

Evaluation of the Bowel Screening Pilot: Role of General Practice

Ministry of Health
Manatū Hauora

15 April 2014

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

LITMUS

Contents

Preface	1
1. Executive Summary	2
1.1 Background	2
1.2 Key findings	2
2. Introduction	4
2.1 Background	4
2.2 Report purpose	5
2.3 Glossary of terms	5
3. Methodology	7
3.1 Immersion visit interviews with general practice	7
3.2 Interviews with Māori and Pacific BSP participants	8
3.3 Other data sources	10
3.4 Research limitations	11
4. Overview of General Practices' Role	13
5. BSP Participant Experience and Preference	16
5.1 Process to receive a positive iFOBT results	16
5.2 Preferred delivery of positive results	18
5.3 Overview of participant experience	20
6. General Practices' Delivery and Preferences	24
6.1 Awareness and knowledge of the BSP	24
6.2 Description of service delivery	24
6.3 Perceptions of the BSP	27
6.4 Value of general practice in the BSP	29
7. Discussion	32
Bibliography	33
Appendices	34
Appendix 1 – General practice research tools	34
Appendix 2 – BSP participant research tools	38
Appendix 3 - Preferred method to hear about positive iFOBT	44

Preface

This report has been prepared for the Ministry of Health by Liz Smith from Litmus Limited with contributions Lisa Davies and John Whaanga (Kaipuke), and Ron Manulevu and Analosa Ulusia-Veukiso (Integrity Professionals Limited).

We thank Dr Juliet Walker, Lisa Davies and Ron Manulevu for their review and feedback on the draft report.

We acknowledge and thank all those who participated in interviews, including representatives of Waitematā District Health Board, Primary Health Organisations, General Practitioners, practice nurses and practice managers. We especially thank Māori and Pacific BSP participants who shared their experiences and perceptions of the BSP.

We also thank:

- Professor Scott Ramsey for his expert review of the Bowel Screening Pilot Evaluation Plan prepared by Litmus Limited and Sapere Research Group
- members of the Ministry of Health’s Bowel Screening Evaluation Advisory Group for their review comments on the Bowel Screening Pilot Evaluation Plan and this report
- Litmus’ Governance Group members for their specialist screening evaluation advice, and ongoing guidance and advice
- staff in the Bowel Screening Pilot teams at the Ministry of Health and the Waitematā 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 Waitematā District Health Board (WDHB) to run a Bowel Screening Pilot (BSP) over four years from 2011/12 to 2015/16. 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.

The role of general practice in informing BSP participants of a positive immunochemical faecal occult blood test (iFOBT) is a unique element of the BSP. The findings from the first immersion visit (Litmus 2013) found that while general practitioners (GPs) and practice nurses are generally supportive of the BSP, across general practice there is variation in BSP processes and practices. Internationally, GP involvement in bowel screening has been shown to have a positive impact on iFOBT screening participants, although this is subject to high variability (Federici et al 2006, Koo et al 2010, Power et al 2009).

Given this unique role and noted variation, it was agreed the role and value of general practice in the BSP needed to be more fully understood, particularly with regard to enhancing participants’ experience and in considering general practices’ role if the Pilot was rolled out nationally. To identify the role and value of general practice in the BSP, this report draws on the quantitative data from the eligible population and provider surveys (Litmus 2014 a & b), the immersion visits interviews with GPs, practice nurses and practice managers as well as face-to-face interviews with Māori and Pacific BSP participants.

1.2 Key findings

Key findings from across the range of data sources are:

- General practices in WDHB have high levels of awareness, knowledge and support of the BSP. In the main, GPs are undertaking their role in the BSP as intended. Three quarters of BSP participants heard about their positive iFOBT result from their general practice.
- For those BSP participants who did not hear about their positive iFOBT result via their general practice, this can reflect their personal choice and circumstances (i.e. not wanting their GP informed, not having a nominated GP in their practice, or not being contactable within ten days) or incorrect consent form completion.
- Māori and Pacific BSP participants interviewed had very positive experiences along the BSP screening pathway. The process of hearing about their positive iFOBT result via general practice or the Endoscopy Unit was a timely and reassuring experience which ensured they understood the need and process for having a colonoscopy.
- Most BSP participants do not have a strong preference on who informs them about a positive iFOBT result so long as their positive iFOBT results are timely, free and convenient, given in a reassuring manner, their GP is kept informed, and the transition to colonoscopy is well explained, timely and streamlined.

- Māori and Pacific BSP participants interviewed who heard received their results from the Endoscopy Unit perceived this approach as more convenient, potentially cheaper (as no need to take time of work or incur transport costs), timely and aligned with the next step of having a colonoscopy than general practice. However, for these participants it is critical that their GP is aware of their iFOBT result.
- BSP participants who are highly anxious, have other health conditions or are reluctant to have a colonoscopy gained benefit from a consultation with their GP about their positive result.
- General Practice staff have high awareness, knowledge and support of the BSP, although there is concern about the impact of the BSP on symptomatic services particularly wait times for colonoscopy for symptomatic patients.
- Promotion of the BSP by general practice is opportunistic. Currently practices are unaware of the non-responders in their practice as there is no system to inform general practice who has received an iFOBT kit and not returned it. A potential enhancement to general practice’s role is following up non-responders in particular Māori and Pacific non-responders.
- Most (but not all) GPs are aware of their role to notify participants with positive iFOBTs within ten days. How participants are informed by general practice varies from face-to-face consult with GP to phone discussion with practice nurse.
- Most GPs and other staff perceive that having general practice involved in the BSP supports more participants to take part and enhances participant experience. In contrast, a few GPs did not perceive an added value role for general practice, and simply wanted to be kept informed of their patients’ results and interventions.

2. Introduction

2.1 Background

The Ministry of Health (‘the Ministry’) has funded Waitematā District Health Board (WDHB) to run a Bowel Screening Pilot (BSP) over four years from 2012–16.¹ 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.² Included in these are three immersion visits, whereby the Litmus evaluation team interviews providers and stakeholders involved in aspects of BSP implementation; qualitative interviews with BSP participants and non-participants; and quantitative surveys of the eligible population and providers.

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

¹ 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.

² Refer to the *Evaluation Plan for the Bowel Screening Pilot 2011–2016* (Litmus 2011) for details of evaluation activities.

2.2 Report purpose

The role of general practice in informing BSP participants of a positive immunochemical faecal occult blood test (iFOBT) is a unique element of the BSP. The findings from the first immersion visit (Litmus 2013) found that while general practitioners (GPs) and practice nurses are generally supportive of the BSP, across general practice there is variation in BSP processes and practices. Internationally, GP involvement in bowel screening has been shown to have a positive impact on iFOBT screening participants, although this is subject to high variability (Federici et al 2006, Koo et al 2010, Power et al 2009).

Given this unique role and noted variation, it was agreed with the Ministry and the Bowel Screening Evaluation Advisory Group, the role and value of general practice in the BSP needed to be more fully understood, particularly with regard to enhancing participants’ experience and in considering general practices’ role if the Pilot was rolled out nationally.

To identify the role and value of general practice in the BSP, this report draws on the quantitative data from the eligible population and provider surveys (Litmus 2014 a & b), the immersion visits interviews with GPs, practice nurses and practice managers as well face-to-face interviews with Māori and Pacific BSP participants.

2.3 Glossary of terms

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

- BSP – Bowel Screening Pilot
- CAR – community awareness raising
- CATI – computer-assisted telephone interviewing
- CNS – clinical nurse specialists
- DHB – District Health Board
- iFOBT – immunochemical faecal occult blood test³. 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
- GP – General Practitioner
- The Ministry – Ministry of Health
- MoH – Ministry of Health
- Non-responders – people who have received a pre-invitation, invitation and reminder letter, have not returned a completed kit, and have not contacted the Coordination Centre to opt out of the BSP
- The Pilot – the Bowel Screening Pilot/BSP
- WDHB - Waitematā District Health Board
- The Register – BSP information system

³ Referred to internationally as Faecal Immunochemical Test for Haemoglobin (FIT)

- 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. Methodology

This section outlines the method used to undertake the immersion visit interviews in general practice and interviews with Māori and Pacific BSP participants. It details the sample frame, recruitment and interviewing approach, analysis and research limitations. The method used for the WDHB population survey and the provider survey can be found in the relevant reports (Litmus 2014 a & b).

3.1 Immersion visit interviews with general practice

Sample

Litmus worked with WDHB and the Primary Health Organisations (PHOs) to develop a sample frame that ensured participation of general practices across WDHB. A purposive sample frame was developed to ensure the inclusion of rural and urban practices, those with high need populations including Māori and Pacific people, practices from both Procure and Waitemātā PHO, and a range of practice size.

Interviews were undertaken across ten general practices. Table 1 provides an overview of the sample structure achieved.

Table 1: Overview of achieve general practice sample

Practice descriptors		Number
Location	Urban	5
	Semi-rural	3
	Rural	2
Size ⁴	Large	4
	Medium	4
	Small	2
PHO	Procure	7
	Waitemātā PHO	3
High needs	High needs practice population	4
Total number of practices		10

Interviews were also undertaken with key WDHB BSP staff who interface with general practice and Primary Health Organisations. In total, 23 people participated in an interview.

Table 2 details the interviews undertaken by provider type.

⁴ Large practices had more than a 1000 patients enrolled, medium between 500 to 1000, and small less than 500.

Table 2: Sample achieved by provider type

Provider type	Number
WDHB (including endoscopy nurses)	3
Primary Health Organisations	2
General practitioners	9
Practice nurses	5
Practice managers	2
Other practice staff	2
Total	23

Fieldwork

Evaluators from Litmus and Integrity Professionals visited WDHB to undertake face-to-face interviews with general practice staff. Interviews took between 30 and 60 minutes, dependent on roles and availability.

In line with Waitemata DHB’s Engagement and Consultation Financial Recognition Policy, general practices that participated in a face-to-face interview could seek reimbursement of reasonable out-of-pocket expenses up to \$125.

Fieldwork was undertaken in October 2013. All interviews were audio-recorded and notes were taken during the interview. All interviews followed an informed consent process.

Research questions

With regard to the role and value of general practice in the BSP, interviews with staff from WDHB, PHOs, and general practice focused on:

- What is general practices’ level of understanding of their role in the BSP?
- How are general practices practically managing their role in the BSP?
- How is the BSP impacting on general practice workload?
- What are their attitudes and perceptions to the BSP?
- What do they perceive as the value for participants of having general practice involvement in the BSP?
- What are the disadvantages of having general practices involved in the BSP?

Refer Appendix 1 for the information sheet, consent form and discussion guide.

3.2 Interviews with Māori and Pacific BSP participants

When the BSP Evaluation Plan was designed, it was initially intended that the 2013 WDHB quantitative survey with the eligible population in WDHB would also be administered face-to-face to five Māori and five Pacific people to validate the CATI questionnaire. This comparison was undertaken for the 2011 benchmark survey and no significant differences in the responses between the two delivery methods were found.

After consultation with the Ministry and the Bowel Screening Evaluation Advisory Group, it was decided that interviews with Māori and Pacific BSP participants who had a positive iFOBT would be undertaken to explore the role of the general practice and the value this interaction added to their experience of the BSP. It was agreed that this approach offered greater insight into understanding the role of general practice and offered more value than revalidating the questionnaire.

Sample

Face-to-face interviews were conducted with ten purposively selected BSP participants. All participants recruited had received a positive iFOBT result and had a colonoscopy⁵. This enabled the exploration of the role of the general practice in telling participants about their positive result.

Recognising potential health inequalities and the need to ensure the evaluation enables the voice of those less likely to do a phone survey, focus was placed interviewing five Māori and five Pacific people. To enable recall of the BSP process, Māori participants had undertaken the test in the last eight months. Reflecting their relatively small number, the sample population for Pacific participants included all Pacific participants who had a positive iFOBT since the commencement of the Pilot. Table 3 presents the achieved purposive sample for the BSP participants in 2013.

Table 3: BSP participant sample achieved

Demographics	Māori (n=5)	Pacific* (n=5)
Male	3	3
Female	2	2
50 – 59 years	4	1
60 – 69 years	1	3
70 – 74 years	-	1
5 year recall 1 kit	3	3
Surveillance	2	2

* Pacific interviewees included 2 Samoan, 2 Niuean, and 1 Cook Island Māori.

Recruitment process

An initial letter with an information sheet was sent out to the potential participants selected from the Register by the BSP Coordination Centre. The letter outlined the purpose of the evaluation and this research project. Participants were given details regarding confidentiality of the research and how their contribution will be used to inform the evaluation and seek improvements to the BSP. Before their contact details were forwarded to Litmus, participants were given the opportunity to opt out of the research by contacting the BSP Coordination Centre. Participants were called on receipt of the non-opted out participant list and invited to take part in the pathway study by Kaipuke for Māori participants and Integrity Professionals for Pacific participants.

⁵ No participants were diagnosed with cancer.

Fieldwork

The interviews were conducted in November and December 2013.

Māori researchers (Kaipuke) undertook interviews with Māori participants. Pacific researchers (Integrity Professionals) undertook interviews with Pacific participants. Māori and Pacific interviews were gender-matched (i.e. interviewer matched with interviewee). Each interview lasted approximately 30 to 60 minutes and was held at a venue preferred by the participants and safe for the researcher. Interviews were audio recorded. Participants received a koha of \$50 for their time and contribution. They were encouraged to have a support person or people present during the interview.

Research questions

The intent of the interview was to explore the value of general practice involvement in the BSP from the participant perspective, and also to identify whether there were any new issues or other feedback arising compared to 2012 BSP participant feedback.

The interviews used a similar approach to the clinical pathways studies undertaken in 2012 (Litmus 2013a). Participants were asked to map their experience of the BSP from first hearing about it to the completion of their colonoscopy, and discuss what worked well and not so well. Particular focus was placed on how they heard about their results, and experiences of this process and perceived pros and cons of alternative processes. Feedback was also sought on the awareness of community awareness raising activities (CAR) activities.

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

Analysis

General practice interview transcripts were coded and grouped into concepts and categories and presented as themes in this report.

On completion of the participant interviews, analysis workshops were undertaken with Māori and Pacific researchers (i.e. Kaipuke and Integrity Professionals) to debrief on the interviews and discuss common themes arising across the interviews. Interview notes prepared by Kaipuke and Integrity Professionals were coded and grouped into themes. Particular focus was placed on understanding the unique Māori and Pacific people’s experience.

3.3 Other data sources

Data was also drawn from the follow-up WDHB population survey and the WDHB provider survey (Litmus 2014a & b).

In the follow-up WDHB population survey some minor revisions were made to measure:

- whether participants received their positive iFOBT results from their general practice
- preference on who informs BSP participants if they have a positive iFOBT result.

It is noted that only 7% of BSP participants have a positive iFOBT therefore the small sample size limited this analysis.

The provider survey sought GPs, practice nurses and practice managers’ feedback on:

- awareness of their role in the BSP
- their perceived performance of their role
- impact of the BSP on general practice workload
- attitudes to the BSP
- perceptions of capacity across the screening pathway
- effectiveness of the interface with the BSP Coordination Centre and the Endoscopy Unit.

3.4 Research limitations

This report draws on a mix of qualitative information and quantitative data. Litmus is confident that the results presented in the report are based on the information and data provided. Table 4 provides a commentary on the data and information used to inform this report and their quality.

Table 4: List of data and information used and their quality

Data sources	Quality rating	Comments on quality
2013 WDHB eligible population survey (Litmus 2014 a)	Medium	<p>In the absence of any other population-level data on awareness and knowledge around bowel cancer and bowel screening, the telephone surveys conducted as part of the BSP evaluation provide useful information. Data limitations:</p> <ul style="list-style-type: none"> ▪ Relatively small sample sizes limit the possibility of extensive sub-group analysis and the reliability of comparisons over time. ▪ People who were less easily identifiable as Māori or Pacific may be less well represented, relative to those who were more easily identifiable as Māori or Pacific. ▪ Non-respondents may have differed from respondents in unknown ways, which would affect the survey results. Weighting will have helped to mitigate the problem. ▪ The response rates achieved for the two WDHB surveys (using a conservative measure) were reasonable, but not exceptional.
2013 WDHB provider survey (general practice responses) (Litmus 2014 b)	Medium	<ul style="list-style-type: none"> ▪ The key methodological limitations of the provider surveys are the low GP and practice nurse response rates and an inability to establish whether GP and practice nurse samples are representative of the wider population of WDHB GPs and practice nurses. Consequently, GP and practice nurse findings are indicative and not definitive.
Immersion interviews with general practice and WDHB staff	Medium	<ul style="list-style-type: none"> ▪ The perspective of primary care on the BSP is limited to the participants from ten general practices from Waitematā Primary Health Organisation (PHO) and Procure. ▪ Variations in processes and opinion on general practice were noted across the ten practices.

Data sources	Quality rating	Comments on quality
Qualitative interviews with BSP participants	Medium	<ul style="list-style-type: none"> ▪ Findings are dependent on participants’ recall of the order of events and experiences on the BSP screening pathway. ▪ Undertaking ten qualitative interviews means the diversity of Māori and Pacific BSP participants may not be covered, and Asian people and European were not included therefore not all experiences of those participating in the BSP have been explored. ▪ Two Māori and five Pacific participants were informed about their iFOBT results from the Endoscopy Unit. Participants were not screened as it was assumed that most would have received their positive iFOBT result via their general practice. Further, the pool from which to draw the purposive sample was relatively small to be screening out participants. The sample achieved enabled the exploration of participants’ experience of hearing about their results via the Endoscopy Unit and whether they would have preferred to have received their results from their general practice.

4. Overview of General Practices’ Role

This section describes the role of general practice in the BSP in particular informing participants of positive iFOBT results and surveillance recall.

Most of the information about the BSP process is drawn from the BSP resource for health providers (WDHB 2012).

Responsibility

Primary care are responsible for informing BSP participants of a positive iFOBT. The BSP Coordination Centre is responsible for all other aspects of 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 was not been implemented. Consequently, GPs are not aware which of their patients have received their iFOBT kit and not returned it.

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. 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:

- For positive result the GP has to discuss the result with the patient and refer for colonoscopy to BSP via Booking and Scheduling Waitematā DHB within ten days.
- For a negative result the GP is informed it is a negative result from BSP, and the patient, if still eligible, will be recalled by the screening programme in two years.

Results are not sent to GPs if BSP participants have indicated this option on their consent form (i.e. ticked the box which states they do not want their GP informed⁶), 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.

For a positive iFOBT result, general practice must on receiving a positive result from LabPLUS:

- inform their participant of the result
- discuss the implications of the result
- provide counselling and advice

⁶ Litmus 2013 and Phoenix 2013 highlighted that BSP participants were incorrectly reading the consent form and assumed that by ticking the box their GP would be informed about their results. From 19 February 2014 a revised consent form is being introduced that does not have a tick box on whether participants want their GP to be informed of their iFOBT results.

- refer their participant to the Endoscopy Unit within ten working days of receiving the result for a screening colonoscopy through the standard referral systems – referrals are faxed to the North Shore Hospital central referral office, marked ‘Bowel Screening Waitematā’. Faxed referrals to the BSP 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 the e-referral system which incorporates a standard form for BSP colonoscopy referrals.

Participants do not have to pay to have an appointment with their GP to discuss a positive iFOBT result.

Participants with a positive result who do not have an identified GP, don’t want their GP informed or who have not been referred by their general practice within ten days, are contacted by the BSP Endoscopy Clinical Nurse Specialist (CNS) within 15 working days of a positive result. Extensive efforts are made by the CNSs 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 Endoscopy Unit. If no contact is made, the participant is placed on the iFOBT recall system and remains on the BSP Register. If the participant contacts their GP or the Endoscopy Unit at any date before their recall day a colonoscopy appointment will be arranged.

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.

Post colonoscopy

Post colonoscopy, the recovery nurse gives the BSP participant a copy of the Endoscopy Report (i.e. the colonoscopy report) and also puts a copy in the mail to their GP.

When a cancer is identified at colonoscopy, the Endoscopist informs the participant of the finding, discusses next steps, makes arrangements for further tests, refers for a specialist appointment and provides a cancer information pack.

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. Participants receive a letter advising them of the histology findings and a management plan and a copy goes to the GP. The BSP Clinical Director 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.

Surveillance

Participants requiring ongoing surveillance are exited from the BSP, referred to a surveillance programme, and not recalled for subsequent screening. The initial BSP process for managing participants requiring surveillance colonoscopies was as follows:

- Participants requiring surveillance colonoscopies within one year were placed on the WDHB Endoscopy Service wait-list (this is a symptomatic list).
- Those requiring surveillance colonoscopy over longer timeframes were discharged to their GP with a request to refer to the WDHB Endoscopy Service at the appropriate time.

This referral process has been revised due to the increasing number of participants requiring surveillance colonoscopies. Since late 2013, participants requiring surveillance colonoscopy are referred to the symptomatic service who send colonoscopy appointments at the recommended surveillance interval.

The BSP Endoscopy Unit is responsible for advising participants they have been referred for surveillance and notifying participants’ GPs. 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*).

5. BSP Participant Experience and Preference

This section details BSP participants’ experience of how they received their positive iFOBT result and their perceptions of the pros and cons of differing delivery processes. An overview is also provided of their screening experience to identify if there are any new issues arising compared to BSP participant feedback in 2012 (Litmus 2013a).

5.1 Process to receive a positive iFOBT result

As indicated within the BSP screening pathway there are a number of ways in which participants may be informed about a positive iFOBT result (i.e. call from GP or CNS from the Endoscopy Unit or less frequently, a letter from GP or Endoscopy Unit).

For the first 18 months of the Pilot, 74% of BSP participants at pre-assessment have been informed of their positive iFOBT result by their GP (Ministry of Health Register dated 29 January 2014). The remaining 26% were informed via the Endoscopy Unit’s CNS. The method by which BSP participants are informed of their positive iFOBT result can reflect their personal choice and circumstances, for example:

- participants not wanting their GP informed indicated by ticking this preference on their consent form
- incorrect completion of the consent form where participants want their GP informed but misread the consent and tick the box not to inform their GP
- participants not having a nominated GP at their general practice. The lab does not send results to a general practice, only a nominated GP, so positive iFOBT results of BSP participants with no named GP are sent to the Endoscopy Unit for the CNS to contact
- participants who due to change of address or phone number may not be contactable within the ten day period by general practice.

In 2013 the WDHB eligible population survey (Litmus 2014a) found that⁷:

- 23 people (out of the 324 people who had received a BSP kit) had a positive iFOBT result. Based on the people who had received a BSP kit, this equates to 7% who completed the kit having a positive iFOBT – which is comparable to the Register results.
- Of the 23 people with a positive iFOBT, 16 received the news of their results from general practice (70% similar to the Register data), three stated they were called by someone from the Endoscopy Unit, one received a letter from the Endoscopy Unit and three did not know⁸).

⁷ Data presented is based on the weighted data.

⁸ Both the qualitative interviews and the quantitative survey highlighted that some BSP participants do not recall how they received the news of their results.

The ten Māori and Pacific BSP participants interviewed received the news of their positive iFOBT via the following processes:

- One Māori BSP participant received a call from the practice nurse of their general practice to say the test came back positive and had a face-to-face consultation with their GP.

I got a phone call from my doctor’s nurse to say that it was positive and that I would have to have a colonoscopy and that she would have to make an appointment for me to see the GP.... It was only three days after I sent the sample so it was really quick. I was so surprised that it was that quick. So yeah, we had the appointment and talked to my doctor who explained that it was positive and that I had to have a colonoscopy and that the bowel screening people would organise the appointment for me.

- One Māori BSP participant received a letter from their GP informing that the test was positive and they had been referred to the Endoscopy Unit for a colonoscopy.

My GP wrote me a letter and said that it has come back positive and he has taken the procedures of, you know, the next step.

- One Māori BSP participant thinks they heard from their general practice, although they were not certain.
- Two Māori BSP participants heard from the Endoscopy Unit. Both discussed the results from their colonoscopy when they were next at their GP about another non-related health matter.

The lady [CNS] I spoke to was really good. She told me not to get worried and it’s not a major but of course my sample showed some signs of blood and I needed to have the colonoscopy. But she made sure that it wasn’t a major issue. You know it’s quite common for that to show up and not mean anything....And then she let me make the booking with her.

All Māori BSP participants interviewed had a positive long-term relationship with their GP.

- Five Pacific BSP participants heard from the Endoscopy Unit – four received a phone call from the endoscopy nurse and one a letter. On prompting, three commented that they had ticked the box on the consent form assuming this meant their GP would be informed about the result. Ticking this box indicates that the participant does not want their GP to be informed⁹.

To me, they did the job to the letter. They found out what was wrong. They get in touch with me straight away. And ask me whether I want to go through this or not – it’s up to me and they are not going to force me... The woman I was with, she had a nice voice, she talked well, she was polite, there wasn’t sort of a commanding voice...I think she was professional anyway, the way she talked.

⁹ The BSP Coordination Centre is aware of this issue, the consent form has been revised and the new version will be used in screening round two from February 2014.

Similar to Māori participants interviewed, three Pacific participants had a long term and very positive relationship with their GPs. Two Pacific participants had a general practice they had attended, although they did not have a regular GP they saw due to the use of locums and limited availability. Only one Pacific participant discussed the results with their GP. For some this may have reflected their assumption they would need to pay for the consult. They were also concerned with time and travel costs involved in getting to the general practice.

That’s why a lot of people don’t want to go and see the Doctor, because of the price...(Pacific BSP participant)

Participants who heard about their positive result from the Endoscopy Unit assumed that their GP was informed about this result and would contact them if they deemed it necessary.

Yes I made sure of that. Because since I had my high blood pressure I always let my Doctor know what is going on. I have a three monthly visit with her and she will bring it up on the system and it tells her what has been done in the past and that tells her about the blood scanning, heart scanning and cancer. (Māori BSP participant)

Regardless how BSP participants heard about their results, their experience was a positive one as their key needs were met:

- Timely – All were pleased (and somewhat surprised) about how quickly they received their result and received a colonoscopy appointment.
- Reassuring – Most acknowledged that receiving a positive result is stressful raising fears they may have cancer. Both general practice and the Endoscopy Unit offered reassurance by explaining it was very unlikely that a positive result is cancer, although it is important to check this out.
- Clear direction – All had an understanding about what happened next with regard to the colonoscopy, and when they were likely to get an appointment.

5.2 Preferred delivery of positive results

Overall BSP participants have differing preferences on how they want to receive their positive iFOBT result. Preference, if stated, tended to reflect their experience. Evident across the interviews regardless of whether they were advised of the results from their GP/practice nurse or the Endoscopy Unit were the elements that enable a positive participant experience:

- the results are timely
- reassurance is offered due to the fear raised by a positive result
- next steps are clear with regard to colonoscopy, the preparation required, and the appointment is timely
- the result process is free and convenient
- GPs are informed of the result.

The WDHB eligible population survey (Litmus 2014a) found that respondents find it very reassuring to receive positive iFOBT results from their general practice, although they are also happy to receive positive results directly from the screening unit¹⁰. The findings highlighted that both methods are acceptable (refer Figure 1 and 2 in Appendix 3).

- Eight in ten respondents (80%) agree it is very reassuring for their GP or practice nurse to tell them if they have a positive iFOBT test result.
- 76% of respondents are happy to be contacted by someone from the BSP to tell them about a positive iFOBT result. Māori (87%) are more likely to agree than the Other ethnic group (75%) that they are happy for the screening unit to contact them.

After Māori and Pacific BSP participants had described their experience of receiving their results they discussed the pros and cons of receiving results via their general practice or Endoscopy Unit. Across the ten interviews:

- One Māori and five Pacific participants noted a preference for the Endoscopy Unit to inform them of their positive result. No one who had heard about their results via the Endoscopy Unit stated they would have preferred to receive their results via their GP even though many had long-term positive relationships with their GP.

Based on their experience, they believed that receiving results via the phone from the Endoscopy Unit’s CNS was more streamlined as it aligned with the next step in the screening pathway (i.e. colonoscopy), more timely and connected them with staff best placed to answer any questions about the result or the next steps. In contrast, they noted that visiting their GP would be less convenient if they needed to make an appointment and may therefore be slower, and concerns were raised about the cost of the visit in terms of GP fees, travel costs and for those working time off work¹¹. However, these participants did reiterate the importance of their GP being informed about their results to ensure their GP has a holistic overview of their health and wellbeing.

I’d rather have it from the hospital because they were the ones that did that thing, the test. (Māori participant)

The hospital, because you’re hearing it straight away otherwise a visit to the GP costs you money. Just sort of being open about it as well. (Pacific participant)

It was good because when I needed to ask any questions I ring the same nurse. There was a specific nurse designated to answer the phone. So she knows who I was instead of going through, starting again and again and again each time different person. (Pacific participant)

The preference of the Endoscopy Unit reflects participants’ experience of the current high standard of service delivery by CNS when informing patients of positive iFOBT results. If a bowel screening programme was to be rolled out nationally, consideration is needed on whether these standards could be maintained.

- Two Māori participants had no preference providing the underlying delivery elements (noted above) of a positive participant experience are met.

¹⁰ The term ‘screening unit’ was used in the survey.

¹¹ BSP participants do not pay to see the GP if they have an appointment to discuss a positive iFOBT result.

- Two Māori participants preferred hearing from their GP about their positive iFOBT result (as was the case for them). These BSP participants had existing health conditions and were anxious about the result and/ or the colonoscopy so appreciated being able to discuss their results with their GP. These participants also commented that receiving their result from their GP was more personal and ensured that they could seek the GP’s assistance if any issues arose from the colonoscopy (e.g. bleeding or delays in receiving the results).

I found that it was. Because they are the people [GP] who have been looking after me all of these years and so they were kept in the loop about what was happening as well. It was a bit more personal because I knew them. (Māori participant)

5.3 Overview of participant experience

As in 2013, feedback from Māori and Pacific BSP participants interviewed was overwhelmingly positive, and their experiences were consistent with the earlier findings. Key themes from interviews include:

- The BSP is seen as important and relevant due to past bowel issues, family/ whānau history of cancer or other cancer experiences, a propensity towards screening for health and wellbeing and/ or wanting peace of mind they do not have bowel cancer. Pacific participants also mentioned maintaining health to be there for children and grandchildren.
- Most first heard about the Pilot via the BSP letters and kit mailed out. A few mentioned hearing about the BSP via family/ whānau and friends, reading about it in the local newsletter and one heard about it from their GP. Before undertaking the tests, Pacific participants seemed to be less likely to discuss the BSP with family and friends. No one mentioned any community awareness raising activities specifically targeting Māori and Pacific people.
- Information received via the BSP letter and kit was understandable, although there was recognition that others in their family/ whānau may struggle to understand it. Pacific participants in particular noted the need for translations into Pacific language and ensuring interpreters are available.

That was no problem. It was straightforward, put in the sample, make sure you get it right, send it out straight away...that was the easy part. The hard part was cleaning out your stomach for the actual screen [colonoscopy]. (Pacific participant)

- The BSP is free and therefore accessible.

The fact that it is free is a factor. I don’t know what it costs for it but yeah that has got to be a major factor. (Māori participant)

To me, it was something that you gotta do...plus it costs you nothing. (Pacific participant)

- Some participants acted promptly to complete the kit. Others required prompting by family/ whānau to act. Hesitancy to complete the kit reflected Māori and Pacific participants dislike of handling faeces and an aversion to posting faecal samples in the mail. For these participants, the benefits of checking their bowel health outweighed their aversion.

I thought oh heck you know because I don't like looking into the [toilet] bowl. So for me to go and do it, it sort of put me off a bit about doing it myself. I had to find out and go ahead with it. It took me three weeks. I kept looking at it; I put it away in a drawer. But I kept thinking about it and I just went aww to heck with it and I did it and I put it in the envelope and took it to the post shop. (Māori participant)

Cause I already sent that stupid (laughs), [participant referring to sending sample in the mail] I said to them, oh my gosh, I only hope that the people at the Post Office don't know what's in there (laughs) but they were good, because they sent me the little envelope, all covered in plastic and another plastic, so all I need is to put it in the little bag they sent me (laughs) that's what's good about it (laughs) I said to my daughter, please take it, 'nah, take that with you..' You know what time I did that? I did it in the night time when everyone's gone to sleep (laughs) when everyone's gone to sleep, ah my gosh, I never told anybody but my son-in-law. (Pacific participant)

My wife insisted, she said, no just do it, it's harmless...to my horror the result came positive. (Pacific participant)

- The process to complete the BSP kit was described as straightforward and easy. As in 2013, Māori and Pacific participants understood the kit instructions, and could undertake the test without other assistance.
- Timely process to receive the iFOBT result and colonoscopy appointment (discussed section 5.2).
- Positive participant experiences with the Endoscopy Unit due to professional and caring staff, clear communications and support through the process. Many participants had expected that having a colonoscopy would be embarrassing, this was not their experience. Participants also noted the process seemed quick and appreciated the discussion with the endoscopist about the findings, and the refreshments provided after the colonoscopy. Due to their positive experience, Māori participants indicated that they would have no hesitation in participating in surveillance colonoscopies or doing further tests as needed.
- Most seem to be aware of what happened next with regard to recall and surveillance, although two Pacific people were not sure and one wanted to be seen earlier than the recommended surveillance period.

Interviews with Māori BSP participants highlighted some other areas for reflection:

- Disability and faecal aversion: One Māori participant had a disability which made the completion of the iFOBT kit challenging due to the small pottle and the need to screw the lid on. The test was important to the participant due to other health concerns therefore they persevered and completed the test. The participant would not seek support from their partner with the pottle given it contained faecal matter.
- Incomplete bowel preparation: Two participants did not complete bowel preparation properly as they ate something on the day of the procedure¹². The Endoscopy Unit have recently revised and updated their information sheets on pre-colonoscopy diet and bowel preparation so this may be addressed.

¹² From January to June 2013, 0.76% of participants have a failed colonoscopy due to poor bowel preparation which is within the indicator of less than 5% (WDHB 2013b).

- Management of participants with diabetes: One Māori participant with diabetes noted that important communications from the pre-assessment interview had not been passed on. The CNS pre-assessment interview identified the need for the participant to be first on the list due to their diabetes. However on the day the participant had been placed fourth on the list. Once identified this was quickly rectified.
- BSP advocates: All Māori participants had in some way become advocates for the BSP by promoting it to their family/ whānau and friends. Given the current focus on increasing participation by Māori, the potential for future promotional campaigns to use this support needs consideration.

I am very pleased with the whole thing and I recommend that our Māori people go and get it done. I was quite pleased with the whole thing. (Māori participant)

I can tell other people yeah I've had that done and I can let others know that it is not a bad thing. I would encourage others that it is not a bad thing and while it is not going to cost anything. Yeah just go and do it aye. Tell other people about it. You know when they are getting up to their fifty mark go and get it done. (Māori participant)

Interviews with Pacific BSP participants highlighted other areas for reflection:

- Need for translators: All male Pacific participants noted the need for translators especially when explaining the result and the need for the colonoscopy. The need to be careful with translation of words was highlighted particularly noting the differences in the language used by those in the older cohorts in the eligible population compared to the younger ones¹³.
- Managing embarrassment: One Pacific participant suggested the need to gender match if possible the participant and the endoscopist and if possible decrease the number of people in the room. Checking whether the participant wants to see the screening of the colonoscopy is also important as not all Pacific (and Māori) participants want to watch.

The most embarrassing part is to go in because you never know whose going to look at your bum. That was the only part I was not comfortable about...I had three of them, two nurses and a doctor...that was the only part that I worry about but anything else it was okay with me...must have some way of doing it instead of people looking at your bum.

- Anxiety stopping action: Fear they may have cancer may discourage Pacific participants to have the colonoscopy.

Usually if you find some blood it's a bad sign aye?...it could be cancer, it could be something else. It was getting me a bit worried aye. I got a bit worried but I thought, no, I have to go through this.

- BSP advocates: Like Māori, Pacific people who had completed the BSP were keen to encourage others.

I feel very strong about this, I wish all Pasifika, Pacific people from age 54 up to 70, if they got a letter from the health, their health district, just go and do it. That's the only concern for me, Pacific Island be strong, stand up for ourselves.

¹³ CNSs are aware of the need to use translators for Pacific participants and offer a translator (at times even when the Pacific participant states they do not want one).

Summary: Māori and Pacific BSP participants interviewed had a very positive experience when on the screening pathway. The BSP is seen as important health check, which is described as easy, timely and free.

Aversion to doing faecal samples in the home and posting them are marked for Māori and Pacific BSP participants. As a result, those people who struggle to complete the BSP kit will not ask for family/ whānau assistance; this is especially pertinent for those with a disability. For Pacific participants, taking part may be impeded by a lack of understanding, fears of cancer and embarrassment about colonoscopies.

The process of receiving a positive iFOBT result via general practice or the Endoscopy Unit is a positive one – being timely, reassuring and ensuring the next step on the screening pathway. BSP participants are comfortable receiving the iFOBT results via the Endoscopy Unit’s CNS and see this process as more convenient, potentially cheaper, timely and aligned with the next step to having a colonoscopy; although it is critical for their GP to be aware of the result. In contrast BSP participants with existing health conditions, those very anxious about the result or having a colonoscopy appreciate their GP consult.

6. General Practices’ Delivery and Preferences

This section summaries the awareness and knowledge of general practice about their role in the BSP. It uses the feedback from ten general practices to describe how they implement these roles, and presents their perceptions of the value of general practice in the BSP.

6.1 Awareness and knowledge of the BSP

The following findings from the 2013 follow-up provider survey show that in the main GPs and practice nurses and managers who completed the survey are aware and knowledgeable about their role in the BSP (Litmus 2014b):

- All are aware of the BSP and view New Zealand’s bowel cancer death rate as a significant health concern.
- There is near universal support for the BSP in WDHB and for a national bowel screening programme, and strong support for use of the iFOBT.
- Most believe they have an important role in the BSP, and feel increasingly confident explaining the BSP to their patients.
- There is strong agreement that it is the role of GPs to inform BSP participants of positive iFOBT results; although one in 20 continue to disagree this is not their role.
- The majority of general practice staff reported their workload increased due to the BSP, although the impact is lower than expected before the Pilot commenced in 2012.
- Performance in delivering relevant BSP activities is rated fairly well. Areas where performance was not rated as highly were referring patients with family history of bowel cancer to the New Zealand Familial Gastrointestinal Cancer Registry, and liaising with the BSP Coordination Centre when unable to contact patients with positive iFOBT results.

6.2 Description of service delivery

Discussions with GPs, practice nurses and managers across 10 general practices in the 2013 immersion visit focused on understanding how the BSP was being implemented within their practice. Across the interviews, a number of core functions emerged, which align with the expected BSP screening pathway:

Promotion of and education about the BSP

General practice staff note that the BSP is not actively promoted. Promotion tends to be opportunistic prompted by patients queries on when they will receive their BSP kit or whether or not they should complete the test. Those with existing health conditions or other special needs were mentioned as more likely to discuss the BSP, usually when visiting their GP on other health matters. A practice with a high Pacific patient population noted some of their patients will make an appointment to discuss whether and how to complete the BSP kit. Most patients however complete the BSP kit without discussing any aspect with general practice staff.

The lack of active promotion reflects the busy workload of general practice including the demands of other screening programmes, and the detailed information in the BSP communications sent directly to eligible participants.

With the bowel screening issue in the media, we have mainly just been giving information to patients when they have been requesting it from us. Well they are very keen to know how they can get on the programme and we just explain that it goes by date of birth and name and that their time will come. They are happy with that, and then other times, people may come in when they have received the kit and they want to talk about the pros and cons of doing it and whether they should and things like that. There have been a handful of those, which I think you would expect. It's a human nature thing that some people still want to run it by their doctor even though they have all the information in the packs. Most people are quite happy to do it and have done it. (GP)

GPs have had success in supporting people who had initially declined to take part in the BSP. The success was due to explaining the benefits of bowel screening and what it involved. Due to the distribution process of the FOBT kit, GPs are not aware which of their patients have received and not completed a kit. Consequently, they are unable to discuss non-completion when they come in for other appointments. Most indicated that this was an area where general practice could further support the BSP, particularly for Māori and Pacific people eligible to take part.

GPs have also supported BSP participants with positive iFOBT who were reluctant to have a colonoscopy to complete this test.

A couple of patients said they didn't want to do it and when they came for something else I explained what it was and then they chose to do it. So that might be an area that we could improve, there will be people who decline who maybe don't understand the practicality of it because it just comes in the mail. I guess there will be people who work it out but my feeling is that if they're non-responders then maybe it's time to let the primary physician know so that we could address that. One patient I had took the test and it came out positive and when it came to her having a colonoscopy she turned around and cancelled it, but she came here and I encouraged her to do it and she did. (GP)

Informing participants of positive iFOBT results

Informing BSP participants when they have a positive iFOBT is recognised as a key role for general practice. GPs receive the results via e-referrals from HealthLink which across the ten general practices interviewed triggers one of the following four models of service delivery:

1. Nurse calls and informs participant of the positive iFOBT results and always makes an appointment for participant to have a consultation with the GP (four out of the ten practices). Informing BSP participants of test results tends to be undertaken with the practice nurses' other recalls.
2. Nurse calls and informs participant of the positive iFOBT results and if deemed necessary the nurse makes an appointment for the participant to have a consultation with the GP (two out of the ten practices)

3. GP calls all the participants with positive result and discusses the results over the phone. If deemed appropriate the participant is invited to have a face-to-face consult. Participants who are particularly anxious, not keen to have a colonoscopy or have other existing health conditions are more likely to be invited in for a face-to-face consult.
4. A mixed in-house model that is delivered according to the preferences of GPs within the practice (three practices). For example, the nurse calls to inform the participant of their result and makes an appointment with the GP or the GP calls to inform of results and will only see the participant if they deem it necessary.

All interviewed are aware they have to refer BSP participants of a positive iFOBT result within ten days of receiving the results. Perceptions on the ten day window is mixed with some feeling the timeframe is manageable as they are able to inform participants within two to three days. In contrast others feel that ten days is too short particularly for those practices with patients who are challenging to contact due to their change of address or phone.

All practices used a range of standard recall mechanisms to inform participants of their results including multiple calls to land and mobile phones, and texts to inform participants that their results are back and to contact the practice. In one practice where patients are mobile and have high needs, there is an escalating process of follow-up including using a family tree of contacts to other family members and in the end, going to the participant's home.

It takes me three or four days to get to the result, which I think is entirely reasonable because it is not an emergency situation and then it takes me three or four days to get the patient in, or to contact the patient, and then it takes them another week to actually come in. I could do it all over the phone but I think particularly for people with English as a Second Language that is actually not appropriate and I think you will get better engagement if you explain what is going to happen to them. (GP)

Referral for colonoscopy

Once BSP participants have been informed about the positive iFOBT, GPs are required to refer the participant to the Endoscopy Unit for a colonoscopy. Standard referral processes are used either by fax or e-referrals. For some the use of e-referrals is fairly recent so there are some teething problems as GPs become more adept at using this tool.

I just copy and paste the result that comes up and then their profile which is their current and past medical problems, medications, smoking status etc. All the background information, but I don't write anything on them. They receive all the information though, and it's good because it's just a click of the mouse and a copy and paste so it's only 60 seconds. (GP)

Feedback from the endoscopy unit staff indicate that most referrals sent follow the agreed pathway, although a few are sent to symptomatic or surgical services. Endoscopy staff also note the variation in the quality and completeness of GP referral information to endoscopy. Some GPs provide the required information, while others simply refer with little relevant information. The introduction of e-referrals in 2013 has standardised information received and improved the quality of referrals.

Supporting participants diagnosed with cancer

GPs appreciate that the WDHB BSP Clinical Director calls if a cancer is diagnosed.

I do remember I think [BSP Clinical Director] rung me for at least two of the patients that I had and was reassuring. We get rung by breast screening too, so I guess it's a similar protocol to that and I think it's great. The benefit for us is that we're very much involved and so for whatever reason the patient might call us then we are informed and we know what's going on. It makes the patient feel more comfortable too, makes it feel more like teamwork. (GP)

Recalling BSP surveillance participants

Discussions with GPs highlight they are using their practice's standard process for participants who need to be recalled for surveillance colonoscopies. In the main, the recall processes are seen to be working well as they align with other screening programmes such as breast and cervical screening. A few perceive there is room for error within their recall processes as they are not automated or they are uncertain whether the recall responsibility lies with the Endoscopy Unit or the GP.

There is little awareness of the changes to the management of appointments for surveillance colonoscopies which reflects this is only a recent change.

The histology results come from [WDHB BSP Lead Endoscopist], a report comes into our inbox and we will usually get a letter from [Lead Endoscopist] as well with his recommendations so he might say they need rescoping for surveillance or something. That process is working well, we already have recall systems in place for smears and mammograms so the surveillance recalls are not a major. (GP)

We put it on our own recall but I think it happens with Bowel Screening too, at least I hope they're doing it. I think that if a patient needs to go back for a colonoscopy in three years' time or something I think personally Bowel Screening needs to have that too because a patient could change GPs or something, it's just so there's nothing that is missing out. Our system is not that great, although it's getting better. So if I do recall but that patient is no longer with our practice or something it may not work so there's room for error. So that's an important aspect I think, particularly for a national roll out. (GP)

6.3 Perceptions of the BSP

Similar to the provider survey findings (Litmus 2014b), general practice staff interviewed are, in the main positive, about the BSP. They describe the Pilot as well explained to primary care, easy for their patients to take part in, and timely in the scheduling of colonoscopies.

I think it is incredibly easy because it is all supplied and a non-medical person can understand easily what they need to do. I don't know what happens when they need a colonoscopy, I presume they get another information pack but most people seem to know what that is. (Practice Manager)

Across general practice staff interviewed there is a perception that the BSP is impacting adversely on the timely availability of symptomatic services, particularly with regard to the delays faced by symptomatic patients to have a colonoscopy. For some this is ethically unacceptable as people with no symptoms are perceived as receiving a superior service than those with symptoms.

I think our usual referral for a colonoscopy is very delayed, it takes a long time for them to get an appointment, two years sometimes. I think this bowel screening is affecting the normal referrals. I have a patient who was referred for (symptomatic) bowel screening for one year, he didn't get an appointment but he got on the bowel screening programme. It was positive and it was cancer and he is on chemotherapy now. He was waiting for the public system and then he got bowel screening in the mail and was seen within four weeks from his positive test kit. Prior to that he had been waiting in the public system for a year. I was thinking he needed to go private to do it because he had anaemia and was getting positive tests here. Luckily the bowel screening project he got in on. I think the BSP is very good but I don't think it should affect the usual pathway for symptomatic. It is good because you are doing screening for everyone in the area but if it is affecting the normal referrals that is not good. (GP)

I think it is really good but, there is a huge problem with waiting lists for gastro procedures at Waitemata. People with symptoms and signs of bowel cancer should be treated, or investigated before people without symptoms and that is not happening. When we do a referral for the bowel screening they are seen relatively quickly for their colonoscopy, whereas if we refer someone through with rectal bleeding they are seen in nine months. That wait time is getting worse. I don't know if that is a result of BSP. (GP)

For a few GPs there is confusion about where to send patients with bowel cancer symptoms. One GP commented that they have advised patients with symptoms to do the BSP test to enable them to receive a colonoscopy faster than in the symptomatic service.

I think it is better now where it actually goes to but there was some confusion around if they have had a positive FOBT previous to the bowel screening, and then whether the referral goes to bowel screen or symptomatic. My initial misunderstanding was that it was the same test and the one we could do overlapped it but it is obviously not the same test. I have been told now they are nothing to do with each other. I cannot actively get someone into bowel screening if I have a positive test, and they must wait for the kit to arrive in the mail. That was the initial problem we had. The bowel screening is not something we can initiate ourselves. If we have a patient who has a positive FOB blood test then we have to refer this patient to gastroenterology in the public system and not to bowel screen, they might actually get a colonoscopy much later than the bowel screen patient. (GP)

GPs are also appreciative that they are receiving payment for their role in the BSP.

We get paid for positive referrals. As primary care we always end up having to do a whole lot of stuff that we don't get funded for. Everything takes time. (Practice Manager)

6.4 Value of general practice in the BSP

Adds significant value

Most general practice staff interviewed (seven out of the ten practices) stated that general practice has an important role in the BSP in particular increasing participation and enhancing participant experience. The following were identified as the key areas where general practice adds value to participant experience within the BSP:

- Promoting and educating eligible participants about the BSP and encouraging them to take part. This role is seen to offer particular value for Pacific people, those with existing health conditions, those who are anxious or have other special needs.

I think patients are more likely to go along with it if it is practice based, they will be less suspicious of it, and there is no cost to them. (GP)
- Using general practice systems and processes to contact participants to inform them of a positive iFOBT results.

We know the clients, we know their history, we are good at contacting them because if we can't get in touch with them we know who the neighbour is to go around and knock on the door so we have the relationship and hopefully a trusted relationship. I think that helps them moving through to the colonoscopy. (Practice Nurse)
- Reassuring BSP participants at all stages of the screening pathway and particularly when they have a positive iFOBT result through offering pastoral support from trusted and known health professionals.

The people who come in for the explanation want the reassurance from people who know them. It is that face-to-face contact that they don't get from a letter in the post that tells them to do the kit and what else. It is the personal touch. [If there was no GP role?] Well, I don't know but I feel people might be more suspicious of it. There might be less pick up of people doing it, there might be less numbers, where a large corporation sends something through the post they might not feel comfortable, people don't always like being handled like that. (GP)
- Being aware of the patients' medical history which enables the appropriate management of their health if diagnosed with cancer or needing ongoing surveillance.

I think it makes it more personal. The doctors or nurses may be able to suggest, like if they know the patient has haemorrhoids or something they might be able to ease their worries and say look well it might just be this. And they have the opportunity to talk to their own doctor about it rather than someone they are not familiar with. I think it is important to have some sort of loop with recalling them at appropriate times and if they have treatment we will have the ongoing care so...(Practice Manager)

Following up with non-responders, particularly Māori and Pacific people, was identified as an area where general practice could add further value to the BSP, if they received the list of non-responders for their practice.

We have predominantly Māori and Pacific at the practice so the predominant responses will be from those patients. I have heard things from some patients like, ‘I didn’t think it was important because it didn’t come from you’, ‘if I needed to have this done you would have given it to me before wouldn’t you doctor?’ So I have definitely heard that and that would be a very Pacific response in that a lot of them will place their absolute trust in you and you are the only source of healthcare for them and if you haven’t said to do it then it is not important for them. We talk to patients all the time about other screening activities and this one might be a little outside of that I think, that might be their perception. We talk about breast screening and cervical screening and people know that they have to get those things done. Our rates are very high for Pacific patients for those things, so I am not sure why it would be so low for this. The personality of a letter rather than an explanation from someone they know and trust might be an underlying reason. I have also heard that it didn’t come from you and so I chucked it out but now what can I do about it and that is very difficult to get them to reengage once they have not engaged. (GP)

For general practice’s role to be effective, financial barriers need to be removed to enable participant access.

With our patients we’re lucky because they get funding for the visits, but coming to the GPs that’s not always the case and you don’t want there to be that financial barrier, particularly because we have a low socio-economic community. (GP)

Informed but no active role in screening pathway

Staff from two general practices did not believe that general practices needed to be involved in the BSP, provided they were kept informed of their patients’ iFOBT and colonoscopy results, and any treatment or interventions arising. The current role of general practice was seen as confusing what should be a more streamlined process and potentially was creating delays.

I would say BSP could work as a national screening programme independent from GPs and we could just be informed about the results. I don’t see our role as particularly important. The role of GPs could just be support for the patient and staying informed about positive tests and colonoscopies. (GP)

One GP felt that general practice did not need to be involved for all participants, but should focus more on those where they could add the greatest value (e.g. people who have difficulty understanding the letter, Pacific people and those who are anxious).

In terms of having that primary care step, most patients would be fine without it but there will be a select few that want that step, and we can bring them in for a consultation or something and I think we can judge that best. So primary care is important. I think cost-effectiveness would be another arm of it all, what we want is as much compliance as possible so the Ministry would have to look at that and how the numbers are stacking up and how they want to fund that. (GP)

Summary: General Practice staff have high awareness, knowledge and support of the BSP, although there is concern about the impact of the BSP on symptomatic services particularly wait times for colonoscopy for symptomatic patients. Promotion of the BSP by general practice is opportunistic. Currently practices are unaware of the non-responders in their practice. A potential enhancement to general practice's role is following up non-responders.

Most (but not all) GPs are aware of their role to notify participants with positive iFOBTs within ten days. How participants are informed by general practice varies from face-to-face consult with GP to phone discussion with practice nurse.

Most GPs and other staff perceive that having general practice involved in the BSP supports more participants to take part and enhances participant experience. In contrast, a few GPs did not perceive an added value role for general practice, and simply wanted to be kept informed of their patients' results and interventions.

7. Discussion

The role of general practice in informing BSP participants of a positive iFOBT is a unique element of the BSP. Internationally, GP involvement in bowel screening has been shown to have a positive impact on iFOBT screening participants, although this is subject to high variability (Federici et al 2006, Koo et al 2010, Power et al 2009). Given this unique role and noted variation, this report explored the role and value of general practice in the BSP. The following discussion draws across the findings of the report.

General practices in WDHB have high levels of awareness, knowledge and support of the BSP, and in the main they are undertaking their role in the BSP as intended. Areas for enhancing knowledge and understanding of general practice roles in the BSP are in relation to:

- referring patients with family history of bowel cancer to the New Zealand Familial Gastrointestinal Cancer Registry
- ensuring general practice staff new to the WDHB are aware of their role in the BSP
- clarifying responsibilities and processes relating to BSP participants requiring recall for surveillance colonoscopies.

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

The consequences of general practice not being involved in informing BSP participants when they have a positive iFOBT result needs to be weighed up, in particular:

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

Bibliography

- Federici A, Giorgi Rossi P, Bartolozzi F, Farchi S, Borgia P, & Guastacchi G. 2006. The role of GPs in increasing compliance to colorectal cancer screening: a randomised controlled trial (Italy). *Cancer Causes Control*, 17(1), 45-52.
- Koo J H, Arasaratnam M M, Liu K, Redmond D M, Connor S J, Sung J J et al. 2010. Knowledge, perception and practices of colorectal cancer screening in an ethnically diverse population. *Cancer Epidemiology*, 34(5), 604-610.
- Litmus. 2011. *Evaluation Plan for the Bowel Screening Pilot 2011–2016*. Prepared for the Ministry of Health. Wellington, New Zealand: Litmus Limited.
- Litmus. 2013. *Evaluation of the Bowel Screening Pilot – Findings from 2012 Immersion Visit*. Wellington, New Zealand: Litmus Limited.
- Litmus. 2013a. *Eligible Population Perspectives*. Wellington, New Zealand: Litmus Limited.
- Litmus. 2014. *Evaluation of the Bowel Screening Pilot – Findings from the 2013 Immersion Visit*. Wellington, New Zealand: Litmus Limited.
- Litmus. 2014a. *Evaluation of the Bowel Screening Pilot – Follow-up WDHB Population Survey Findings*. Wellington, New Zealand: Litmus Limited.
- Litmus. 2014b. *Evaluation of the Bowel Screening Pilot – Follow-up Provider Survey Findings*. Wellington, New Zealand: Litmus Limited.
- Phoenix. 2013. *Communication Testing Research*. Auckland: Phoenix.
- Power E, Miles A, von Wagner C, Robb K & Wardle J. 2009. Uptake of colorectal cancer screening: system, provider and individual factors and strategies to improve participation. *Future Oncology*, 5(9), 1371-1388.
- Waitematā District Health Board. 2012. *Bowel Screening: Resource for providers working with the Bowel Screening Pilot*. Auckland, New Zealand:
- Waitematā DHB. 2013b. *Bowel Screening Pilot: Biannual Report – January 1 – June 30 2013*. Auckland: Waitematā DHB.

Appendices

Appendix 1 – General practice research tools

Primary Care - Information Sheet

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?	Primary care has a unique and very important role in the Bowel Screening Pilot (BSP). Understanding the role of General Practice in the Pilot will provide information critical to the potential implementation of a national bowel screening programme. Litmus is interviewing a small number of general practices to gain more detail on how the BSP is being implemented within their practice . Interviews with GPs, practice nurses and other practice staff will explore what is working well, not so well and the value that primary care involvement offers to BSP participants . Procure and Waitematā PHO have identified a list of general practices and provided names and contact details to Litmus.
What is involved?	We will interview as appropriate GPs, practice nurses and other practice staff involved in the BSP either individually or as a group. Interviews will take between 30 and 60 minutes, dependent on roles and availability. Most interviews will be conducted face-to-face, but some may be by phone. In line with Waitematā DHB’s Engagement and Consultation Financial Recognition Policy, general practices that participate in a face-to-face interview can seek reimbursement of reasonable out-of-pocket expenses up to \$125 .
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: Liz Smith, Partner, Litmus, ph 04 473 3885, liz@litmus.co.nz Gaye Tozer, Project Manager BSP, Waitematā DHB, ph 09 486 8920 ext 3878, Gaye.Tozer@WaitemataDHB.govt.nz Mhairi Porteous, National Bowel Cancer Programme Manager, Ministry of Health, ph 04 816 4359, mhairi_porteous@moh.govt.nz

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, Waitematā 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: _____

General Practice 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 the unique role of General Practice in the BSP to inform the potential implementation of a national bowel screening programme. The interview will explore how the BSP is being implemented within general practice, what is working well, not so well and the value that primary care involvement offers to BSP participants.
- Information sheet, informed consent and audio recording.
- Time: 30-60 minutes.

Role of general practice in the BSP

- Please describe your role and the practice’s role in the BSP [*exploring unprompted knowledge of different roles of general practice*]:
 - What happens?
 - Who is involved / responsible for the BSP?
 - What systems or dedicated specific resources does the practice have for the BSP?
- In general, what is working well with the BSP?
 - In general, what are issues or challenges with the BSP?
- Overall what is working well with the BSP in the practice?
 - What are the challenges for the practice?
- What interfaces does the practice have with other parts of the BSP programme? (Probe: Endoscopy Unit, BSP Coordination Centre, treatment services, LabPlus)
 - Which aspects of these interfaces work well?
 - Which aspects, if any, do not work so well?

Understanding BSP implementation in general practices

Invitation to participate:

- What conversations are occurring with patients about taking part in the BSP?
 - Who initiates these conversations? What do patients ask about it?

Management of iFOBT results:

- Approximately how many positive iFOBT results has your practice dealt with from the BSP?
- What is the process for telling patients that they have a positive iFOBT result?
 - What happens if a patient with a positive iFOBT cannot be contacted?
- How long does it generally take from the time a positive iFOBT result is received to informing the participant?
 - How does the 10 day window fit with your practice?
- What is the process for referring a patient with a positive iFOBT result to endoscopy?

- Which aspects of the results management process work smoothly?
 - What aspects could be improved?
 - What if any changes has your practice made to the result management process?
- What happens when a patient with a positive iFOBT result wants to get their colonoscopy through the private system?
 - What conversations do you have with patients about the difference between having their colonoscopy through the public vs private system?

Pre-assessment and colonoscopy:

- How if at all does the practice support patients with a positive iFOBT result through the colonoscopy, and if need to treatment?
- How well is the communication of histology results working? What are the challenges?

Surveillance:

- Does the practice have any patients receiving ongoing surveillance?
- What is general practice’s role in the ongoing surveillance of BSP patients?
- How does the process of surveillance work?
 - What is working well? Needs to be improved?

Symptomatic services:

- What impact if any has the BSP had on symptomatic services for bowel cancer?
- Are more patients enquiring about bowel symptoms or concerns?

Unique role - Lessons from the BSP for a national roll-out (10 min)

Unlike other screening programmes, general practice has a unique role in the BSP of informing participants with about their positive iFOBT result.

- Reflecting on the last 12 months, what are the benefits of having general practices involved in the BSP?
 - For the screening programme?
 - Patients?
 - General Practice?
- What are the disadvantages of having general practices involved in the BSP?
 - For the screening programme?
 - Patients?
 - General Practice?

The overall goal of the BSP 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.

Reflecting on a potential national roll-out of a bowel screening programme, what would be the role of general practice on this scale? What would be the advantages of maintaining the role of general practice? What would be the challenges? Disadvantages?

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

Thanks, close and next steps

Appendix 2 – BSP participant research tools

Letter from BSP Coordination Centre

[date]

[Address]

Dear [name]

Evaluation of the Bowel Screening Pilot

The Ministry of Health is trialling a Bowel Screening Pilot in the Waitematā District Health Board (DHB) area. Litmus, an independent evaluation company (www.litmus.co.nz), is assessing the Bowel Screening Pilot to find out if it could be introduced to all of New Zealand in a way that works well, is safe and acceptable.

To find out how the Pilot is working, Litmus wants to talk with people like you who have taken part. We want to hear about your experience of the Bowel Screening Pilot, what is working well and not so well. Your feedback will help us improve the service provided by the Pilot, and help the Ministry of Health decide if bowel screening should take place across New Zealand.

If you agree to take part, one of the Litmus evaluators will meet with you and ask about your experience of taking part in the Bowel Screening Pilot. The interview will take no more than 60 minutes, at a time and place that suits you. No preparation is needed for the interview. You will receive \$50 to thank you for your time.

The attached sheet provides more information about the evaluation and the sorts of questions you will be asked.

You do not have to take part in an interview. If you don't want Litmus to contact you, please call us on 0800 924 432 within seven days of the date on this letter. If you choose not to take part it will not affect any health care you receive.

If we do not hear from you, your name and contact details only will be forwarded to Litmus. Not everyone on the list will be contacted. If you are selected, a Litmus evaluator will call and ask if you are happy to meet with them. You can say no to taking part at that stage.

Thank you for taking the time to read this letter. It is with the help of people like you that the Bowel Screening Pilot can be improved for everyone.

Yours sincerely

[signatory: name, title, contact details]

Information Sheet

Thank you for your interest in this project. Should you decide to take part, your information will help in understanding peoples’ experiences of the Bowel Screening Pilot, being trialled in Waitematā District Health Board.

What is the purpose of the project?	Litmus (an evaluation company) has been asked by the Ministry of Health to find out how the Bowel Screening Pilot is working in Waitematā DHB. The purpose of the project 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.
What will people be asked to do?	We want to talk with people who have taken part in the Bowel Screening Pilot. The interview will take about 60 minutes and will be face-to-face .
What types of questions will you ask?	In the interview we want to hear about peoples’ experience of the Bowel Screening Pilot , their views of the service they received, what worked well and what could have been done better.
Who will be asked to take part?	We want to speak with people who have taken part in the Bowel Screening Pilot. The Pilot is being trialled in Waitematā DHB and includes people aged 50 to 74 years.
How will the evaluators ensure personal information is kept confidential?	Litmus will ensure peoples’ contributions are kept confidential . What people say in the interview will be written down, with their permission. Notes will be kept securely for up to 2 years, and then securely destroyed. Names and addresses and any other identifying information will not be used in any report.
Can people change their mind?	People can stop the interview at any time . They will not need to give a reason. People only need to answer the questions they want.
Who is doing the evaluation?	The evaluation is being done by Litmus, an independent research and evaluation company. For more information about Litmus go to www.litmus.co.nz . This project has been reviewed and approved by the Ministry of Health’s Multi-Region Health and Disability Ethics Committee.
What if I have any questions?	If you have any questions about this project, please contact: Liz Smith , Partner, Litmus, ph 04 473 3885, liz@litmus.co.nz

Consent Form

I (write name)

of (write address)

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

- I do not have to take part in the interview.
- I can choose not to answer any questions I do not wish to answer (without saying why).
- I can stop the interview at any time without saying why I no longer want to take part.
- Litmus will keep my information confidential. That is, I will not be named in the final report.
- Whether or not I participate will not affect any current or future health care I receive from Waitematā DHB or my doctor.
- The interview will be recorded with my permission, and I can ask for the recording to be stopped at any time during the interview.
- After the interview, I can ask to have my information removed from the evaluation at any time before the report is written.
- Recordings, notes, and summaries will be stored securely at Litmus and will not identify me by name. They will be kept for two years and then securely destroyed.

I have read 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: _____

BSP Participant Interview Guide

This guide is indicative of the relevant subject matter to be covered. It is designed to allow freedom to explore any additional relevant topics that may arise during the interview discussion. The questions asked will be tailored to participants’ position on the Bowel Screening Programme pathway.

1. 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.
- Interview purpose: To understand participants’ experience going through the Bowel Screening Pilot. This will help the Ministry of Health and Waitematā DHB improve the Pilot.
- Informed consent/time.

2. Participant journey

Awareness of BSP

How did you find out about the Bowel Screening Pilot?

- Where from? Where else? etc
- What did you hear?
- How useful was the information?

[Explore role of CAR]

Please share with me what happened with the Bowel Screening Pilot after you were first sent a letter explaining that you were eligible to take part.

Using these post-it notes, pens and sheet of paper, we will draw a visual map of the path that you took on the Pilot.

There are only right answers, and it doesn’t matter if you don’t remember everything. Let’s begin at the time you received the first letter and I will guide you through the exercise.

Pre-invitation

- How did you feel when you received this letter?
- What did you do? Who did you talk to?
- How easy was the information to understand?

Receiving, using and returning the kit

- How did you feel when you received this letter?
- What did you do? Who did you talk to?
- How easy was the kit to understand?
- For what reasons did you decide to complete the kit?

- When did you decide this?
- Who did you talk to about whether or not to do the test?
- What was the main reason?
- What if anything put you off the idea of completing the test?
- How easy was it to complete? How did it make you feel completing the kit?
- What did you do with the test once you had completed it?

Receiving results (General Practice/Endoscopy Unit by phone or letter)

- How did you find out about the results of your test? *[General Practice/Endoscopy Unit by phone or letter]*
- *[if GP]* Who from your General Practice called you?
 - How were you told about the results [phone/ face to face]?
 - What did they tell you about your results?
 - What did they tell about what happened next?
 - How did you feel about being informed this way? What was good about being told by GP/ Practice Nurse? Not so good?
 - What was good about being informed by the GP/ Practice Nurse? Not so good?
- *[If not GP, ask]* Did someone call from the Endoscopy Unit where you had the colonoscopy? Or did you receive a letter?
 - What did they tell you about your results?
 - What did they tell about what happened next?
 - How did you feel about being informed by the Endoscopy Unit about your results?
 - What was good about being informed by the Endoscopy Unit? Not so good?
 - Do you have a GP? *[If yes]* People who have a positive result are usually contacted by someone from their general practice to tell them about the result and to discuss what it means. Did you tick the box on the consent form saying you did not want your GP informed? *[Check whether this was in error if done ie they did want their GP to be informed and thought ticking the box meant this would happen]*
 - *[If have a GP and not called]* BSP has very strict rules to ensure people are told about positive results quickly, this may have resulted in the Endoscopy Unit calling you first. Would you have preferred to hear about your results from your GP or Practice Nurse instead of the Endoscopy Unit? How come?
- One of the things that the BSP is exploring is the best way to inform people if they have a positive result from the iFOBT via a call from their General Practice or the Endoscopy Unit.
 - What are the benefits in hearing about a positive result from your GP? What are the downsides?
 - What are the benefits in hearing about a positive result from the Endoscopy Unit? What are the downsides?
 - Which do you prefer? Why?
- *[if strongly pro-GP or no preference explore]* People who do not have a GP are called and told about their positive result by nurse from the Endoscopy Unit – these people tend to hear

about their results faster (by about two weeks) than those who receive their results from their GP. To what extent are the benefits of having your GP inform you more important than having a slightly faster test result?

- If your General Practice was not involved in the BSP – that is if it was just the Endoscopy Unit that called with positive results – how would this have effected your decision to undertake a colonoscopy?
- Please describe your relationship with your General Practice? GP?

Pre-assessment with the Endoscopy Unit

- How did you feel about the preassessment phone call, when the nurse from the Endoscopy Unit called to find out more about you and your health?
 - What was good about it?
 - What could be improved?
 - What other/different information did you need at this time?
 - [If Pacific] where you offered support/ translator?

Colonoscopy (incl. appointment process)

- How did you feel about the colonoscopy?
 - What went well?
 - What could be improved?

Next steps

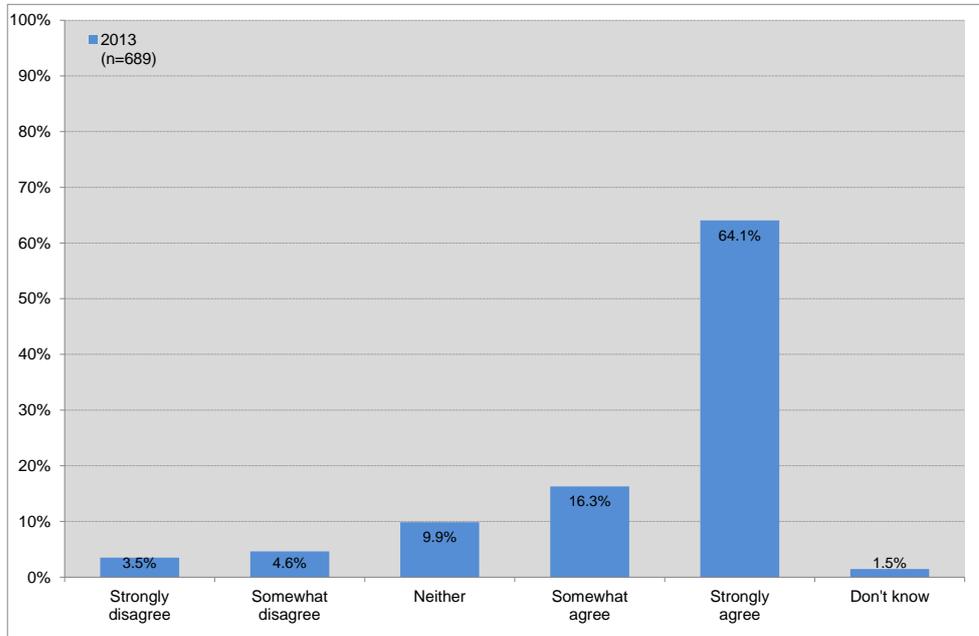
- What happens next for you? [*probe awareness of surveillance or follow up in 5 years*]

3. Close

- What other comments would you like to make about the Bowel Screening Pilot?

Appendix 3 - Preferred method to hear about positive iFOBT

Figure 1: Level of agreement with the statement ‘it is very reassuring if your GP or practice nurse is the one who tells you if you have a positive FOBT test result’, Waitemata District Health Board, 2013

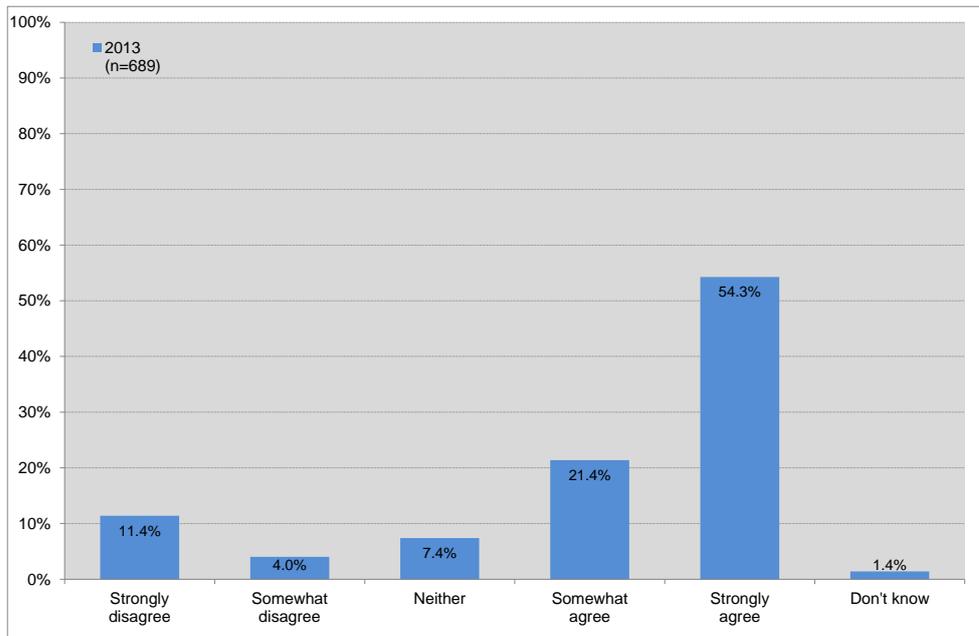


Base: Respondents who have never had bowel cancer except those diagnosed by the BSP

Source: BSP Evaluation telephone survey, 2013

Note: Not asked in 2011

Figure 2: Level of agreement with the statement ‘you are happy for someone else from the screening programme to contact you if you have a positive FOBT result’, Waitemata District Health Board, 2013



Base: Respondents who have never had bowel cancer except those diagnosed by the BSP

Source: BSP Evaluation telephone survey, 2013

Note: Not asked in 2011