treatment (such as surgery) or other management (such as palliative care) from decision-to-treat	Within 31 days **	Data will be available from mid-2013
18	Time to first treatment	This is the length of time taken for a participant with a confirmed diagnosis of cancer to receive their first cancer treatment (such as surgery) or other management (such as palliative care) from urgent referral. For Pilot participants the colonoscopy date is used as the referral date.	Within 62 days	Data will be available from mid-2013

* 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.

** Faster Cancer Treatment Indicators: Data definitions and reporting for the Indicators, Ministry of Health, October 2012.

Note: Unless otherwise stated, all Indicators are based on the European Guidelines for Quality Assurance in Colorectal Cancer Screening and Diagnosis.

Appendix 2: Research Tools

Information sheet

Stakeholder and Provider Interviews - Information Sheet

Thank you for your interest in this project. The information you provide will assist in understanding the implementation strengths and challenges of the Bowel Screening Pilot (BSP) being trialled in Waitemata DHB. Please read this information carefully before deciding whether or not to take part.

What is the purpose of the project?	The purpose of the BSP evaluation is **to find out if organised bowel screening could be introduced to all of New Zealand** in a way that is effective, safe and acceptable.
Who is doing the evaluation?	The evaluation is being done by **Litmus**, an independent research and evaluation company (www.litmus.co.nz). This project has been reviewed and approved by the Ministry of Health's Multi-Region Health and Disability Ethics Committee.
Why have you asked me to participate?	Litmus is interviewing a range of stakeholders and providers involved in all aspects of the BSP. This includes Ministry of Health, Waitemata DHB (clinical and non-clinical personnel, and the BSP Coordination Centre), Waitakere Hospital Endoscopy Unit, LabPlus, PHOs and general practices. Waitemata DHB and the Ministry of Health identified a list of stakeholders and providers involved in implementation of the BSP and provided names and contact details to Litmus.
What is involved?	The focus of interviews is on **understanding set-up and early implementation of the BSP**, in particular, what has worked well, what has been challenging and what could be done differently. Interviews will take between 30 and 60 minutes, dependent on your role and availability. Most interviews will be conducted face-to-face, but some may be by phone. There are no right or wrong answers.
How will the evaluators ensure my personal information is confidential?	Litmus will ensure **your contribution is kept confidential**. What you say in the interview will be written down, with your permission. Notes will be kept securely for up to 2 years, and then securely destroyed. No information in the evaluation report will be attributed to individuals.
Do I have to take part?	No, you do not have to take part. Your **participation is voluntary.**
Can I change my mind and withdraw from the project?	**You may stop the interview at any time**. You do not need to give a reason and there will be no disadvantage to you of any kind. After the interview, you can ask for some or all of your feedback to be removed from the evaluation without explaining why. This can be done up to the reporting stage.
How can I find out more?	If you have any questions about this project, please contact: Kiri Milne, Principal Consultant, Litmus, ph 04 384 1270, kiri@litmus.co.nz Gaye Tozer, Project Manager BSP, Waitemata DHB, ph 09 486 8920 ext 3878, Gaye.Tozer@waitematadhb.govt.nz Mhairi Porteous, National Bowel Cancer Programme Manager, Ministry of Health, or 04 816 4359, mhairi_porteous@moh.govt.nz

Consent sheet

Stakeholder and Provider Interviews – Consent Form

I (insert name) ……

of (insert organisation) ..……..……

agree to participate in this project for the evaluation of the Bowel Screening Pilot, as outlined in the information provided to me by Litmus. I understand that:

- My participation in the project is voluntary and I can withdraw at any time.
- Whether or not I participate will not affect any current or future relationships with the Ministry of Health, Waitemata DHB, or other organisations.
- If I withdraw, I can request that any information collected from me be returned or destroyed.
- I can choose not to answer any questions I do not wish to answer (without saying why).
- I can request any information collected from me be withdrawn at any time up until the reporting stage.
- The process followed by Litmus will seek to keep my information confidential. No information in the evaluation report will be attributed to me.
- The interview, with my permission, will be taped and may be transcribed.
- I have the right to request a copy of the audio or written notes of my discussion.
- Digital recordings, notes and summaries will be securely stored at Litmus and will not identify me. They will be kept for two years and then securely destroyed.

I have read the information sheet and this consent form, and have been given the opportunity to ask questions and have them answered. I give my consent to participate in this evaluation.

Participant's signature: _____

Date: _____

Discussion areas

Stakeholder and Provider Interviews – Interview Guide

Introduction

- Introduce self/Litmus.
- Evaluation purpose: To find out if organised bowel screening could be introduced to all of New Zealand in a way that is effective, safe and acceptable, equitable and economically efficient.
- Interview purpose: To understand early implementation of the Bowel Screening Pilot (BSP) and identify lessons learned from the BSP for national roll-out of a bowel screening programme.
- Information sheet, informed consent and audio recording.
- Time: 30-60 minutes.

Involvement with the BSP (5-10 mins)

- What is your role in the implementation of the BSP? When did you get involved?
- [As appropriate] How does the BSP fit within your organisation?
  - Probe: priority given to BSP, resource allocated to BSP, systems set up for BSP
- [As appropriate] What interfaces does your organisation have with other parts of the BSP programme? Which aspects of these interfaces work well? Which aspects, if any, do not work so well?

Lessons from the BSP for a national roll-out (10-20 mins)

Thinking about lessons to be learnt from the BSP for a national roll-out of a bowel screening programme:

- What factors have been critical to the set-up and roll-out of the BSP?
  - Probe: For what reasons do you say that?
- What factors have hindered the set-up and roll-out of the BSP?
  - Probe: For what reasons do you say that?

Understanding BSP implementation (10-20 mins)

Focusing now on the *implementation* of the BSP:

[ask evaluation questions relevant to participant's role – see *Evaluation Questions* table]

Final comments

- What other comments do you have on BSP implementation and lessons for a national bowel screening programme roll-out?

Thanks, close and next steps

Evaluation questions (from *Evaluation Plan for BSP 2011-2016*)

Original programme design
▪ Was consideration was given to Māori and Pacific people's needs and potential issues/barriers in the design of the programme?
▪ Was expert advice (internal or external) sought about how the programme could be designed to ensure effectiveness for Māori and Pacific?
▪ Who was consulted and what advice was provided?
▪ Are targets and/or service delivery standards in relation to Māori and Pacific included in contractual/performance arrangements with Waitemata DHB?
Leadership, governance and management
▪ What leadership, governance and management structures are in place for BSP?
▪ How are these structures designed and implemented?
▪ Which aspects of the leadership structure work effectively? Which do not?
▪ What is the impact of the structures on service providers?
▪ What monitoring information is used by management to assess the BSP's performance?
▪ How effective are the relationships between management and key stakeholders from primary/secondary care and laboratory services?
▪ Are there mechanisms in place to ensure that decisions taken by leaders, governors and managers are well informed by advice about the needs of Māori and Pacific people and any potential issues/barriers they may face?
Regional coordination, local involvement, community engagement and awareness raising and opportunities for self-referral
Coordination Centre
▪ Which organisations are involved in regional coordination of BSP, and how?
▪ What activities, strategies and relationships are used to engender, facilitate and maintain regional coordination of BSP? What resources are used? How effective are these?
▪ What specific features of regional coordination are applied to engage different population sub-groups?
▪ How effective is regional coordination in helping achieve BSP goals and objectives? What facilitates it? What impedes it? Is there a sense of ownership of BSP amongst regional organisations?
▪ How does regional coordination contribute to Māori and Pacific participation in the programme?
Local community engagement
▪ Which organisations are involved in local community involvement of BSP, and how?
▪ What 'grass-roots' activities are used to involve and engage local communities in BSP? What resources are used? How effective are these?
▪ How is local community engagement applied at different points along the screening pathway? What specific features of local community engagement are applied for different population sub-groups?
▪ How effective is local community engagement in helping achieve BSP goals and objectives? What facilitates the process? What impedes it? Is there a sense of ownership of BSP amongst local communities? How is local community involvement maintained?
▪ How effective is local community engagement at raising awareness among Māori and Pacific of the programme and facilitating their engagement in the programme?
Register
▪ How is the Register designed, developed, implemented and operated on an ongoing basis?
▪ What systems and tools are in place to populate the Register? How effective are these?
▪ Is the information held in the Register adequate for patient follow-ups? Is it adequate for monitoring and evaluation purposes?
▪ In addition to the National Health Index, what sources are used as primary identification mechanisms to include people on the Register (e.g. General Practice, self-referral, Cancer Registry)? How adequate are the primary identification sources? What gaps exist, and why?
Advance notification

▪ What is the role of the advance notification letter? How does the target population respond?
▪ Are any other methods or mechanisms used to provide 'advance notification' of BSP? How effective are these?
Screening Pathway 1: iFOBT kit sent – invitation to participate in iFOBT screening
▪ What is the format for the 'pre-invitation information' (including information on the BSP and iFOBT kit)? How was it developed and confirmed?
▪ Has the overall literacy, and health literacy of the different target groups been considered and addressed? Have the needs of people with English as a second language been considered and addressed?
▪ Have privacy issues been considered and addressed for participants who may be relying on family members to engage?
▪ Was consideration given to the lower levels of literacy in general, and health literacy in particular, of Māori and Pacific populations? If so, how was this addressed in the development of communication mechanisms?
Information phone line
▪ How is the free information phone line designed, developed and implemented and operated on an ongoing basis?
▪ What systems are in place to collect information about calls made to the phone line?
▪ What systems are in place to follow-up queries to the phone line?
▪ How many calls, of what nature, are made to the phone line (including Māori and Pacific peoples) respond to the phone line?
▪ Are any other methods or mechanisms used to provide additional support/information to people who receive 'pre-invitation information'? How does the target population (including Māori and Pacific people) respond to these methods?
Reminders/active follow-up
▪ What other methods or mechanisms are used to provide reminders, or further active follow-up to people sent an iFOBT? How does the target population respond to these methods?
▪ What procedures are used to ensure people with a positive iFOBT continue in the screening pathway? How does the target population respond to these procedures?
Screening Pathway 2: iFOBT result – laboratory and Coordination Centre management of iFOBT kits and results
Laboratory
▪ What systems, structures and facilities are in place at the laboratory, to ensure high quality screening?
▪ What systems are used to enable the laboratory to forward screening results to the Coordination Centre, for loading into the IT system? What systems are used to forward results to the participant's GP?
▪ What is the overall impact on laboratory services, particularly in terms of demand and delivery? What is the impact on other services?
Notification of results
▪ How is the system for notifying participants of iFOBT results developed and implemented?
▪ What are the roles and responsibilities of the Coordination Centre and GPs, in terms of results notification?
▪ What processes and support are in place, for people notified of a positive iFOBT result?
▪ To what extent is the Coordination Centre equipped to support people with positive iFOBT results (i.e. to facilitate support, navigation, transport, appropriate appointment times)?
▪ Overall, where does the accountability for follow-up sit? Is there clarity between the GP's ongoing role in overall participant care and the role of the Coordination Centre in managing this one result?
▪ What happens to people with co-morbidities that may make them ineligible etc for further referral/treatment?
Screening Pathway 3: Pre-assessment – management of people with a positive iFOBT result
▪ How is the process for managing participants from the Endoscopy Unit developed and implemented?
▪ Contact from Endoscopy Unit
▪ What is the process and timeframe for contacting participants from the Endoscopy Unit? What systems, resources and personnel are involved?
Pre-assessments
▪ What is the process and timeframe for undertaking participant pre-assessments? What alternative methods are used (e.g. phone

or face-to-face)? Who leads the pre-assessments (e.g. nurses, other clinicians)? What support is provided to participants through the pre-assessment phase?
▪ What systems, resources and personnel are involved?
▪ What is the overall impact on GP services and other providers?
▪ What is the acceptability and completion of the pre-assessment process by participants, and the timeframes? What is the impact on knowledge and attitudes about bowel cancer and bowel screening? How does this differ by sub-group?
Confirming colonoscopies
▪ What is the process and timeframe for setting and confirming appointments for colonoscopies?
▪ What information and support is provided/offered to people about the colonoscopy procedure? Who provides this information/support and how?
▪ What systems, resources and personnel are involved?
▪ What is the overall impact on colonoscopy services?
Overall
▪ Who is responsible for supporting participants with positive diagnoses through the care pathway through primary care, diagnostic services and secondary/tertiary services?
▪ Are there adequate communication/handover between the Endoscopy Unit and general practice and processes in place to ensure follow-ups?
Screening Pathway 4: Colonoscopy
Attending colonoscopy appointments
▪ What systems and processes are in place to avoid 'Did not attend' (DNA) appointments (e.g. flexible appointment times, reminders and provision of further information)?
▪ What systems and processes are in place to follow-up DNAs?
▪ What systems, resources and personnel are involved?
▪ What is the overall impact on GPs, other providers and colonoscopy services?
▪ **Administering colonoscopies**
▪ What systems, resources and personnel are involved?
▪ What is the overall impact on colonoscopy services, particularly around demand and delivery? What is the impact on other services?
Screening Pathway 5: Alternative investigation
Notification
▪ What is the process and timeframe for notifying participants who are assessed as being unfit for colonoscopies? What systems, resources and personnel are involved?
▪ How are participants assessed unfit for colonoscopy notified about this?
Attending Computerised Tomographic Colonography (CTC) appointments
▪ What systems and processes are in place to avoid 'Did not attend' (DNA) appointments (e.g. flexible appointment times, reminders and provision of further information)?
▪ What systems and processes are in place to follow-up DNAs?
▪ What systems, resources and personnel are involved?
▪ What is the overall impact on service providers?
Administering CTCs
▪ What systems, resources and personnel are involved?
▪ What is the overall impact on radiography services, particularly around demand and delivery? What is the impact on other services?
Surveillance
▪ Is there adequate handover to general practice to undertake this role for those identified at risk but not requiring further referral at

this stage?
Treatment
Multi-disciplinary Team (MDT) referral
▪ What is the process for referral to a MDT?
▪ How does the MDT process occur and how do participants respond? Is it culturally appropriate? What advice and support is offered?