



# **Independent Assurance Review for the National Bowel Screening Programme**

**July 2018**

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## **Preface**

This Independent Assurance Review was conducted between March and July 2018 to provide the Minister of Health with assurance regarding the readiness and effectiveness of the National Bowel Screening Programme, and to advise the Ministry of Health of changes that would improve the roll-out of other national programmes.

The review panel would like to place on record its thanks to the Health Quality & Safety Commission Board and staff for their generous support to the review panel. Particular thanks are due to Dr Janice Wilson, Karen Orsborn, and the secretariat team of Julene Hope, Hilary Sharpe, Jadria Cincotta, Dr Maria Poynter and Dr Chris Walsh.

The review panel would also like to acknowledge the help and cooperation from the Ministry of Health and the National Screening Unit. It wishes to express its thanks to all the participants who willingly gave their time for interviews or to provide written submissions.

The review panel acknowledges the distress and uncertainty caused by the pilot invitation issues and extends condolences to those patients and whānau who were inappropriately excluded from the Bowel Screening Pilot. However, we must not freeze in the act of looking backwards, nor minimise this impact. We can only move forward with the compassion, openness and courage to learn from past mistakes and put things in place so this never happens again.

### **Disclaimer**

To complete this report, the reviewers have relied on information provided by multiple parties and on documentation provided by a variety of organisations. The reviewers accept staff accounts of events and documented records in good faith. The report was provided in draft to the Ministry of Health for factual correction.

The reviewers accept no liability and will not be responsible for any omission or misrepresentation arising from relying on this information, nor for information that was not corrected during circulation of the draft, nor for information not made available to the reviewers during the review, nor for information that would have been provided by people who were unavailable to interview.

## Abbreviations

BSP+	Bowel Screening Pilot Information Technology System (enhanced version)
Commission	Health Quality & Safety Commission
DHB	district health board
EGGNZ	Endoscopy Governance Group for New Zealand
ERCP	endoscopic retrograde cholangio-pancreatography
FIT	faecal immunochemical test (also known as immunochemical FOBT or iFOBT)
FOBT	faecal occult blood test
GNA	gone no address
GP	general practitioner
HPV	human papillomavirus
IT	information technology
MBIE	Ministry of Business, Innovation and Employment
NBSP	National Bowel Screening Programme
NCC	National Coordination Centre
NES	National Enrolment Service
NHI	National Health Index
NSS	National Screening Solution (IT system)
NSU	National Screening Unit at the Ministry of Health
PHO	primary health organisation
The pilot	The Bowel Cancer Screening pilot undertaken in Waitemata DHB
PPV	positive predictive value
QA	quality assurance
RCC	NBSP Regional Coordination Centre
The review	The Independent Assurance Review for the National Bowel Screening Programme

# 1. Executive summary

This Independent Assurance Review for the National Bowel Screening Programme was established in March 2018 in response to a number of issues that arose from the Waitemata Bowel Screening Pilot. The purpose of the review is to provide assurance that the National Bowel Screening Programme is positioned to successfully implement and deliver bowel cancer screening across New Zealand. This includes identifying where lessons can be learned from the pilot, any potential risks to the programme, and wider learning for future national initiatives.

The review panel was led by Professor Gregor Coster, Dean of the Faculty of Health at Victoria University of Wellington; the other members are Dr William Rainger, Dr Mary Seddon and Professor Graeme Young. During the course of the review, the panel interviewed over 60 individuals, received eight written submissions and reviewed over 200 documents relating to the Bowel Screening Pilot and the National Bowel Screening Programme.

The panel recognises the considerable work by all involved to make the Waitemata pilot a success. The panel's international expert, Professor Young, reported that by international comparisons the pilot was well conceived, had performed well and in several respects was of higher quality than a number of other international pilots. The pilot demonstrated the feasibility and cost-effectiveness of introducing a bowel screening programme in New Zealand. It also resulted in significant learning for future roll-out, particularly around increasing screening uptake in priority groups.

In late 2016, following the Waitemata pilot and a successful business case, responsibility for the roll-out of the National Bowel Screening Programme was moved to the National Screening Unit within the Ministry of Health. To date, Hutt Valley, Wairarapa, Waitemata and Southern District Health Boards (DHBs) have successfully joined the national screening programme. Full roll-out across the country is due to be completed by June 2021.

The panel acknowledges the substantial effort undertaken by the National Screening Unit to transition from the pilot to a national screening programme. The scale of this challenge should not be overlooked, given the complexity and scale of the programme. As with any national implementation process, the programme is becoming increasingly refined as it progresses and as policies and processes are tested and formalised.

The panel is fully supportive of the National Bowel Screening Programme and endorses its continued roll-out as planned. The National Bowel Screening Programme is in a good position and has considerable strengths. The panel provides the following feedback and recommendations to support the continued improvement of the programme.

## **National roll-out of bowel screening**

Whether the National Bowel Screening Programme is well positioned for successful roll-out (including the adequacy of current governance arrangements, operational management and resourcing).

National roll-out is progressing well and the Ministry of Health continues to improve its processes to support this. The current governance structure for the National Bowel

Screening Programme has evolved over time and is currently under review by the Ministry of Health. The panel supports this work as the current governance structure appears to be overly complicated, which could hinder the effective escalation and management of issues and risks. The panel found it difficult to understand the roles, responsibilities and accountabilities of the numerous governance groups. Consideration should be given to reducing the number of groups involved in governance and providing clear statements of function and accountability for each. Clinical governance and Māori leadership could also be strengthened across all aspects of the programme, including governance arrangements for information technology (IT). Clinical governance should include a balance of both frontline clinical and population health expertise.

The pilot evaluation highlighted concerns that the National Bowel Screening Programme may increase inequities through low participation of Māori and Pacific peoples. It is evident that low participation of these priority groups will continue to be a problem without a concerted effort to address inequities. The National Screening Unit recognises the importance of equity, but efforts to improve screening uptake and equitable outcomes must be prioritised so that the National Bowel Screening Programme can be 'equity led' as recommended in the final evaluation report on the pilot.<sup>1</sup> Increased leadership by Māori, Pacific peoples and consumers is essential, with greater accountability for equity. It is necessary to develop, test and resource innovation and continuous quality improvement to address inequities, building on the experience of the Waitemata pilot.

Programme management processes need to be strengthened to ensure that all aspects of this complex programme are adequately monitored and managed, and that risks are identified and addressed early. This includes improving stakeholder engagement and communication and robust risk management and oversight. Strong programme management is particularly important for the successful development and implementation of the new National Screening Solution IT system.

Currently funding is secured through an annual business case to The Treasury. While this approach provides assurance to The Treasury, the process is time consuming and impacts on DHB planning processes. A multi-year funding pathway is required to embed the programme throughout the sector. This should include resourcing for planned workforce increases, IT integration with primary care and health promotion.

## **Lessons learned from the Bowel Screening Pilot**

How lessons learned from the operation and implementation of the pilot can be applied to ensure a safe and successful roll-out.

The panel has collated the key recommendations from the pilot evaluation and reviewed these against the roll-out of the programme as documented by the National Screening Unit and experienced by those interviewed. Evidence indicates that efforts have been made to address a number of lessons from the pilot evaluation. However, some areas have only been partially addressed and there are opportunities to further embed the pilot learnings to support the ongoing development of the programme.

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<sup>1</sup> Litmus et al. 2016. *Final Evaluation Report of the Bowel Screening Pilot: Screening rounds one and two*. Wellington: Ministry of Health.  
*Independent Assurance Review for the National Bowel Screening Programme – 2018*

The transfer of the National Bowel Screening Programme to the National Screening Unit, together with high staff turnover at the Ministry of Health, resulted in a loss of institutional knowledge related to the pilot. This has been exacerbated by an apparent breakdown in relations between the National Screening Unit and Waitemata DHB. The panel believes this was partly due to differing perspectives between clinicians and population health professionals, particularly around handling the invitation issues. Rebuilding these relationships will help to effectively capture and build on learning from the pilot.

## **IT readiness for roll-out**

Whether the Bowel Screening Pilot IT System's (BSP+) functionality and associated operational processes are sufficient to support the initial roll-out to the first eight DHBs.

The panel has undertaken an in-depth review of the BSP+ assurance documentation provided by the Ministry of Health. It found that a thorough review had been undertaken and that the Ministry of Health continues to monitor and enhance the BSP+ to support its integrity and safety.

Despite improvements to the BSP+, the IT system still has limited functionality, which impacts on its ability to handle the population register, invitation process and clinical data. The Ministry of Health has undertaken work to improve the functionality and to reduce the need for manual workarounds, where possible. The panel has been assured that the upgraded version of BSP+<sup>2</sup> has the technical capacity to support the invitation process for the initial eight DHBs; however the functional limitations remain. The Ministry of Health is providing DHBs with IT support and training to use the BSP+, in order to maximise functionality of the system and to mitigate against known risks.

## **Developing a national screening IT solution**

That the high-level design of the National Screening Solution is fit for purpose.

The panel is satisfied that the Ministry of Health conducted a robust and comprehensive process in procuring the National Screening Solution (NSS). The panel supports the strategic intent of the NSS. Using the system across screening programmes will create a comprehensive view of each participant's screening history and will lead to significant efficiencies. The panel wishes to reiterate the importance of adequately overseeing the NSS while it is designed, built and implemented. The level of oversight must reflect the level of risk inherent in an IT procurement process of this scale and complexity.

The panel recommends that the Ministry of Health involves DHBs, the primary care sector and the National Coordination Centre in designing and testing the NSS, to help maximise functionality.

The panel notes that integration of the NSS with IT systems has been considered as part of the NSS design phase. The panel advises the Ministry of Health to seek maximum interoperability of the NSS with other health IT systems, to maximise its functionality. This includes giving urgent consideration to 'real-time' integration with primary care IT systems.

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<sup>2</sup> The term BSP+ is used throughout this report to refer to all enhancements of the BSP pilot IT system, including descriptors such as BSP++.

Having this form of integration would help increase participation in the programme as intended through primary care's access to a participant's full screening progress.

The panel considers that failing to deliver the NSS on time would have significant implications for the National Bowel Screening Programme. It recommends bolstering the contingency plans for using BSP+ for an extended period if the detailed design of the NSS takes longer than expected.

### **Developing robust protocols and policies**

That the protocols and policies for operationalising the National Bowel Screening Programme are robust and fit for purpose.

A significant amount of work has already been undertaken to support the roll-out of the National Bowel Screening Programme, including development of programme documentation and quality monitoring processes. However, the ambitious timeframes for roll-out and the decision to not begin roll-out preparation during the pilot phase have meant that not all of the necessary protocols and policies have been completed, and many were not available for initial DHB roll-out. This has been further complicated by significant staff changes at the Ministry of Health, and limited partnership with other organisations that can provide knowledge about and expertise in bowel screening, including Waitemata DHB.

The National Screening Unit has developed Interim Quality Standards for the National Bowel Screening Programme to support national roll-out. In addition, the Endoscopy Governance Group for New Zealand has developed quality standards for endoscopy units and individual colonoscopists. The Ministry of Health is currently looking at how these standards can be incorporated into the Interim Quality Standards. The panel supports this work and recommends that consistent standards are applied across screening and non-screening colonoscopies.

### **Embedding a population health screening approach**

Whether a population health screening approach is embedded in the programme and those responsible for operationalising the National Bowel Screening Programme have the tools, resources and expertise to do so.

The panel considers that a population health screening approach has been well embedded in the programme, supported by population health expertise at the National Screening Unit. A population health screening approach should also be well embedded at the DHB level. This needs to be supported and linked with clinical leadership within the wider Ministry of Health and the DHBs. This is particularly required for governance and management of the register, ensuring equity, and for monitoring and evaluation.

While awareness of the importance of equity in the programme exists, it needs to be supported with visible leadership, effective engagement with communities, resources and clear accountability for equity at all levels. The panel notes the sector's concern about the current age range, in particular the equity impact for Māori. The panel is assured, however, that the Ministry of Health is committed to closely monitoring programme data and reviewing the programme parameters, including age range, as more DHBs join the programme.

## **DHB readiness for implementation**

How robust the planning and implementation processes are to ensure DHBs can effectively plan and manage increased capacity requirements, including for workforce, facilities, equipment and IT, to safely implement the National Bowel Screening Programme within the projected roll-out timeframes.

The panel notes that a clear roll-out readiness process is in place for DHBs. However, the relative lack of process documentation available for DHBs initially was perceived as a challenge. Waitemata DHB was contracted to provide pilot expertise to support Hutt Valley and Wairarapa DHBs with implementation until December 2017. This exchange of learning was highly valued; it should continue and be strengthened by the regional hubs.

The panel notes a level of disconnect between the health and disability sector and the Ministry of Health, which presents an opportunity for the National Bowel Screening Programme as it moves into the next phase of the roll-out. The panel recommends that the Ministry of Health provides regular communication to all parties involved in the roll-out, including technical updates related to the IT systems (BSP+, NSS), clinical standards development, performance measures reporting, and lessons learned from other DHBs during the roll-out.

The most pressing areas of concern for DHBs are colonoscopy capacity and quality, and equity. Colonoscopy wait-time data highlights that DHBs are currently struggling to meet their wait-time targets, even before the roll-out. The panel noted some concern about the capacity and fragility of the colonoscopy workforce. The current roll-out is in part constrained by workforce issues. The only way these constraints can be removed in the medium to long term is to increase the number of colonoscopists being trained. There is an urgent need to progress workforce development efforts so that a sufficiently skilled workforce is available and funded into the future, particularly in anticipation of any future plans to broaden access to the programme.

DHB implementation of the National Bowel Screening Programme has not focused consistently on equity, although pockets of excellence are evident. The panel believes that DHB capability and resourcing for equity needs to be increased. This includes leadership and engagement with priority populations, supportive health promotion resources and local equity accountability.

## **Learnings for other national programmes**

What the Ministry of Health can learn to support the design and roll-out of future national initiatives.

The experience of implementing the National Bowel Screening Programme has provided learning that can be used to support the design and roll-out of further national initiatives. Much of the learning focuses on appropriate governance including clinical governance, leadership and programme management capability, especially for high-risk initiatives. Strong functional relationships both within and across programme teams, and between the Ministry of Health and partner agencies should also be prioritised to encourage and enable knowledge sharing and appropriate risk management.

## High-level recommendations

The panel supports the ongoing roll-out of the National Bowel Screening Programme and recommends taking the following actions to make the success of implementing bowel screening across New Zealand more likely.

The panel has given these recommendations two gradings: critical – to be addressed over the next six months; and essential – to be addressed over the next 12 months.

These recommendations are a summary of the more detailed recommendations included in individual chapters of this report.

1. The Ministry of Health should strengthen the population health governance of the National Bowel Screening Programme's population register to ensure that every effort is made to avoid a repeat of the issues that led to eligible participants missing out on bowel screening during the pilot. **[critical]**
2. The Ministry of Health should review the functionality and operation of the population register, to increase its accuracy and completeness. **[critical]**
3. Urgent consideration of 'real-time' integration with primary care IT systems should be given in order to increase participation in the programme through primary care's access to a participant's full screening progress. **[critical]**
4. The Ministry of Health needs to continue to monitor and manage carefully the ongoing risk that the limited functionality of the BSP+ presents. **[critical]**
5. The Ministry of Health should continue to strengthen project management during the design, build and implementation of the National Screening Solution to ensure deliverables are met within the planned timeframes. It should review IT governance arrangements to ensure they are fit for purpose. **[critical]**
6. DHBs, the primary care sector and National Coordination Centre should be appropriately involved during the design, build and subsequent phases of the National Screening Solution. **[critical]**
7. To achieve equitable outcomes, the National Bowel Screening Programme should strengthen its approach to, and accountability for, equity at all levels. This includes increasing leadership and engagement of Māori, Pacific peoples and consumers. Funding to achieve this outcome should be budgeted for and directed. **[critical]**
8. The Ministry of Health should note the health and disability sector's concern about the current age-range restrictions, in particular in relation to the equity impact for Māori. The Ministry should continue to closely monitor programme data and review the programme parameters, including age range, as more DHBs join the programme. **[essential]**
9. A workforce development plan needs to be developed to ensure availability (and funding) of a sufficiently skilled workforce into the future. **[essential]**
10. The current governance structure for the National Bowel Screening Programme should be refined and more clearly articulated, ensuring appropriate pathways exist for escalation of issues and risks. **[essential]**

11. Stronger evidence of clinical governance is needed across all aspects of the National Bowel Screening Programme and at all levels, including within IT governance arrangements. This includes the programme Clinical Director formally and regularly reporting to the relevant executive governance groups to ensure clinical sector feedback. **[essential]**
12. The National Bowel Screening Programme must use robust programme management to ensure all aspects of this complex programme, including risk, stakeholder engagement and quality assurance, are closely monitored and well managed. **[essential]**
13. A full set of protocols and policies supporting the readiness and roll-out of the National Bowel Screening Programme should be developed as a matter of urgency, to provide greater support and clarity to the sector. **[essential]**
14. The Ministry of Health and National Screening Unit should strengthen partnerships with external agencies and organisations, to ensure effective knowledge sharing. This includes partnerships with the Corporate Centre (State Services Commission, The Treasury and Department of Prime Minister and Cabinet), Waitemata DHB, Bowel Cancer New Zealand and Hei Āhuru Mōwai (Māori Cancer Leadership Group). **[essential]**
15. A single set of national quality assurance standards for colonoscopy (including colonoscopy units) should be endorsed, with clear agreement on accountability. This involves bringing together the Endoscopy Governance Group for New Zealand's quality assurance standards and the National Bowel Screening Programme's interim quality standards. **[essential]**
16. A comprehensive multi-year funding pathway should be developed to help embed the programme throughout the sector. **[essential]**
17. The Ministry of Health should provide regular written communication to all parties involved in the roll-out. This would include a technical section updating issues related to the IT systems (BSP+, NSS), as well as reports on clinical standards development, performance measures and learnings from other DHBs during the roll-out. **[essential]**
18. A strong learning culture at the Ministry of Health and across the NBSP needs to be promoted. This includes an openness to feedback, involvement of external expertise, transparency in decision-making and shared ownership of issues. **[essential]**
19. Innovation and continuous quality improvement should be encouraged to achieve equitable access. This includes the provision of additional resource to develop, test and disseminate this learning. **[essential]**

## 2. The review

The Independent Assurance Review of the National Bowel Screening Programme (NBSP) was established on 21 March 2018. The review seeks to provide the assurance that the NBSP is positioned to successfully implement and deliver bowel cancer screening across New Zealand.

In particular, as stated in its Terms of Reference, the review will:

provide assurance on the NBSP governance, operational management and resourcing, making recommendations for any changes as required, including:

- an in-depth review of the Bowel Screening Pilot IT System (BSP+) and associated operational processes to provide advice and assurance on its functionality to support the NBSP in the initial roll-out phases (DHBs 1–8) and as the programme continues to be rolled out.
- assurance and evidence based recommendations about the transition from the Pilot to the NBSP, including the high level design of the National Screening Solution (NSS) as a fit for purpose system.
- assurance and evidence based recommendations on the protocols and policies for operationalising the NBSP, ensuring they are robust and fit for purpose.
- assurance that a population health screening approach is embedded in the programme and those responsible for operationalising the NBSP have the tools, resources and expertise to do so.
- assurance that the planning and implementation processes to ensure DHBs are able to effectively plan and manage increased capacity requirements, including workforce, facilities, equipment, and IT to safely implement the NBSP within the projected roll-out timeframes.

Excluded from the scope of the review is ‘a clinical review of the evidence that supports the introduction of a population-based bowel screening programme’. The Terms of Reference note that the programme has already been evidenced through international research. For the full Terms of Reference, see Appendix 1.

The review panel was led by Professor Gregor Coster, Dean of the Faculty of Health at Victoria University of Wellington; the other members are Dr William Rainger, Dr Mary Seddon and Professor Graeme Young. (For further details on the panel members, see Appendix 2). The Health Quality & Safety Commission (the Commission) provided secretariat support to the programme, including consumer engagement advice.

The impetus for the review was that a number of issues relating to the pilot were identified that resulted in failure to invite some eligible participants for screening. For some eligible participants, this may have delayed their bowel cancer diagnosis. The issues identified concerned the functioning of the BSP+ and related operational processes. The panel is aware of four separate issues in total, two of which came to light after the review was initiated. Chapter 7 gives an overview of these four incidents.

In addition to this assurance review, two other independent reviews were commissioned after these incidents were identified:

1. an independent review of the invitation issues related to address updates within the Bowel Screening Pilot Programme<sup>3</sup>
2. a clinical review of the 'Withdrawal' incident.<sup>4</sup>

During the review, the panel met in person six times. Members of the panel, accompanied by a staff member from the Commission, interviewed over 60 individuals who had been involved with the pilot or the NBSP. This included individuals from across the health sector, as well as representatives from wider government agencies. Comments from these interviews (anonymous to protect confidentiality) are included throughout this report. For a full list of interviewees, see Appendix 4.

The panel also reviewed over 200 documents and received eight written submissions. Please note that the panel was not required to seek public submissions and had neither the time nor the resource to do so.

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<sup>3</sup> MacIntyre K. 2018. *Review of Invitation Issues Following Address Update – Bowel Screening Pilot (Final Draft)*. Unpublished.

<sup>4</sup> Weston M. 2017. *Review of Clinical Records of Patients Who Did Not Receive an Invitation to Participate in the Bowel Screening Programme and Who Subsequently Received a Cancer Diagnosis*. Auckland: Counties Manukau DHB.  
*Independent Assurance Review for the National Bowel Screening Programme – 2018*

### 3. Background

In New Zealand, bowel cancer is the third-most common cause of cancer and the second-most common cause of cancer death. New Zealanders with bowel cancer are more likely to be diagnosed with advanced stage cancer than people in Australia, the United States and the United Kingdom.<sup>5</sup> Bowel cancer incidence increases with age: 82 percent of cases occur in those aged 60 years and over. While bowel cancer incidence is slightly lower in Māori than non-Māori, survival from bowel cancer is poorer in Māori.

Bowel cancer screening enables earlier detection of cancer, supporting earlier and improved treatment options. International evidence suggests that bowel cancer screening could reduce bowel cancer mortality in the screened population by at least 16–22 percent, after 8–10 years.<sup>6</sup> Screening can also help identify and remove polyps or adenomas, which can be a precursor to bowel cancer.

The NBSP is expected to save significant costs by reducing the need for aggressive bowel cancer treatment. While the cost of delivering a national screening programme will be significant, the anticipated long-term savings are estimated to outweigh that cost.<sup>5</sup>

#### Bowel Screening Pilot

From 2012 to 2017, Waitemata District Health Board (DHB) ran a Bowel Screening Pilot (the pilot), for those aged 50 to 74 years, to test the feasibility and likely impact of delivering bowel cancer screening in New Zealand. As at 31 December 2017, the pilot had invited almost 200,000 people to participate, had screened 116,000 and had undertaken around 12,100 colonoscopies.<sup>7</sup>

By March 2017, the pilot had identified bowel cancer in 375 people and had identified and removed many adenomas. The bowel cancers it identified were more likely to be picked up at an earlier and more treatable stage than they would be through normal practice. Around 66 percent of cancers identified by the pilot were classified as stage I or II, compared with around 40 percent in people who present with symptoms.<sup>8</sup>

Participation rates were approximately 59 percent in the pilot, similar to other international pilots. However, participation rates were lower for Māori (46%) and Pacific peoples (31–37%). The pilot evaluation concluded that an organised, high-quality bowel screening programme could be safely introduced in New Zealand. However, it identified the need for the programme to be equity led. The evaluation also identified a number of quality issues to be addressed, including weaknesses with the national screening register, IT functionality issues, a need for improved quality monitoring and concerns over colonoscopy capacity.

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<sup>5</sup> Ministry of Health. 2016. *Programme Business Case & Tranche 1 Business Case. National Bowel Screening Programme draft v3.1*. Wellington Ministry of Health.

<sup>6</sup> Litmus et al. 2016. *Final Evaluation Report of the Bowel Screening Pilot: Screening rounds one and two*. Wellington: Ministry of Health.

<sup>7</sup> Ministry of Health, personal communication, 6 June 2018.

<sup>8</sup> Ministry of Health. 2017. Bowel Screening Pilot results. URL: [www.health.govt.nz/our-work/preventative-health-wellness/screening/bowel-screening-pilot/bowel-screening-pilot-results](http://www.health.govt.nz/our-work/preventative-health-wellness/screening/bowel-screening-pilot/bowel-screening-pilot-results) (accessed 6 June 2018). *Independent Assurance Review for the National Bowel Screening Programme – 2018*

## National Bowel Screening Programme

Phased implementation of the NBSP began in July 2017. Hutt Valley and Wairarapa DHBs were the first to begin screening, followed by Waitemata DHB in January 2018 and Southern DHB in May 2018. Counties Manukau DHB was due to start in July 2018.

The initial timeframes for national implementation were extended in December 2017 (Table 1), due to delays in the procurement of the NSS information technology (IT) system to support the NBSP. Full roll-out of the NBSP is now expected by June 2021. In the interim, DHBs that are starting screening before the NSS is available will use an upgraded version of the pilot IT system (BSP+).

**Table 1: Timeline for roll-out of the National Bowel Cancer Screening Programme, December 2017**

Milestone	Date
Hutt Valley and Wairarapa DHBs go live	July 2017
Waitemata DHB changes from a pilot to NBSP	Jan 2018
Southern and Counties Manukau DHBs go live	Feb–July 2018
Nelson Marlborough, Lakes and Hawkes Bay DHBs go live	July–Dec 2018
NSS released	March 2019
Whanganui and MidCentral DHBs go live	March–June 2019
Auckland, Canterbury, Capital & Coast, South Canterbury and Tairāwhiti DHBs go live	July 2019 – June 2020
Bay of Plenty, Northland, Taranaki, Waikato and West Coast DHBs go live	July 2020 – June 2021
DHBs 1–8 transition to NSS	By June 2021

The NBSP involves a number of different organisations, each with specific roles, functions and responsibilities along the screening pathway (see Appendix 5). These organisations include:

- **Ministry of Health, National Screening Unit (NSU)** – overall responsibility for the delivery of a high-quality and safe NBSP
- **National Coordination Centre (NCC)** – responsible for coordination of inviting people to participate and following up patients along the bowel screening pathway
- **Faecal Immunochemical Test (FIT) Laboratory** – analyses the returned test kits and provides results to the NCC and primary health care providers
- **four Regional Coordination Centres (RCC)** – provide clinical leadership, equity, quality assurance (QA) and quality improvement support to DHBs as well as helping ensure consistency in roll-out across the country
- **district health boards** – manage diagnostic and treatment services for bowel cancer as well as working with local communities and primary care to increase participation
- **endoscopy units** – facilities within DHBs that undertake endoscopies

- **primary care providers** – inform participants of positive results and refer them for colonoscopy. They may also help to increase participation among their eligible population by reminding them and opportunistically inviting them to participate.

For further details on the roles and responsibilities of each of these organisations, see Appendix 6.

Once fully implemented, the NBSP will potentially invite over 700,000 people every two years to participate. It may detect approximately 500–700 cancers each year during the early rounds of population bowel screening, assuming a participation rate of 62 percent (similar to the rate in the pilot). To support the NBSP, the NSS must be able to:

- handle up to 680,000 newly invited participants in any year
- repeat the invitation for up to 380,000 negative screening result participants after two years, and an estimated 440,000 new participants each year by 2030
- load up to 16,000 lab results each day
- handle up to 50 concurrent NCC users for the NBSP, and 150 concurrent users based in the 20 DHBs (which includes staff working in the laboratories and colonoscopy clinics).<sup>9</sup>

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<sup>9</sup> Ministry of Health. 2017. *Request for Proposal: National Screening Solution*. Wellington: Ministry of Health. *Independent Assurance Review for the National Bowel Screening Programme – 2018*

## 4. Learnings from the Bowel Screening Pilot

The New Zealand pilot compared favourably with pilots in the United Kingdom and Australia (see Chapter 11 for an overview and Appendix 7 for a detailed analysis). The evaluation found bowel screening to be not just cost-effective, but also cost-saving in certain scenarios.<sup>10</sup> While many lessons were learned that should inform a wider roll-out, the evaluation report concluded that an organised screening programme could be safely introduced in New Zealand with the prospect of improving mortality from bowel cancer. It did not identify any area of sufficient concern to halt progress. Furthermore, the lessons learned were what would have been expected in light of other pilots conducted internationally and all are amenable to practical and feasible solutions.

While the pilot may have been comparable with the approach of other jurisdictions, the Ministry of Health cannot be complacent or assume that New Zealand is doing as well as it might. The NBSP must establish comprehensive strategies to address the lessons learned from the pilot and closely monitor them during roll-out.

Table 2 summarises a number of key learnings from the pilot and how the Ministry of Health has responded to these issues. Although many of these learnings have been only partially addressed, the panel notes this approach is appropriate given that the national roll-out of the NBSP is still under way and that some of these learnings are complex issues that will take time to address. A number of additional learnings from the pilot, not included in this table for reasons of brevity, have already been addressed and embedded in the NBSP. The table includes helpful comments to support the ongoing development of the programme.

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<sup>10</sup> Litmus et al. 2016. *Final Evaluation Report of the Bowel Screening Pilot: Screening rounds one and two*. Wellington: Ministry of Health.  
*Independent Assurance Review for the National Bowel Screening Programme – 2018*

**Table 2: Summary of key learnings from the final evaluation report of the Bowel Screening Pilot<sup>11</sup>**

Learning from pilot	Current status	Progress to date
<p><b>Effectiveness:</b> Key indicators should be developed to closely monitor uptake, positivity, positive predictive value (PPV) and detection rates, and adverse events.</p>	<p>The quality assurance indicators are monitored robustly and regularly at individual colonoscopist, DHB and national levels. However, the relationship between monitoring and governance should be more clearly defined.</p>	<p>Partially met</p>
<p><b>Economic efficiency:</b> The policy and clinical decisions involved in planning an implementation of bowel screening will need to trade off cost-effectiveness against the sensitivity, specificity and PPV that can reasonably be achieved and supported in a live screening programme on a national basis in terms of both absolute resource and effectiveness.</p>	<p>The revised age range and FIT thresholds will have reduced the cost of the programme. However, these changes will also lower the number of cancers detected. These thresholds need to be kept under review, as more data becomes available and in line with what has transpired through international experience.</p>	<p>Met</p>
<p><b>Equity:</b> A national programme must be equity led. What this means should be clear to all, with a documented equity statement.</p> <p>Dedicated resource is required to support continuous quality improvement and to strengthen equitable access to screening and the screening pathway.</p>	<p>While awareness of equity is high, it must be embedded in governance, accountability and funding structures. The development of a clear equity statement for the programme could help to achieve this.</p> <p>Dedicated funding to support health promotion and innovation is needed.</p>	<p>Partially met</p>
<p><b>Leadership:</b> Māori and Pacific leadership at the governance level is needed to ensure that the design, funding and implementation of the programme are informed by expert cultural and clinical</p>	<p>Some evidence indicates Māori and Pacific leadership is available at the governance level; however, this remains patchy and the panel strongly supports progress in the area. The panel notes many DHBs have strong Māori and Pacific leadership and advises</p>	<p>Partially met</p>

<sup>11</sup> Litmus et al. 2016. *Final Evaluation Report of the Bowel Screening Pilot: Screening rounds one and two*. Wellington: Ministry of Health. *Independent Assurance Review for the National Bowel Screening Programme – 2018*

<p>advice, and a real-time cultural lens is applied when monitoring the results of the programme at the governance level.</p>	<p>the NSU to collaborate with these established networks in a way that both is flexible and allows for innovation tailored to local populations.</p>	
<p><b>Monitoring equity:</b> Close monitoring, target setting and accountability are important to determine whether or not equity is being achieved. Ideally, an independent Māori and Pacific monitoring group will be established to assess the key performance indicators (KPIs) by ethnicity, age, gender and deprivation and receive reports annually.</p>	<p>The NSU and the Māori monitoring and equity group currently monitor equity data. DHBs are also able to access stratified data through the RShiny app.</p>	<p>Met</p>
<p><b>Population register:</b> The register needs to be up to date and invite all those eligible to take part. It needs to inform ‘real-time’ follow-up activities and support reminder processes through interfacing with existing primary care systems. Further, the register needs to enable the monitoring of uptake and equity across the pathway.</p>	<p>Work is ongoing to improve the coverage and quality of data within the register. However, the health and disability sector continues to have concerns about data quality and the potential to exacerbate inequities through poor capture of contact information. It is necessary to undertake further research and investigation into the data quality, as well as to explore ways to actively enrol individuals with the register.</p> <p>Current plans to interface with existing primary care systems will not achieve the intended ‘real-time’ data transfer. Urgent consideration should be given to ‘real-time’ integration with primary care systems to increase participation in the programme through primary care’s access to a participant’s full screening history.</p>	<p>Partially met</p>
<p><b>Governance:</b> The national programme needs to have an appropriate governance and management structure and a population health focus. Clinical leadership and programme management will be critical in building on and sustaining a high-quality programme.</p>	<p>A population health focus has been well embedded in the programme. The governance structure is currently under review to ensure it is fit for purpose and efforts are being made to strengthen the programme management approach. A stronger programme management approach is needed to ensure adequate oversight of risk and to improve stakeholder engagement and</p>	<p>Partially met</p>

	communication. Clinical leadership is evident in the programme, but clinical leadership throughout the governance structure needs to be more visible.	
<b>Quality improvement:</b> An intense focus on quality improvement will be required in the early implementation phases.	Developing quality assurance mechanisms for the programme has been a clear focus. Quality improvement now needs to be built in as the programme progresses. This includes strengthening DHB networking and sharing of good practice.	Partially met
<b>IT system:</b> A systematic review of the operational functionality of BSP+ is needed to determine whether it can work efficiently for the national programme. This includes keeping participant and general practitioner (GP) information on the register up to date, increasing operational automation and linkages to other health systems, and enhancing reporting templates.	A due diligence review of BSP+ was undertaken and substantial efforts have been made to improve its functioning while the NSS is being developed. However, there is a need for ongoing user support and monitoring of the system to manage known functional limitations and to identify any additional issues that arise.  Reporting has improved with the development of the RShiny app, fail-safe and quality assurance reports. Stakeholder feedback should be sought to ensure these reports are meeting end-user needs.	Partially met
<b>Colonoscopy capacity:</b> Adequate endoscopy capacity is needed to meet the growing demand for both screening and symptomatic colonoscopies.	Changes to the screening age range and FIT threshold have alleviated some pressure on colonoscopy capacity; however, concerns remain about colonoscopy capacity across the country. Wait-times need to be closely monitored, recognising the pressure of added volumes from both symptomatic and screening colonoscopies. An increase in the number of training places for colonoscopists is urgently needed.  The additional resourcing needed to outsource colonoscopies should also be monitored.	Partially met

<p><b>Histopathology:</b> It is necessary to ensure that histopathology capacity is adequate and that guidelines and quality standards are in place.</p>	<p>This has been achieved by developing the Interim Quality Standards and by establishing the need for laboratories to be accredited by International Accreditation New Zealand. DHBs have also undertaken additional work to develop local guidelines. Locally developed documents need to be shared across DHBs and, where appropriate, adopted nationally.</p>	<p>Met</p>
<p><b>Acceptability:</b> To build provider acceptability, the NBSP needs to focus on establishing and maintaining provider relationships. This includes expanding the role of primary care, which could be supported by IT integration.</p>	<p>DHBs reported that their chief executive officers, Māori and Pacific leadership, GPs and clinical leaders were engaged in rolling-out the NBSP.</p> <p>However, the Ministry of Health could strengthen external relationships as a way of supporting sector buy-in to and confidence in the NSBP. The role of primary care in the NBSP is underdeveloped and needs to be given greater priority.</p>	<p>Partially met</p>
<p><b>Areas for further study:</b> The pilot identified a number of areas for further research.</p>	<p>Some of the suggested areas for further study have already been incorporated into the NBSP monitoring processes. A research and evaluation plan should be established to provide independent review of different aspects of the programme.</p>	<p>Partially met</p>

## 5. National Bowel Screening Programme readiness

### Overview

NBSP roll-out to all 20 DHBs will occur over four years. While some would like the timeframes to be shorter, this is already a tight timeframe for developing a high-quality, fully operational screening programme. Rolling out complex, population-based screening programmes is difficult and brings risks if it happens too hastily. The report into the introduction of a new laboratory provider to Auckland in 2010 demonstrated issues that resulted from unrealistic timeframes.<sup>12</sup>

This chapter provides the panel's assessment of how well prepared different aspects of the NBSP are for roll-out.

### National Screening Unit

The NSU leads and manages the NBSP and its roll-out throughout the country. It is accountable to the Executive Leadership Team in the Ministry of Health for delivery on the outcomes agreed in the business case that Cabinet approved in August 2016. The NSU holds responsibility for providing quality standards, clinical guidelines and governance to the NBSP, as well as monitoring the quality and safety of the programme, including diagnostic and treatment outcomes.

The NSU has come under pressure to deliver the national programme within a timeframe that is tight even with the extensions Cabinet granted.<sup>13</sup> The extensions allowed for revised timing of the IT business case as procurement was delayed by the decision that the NSS should support multiple screening programmes and would be externally contracted using a Commercial Off The Shelf product.

In retrospect, delays in the roll-out of the programme may have been mitigated had better preparation for national roll-out begun during the pilot phase. The panel is of the impression that the pilot tended to be seen as a time-limited clinical intervention and, as a result, future thinking around IT infrastructure, QA and workforce development was not adequately progressed or resourced. Preparation was further hindered by the significant workload involved in developing the programme business case.

Developing the Treasury better business case completely consumed the entire bowel cancer team ... Implementing a national roll-out became secondary.

I think a lot was missed because the population screening principles and systems and processes were not put in place so we're kind of retrofitting that now.

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<sup>12</sup> Milne G, Mueller J. 2010. *Review of Transition to New Community Laboratory Services Provider*. Auckland Region District Health Boards.

<sup>13</sup> In August 2017 Cabinet extended the timeline for full DHB implementation from 1 January 2020 to 1 July 2020, and did so again in December 2017 to 30 June 2021.

Responsibility for the NBSP transferred from the Ministry of Health's Cancer Team, who oversaw the pilot, to the NSU in November 2016. This shift resulted in significant staff changes and a loss of institutional knowledge about the pilot. The NSU significantly increased the size of the team supporting the NBSP and it already had significant operational, technical and clinical expertise from implementing and managing other population health programmes in the past.

However, DHBs noted that the NSU's knowledge of operational aspects of bowel screening was not fully informed. This was initially addressed through the contract with Waitemata DHB to provide implementation support, up until December 2017. This support was reported to have been highly valuable and the panel considers that this exchange of learnings needs to continue and should be strengthened by the regional hubs. The NBSP would also benefit from increasing the visibility of the NSU's expertise across the sector.

Although a number of Waitemata DHB staff were involved in the initial phase of roll-out, opportunities to learn from the pilot appear to have been hindered by an apparent breakdown in relations between the NSU and Waitemata DHB. The panel believes part of the reason for this breakdown was that clinicians and population health professionals held different perspectives, particularly around the handling of the invitation issues. The expertise and lessons learned from the pilot need to be used to support the ongoing implementation of the NBSP.

The NSU has undertaken a significant amount of work to bring the NBSP up to the standard of other national screening programmes. This includes developing programme documentation, establishing QA processes, building project management discipline and supporting DHB readiness. However, not all of the necessary protocols and policies have been completed, which has hindered the DHBs that were early implementers. A full set of protocols and policies needs to be pulled together to support DHBs with implementation.

The panel has identified several issues that could be addressed through stronger programme management processes. These include the need to improve stakeholder engagement and communication to ensure stakeholder concerns are listened to and decisions are accepted across the sector. Issues the sector raised include the age-range cut-offs and the way results are fed back to individuals, which the NSU believes have already been addressed. The Ministry of Health, the wider health sector and consumers should have stronger joint ownership of these decisions.

The panel heard that stronger programme management processes are needed to reflect the NBSP's scale, complexity and level of inherent risk. This includes ensuring risk management and contingency planning is robust, more visible and well embedded within the programme. The NBSP could learn from other large-scale Ministry of Health IT programmes that were understood to have more robust governance and risk management processes in place. The programme to develop the Electronic Health Record is one example.

The need to prepare multiple business cases for rolling out specific aspects of the programme is a considerable opportunity cost to the NSU and leads to uncertainty for DHBs. Consideration should be given to a streamlined process based on agreed multi-year budgets with appropriate delegations and control systems.

Going forward, the NSU needs to build stronger partnerships with other organisations that can provide expertise and support to the NBSP roll-out. This includes building stronger

relationships with the Corporate Centre,<sup>14</sup> Bowel Cancer New Zealand, Hei Āhuru Mōwai (Māori Cancer Leadership Group), and Māori and Pacific leaders, as well as rebuilding relationships with Waitemata DHB to ensure learning from the pilot is not lost.

The success of the roll-out is highly dependent on the future NSS IT system. If the NSS is not delivered on time, the roll-out of DHBs beyond the initial eight will have inevitable delays. Chapter 7 discusses IT readiness in more detail.

The panel notes a level of disconnect between the health and disability sector and the Ministry of Health, which presents an opportunity for the National Bowel Screening Programme as it moves into the next phase of the roll-out. The panel recommends that the Ministry of Health provides regular communication to all parties involved in the roll-out, including technical updates related to the IT systems (BSP+, NSS), clinical standards development, performance measures reporting, and lessons learned from other DHBs during the roll-out.

## District health boards

DHBs are subject to the NSU's robust readiness process, which includes the need to address each of the outputs summarised in Table 3. After addressing the phase 2 deliverables, DHBs undertake and present a readiness assessment to the NSU, with a readiness site visit then occurring six weeks before going live. The readiness report includes a requirement for DHBs to have met their colonoscopy wait-time targets for the previous three months. If they have not, they are supported to take remedial action.

**Table 3: DHB readiness deliverables**

Readiness phase	Outputs
Phase 1 (required before funding confirmed)	Output 1: Information to inform Ministry of Health business case to joint Ministers of Health and Finance
	Output 2: Resource allocation (dedicated lead, clinical leader and an IT specialist)
	Output 3: Steering group established
Phase 2 (required before going live)	Output 4: Project management and governance framework
	Output 5: Primary care engaged
	Output 6: Diagnostic service readiness (agreement on audit process, standard operating procedures and risk management)
	Output 7: Histopathology service readiness (including IT integration)
	Output 8: Quality Services (ensure providers are able to follow NBSP quality standards and guidelines)
	Output 9: IT integration work plan confirmed

<sup>14</sup> The State Services Commission, The Treasury and the Department of Prime Minister and Cabinet work together as a 'Corporate Centre'. See Appendix 3 for further information.  
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## **Readiness reports for Waitemata, Wairarapa, Hutt Valley and Southern DHBs**

The panel reviewed the readiness reports for those DHBs that had already begun and noted that the reports were robust, detailed and generally of high quality. This is a credit to the DHBs, NSU and NBSP Implementation Manager and Clinical Director, who have all clearly worked very hard to ensure readiness.

The reports document readiness in the areas of governance, leadership and management; equity and participation; primary care; referral and pre-assessment; colonoscopy and alternative investigations; histopathology; and multidisciplinary teams, treatment and surveillance. In each given area, the DHBs demonstrated that it was ready to participate in the programme. The panel understands that this process of assessing and documenting DHB readiness will continue.

## **DHB experience with NBSP roll-out**

Waitemata DHB, because it had piloted the programme, transitioned to the NBSP without difficulty. Hutt Valley and Wairarapa DHBs prepared together for their August 2017 launch and tailored the implementation for their respective regions. Southern DHB launched the NBSP in May 2018 and Counties Manukau DHB is intending to launch in July 2018. Lakes DHB intends to be ready three months before its scheduled September 2018 launch.

All DHBs reported that their chief executive officers, Māori and Pacific leadership, GPs and clinical leaders were engaged, which further facilitated their respective launches. DHBs are enthusiastic about starting screening and are confident that the investment (of both time and resource) will pay off in the long term.

The incomplete nature of protocols and guidance has been an issue for the early implementers. The NSU holds monthly one-hour teleconferences with DHBs as they prepare to launch, drawing on the experience of those that have already rolled out. However, DHBs noted the lack of directive documentation and/or communication regarding clinical standards and NBSP processes. DHBs that are implementing later have received better templates as the NSU and the early adopter DHBs develop and finalise them.

All agreed it would have been beneficial to have better documentation ahead of time, but in reality they had to improvise as they rolled out.

Of course there'd be some localisation required, but it appeared to us that we were starting from scratch.

We were almost reinventing the wheel ... and I found that quite difficult because I wasn't really sure what the bowel screening team were actually after some of the time.

The panel notes that the NSU has undertaken work to document and address the lessons learned from the Hutt Valley and Wairarapa DHB roll-outs. It recommends continuing this work throughout the implementation process.

As DHBs come on to the NBSP, a network of support has begun where clinical directors, project managers and others involved in the NBSP implementation are able to ask questions

and share learnings. This network will be further enhanced as the RCCs are established. The panel supports this work as it has identified a clear need for sharing of learning across the sector.

All DHBs noted that they had to work overtime to reach readiness and that the role of the DHB project lead was vital. The hard work that is under way in the DHBs should be recognised, as well as minimised as much as possible. One way to reduce the burden would be to develop and share a set of policies and protocols to support implementation.

Without the support of Waitemata, we would not have gone live. I would have gone to Waitemata 75 if not 80 percent of the time to progress our work.

Funding to support local health promotion is limited. Notably, no funding specific for local equity strategies and implementation is available. DHBs have been creative with addressing this issue: some have chosen to dip into other programmes' funding streams while another nested its equity strategy under communication.

Another contributing factor around putting communications and equity together is that we just have no money, literally, to develop the equity strategy and plan. Because we did not have resource.

DHBs feel that they were in a better position than the NCC to support increased uptake through community engagement activities. The appointment of a Māori and Pacific liaison staff member in one DHB made it possible to visit priority populations at home or in the community. One concern was that learning from the pilot about the need for alternative sample drop-off strategies had not been brought through to the national programme.

I'm nervous starting something that isn't culturally appropriate ... we are feeling awkward about not being able to let people drop their test kits off.

A number of interviewees indicated concern about low enrolment of Māori and Pacific peoples with primary care practices. DHB staff mentioned that a national media health promotion campaign would be very useful for spreading the message but recognised that this is on hold until national roll-out is completed.

Establishing DHBs on the BSP+ IT system is a key aspect of the DHB readiness process. Preparation includes providing training, resources and support, as well as testing the system before going live. As DHBs become familiar with the BSP+ IT system, they become more aware of its limitations and the requirement for manual workarounds. DHBs need to be able to have confidence in the BSP+. As one DHB interviewee notes:

I've actually asked the Ministry for a brief on what happened, what mitigations have been put in place, and I'm still waiting on it. So we're presuming it's not happening for our population, we're presuming they've picked up the issue.

DHBs using BSP+ would like increased access to the data. The introduction of the RShiny app offers some improvement as it provides DHBs with access to data reports for key monitoring indicators. However, DHBs noted the difficulty in using the app and in being able to customise data reports.

The only other reporting that we have access to is what Ministry of Health put on the RShiny reports. And I have to say that is not at all user friendly in any way, shape or form as a DHB.

DHBs are not approved as 'ready to launch' until they can demonstrate that they have met all wait-time targets for symptomatic (urgent and non-urgent) and surveillance colonoscopies for the previous three months, and have production plans in place. However, the panel heard that DHBs did not always meet the wait-time target requirement before going live.

Wairarapa DHB met the requirement when it went live but has been under pressure to maintain its targets since then. Hutt Valley DHB made excellent headway towards reducing wait-times before beginning the NBSP, but fell off targets in the meantime due to difficulty with recruiting another gastroenterologist. Southern DHB did well, but the consequence of addressing a surveillance backlog some years ago meant follow-ups placed pressure on surveillance targets, although these were met before going live. Counties Manukau DHB is close to meeting the targets, despite a recent surge in referrals.

DHBs reported that they were working extremely hard to meet the wait-time targets, through a combination of recruiting colonoscopists, maximising colonoscopy lists, reviewing prioritisation policies, freeing up clinic space and contracting private providers. In summary, DHBs are under pressure with colonoscopy capacity, which presents a risk to the programme. This is further evidenced by wait-time data discussed in Chapter 6.

### **Workforce readiness**

In June 2016 the NBSP surveyed all 20 DHBs and obtained agreement in principle regarding their readiness to begin delivery of bowel screening services according to the national bowel screening pathway and standards from the proposed start date that applied at that time. DHB chief executive officers stated their estimates for additional workforce capacity for colonoscopists, endoscopy nurses, surgeons, oncologists, radiologists, histopathologists and laboratory technicians. Estimates for additional funding were provided for the next five years.

Because cancer cases will be detected at an earlier stage through the NBSP, surgery may get easier and oncology and radiotherapy may be needed less often, although for surgery a small initial surge may occur (fewer cases requiring urgent surgery will be the earliest sign though). The pilot report indicated that the histopathology workload was manageable.

As mentioned above, one of the delivery milestones for the readiness assessment is each DHB's ability to meet the colonoscopy wait-times for urgent, non-urgent and surveillance colonoscopies. See Chapter 6 for more information on workforce readiness.

Overall, the panel considers that DHBs face significant risks to their ability to implement the NBSP. Among these risks are clinical and other workforce capacity, IT including manual workarounds, eligible patient registers, policies and protocols. However, these risks can be mitigated by high-quality planning and management, alongside ensuring that a ready workforce of colonoscopists is available.

## National Coordination Centre

The NCC was established in November 2017 and is run by Homecare Medical, which is owned by two large primary health organisations (PHOs) – ProCare and Pegasus. Homecare Medical feels that this gives the NCC a primary care lens and support for integration.

The NCC covers the screening journey from invitation to return of the FIT kits. It has set up standing operating procedures and policies in line with the clinical guidelines from the pilot coordination centre. The BSP+ automatically notes where the person is on the screening journey and what tasks need to be done when (eg, pre-invitation letter, FIT kit sent).

The Ministry of Health sends the NCC data on people eligible for screening based on the NHI. This data excludes people that have had a colonoscopy within the last five years, are already on the bowel cancer surveillance programme, have died or have not had contact with the health system within the last three years. The NCC reported that full address and contact details are available from the NHI for approximately 45 percent of those on the register. The NCC then sends the data to PHOs for further verification and identification of contact details for those eligible. Through this method, contact details are retrieved for an additional 12–20 percent of individuals. The NCC members interviewed suggested that the NBSP could potentially look outside health care for up-to-date contact information (eg, IRD or other databases).

If a FIT kit has not been returned within four weeks, the NCC follows up actively, with three attempts to phone the person over four weeks. The NCC is recruiting so that employees in these roles are able to connect with the culture and language of priority groups, reflecting learning from the pilot. Some DHB interviewees wondered whether DHBs should produce this active follow-up list as they often know their priority populations well. The NCC service model states that DHBs should be informed of details of non-responders eight weeks after the initial invitation. However, early adopter DHBs have experienced considerable lag before they were advised of non-responders.

The NCC is aware of some of the barriers to people answering their phone (eg, concern over debt collectors) and has changed its standard text to put people at ease early. The NCC is also consulting with iwi and finalising an equity strategy so that it can ensure its processes are culturally appropriate.

Any FIT kits returned with a 'Gone No Address' notice are sent back to the NCC. The staff will look the person up on the system and check that the address is correct or if it has been updated. They will attempt to phone the person and, if they cannot reach them, the staff contact their GP. After two weeks if the NCC has not been able to get an updated address, the person is marked as 'Gone No Address' and will be reactivated only if an updated address emerges. The NCC staff interviewed are concerned that most of the returned kits (about 10% currently) are returned by New Zealand Post because the address is not complete (eg, an address reads only 'unit 4'). Alternatively, a kit could be delivered but the new occupants at that address may not take the trouble to send it back. The NCC is concerned that the return rate could therefore be under-represented.

The NCC subcontracts the mail-out of invitations. The NCC staff interviewed thought that it would be relatively straightforward to set up systems for sending an electronic message to

the person's GP, informing them that the invitation has been sent out. This could be done by updating BSP+ to run HL7, or the NCC itself could run the register through its HL7 engine and send lists to GPs. However, introducing this process would require modifying the way participants are asked for consent to provide information to their GP.

The NCC reports to its board and the Clinical Governance Committee. The Clinical Director of the NSU sits on this committee. The NSU have also supported a clinical person to work with the NCC for 12 months and that person also reports to the Clinical Governance Committee. The NCC has a monthly meeting with DHB programme leads and the NSU as well.

The NCC is responsible for ensuring participants progress through the screening pathway in a timely and safe way. It coordinates participants' national bowel screening pathway, acting as the safety net for participants across the pathway and maximising participation for eligible people.

The NBSP Service Delivery Model appears to be well documented and sets out the functions, roles, activities and responsibilities of the NCC. The panel notes that the NCC appears to be functioning well at present.

## **Bowel Screening Regional Coordination Centres**

The NBSP has four Regional Coordination Centres (RCCs) across New Zealand: Northern, Midlands, Central and Southern, each based in a DHB.

Key informants advised that these centres are in the early stages of forming and resourcing will increase as additional DHBs go live in their regions. DHBs using these regional centres reported receiving excellent support, although they appear under-resourced presently. The Southern RCC is providing reporting templates and guidance standards to the other RCCs, which it had developed for its region.

The NSU regards the RCCs as 'super users' in that they become familiar with the way that the NBSP operates and can provide advice to DHBs as they roll out. The RCCs will each have a clinical director to provide advice around QA to the DHBs. Conversely, DHBs reported that the governance and role of the RCCs is not clear and caused confusion. It is likely that the RCCs' role will evolve over time as the NBSP moves from implementation to business as usual.

## **FIT laboratory service**

The FIT laboratory service is responsible for analysing the test samples participants provide using the FIT. From its interviews with staff at the FIT laboratory service (LabPlus at Auckland DHB, which holds the national contract), the panel is satisfied that the laboratory can cope and is coping with the volume of samples. No issues were uncovered with respect to this provider and it holds national laboratory standards accreditation.

## **Primary health care**

Primary health care refers to the roles that PHOs and general practices play in supporting the NBSP. Several GPs interviewed asked why practices were not being used to initiate

invitations and recalls, and undertake opportunistic screening, as occurs with the National Cervical Screening Programme.

The Ministry of Health advises that the NBSP is a population-based programme, which will be run centrally through the use of a national register. The aim of this approach is to improve equitable access to screening by including those that are not registered with a GP. While the panel appreciates this intent, the approach has unintended consequences. Failing to leverage a primary care based model leads to missed opportunities to encourage those visiting their GP or primary health care nurse to participate.

The panel believes that the role of primary health care should be strengthened. Ideally, practices should be notified immediately after a letter is sent to invite people to participate in the NBSP. This could be done by integrating primary care IT systems with the NSS. This would then enable GPs and primary health care nurses to see a dialogue box in the participant's Electronic Health Record and allow a discussion to reinforce the benefits of participation in the NBSP, thus improving screening uptake.

The option of allowing participants to return samples to their GP practice rather than sending them by post should also be explored in order to address cultural concerns.

Another concern expressed was how FIT results are communicated to participants, particularly where blood is detected in a sample, but at a level below the 200 ngHb/ml positivity threshold. The Ministry of Health has advised that the Bowel Screening Advisory Group and the National Screening Advisory Committee, supported by advice from international experts, have considered this issue extensively.

The NBSP will provide numerical results to participants on request. However, the panel notes it may be of benefit for GPs to receive the detailed results (ie, the FIT result and the actual haemoglobin level in faeces) so that they can support the appropriate management of individuals presenting with symptoms. The panel recommends further consideration of this issue in consultation with primary health care.

It would be very useful to know if someone's level was 12 versus 180 ... just in terms of if they've then presented with symptoms.

## Summary: National Bowel Screening Programme readiness

It is clear that a significant amount of work has already been undertaken to support roll-out of the NBSP, including development of programme documentation and quality monitoring processes. However, the ambitious timeframes for roll-out have meant that not all of the necessary protocols and policies have been completed. This has been further complicated by significant staff changes at the Ministry of Health, limited transfer of knowledge from the pilot and lack of partnership with other organisations that can provide knowledge and expertise in bowel screening.

DHBs have valued the support offered from the NSU and other DHBs, particularly from Waitemata DHB, and are enthusiastic about starting bowel screening. DHBs are working hard to implement the NBSP and to meet colonoscopy wait-time targets.

It is necessary to make the DHB implementation process as smooth as possible by providing robust, easily accessible documentation, expert advice and peer support. The

role of each organisation involved in the NBSP needs to be appropriate and well understood. This includes strengthening the role of primary care and local community engagement.

### **Risks**

- Colonoscopy workforce capacity is a key risk for DHB roll-out (see also Chapter 6).
- A failure to learn from the pilot and to seek support from other external organisations presents the risk of not identifying or addressing issues early.
- The success of DHB implementation and the overall effectiveness of the NBSP are at risk if DHBs are not well supported with standard policies and protocols, and lack good support from the NSU, the RCCs and other DHBs.
- Incomplete and inaccurate personal contact information on the register may hinder the NBSP's ability to achieve adequate and equitable participation rates.
- The NBSP may lose support if there is no work to improve engagement with primary care and clarify the role of the RCCs.
- Other DHB programmes and activities may be adversely impacted by the considerable effort and resource required to get ready for screening roll-out.

### **Chapter recommendations**

1. The NSU needs to strengthen partnerships with external organisations to share knowledge and experience to support the NBSP roll-out.
2. Efforts should be made to rebuild relationships between the NSU and Waitemata DHB to ensure lessons learned from the pilot are not lost and to reach agreement on policies and protocols for handling invitation issues.
3. The Ministry of Health should undertake a review of the functionality and operation of the population register, to increase its accuracy and completeness.
4. The NSU needs to provide greater support to the DHBs during implementation, ensuring relevant documentation and data are easily accessible, including a full set of protocols and policies to support roll-out.
5. The role of primary care in the NBSP should be reviewed and strengthened, to maximise opportunities to increase participation rates.
6. The role of the RCCs both during implementation and in the long term should be clarified.
7. Robust programme management must be used within the NBSP to ensure all aspects of this complex programme, including risk, stakeholder engagement and quality assurance, are closely monitored and well managed.
8. A comprehensive multi-year funding pathway should be developed to embed the NBSP throughout the sector.

## 6. Workforce capacity, capability and readiness

### Overview

Workforce is critical to the success of a national bowel screening programme. Appendix 6 outlines the roles and responsibilities that must be carried out. Fulfilling them requires a broad range of skill sets, including: public messaging, systems design and logistics, population health and data analysis; clinical skills including nursing, colonoscopy, laboratory and pathology expertise, and radiology; treatment services from surgery to oncology.

International experience has highlighted that having adequate colonoscopy capacity is crucial in bowel screening programmes, and that limited colonoscopy capacity is a risk for programme roll-out. The New Zealand Pilot Evaluation<sup>15</sup> and Programme Business Case<sup>16</sup> both highlighted colonoscopy workforce as one of the main issues to be addressed.

Colonoscopy is a skill that requires rigorous training and ongoing maintenance of standards to ensure a quality (low-risk) procedure. It is therapeutic as well as diagnostic, with polypectomies performed as part of many colonoscopies.

This chapter focuses on the colonoscopy workforce as an ongoing risk, and comments on other relevant workforces in brief.

### Colonoscopy workforce: Pilot and modelling

The pilot evaluation documented concerns about colonoscopy capacity and a need to closely monitor capacity to meet target wait-times. The pilot evaluation concluded that colonoscopy resource requirements 'may pose a constraint on how a national programme may be delivered'.<sup>16</sup>

Health Workforce New Zealand undertook colonoscopy capacity modelling in June 2015. The modelling concluded that capacity (at the time) of a sufficiently trained and skilled workforce was insufficient to proceed with a roll-out that conformed to the evidence base for efficacy (ages 50–74 years). Following expert advice from the Bowel Screening Advisory Group and international advisors, it was agreed that two modifications to the NBSP roll-out would be made.

1. Limit the eligible population by changing the age range from 50–74 years to 60–74 years.
2. Increase the threshold for FIT positivity from 75 ngHb/ml to 200 ngHb/ml.

The revised age and positivity thresholds aimed to strike a balance among the following factors:

- the number of cancers detected
- benefits and harms for participants

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<sup>15</sup> Litmus et al. 2016. *Final Evaluation Report of the Bowel Screening Pilot: Screening rounds one and two*. Wellington: Ministry of Health.

<sup>16</sup> Ministry of Health. 2016. *Programme Business Case & Tranche 1 Business Case. National Bowel Screening Programme draft v3.1*. Wellington: Ministry of Health.

- the projected available resources (particularly colonoscopy capacity)
- reduced deaths from bowel cancer over time
- cost-effectiveness

Chapter 9 discusses the impacts of these modifications.

## **Current colonoscopy workforce**

### **Supply**

Since 2013 the Royal Australasian College of Physicians and the New Zealand Society of Gastroenterology have been working with Health Workforce New Zealand to increase the number of gastroenterology training positions in order to train sufficient numbers of gastroenterology registrars each year. Four training posts have been added since 2013. In addition, the first cohort of four nurse endoscopists completed their training last year and four more will begin training this year.

The panel was informed that the existing colonoscopy workforce is adequately skilled, and will be able to manage the workload inherent in the first few years of the NBSP. However, the panel believes this workforce is at risk in several ways.

- The workforce is not distributed well geographically in relation to the places where greater demand is likely.
- The workforce is 'brittle', in that losing even a few staff in a region will put stress on the system.
- While new training positions are being established, the lag time in the training process (approximately four years) means that the colonoscopy workforce will remain a risk for the medium term.
- Due to increased bowel cancer awareness, demand for symptomatic colonoscopy has increased by an estimated 20 percent in DHBs introducing screening.<sup>17</sup>

It is necessary to increase training positions, but the panel notes that this is currently constrained by the number of hospital units that meet the Royal Australasian College of Physicians Gastroenterology training requirements. Ongoing discussions with Health Workforce New Zealand, colleges and DHBs are aiming to address this and the panel suggests that these need to be progressed as a matter of urgency.

### **Colonoscopy wait-time and prioritisation processes**

Monitoring colonoscopy wait-times is important to avoid harm from delayed diagnosis following a positive FIT. Some DHBs are struggling to meet the current wait-time standards, particularly for non-urgent and surveillance colonoscopies. The failure of DHBs to meet these important targets is an indicator that colonoscopy services are already under pressure.

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<sup>17</sup> See Appendix 3 for the definitions of symptomatic versus surveillance colonoscopy.

**Table 4: Ministry of Health colonoscopy wait-time standards, 2018<sup>18</sup>**

<b>Urgent colonoscopies</b>	90% within 14 days 100% within 30 days
<b>Non-urgent colonoscopies</b>	70% within 42 days 100% within 120 days
<b>Surveillance colonoscopies</b>	70% within 84 days 100% within 120 days

The panel believes that the Ministry of Health standard for urgent colonoscopy places pressure on providers, and some DHBs told the panel that they see screening colonoscopies as interfering with capacity to deliver urgent and non-urgent colonoscopy for other indications. This is at odds with the likelihood of bowel cancer given specific risks: studies now show that a positive FIT is a stronger predictor for the presence of colorectal cancer than any patient-reported symptoms.<sup>19</sup> In contrast, the Interim Quality Standards for the NBSP require 95 percent of participants to have a first offered colonoscopy date within 45 working days from the date when the BSP+ system receives the positive screening result.

A related issue is ensuring that existing colonoscopy services are efficiently managed. This includes following clinical guidelines for when colonoscopy is indicated (symptoms, family risk, etc). Other countries have managed demand by reducing over-servicing through implementing such guidelines. Waitemata DHB reports undertaking work in this area and any lessons it learned should be shared across the country.

We have wide variability through the country on the acceptance of referrals from primary care into secondary care for colonoscopy for symptomatic patients, and variability in the use of surveillance [colonoscopies] for people at increased risk.

The panel considers that urgent action is required to ensure that DHBs have the capacity to provide screening colonoscopies without causing harm to the delivery of symptomatic and surveillance colonoscopies. It is necessary to conduct a complete review of colonoscopy prioritisation processes, for screening and other indications, and to better align colonoscopy timeliness with severity of risk.

### **Ensuring workforce competency**

A workforce development plan is needed to ensure that the colonoscopy workforce, regardless of speciality, is sufficiently skilled. Training standards should be explicitly defined and implemented when appointing the colonoscopy workforce. In considering training to ensure competency, it is necessary to:

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<sup>18</sup> Ministry of Health, personal communication, 2018.

<sup>19</sup> Li et al. 2018. Predicting the risk of colorectal cancer with personal characteristics and fecal immunochemical test. *Medicine* 97(18):e0529.

- clarify what credentialing and accreditation are appropriate in the New Zealand setting
- examine capacity to train in terms of: accessibility of training devices; patients willing to be used for training; time on colonoscopy lists that allow training; and the capacity and capability of the teachers to train
- define what constitutes an adequate training programme in terms of the aspects of colonoscopy in which competency is demanded and how much experience during training is required for each of these
- address ongoing quality assurance and recertification of colonoscopists to maintain professional standards.

The panel recognises that substantial effort is under way in all of these areas, supported by the establishment and ongoing funding of the National Endoscopy Quality Improvement Programme and Endoscopy Governance Group for New Zealand (EGGNZ). In line with Australia, the panel believes a recertification process should be in place, overseen by a national body.

## **Other workforces involved in national bowel screening**

The panel is reassured that other workforces involved in the NBSP are generally adequate and that navigating people to colonoscopy can be adequately managed by endoscopy facility staff.

- Pathology services seem to be adequate and there was no evidence of poor-quality treatment for bowel cancer.
- The panel has been advised that the vast majority of colonoscopies (98–99%) are done without an anaesthetist. Larger centres have a list per week for endoscopic retrograde cholangio-pancreatography (ERCP) cases or difficult colonoscopies, which do involve an anaesthetist. Smaller centres may perform endoscopies in a theatre setting, ensuring an anaesthetist is close at hand if required.
- To be 'equity led', the NBSP, particularly at the DHB level, will require additional staff from health promotion, Māori health and Pacific health workforces. See Chapter 9 for further discussion.
- The important role of primary care reception staff in ensuring contact information for patients is kept up to date was iterated.

### **Summary: Workforce capacity, capability and readiness**

Colonoscopy workforce capacity remains a significant risk and is constraining the current NBSP roll-out. Colonoscopy wait-time data highlights that DHBs are struggling to meet their wait-time targets, even before the roll-out. The panel is concerned about the capacity and fragility of the colonoscopy workforce.

Colonoscopist training posts must be increased, particularly before access to the NBSP is potentially widened to include those aged 50–59 years. This work includes giving greater consideration to which professional groups will be involved in any training undertaken with the purpose of increasing workforce capacity, including the role of nurse endoscopists. Policies and processes regarding the credentialing, accreditation and recertification of colonoscopists need to be clarified and formalised.

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## **Risks**

- The constraints on age range and FIT-positivity will result in missed opportunities to identify cancers and have potential implications for equity.
- If a comprehensive approach to increasing colonoscopy workforce capacity is not provided, then adverse outcomes in terms of wait-times, quality measures and public opinion seem likely.

## **Chapter recommendations**

1. Further modelling of colonoscopy requirements should be undertaken with urgency, including giving greater consideration to which professional groups will be involved in any training undertaken with the purpose of increasing workforce capacity.
2. A workforce development plan is needed, with dedicated funding, to ensure a sufficiently skilled workforce is available into the future. Training standards across different specialties should be explicitly defined and implemented when appointing the colonoscopy workforce.
3. Policies and processes need to be clarified and formalised regarding the credentialing, accreditation and recertification of colonoscopists.
4. It is necessary to conduct a review of colonoscopy prioritisation processes, for screening and other indications, and to better align colonoscopy timeliness with severity of risk.
5. Wait-times for colonoscopy (all indications) must continue to be closely monitored.
6. Relevant professional groups (including physicians, surgeons and nurses) should be encouraged to maximise their use of colonoscopy lists for training.

## 7. IT readiness

### Pilot IT system (BSP+)

The panel was not in the position to undertake a detailed technical review of the BSP+ in the timeframe provided. Instead, it has reviewed the history of the development of the system and has scrutinised the various reviews and assurance documentation that have already been done to date.

BSP+ invites members of the target population to participate, uploads the FIT test results and tracks the person's journey along the screening pathway. The system was originally built in a very short timeframe and with limited scope, which was deemed sufficient for the four-year pilot. It was designed to cope with a limited number of participants during the pilot rather than to be the IT system for national roll-out.

Waitemata DHB staff became aware of functional limitations of the system early on in the pilot. These issues were raised with the Ministry of Health and the Ministry's IT Board. However, applications for funding to rectify these IT issues were often unsuccessful, as plans for a national IT platform were being made at that stage. The root cause analysis of the 'Withdrawn' issue highlights the impact of the lack of investment in the BSP+. <sup>20</sup> It has been contended that the Ministry of Health decision-makers did not fully understand the clinical implications of these issues.

The 2015 Treasury Gateway Review Report notes that 'the availability, reliability and functionality of IT systems are the highest risk to the successful implementation of the programme'. <sup>21</sup> It concludes that strategic leadership, governance and development of the IT system are urgently needed.

The Treasury report further notes that there was 'a plethora of advisory groups associated with the programme and more broadly the screening activities of the Ministry of Health's bowel screening programme' and that the new governance structures should replace a number of these committees.

An external IT review of the NBSP, conducted in August 2016, concluded that the proposed overall IT delivery for the phased roll-out involving early deployment of the interim solution to DHBs was sound, and unavoidable if the roll-out was to be achieved by mid 2017. It proposed that the enhanced pilot IT, BSP+, was sensible as an interim solution, subject to 'due diligence'. <sup>22</sup>

A 2017 due diligence report assessed two key capabilities of the BSP+ IT system: will it work and is it safe? (Figure 1). <sup>23</sup>

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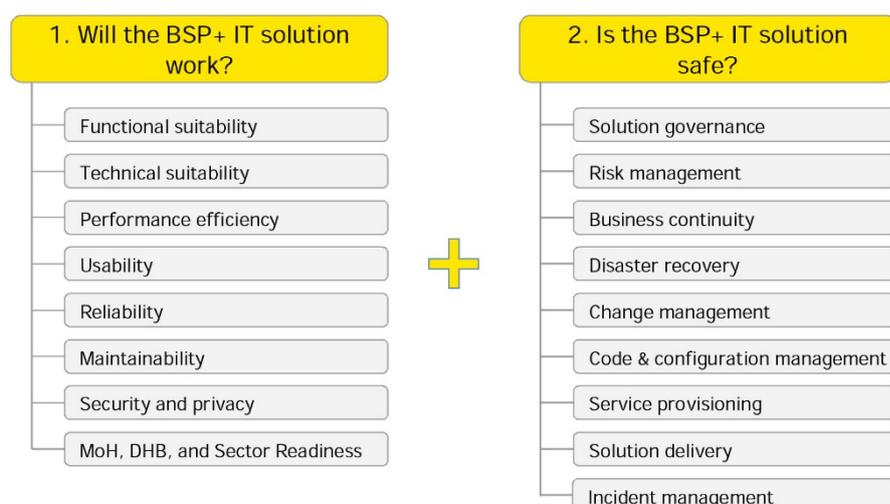
<sup>20</sup> MacIntyre K. 2018. *Review of Invitation Issues Following Address Update – Bowel Screening Pilot (Final Draft)*. Unpublished.

<sup>21</sup> The Treasury. 2015. *Gateway Review Report, Ministry of Health – National Bowel Screening Programme*. Unpublished.

<sup>22</sup> Accenture Consulting. 2016. *External IT Review: National Bowel Screening Programme (NBSP)*.

<sup>23</sup> EY. 2017. *BSP Due Diligence Interim IT Solution Assessment*. Wellington: Ministry of Health. *Independent Assurance Review for the National Bowel Screening Programme – 2018*

**Figure 1. Questions and capabilities assessed in due diligence report on BSP+**



The due diligence report identified seven risks with the BSP+ system. Four of these risks were considered ‘Significant’ and were to be tackled before 1 July 2017. These risks included: concerns around the lack of business continuity and disaster recovery; inconsistent, poorly documented governance and risk management; and the fact that the BSP+ IT system was running on unsupported technology. The other three risks were rated as ‘High’ and were to be addressed before the roll-out to the fourth and fifth DHBs (Southern and Counties Manukau). The report concluded that although release seven of the BSP+ would satisfy the functional needs of the NBSP, it could not safely support DHBs that were ‘currently onboarded, or onboarding to, the IT solution’.

In response to the report, the Ministry of Health proposed actions to address the seven risks. The majority of these actions have now been completed. However, mitigation of three of the four significant risks is still in progress, due for completion by December 2018. The Ministry of Health is planning further enhancement of BSP+ in 2018 and is undertaking a review of governance arrangements for the IT system.

### **Invitation issues with the BSP+**

In September 2017 the NSU became aware of a number of issues with BSP+ that had resulted in potentially eligible people missing out on their invitation to take part in the screening process in Waitemata DHB. These were the same issues that Waitemata DHB had been alerting the Ministry of Health to for three years. A root cause analysis was commissioned to investigate and report.

The panel understands that four separate issues related to the invitation process arose during the Waitemata pilot.

#### **Issue 1: Withdrawals**

A group of 12,834 people was excluded from the pilot due to an incorrect address, even though they were eligible for screening. Around 2,500 of these people had an updated address in the NHI, but this did not lead to a re-invitation to be screened.

The root cause of this error was identified as ‘the management of the returned mail GNA [Gone No Address] issue that was not addressed by proposed IT functionality when the

register was first set up'.<sup>24</sup> Through the manual workarounds that were put in place, people who could not be contacted were assigned 'withdrawn' rather than 'recall' status in the pilot register. As a result, they could not be sent a new invitation even if their address was subsequently updated in the data associated with the NHI.

After the NSU became aware of this issue, it took actions to stop the workaround practice, reassign affected people to two-year recall rather than 'withdrawn' and re-invite the people affected. The root cause analysis also reports that the following mitigations and controls have been put in place.

- The NSU runs weekly checks to identify any address updates in the NHI.
- A list of updated addresses from the NHI is provided to the NCC weekly. These addresses are then manually updated in the national population register.
- The National Enrolment Service online provides a live PHO data set and the national population register is linked to this service.
- At the same time, the NSU continues to look at address records to identify any further issues.

### **Issue 2: Address override**

This issue affected 5,957 people. Of those, 333 people did not receive an invitation to screening.

When the pilot began, coordination centre staff had 'look-up' access rather than 'look-up and change' access to the NHI. If they were contacted by a person who had moved house, the staff did not have the ability to record this new address on the NHI. They therefore devised a manual workaround to update the address in the BSP+, by locking the address so that it would not be changed back to the old (incorrect) address at the next NHI update. However, once the team received 'look-up and change' access to the NHI, the temporary override was not disabled and so this introduced a problem where the details that had been entered manually remained.

This issue has been resolved as NCC staff now have 'look-up and change' access to the NHI and the manual override has been disabled. Those affected have been sent an apology letter and invited for screening. The NSU will closely monitor the results for these individuals and will undertake a clinical review of any identified bowel cancers.

### **Issue 3: Do Not Load File**

This issue affected 87,748 people, of whom 9,450 did not receive an invitation to be screened.

In 2011 when the pilot began, it was recognised that the Waitemata population cohort in the NHI system was a third larger than the census data for Waitemata DHB. The larger number would have included many people who had transient contact with the health system (eg, visitors to the region). To confine the NHI extract to those that should be invited, an algorithm was used to create a 'do not load' list. A 2014/15 extract from the NHI was then

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<sup>24</sup> MacIntyre K. 2018. *Review of Invitation Issues Following Address Update – Bowel Screening Pilot (Final Draft)*. Unpublished.  
*Independent Assurance Review for the National Bowel Screening Programme – 2018*

incorrectly loaded into the 'do not load' list, instead of into the BSP system. As a result, those people who were on the 2014/2015 NHI extract were removed from the register.

The use of the 'do not load' list was stopped in April 2018. Invitation to screen has been started for those who missed out on an invitation and will be completed by the end of September 2018. The health outcomes for individuals in this group will be closely monitored and the NSU is undertaking a clinical review of the records of participants who have had a diagnosis of bowel cancer to determine whether or not the delay in invitation has had an adverse impact on their outcome and may have caused harm.

#### **Issue 4: Duplicate NHI**

The panel understands that this issue affected between 200 and 300 people.

This issue arose when people had more than one NHI number. In this situation, the pilot register had some difficulty with how this information was uploaded. The underlying cause continues to be analysed, but it appears to be related to the code that was written to avoid duplication.

Improvements have since been made to reduce the number of duplicate NHIs. All people affected by this incident have been sent an invitation to screen and their outcomes are being closely monitored.

#### **Actions taken to resolve invitation issues**

Since the first issue was identified by the NSU in November 2017, anomalies have been corrected and systems and processes put in place that will provide assurance around the invitation process. These include:

- making IT enhancements to address known issues and remove workarounds
- continuously reviewing all data anomalies across the screening pathway for all participants
- developing a tool to measure invitation cohorts for each DHB against census data to identify significant differences
- introducing a programme of work to improve the quality of NHI data
- expanding 'Fail Safe' reports to cover 'known issues' to mitigate the risk of reoccurrence.

The Ministry of Health advises that all of the known issues to do with the BSP+ have been addressed. So far, no new issues have been identified and, with the passage of time and as more DHBs are added, confidence is growing that further major issues are less likely to arise.

The panel was provided with varying estimates as to the safety of the BSP+. Some gave certainty that the underlying software was robust, while others were less certain. Most of those we interviewed that had user experience with the BSP+ consider it to be operationally inefficient. Its ability to adequately manage the population register, invitation process and clinical data remains a concern as more DHBs are added.

The NSU actions to mitigate known risks are adequate but the user support needed to successfully operate the BSP+ is resource intensive and will come under pressure as the

programme rolls out with larger volumes. The significance of the amount of work involved with manual workarounds should not be minimised, while it is also important to recognise what happens if these do not occur. Therefore, the BSP+ needs to be adequately resourced for intensive monitoring.

The near unanimous view is that to extend this system beyond the eight DHBs planning to launch by year end would be unwise. This means that the roll-out of further DHBs may be delayed if the proposed NSS does not come online by March 2019, ready for the next DHBs as they launch. Robust contingency plans need to be in place and ready for use if the NSS does not launch in time. The panel has reviewed the current contingency plans for the NSS and believes these need to be strengthened.

## **National Screening Solution**

The IT approach has been through several changes, which led to a lengthy planning and scoping phase. Agreement was made to externally contract for an IT system that can support multiple screening programmes. The impact of this delay has put pressure on the timeframes for developing the NSS, with national roll-out now planned for March 2019. The Ministry of Health is currently finalising an IT contract with the preferred provider.

The panel is satisfied that the Ministry of Health conducted a robust and comprehensive process in procuring the NSS. It also supports the strategic intent of the NSS. Use of the system across screening programmes will create a comprehensive view of each participant's screening history and will create significant efficiencies.

The NSU intends for the NSS preferred provider to be contracted to undertake a two-phase process to minimise any risk of project failure. The first is the design phase, intended to be complete by the end of July 2018. Should the design phase meet project requirements, the provider would proceed to the build phase with a March 2019 delivery date. An independent QA process is in place for the development of the NSS.

The Ministry of Health has high expectations of the NSS and is confident that the preferred provider's proposal is comprehensive. The national roll-out represents a very large and complex change to processes for the Ministry of Health, DHBs, laboratories, colonoscopy units, GPs, PHOs, management of the NHI, NCC, RCCs, National Enrolment Service and the various complex IT systems that these entities are involved in.

A number of issues that involve IT integration were raised with the panel. Experts advised us that the delivery of the 'core IT solution' (creating a pathway engine and administrative application) should not be highly complex technically, but that the risks lie in integrating the 'core IT solution' with all the other relevant IT systems.

The topography of the New Zealand health sector, statute environment and common information assets (eg, NHI, various regional lab results systems) create a unique landscape into which any new system must integrate ... The greatest risk is in the connections from the core pathway engine to the many and varied organisations nationally, each of whom must agree and conform to a common process and information model despite systematic differences in their own delivery approaches, IT architectures and commercial frameworks.

The panel notes that integration of the NSS with IT systems has been considered as part of the NSS design phase. The Ministry of Health appears to have a clear understanding of the integrations required and is planning how these will be achieved. The panel was advised that the project team has a significant amount of experience with these types of IT builds and that the requirements are well understood.

The panel notes that efforts have been made to involve stakeholders in the initial conceptualisation of the NSS. It recommends that sector engagement, particularly with primary care, DHBs and the NCC, continues during the design, testing and implementation phase, to help maximise functionality of the NSS.

While the Ministry of Health has identified integration as a requirement for the NSS, the panel has been advised that the proposed NSS design will not integrate with GP systems. Instead, it is intended that an application programming interface will allow GP practice management systems to link in and obtain screening information about their patients. All the individuals that commented on primary care engagement with the NBSP highlighted the value of giving timely information to primary care at all stages of the patient journey so that primary care providers can encourage their patients to actively participate in the programme.

The panel notes that the pilot evaluation identified the need for an interface between the register and practice management systems. In the panel's view, the NSS should be integrated with practice management systems so primary care providers receive information (push rather than pull) so they are aware of when their patient has been sent an invitation letter and can then monitor their progress through the NBSP. Prioritising primary care integration with the NSS will also help future-proof the NSS for when it is rolled out to other screening programmes.

In common with other large-scale IT projects, this IT solution brings a general risk that it may not be achieved within the timelines proposed. In particular, the panel notes that the design and build phases will need to be completed in time for servicing those DHBs beyond the first eight that will have been rolled out on the BSP+ system. If the NSS is delayed significantly, then the roll-out of the programme may be delayed. The panel wishes to reiterate the importance of providing adequate oversight of the NSS development, reflecting the level of risk inherent with an IT procurement process of this scale and complexity.

The panel has been advised that the NSS will not involve an active migration of participants from the BSP+. Instead, participant records will be created within the NSS and a number of data items will be migrated and linked to the NSS participant record. Participant records will then be activated within the NSS and deactivated within the BSP+. When participants are transitioned from BSP to NSS, a reconciliation process will run to ensure that the screening record in the NSS is accurate. This reconciliation will include checking that all FIT test results are accurate and correct within the NSS.

This approach removes technology and data migration constraints for DHB on-boarding, as the transition from inactive to active is a status change on the participant record. This panel has been assured that this approach will support the development of a robust population register within the NSS and will help minimise any potential risks associated with data migration. The Ministry of Health must ensure robust processes are in place around the points of transition and reconciliation from the BSP+ to the NSS.

Clinical input into the design and functioning of the NSS needs to be adequate to prevent clinical issues, such as those that arose in the Waitemata pilot, from arising. The Ministry of Health has advised that direct and extensive clinical engagement has occurred throughout the NSS design and procurement process. However, a number of interviewees, including those familiar with the limitations of the BSP+ system, expressed concern that they had not been consulted during the development of the NSS request for proposals. The panel cannot overemphasise the importance of clinical engagement in the IT development process as well as at an IT governance level. Chapter 8 considers this issue further.

## **Other matters**

### **IT expertise**

The panel was reassured by the experience of the senior leaders and managers of the Technology and Digital Solutions branch of the Ministry of Health. However, concerns have been raised about the need for a stronger project management approach to ensure risks with the BSP+ and NSS IT systems can be successfully identified, mitigated and managed. A need for strong data management expertise at the Ministry of Health has also been identified.

### **Support for new users of the BSP+**

Comments varied on the level of support for new users of the BSP+, but overall the panel feels that more support should be available to new users as additional DHBs come on board. This includes learning from the experience of those involved with using the BSP+ at Waitemata DHB. Failing to provide sufficient support would bring safety risks, including the potential for more invitation issues to arise.

### **Risk of running two parallel IT programmes**

The panel is mindful of the risks associated with running two IT programmes in parallel (BSP+ and NSS), and trusts that this risk can be managed. The sooner the BSP+ can be phased out, the smaller this risk becomes. One suggestion to the panel was that the NSU might like to consider the merits of migrating DHBs already familiar with the NBSP and the BSP+ to the NSS first, rather than beginning with a DHB new to the NBSP. Those already familiar with BSP+ will be better placed to spot issues than DHBs unfamiliar with the NBSP. More likely than not, early retirement of the BSP+, rather than continuing with manual workarounds, seems advisable.

### **Social licence for the NSS**

Social licence refers to building acceptance of data use practices by having ongoing conversations with New Zealanders to understand public feelings and perspectives on data use.<sup>25</sup>

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<sup>25</sup> Data Futures Partnership. 2017. *Social Licence: Guidelines for trusted data use*. URL: <https://trusteddata.co.nz/wp-content/uploads/2017/08/Summary-Guidelines.pdf> (accessed 19 May 2018), p 5.

The growing use of technological services such as cloud services requires public engagement in order to properly consider the impact of their use and convey their benefits to the public. Social licence attaches conditions to services that impact the public. The conditions must be adequately addressed in order to gain social licence when delivering these services.

The panel understands that the proposed NSS IT solution will use cloud technology, with the server based offshore. Public acceptance will be required, including meeting obligations under the Treaty of Waitangi through open dialogue with Māori, Pacific peoples and other communities.

The panel has been advised that the NBSP has followed the government strategy for cloud computing throughout the procurement process and that the roll-out of the NSS will be advised by cross-government work looking at social licence and cloud-based solutions.

While these issues are being canvassed, the opportunity should be taken to understand how to obtain informed consent from participants in the NBSP, and in other screening programmes, for research purposes. This aspect is often left till last, or not considered at all, leaving doubts as to whether the data may be used for research purposes for public benefit and programme improvements.

### **National Enrolment Service**

The National Enrolment Service (NES) has been developed to provide a centralised register with real-time data on the enrolment status of patients enrolled in primary care.<sup>26</sup> This includes validated NHI and up-to-date patient demographics, supporting accurate identification of patients. Information from the NES will be used to update the NBSP register.

The majority of practices are now linked to the NES. However, during the interview process it became apparent that not all practices are actively reporting data via the NES and some practice-held data, including telephone contact details, is not being captured in the NES. The panel has concerns about the validity and completeness of NES data that may reduce its effectiveness as a means of obtaining patient contact information. This may impact on the ability of the NBSP to actively follow up non-responders and to contact participants with results. A review of the ability of the NES to provide participant contact details should be undertaken, which should include any privacy issues related to the use of this information.

### **Summary: IT readiness**

The NBSP IT infrastructure is a key aspect of the screening programme and a key source of risk for the NBSP. The panel has undertaken an in-depth review of the BSP+ assurance documentation provided by the Ministry of Health. It has found that this work has been robust to date and the Ministry of Health continues to make enhancements to the BSP+ to support the integrity and safety of the system.

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<sup>26</sup> Ministry of Health. 2018. *National Enrolment Service*. URL: [www.health.govt.nz/our-work/primary-health-care/primary-health-care-subsidies-and-services/national-enrolment-service](http://www.health.govt.nz/our-work/primary-health-care/primary-health-care-subsidies-and-services/national-enrolment-service) (accessed 19 May 2018).

Despite these updates, the BSP+ still presents a risk to the NBSP due to its limited functionality. It is necessary to continue to monitor and manage the ongoing risks presented by the BSP+, as well as to support the DHBs using the system.

The panel is satisfied that the Ministry of Health conducted a robust and comprehensive process in procuring the NSS. It also supports the strategic intent of the NSS. Using the system across screening programmes will provide a comprehensive view of a participant's screening history and create significant efficiencies.

The panel is concerned, however, that, in common with other large-scale IT projects, the IT solution brings a risk that it may not be achieved within the timelines proposed, or that the final deliverable may not meet the expectations of all stakeholders. Adequate oversight of the NSS development, together with sector engagement, is needed to maximise the functionality of the system. This includes prioritising integration with primary care systems.

## **Risks**

- There is a risk that the NSS design, build and roll-out will not be achieved within the tight timeframes, or within budget.
- NSS implementation may be delayed due to complications resulting from the considerable amount of work required to integrate the NSS with other IT systems.
- Public concern may arise about the use of cloud-based IT solutions and data sovereignty, which may delay the implementation of the NSS.
- The validity and reliability of the NES data have not been adequately reviewed, which may impact on the ability of the NBSP to undertake participant follow-up.
- There is a risk around the level of resource required to support eight DHBs using the BSP+ at the same time as developing and implementing the NSS.
- Further invitation issues cannot be ruled out, due to inadequacies with the BSP+ IT system, including the need for manual workarounds.

## **Chapter recommendations**

1. Urgent consideration should be given to 'real-time' integration with primary care practice management systems as a way of increasing participation in the programme as intended through primary care's access to a participant's full screening progress.
2. The Ministry of Health needs to continue to monitor and manage carefully the ongoing risks presented by the limited functionality of the BSP+.
3. DHBs, primary care and the NCC should be appropriately involved during the design and subsequent phases of the NSS.
4. The Ministry of Health should continue to strengthen project management during the design, build and implementation of the NSS to ensure deliverables are met within the planned timeframes. IT governance arrangements should be reviewed to ensure they are fit for purpose.
5. Contingency plans for potential delays in the NSS roll-out should be strengthened and more clearly articulated.
6. The Ministry of Health should undertake a review of the functionality and operation of the population register, to increase its accuracy and completeness. This includes a review of the ability of the NES to provide participant contact details.

## 8. Governance and quality assurance

### Corporate governance

The New Zealand Institute of Directors refers to the four pillars of good corporate governance: determination of purpose; holding to account; governance culture; and compliance.<sup>27</sup>

The current governance structure of the NBSP appears to be overly complex, with a lack of clarity of how information and risks are escalated within this structure (Figure 2). The panel found it difficult to understand the roles, responsibilities and accountabilities of the numerous governance groups, as well as some individuals within these groups. While the NBSP Leadership Group feeds into the NSBP Governance Group, the panel has been advised that the Governance Group is heavily engaged in operational issues.

Interviewees similarly expressed confusion over the NBSP governance structures, with some members of the different governance groups not clear on where their group sits within the overall governance structure. The Ministry of Health has advised that the governance structure programme is currently under review and will continue to be refined as the programme moves from roll-out to full implementation. The panel supports this work and suggests considering reducing the number of groups involved in governance and/or providing statements of function and accountability that observers outside of the Ministry of Health, as well as the groups themselves, can clearly understand. Any changes to the governance structure should be well documented and communicated.

While Māori leadership exists within the NSBP Governance Group, it needs to be clearly evident at all levels of the NBSP governance structure. Chapter 9 further discusses the need for Māori to have a stronger voice within the programme.

The Corporate Centre raised the issue of the lack of transparency over the governance of the NBSP, including a failure to share governance reports. It expressed its wish to develop a stronger partnership with the NBSP. This would include a more direct relationship with the NBSP's Senior Responsible Officer and the NBSP/HPV Governance Group.

The panel believes that the governance culture at the Ministry of Health has suffered from high staff turnover, ongoing restructuring and a loss of institutional knowledge at all levels. Feedback from interviews and submissions also speaks to a culture that is not open to questioning and feedback.

Rather than questioning being welcomed, it was interpreted as a challenge, nuisance or threat, as opposed to an opportunity to test assumptions and strengthen design.

Robust risk management is important for a programme of this scale and complexity. The NBSP faces a number of risks, some of which were highlighted in the pilot and some of which are new to the roll-out. The NSU maintains a risk register that appears to be comprehensive and up to date. However, some of the actions to mitigate risk do not appear

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<sup>27</sup> Institute of Directors in New Zealand (inc). 2012. *The Four Pillars of Governance Best Practice: for New Zealand Directors*. Institute of Directors in New Zealand.  
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to reflect the severity and complexity of the corresponding risk. Adequate management and oversight of risk need to be in place, supported by strong governance arrangements.

## Clinical governance

Clinical governance is especially important for the NBSP as, unlike other population screening programmes, it is clinically complex, and has primarily been advocated for and led by clinicians. Effective clinical governance must include the key principles of:<sup>28</sup>

- a strong consumer/patient-centred ethos
- an open and transparent culture
- all staff actively participating (and partnering) in clinical governance
- continuously improving the care provided.

Clinical governance requires a good working relationship between clinicians and management. The panel notes several clinicians are working closely with the NBSP. Their involvement should be supported in the roll-out and when the NBSP becomes business as usual. While six advisory groups are involved (see Figure 2),<sup>29</sup> they do not appear at a high level of the overall NBSP governance and their voice is not always heard.

The NBSP Clinical Director sits on the NBSP/HPV Governance Group and the NBSP Leadership Group. However, the panel was made aware that neither group has a space on its meeting agenda for a report from the Clinical Director on the progress of the NBSP and on any clinical risks identified. Two new groups have recently been established that could mitigate this gap: a Colonoscopy QA Group (chaired by the NBSP Clinical Director) and a Clinical Oversight Group (chaired by NSU Clinical Director).

So it's been an iterative process of trying to get clinical leadership right and I don't know that we've quite reached it yet ... the focus [of the governance group] was very much on the programme and on the dollars and the work plan.

To give the Director-General of Health confidence that he has line of sight of the clinical risks for the NBSP, the panel recommends that the relevant executive governance groups should receive regular formal reports from the NBSP Clinical Director.

The other area of concern is clinical input into the development of the NSS IT solution. The root cause analysis of the pilot withdrawal issue highlighted the need for clinical input into IT governance at the Ministry of Health.<sup>30</sup> A 2016 external IT review also identified a lack of alignment between 'the business' and IT, noting a need to 'put in place the right structures,

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<sup>28</sup> Health Quality & Safety Commission. 2017. *Clinical Governance. Guidance for health and disability providers*. Wellington: Health Quality & Safety Commission.

<sup>29</sup> National Bowel Cancer Working Group, Bowel Screening Advisory Group, National Screening Advisory Group, National Endoscopy QI Group, Endoscopy Governance Group for NZ, Colonoscopy QA Group.

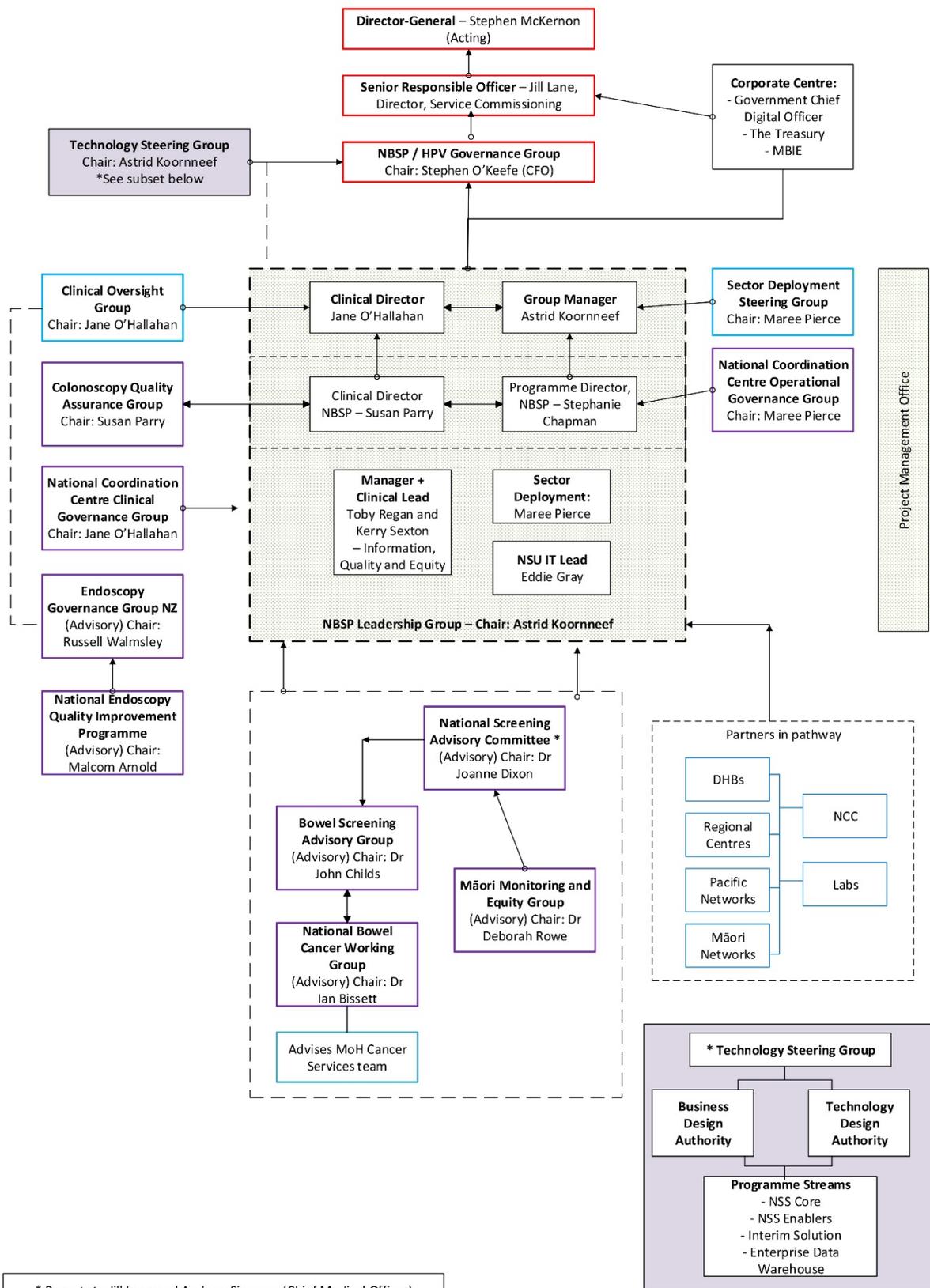
<sup>30</sup> MacIntyre K. 2018. *Review of Invitation Issues Following Address Update – Bowel Screening Pilot (Final Draft)*. Unpublished.

governance, resources, approach and delivery disciplines for a programme of this size and complexity'.<sup>31</sup>

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<sup>31</sup> Accenture Consulting. 2016. *External IT Review: National Bowel Screening Programme (NBSP). Independent Assurance Review for the National Bowel Screening Programme – 2018*

**Figure 2: NBSP governance structure**



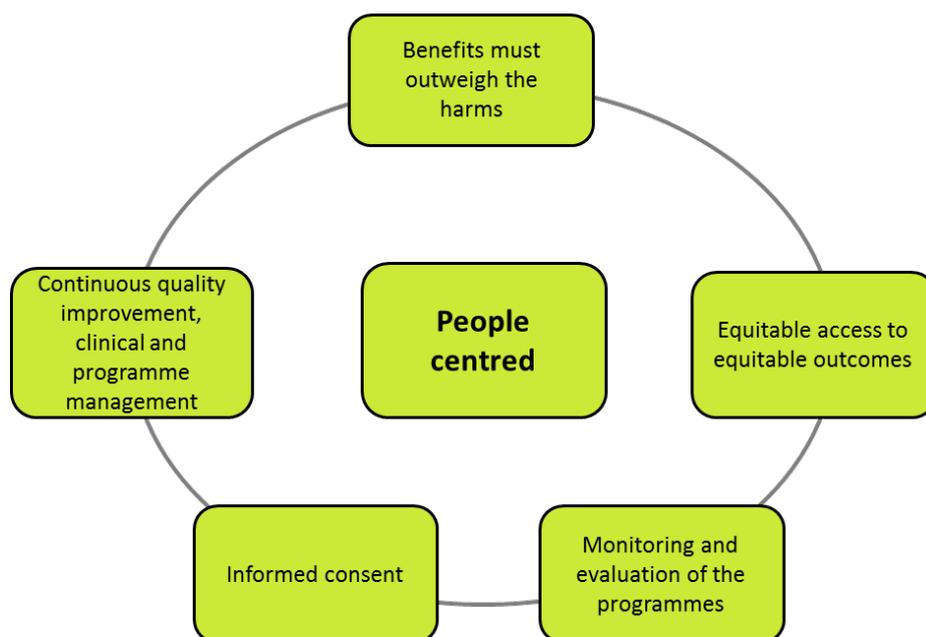
Note: DHBs = district health boards; MBIE = Ministry of Business, Innovation and Employment; MoH = Ministry of Health; NBSP = National Bowel Screening Programme; NCC = National Coordination Centre; NSS = National Screening Solution; NSU = National Screening Unit.

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## Quality assurance

Quality assurance measures compliance against standards that reflect the minimum performance required of a national screening service. Robust QA is an essential aspect of all screening programmes due to the risk of harm at both individual and population levels. In the NBSP, QA is particularly important as colonoscopy involves risk of significant harm (eg, the rare but serious complication of bowel perforation). The NSU has presented six principles for a screening programme quality framework (Figure 3).

**Figure 3: NSU quality framework**



The NBSP has QA standards at three distinct levels:

1. the population bowel screening process, with specific standards for different components of the screening pathway:
  - the NCC – standards for the process of invitation, participation and screening
  - the laboratories – standards for FIT testing and histopathology
  - primary care – standards on handling positive FIT tests and referral pathways
  - DHBs – standards on responding to referrals
2. provision of colonoscopy services:
  - endoscopy unit standards for performing bowel cancer screening (accreditation)
  - endoscopy standards of individual colonoscopists performing bowel cancer screening (including credentialing)
3. management of risks and incidents.

The NSU has brought together these distinct areas for QA standards to publish them as the Interim Quality Standards, released in July 2017. According to the NSU, these standards will remain interim quality standards until the NBSP has been fully rolled out, at which point they will be finalised. The standards will be monitored and updated to ensure they are appropriate as new DHBs come on board.

The mandatory Interim Quality Standards cover:

1. invitation, participation and screening process (NCC)
2. FIT testing and laboratory process (Labtests)
3. pre-assessment (DHB)
4. colonoscopy (DHB)
5. histopathology (DHB)
6. referral pathways (primary care and DHBs)
7. management of risks and incidents (NSU).

The panel was advised that the standards the EGGNZ developed for endoscopy units and individuals (Appendix 8) were not incorporated into the NSU's interim quality standards. This decision was based on timing, with the draft EGGNZ standards published in July 2017, when the Interim Quality Standards were being finalised.

This is a missed opportunity as the EGGNZ has good sector buy-in and the disconnect should be rectified as soon as practicable. The existence of a single agreed set of standards is important for monitoring the effectiveness of the NBSP and for ensuring consistency in quality across all types of colonoscopy. This will help mitigate the risk of developing a 'two-class' system in providing colonoscopies, which could arise through applying different standards to screening, surveillance and symptomatic colonoscopies.

In addition, no 'balancing measures' are apparent – that is, measures of how other services may be impacted by the emphasis on screening. It is likely that access to other endoscopy services (symptomatic, surveillance, upper gastrointestinal and ERCP) will be adversely affected and these impacts should be measured.

If a serious adverse event (eg, bowel perforation) occurs during a screening colonoscopy then the DHB is required to notify the NSU. The event is immediately reviewed by the NBSP Clinical Director to ascertain if there are any learnings to share with other DHBs.

The responsibility for overall clinical review of adverse events remains the responsibility of DHB clinical review committees who make recommendations for clinical practice improvements if required within their DHB.

The panel considers that a research and evaluation plan should be established to provide independent review of components of the programme. This includes the need to undertake an external evaluation of the NBSP within the next five years.

### **Credentialing and accreditation**

Credentialing of clinicians is an area that is done well in some DHBs but no overarching visibility of what standards and processes are used is apparent. The need for credentialing applies to clinicians conducting all colonoscopies, rather than just screening colonoscopies. The NBSP Clinical Director maintains some oversight but a more formalised process is needed. Ideally the EGGNZ standards for individual colonoscopists should be adopted (Appendix 8). Australia has now established a three-year re-credentialing approach, which New Zealand could also adopt.

Endoscopy units also do not need to be formally accredited as part of the DHB readiness process. Currently, the NBSP Clinical Director and senior sector clinicians are visiting each unit before the roll-out goes live and are thoroughly reviewing the facilities and processes. However, it would be better to have a formal process based on the EGGNZ endoscopy unit standards for consistency and safety of care.

## Summary: Governance and quality assurance

The current governance structure for the NBSP has evolved over time and is currently under review by the Ministry of Health. The panel supports this work as the current governance structure appears to be overly complicated, which could hinder the effective escalation and management of issues and risks. Consideration should be given to reducing the number of groups involved in governance and providing clear statements of function and accountability for each.

Clinical governance and Māori leadership could also be strengthened across all aspects of the programme, including IT governance arrangements. Clinical governance should include a balance of both frontline clinical and population health expertise.

Programme management processes need to be strengthened to adequately monitor and manage all aspects of this complex programme, and to identify and address risks early.

The NSU has developed Interim Quality Standards for the NBSP to support national roll-out. In addition, EGGNZ has developed quality standards for endoscopy units and individual colonoscopists. The panel supports the Ministry of Health's plans to combine these standards, and recommends that consistent standards are applied across screening and non-screening colonoscopies.

### Risks

- Risks may not be appropriately escalated or addressed within the current governance structure, due to its complexity and lack of clear reporting mechanisms.
- Lack of clinical input at the appropriate clinical governance level may limit the effectiveness of the NBSP.
- Lack of Māori leadership within the governance structure may adversely impact the outcomes of the NBSP.
- Duplication of standards may lead to confusion and re-work and may limit the effective accountability of the NBSP.
- Credentialing of individual colonoscopists and accreditation of colonoscopy units are currently ad hoc, which may limit the effectiveness of the NBSP.
- Applying different standards to screening and other colonoscopies presents a risk of developing a 'two-class' system in providing colonoscopies.

### Chapter recommendations

1. A strong learning culture needs to be promoted at the Ministry of Health and across the NBSP, which includes an openness to feedback, involvement of external expertise, transparency in decision-making and shared ownership of issues.

2. The current governance structure for the NBSP should be refined and more clearly articulated, ensuring appropriate pathways for escalation of issues and risks.
  3. Stronger evidence of clinical governance is needed across all aspects of the National Bowel Screening Programme and at all levels, including within IT governance arrangements. This includes the NBSP Clinical Director formally reporting regularly to the relevant executive governance groups to ensure clinical sector feedback.
  4. A single set of national QA standards for colonoscopists should be endorsed, with a clear statement of agreement on accountability for the standards.
  5. A more formalised national approach is needed to overseeing the credentialing of colonoscopists and the accreditation of colonoscopy units.
  6. Partnerships with the Corporate Centre need to be strengthened to ensure adequate support and oversight of this high-risk programme.
  7. A research and evaluation plan should be developed for the NBSP to provide independent review of different aspects of the programme.
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## 9. Population health

### Population approach

A population approach focuses on systems and quality issues across all phases of the NBSP, including policy, whole-of-system design, operation of the register, health promotion, the screening test (FIT) and follow-up investigation (colonoscopy), diagnosis and treatment. It also privileges equity considerations at all levels. Screening programmes that lack expertise and rigour in these domains are at significant risk of failure – that is, a major investment will not deliver a return in terms of health gain and may, in fact, do harm.

As the NBSP extends to a greater variety of DHBs and populations, it becomes more important that the population approach is well understood and is properly integrated with the clinical aspects of the NBSP. Practically this means that:

- leadership for the NBSP needs to unite clinical and public health expertise
- the elements of a population-approach need to be clearly articulated and understood at the executive level of key organisations (the Ministry of Health and DHBs).

### Population register

Taking an appropriate approach to the design, governance and operation of the population register is central to the success of the NBSP. The register is not composed merely of a database and IT infrastructure; it also involves policies, detailed operating protocols and systems for review and audit. It is important that the NSU continues to provide robust oversight of the register and its operation, to ensure its management aligns with best practice.

Both the final evaluation of the pilot and the recent report on the root cause analysis of the Waitemata pilot register issue recommend a thorough, expert review of the functionality of the register before national implementation.<sup>32,33</sup> The panel supports this view. Without such a review, as-yet unknown deficiencies in how the register operates could be built into the design of the NSS.

The next section discusses issues to do with operation of the register from an equity perspective.

### Identifying the eligible population

The NBSP register is populated with information derived from people's interactions with health services (hospitals or primary care). If these interactions are infrequent, or if people are highly mobile (frequently change address) or if the details collected are incorrect, then errors can arise. If these factors are more common in specific groups, as they are known to be for Māori, then they become a barrier to the participation of that group. For example, the panel understands that the register population is derived from people who have had contact

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<sup>32</sup> Litmus et al. 2016. *Final Evaluation Report of the Bowel Screening Pilot: Screening rounds one and two*. Wellington: Ministry of Health.

<sup>33</sup> MacIntyre K. 2018. *Review of Invitation Issues Following Address Update – Bowel Screening Pilot (Final Draft)*. Unpublished.

with the health system in the past three years. For all ethnic groups except Māori, this was at least a 99 percent match with the estimated resident population from the census. For Māori, this match was only 86 percent.<sup>34</sup>

Therefore, it is essential to manage all aspects of the register with utmost rigour and with a focus on equity. To do so, the operation of the register needs to be connected with other information systems such as those in primary care and other mechanisms for community outreach, including direct engagement with iwi.

One well-known, sector-wide issue is the inaccuracies involved in ethnicity coding. If a consumer's ethnicity is incorrectly recorded, it can have a negative impact on equity of access (deficits in participation in high-need groups not identified) and on the accuracy of monitoring of coverage/uptake by ethnicity. This is an issue for the whole of the health sector but one that the NBSP has a strong interest in helping to improve.

## Equity

By their very nature, screening programmes can cause harm. This harm may result from an adverse event or a complication of the test itself. More commonly, the cause of screening programme harms can be worsening population inequities in health status. This is because those who are quickest to take up screening tend to have greater health literacy and understanding of the health system, so any existing disparities will be exacerbated as the health status of screened groups improves.

Accordingly, screening programmes must be very well organised and take a population approach for the benefit of all. They must also have a particular focus on issues of equity to prevent worsening inequities. These requirements cross all dimensions of screening including: leadership and programme design; operation of the register; health promotion and education; invitation to participate; screening, diagnosis and treatment; QA; and monitoring and evaluation.

It's essential to solve [the equity gap] early and right at the beginning of the programme because it shows up very, very quickly and it just gets wider as time goes on.

## Leadership

The final evaluation report of the pilot<sup>35</sup> recommended that the NBSP take an 'equity-led' approach, rather than considering equity as an 'add on' component of the programme. The report provided a set of principles that would support an equity-led approach, which include: a clear statement of what equity means for the programme; participation of key groups such as Māori in leadership and governance; dedicated resources; multifaceted and flexible approaches; and clear, equity-related key performance indicators. As discussed in Chapter 4, some of these recommendations have not been addressed to date.

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<sup>34</sup> Ministry of Health, personal communication, 2018.

<sup>35</sup> Litmus et al. 2016. *Final Evaluation of the Bowel Screening Pilot: Screening rounds one and two*. Wellington: Ministry of Health.

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There is broad sector agreement with this sentiment and a wide commitment at all levels for ensuring equity. The panel identified several ways by which leadership for equity could be enhanced as the NBSP is rolled out.

- Equity needs to be championed and have high visibility at all levels, including within the Ministry of Health, the NCC and DHBs. Part of leading for equity involves clearly articulating what this means for the NBSP, particularly in terms of accountability and ensuring protected resources from the beginning.
- Māori and other priority groups should participate in both governance and delivery at the various levels of the programme. Innovative mechanisms are needed to enabling this participation, supported by resourcing.
- Leadership in the design of the programme should allow for some flexibility and innovation at the local level as a single 'one size fits all' for some aspects of the programme (eg, return of samples) may not be appropriate for all.
- Tools to support equity analysis should be available and used and the workforce involved in screening should have training in equity and cultural competency.

### **Operation of register for equity**

A population-based register offers significant potential advantages in supporting uptake and coverage of the NBSP. However, it also has the potential to exacerbate inequities.

The design, governance and day to day management of the register (whether the interim BSP+ or the definitive NSS) need to include practitioners with expertise in population-based screening programmes. This work must also involve Māori and other groups at risk of low participation.

Similarly, there is concern that over 10,000 people in the Waitemata DHB area remain effectively 'lost' to the programme because the pilot was unable to establish initial contact. Some of these people will still be eligible for the Waitemata DHB cohort but are not included in the population denominator. While it is assumed that the majority of these people have left the district, further efforts to confirm their whereabouts may be warranted.

The Ministry of Health advises that addresses held in the NHI database are the most accurate default addresses available. However, the panel notes that the NHI system contains a number of known deficiencies, including inadequate population capture and delays and errors when updating patient contact information from multiple sources. The NHI updates the bowel register that sends the screening invitations. If an address is out of date in the NHI, which the bowel screening register relies on, the NBSP cannot contact people to offer screening. It is only when people visit a GP or hospital and their addresses are updated that the NBSP can contact them.

The population register model is for passive enrolment with the option to 'opt off'. A supplementary approach could be to conduct campaigns targeted at low-uptake groups to promote active enrolment – for instance, by using toll-free phone lines, mail-outs and community outreach events.

### **Promotion, education and health literacy**

Although enrolment on the register is passive, a decision to participate in the NBSP screening process requires understanding of basic anatomy, bowel cancer and its

implications, the nature of the test and the benefits and risks of screening. The panel heard that among some groups, understanding of these basic facts, which is essential for informed consent, is minimal. This highlights the important role that health professionals can play in improving health literacy.<sup>36</sup>

While national-level campaigns and materials are needed, it is probable that the greatest effect will be derived from actions delivered locally with the participation of the populations targeted and linked with physical outreach to communities. Adequate and tagged resource must support this. Currently, existing services and associated budgets are absorbing this work. Potentially this outreach could be aligned with wider health literacy work in high-need populations.

It is likely that the involvement of local providers, including primary care and non-governmental organisations, will enhance the effectiveness of outreach measures. Chapter 5 discusses opportunities to strengthen the role of primary care.

The pilot tested a number of evidence-based strategies, including a pre-invitation letter and active follow-up. Evaluation of active follow-up found a statistically significant improvement in uptake by Māori and Pacific peoples but not by Asian people.<sup>37</sup> Innovations, such as those used by the pilot, should be developed in collaboration with the community involved and be properly evaluated. The results should also be widely disseminated throughout the NBSP.

## **Screening, diagnosis and treatment**

The screening process itself may be refined to support increased participation. In the pilot, some Māori participants found returning the specimen by post to be unacceptable. The pilot tested an option where participants were able to drop off specimens to community laboratories. This was evaluated and found to increase participation among males, patients under 60 years of age, Māori, Pacific peoples and European/other – but not among Asians.<sup>38</sup> Consideration should be given to adopting this option nationally.

Pathways for communication of positive FIT test results, referral and support for colonoscopy, communication of pathology results and treatment all need to be considered and supported from the perspective of reducing inequities. An example of a national resource that supports greater awareness of equity is the National Bowel Cancer Working Group Māori Equity Statement.<sup>39</sup>

## **Quality, monitoring and evaluation**

Equity is fundamental to the overall success of the NBSP and equity considerations are central to all quality, monitoring and evaluation processes. Accordingly, those who bring a strong equity focus should be involved in the governance, design and implementation of the

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<sup>36</sup> Health Quality & Safety Commission. 2015. *Three Steps to Better Health Literacy: A guide for health professionals*. Wellington: Health Quality & Safety Commission.

<sup>37</sup> Sandiford P, Buckley A, Holdsworth D, et al. 2018. *A Randomised Controlled Trial of an Active Follow-up Service to Reduce Ethnic Inequalities in Bowel Screening Participation in New Zealand*. Edinburgh: Proceedings of 1st World Congress on Migration, Ethnicity, Race and Health.

<sup>38</sup> Sandiford P, Buckley A, Robinson T, et al. 2017. A community laboratory drop-off option for bowel screening test kits participation rates: results from an interrupted time series analysis. *Journal of Public Health*.

<sup>39</sup> Ministry of Health. 2017. *National Bowel Cancer Working Group Māori Equity Statement*. Wellington: Ministry of Health.

relevant processes. This includes population health leadership, involvement of practitioners with expertise in screening programmes, and effective leadership and engagement of Māori and other groups with low participation.

Performance and quality measures tailored to reducing inequity should be a formal part of accountability for the programme at all levels.

## **Age range of screening**

International evidence shows that bowel cancer screening programmes are beneficial for people aged 50–74 years. Partly because of concerns about colonoscopy workforce capacity, the NBSP business case recommended both narrowing the age range to 60–74 years and changing the FIT cut-off from 75 to 200 ngHb/ml. The NSU has documented this rationale.<sup>40</sup>

The panel recognises the pragmatism behind this decision, noting that screening programmes must minimise potential harms while working within capacity constraints. Nevertheless, the panel considers that the NBSP must review the age-range eligibility when colonoscopy (and other system) constraints have been resolved.

The panel notes that the Ministry of Health has committed to continuing to review the data while rolling out the programme. The Ministry will review the age range and FIT threshold when sufficient data is available to make an evidence-based decision.

## **Differential age range of 50–75 years for Māori**

Several interviewees raised the possibility of extending the screening window to 50–74 years for Māori. Reconsideration of this decision is beyond the scope of the review. Multiple factors are involved, and the panel notes that it was the subject of much debate before the Bowel Screening Advisory Group made the final decision (setting the age range of 60–74 years for all ethnicities).

The panel considers that advocacy for an earlier age range for Māori remains a ‘live issue’, in part because the current NBSP has not adequately addressed inequities for Māori in its design and implementation. However, it is not clear whether the balance of harms and benefits of a differential age range would be favourable for Māori. For this reason, the panel believes that the NBSP should strengthen its approach to, and accountability for, equity at all levels, and that these actions should occur alongside any reconsideration of a differential age range for Māori.

## **Summary: Population health**

The benefits of the NBSP are directed at the whole of the eligible population and therefore require a population health screening approach. While this approach is embedded in the NSU, it also needs to be supported and linked with clinical leadership within the Ministry of Health and the DHBs. This is particularly important for the governance and management

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<sup>40</sup> [www.health.govt.nz/our-work/preventative-health-wellness/screening/national-bowel-screening-programme/key-documents-national-bowel-screening-programme](http://www.health.govt.nz/our-work/preventative-health-wellness/screening/national-bowel-screening-programme/key-documents-national-bowel-screening-programme)

of the register, in order to ensure equity and to support monitoring and evaluation of the NBSP.

While awareness of the importance of equity in the NBSP exists, it is necessary to support this with visible leadership, effective engagement with communities and iwi, resources and clear accountability for equity.

### **Risks**

- A population health approach may not be well understood outside the Ministry of Health or properly integrated with the clinically led aspects of the NBSP. This could result in conflicting perspectives and approaches that undermine the effectiveness, efficiency and safety of the NBSP.
- Potentially, neither population health nor clinical leadership could have appropriate visibility at senior levels within the Ministry of Health and DHBs. This could result in poor decision-making and, in turn, failures in the NBSP.
- Hidden deficiencies in how the register operates (including identifying and inviting people to participate) may not be identified. As a result, the NBSP would not achieve its objectives for both efficiency and equity.
- Inadequate resourcing of health promotion, outreach, community engagement, workforce development and innovation may contribute to inequities in screening uptake and outcomes.

### **Chapter recommendations**

1. The Ministry of Health and DHBs must effectively involve Māori, Pacific peoples and consumers in the programme design, governance, delivery and monitoring.
2. Innovation and continuous quality improvement should be encouraged to achieve equitable access and improve cultural competence. This includes providing additional resource to develop, test and disseminate this learning.
3. The Ministry of Health and DHBs should ensure that both population health and clinical leadership operate effectively at a senior level.
4. Clear accountability for equity in programme delivery is needed, including intensive monitoring of bowel cancer epidemiology between different ethnic groups.
5. A national approach to addressing cultural concerns about posting samples is needed, including discussions with primary care providers for sample drop-off.
6. The Ministry of Health should undertake a review of the functionality of the population register, to increase its accuracy and completeness, with a focus on improving equity.
7. The NSU should begin planning to extend the age-range eligibility to 50–74 years for all population groups, so that the NBSP aligns with the evidence base for effective bowel screening programmes.
8. The NBSP should continue to monitor and review the evidence base for lowering the age range for Māori, as additional data becomes available.

# 10. Consumer engagement

## Overview

An established body of evidence supports the assertion that patient experience, clinical effectiveness and patient safety are linked. Further, engaging consumers in the design and delivery of health and disability services brings benefits: it is an essential component of quality and safety in health services and there is global interest and action to understand and improve consumer engagement.<sup>41,42,43</sup> It is well past time for health and disability services to prioritise and cultivate a culture that implements patient- and whānau-centred care.

The term 'consumer' has a variety of meanings. For the purposes of this report, it refers to patients and their families and whānau who have had personal experiences in the health and disability system. The term also includes those who might use health and disability services in the future. As members of the public, consumers have a right to provide input to services.<sup>44</sup>

To understand how consumers were involved in the design, delivery and decisions made in pilot, the panel sourced information from relevant documents and interview transcripts.

## Observations about consumer engagement in the pilot

Interviewees differed in their views of how well consumers were involved in the development and initiation of the pilot. When it became clear that a stronger focus on increasing participation with certain ethnic groups was needed, changes were made based on input from Māori and Pacific communities. This included a piece of community-based research to improve the invitation letter and test instructions.

We spent so much time consulting and [undertaking] literacy work and involving our Māori and Pacific communities ... to ask the community: To what extent does the way in which these types of letters and instructions that you're getting enhance the likelihood that you engage or put you off?

However, interviewees had concerns about how well the NBSP has taken up the health literacy work, given the NSU has subsequently rewritten the invitation letters.

With regard to the pilot and wider roll-out of the NBSP, consumer representatives raised concerns around transparency, QA, changes in age thresholds, equity, information and messages to the public and methods of inviting people to participate. This highlights the need to engage consumers and communities early to find out what matters most to these diverse populations, with the aim of preventing problems and issues from arising.

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<sup>41</sup> Baker RG, Fancott C, Judd M, et al. 2016. *Expanding Patient Engagement in Quality Improvement and Health System Redesign: Three Canadian case studies*. Healthcare Management Forum.

<sup>42</sup> Coulter A. 2012. *Leadership for Patient Engagement*. Kings Fund.

<sup>43</sup> Doyle C, Lennox L, Bell D. 2013. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*.

<sup>44</sup> Health Quality & Safety Commission. 2015. *Engaging with Consumers: A guide for district health boards*. Wellington: Health Quality & Safety Commission. URL: [www.hqsc.govt.nz/our-programmes/partners-in-care/publications-and-resources/publication/2162/](http://www.hqsc.govt.nz/our-programmes/partners-in-care/publications-and-resources/publication/2162/) (accessed 4 July 2018).

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## Consumer engagement in the NBSP

It is unclear how involved consumers have been with the NBSP roll-out to date, but greater consumer participation is needed at both the governance and service delivery levels. Increasing their engagement requires a culture at the Ministry of Health and DHB leadership levels that understands and values consumer input. Commenting on consumer engagement in the NBSP, one of the programme leads said, 'yet again, that's another score card we can do better'.

Several other comments reflected the need for the NBSP to engage consumers more.

There needs to be a really open, constructive engagement of Māori, I think. A willingness to try different things, not just do the same old same old.

Our input [consumer group] hasn't been welcomed, facilitated, even down to phrasing in letters and things. We kind of see things from a different perspective and think that that could be useful and helpful.

Attention to the infrastructure to support consumer engagement is needed to develop policies and procedures with clearly defined roles and responsibilities. It is important to set expectations together to meet the interface between changing realities and what can be achieved.

Experience has shown that actively involving health consumers at all levels of the health and disability system helps to:

- identify care that is most likely to be acceptable to consumers
- identify areas where waste can be reduced or where services can be reconfigured so that more people use them
- uphold consumer rights and reduce the chance of harm.

Enabled and knowledgeable consumers are far more likely to seek information about their care, participate in the management of their care and make the choices that are best for them. Poor health literacy was identified as a barrier to participating in screening, with anecdotal concerns about how well people understand basic anatomy (eg, what the bowel actually is). Another concern is how results of the FIT are communicated to participants, particularly where blood is detected in a sample, but at a level below the 200 ngHb/ml positivity threshold.

The current language used is words like 'negative' but actually it's only negative according to where the threshold has been placed.

Consumers also need to know more about the NBSP roll-out, including what is happening, what is expected to happen and how they can be involved. One interviewee observed:

What a lot of consumers would like is they would like to see kind of like a dashboard or a readiness assessment which is in phase, so although [your DHB] might be rolled out in three years' time, or two years' time, here are the milestones that you've got to achieve on the way to that roll-out so capacity,

facility, staffing, whatever it is that people deemed is appropriate for those milestones to be met.

New Zealand has many access points to source input from cancer consumers, with Bowel Cancer New Zealand being an obvious partner for the NBSP. The regional cancer networks also have consumer groups who meet regularly to provide input at a regional level and to national initiatives such as tumour standards.

At a more generic level, the Ministry of Health works with Health Navigator to provide consumer input across health and disability services. All DHBs are required to have a consumer council in place or to be in the process of setting one up. These existing networks could be better leveraged and involved with the NBSP.

## Summary: Consumer engagement

Consumers were involved in the development of the pilot; however, this could begin earlier to improve screening uptake from the start. The panel was disappointed to hear of limited consumer engagement in the roll-out of the NSBP and that much of the learning from the pilot was not taken forward.

The lack of consumer involvement to date needs to be addressed so that consumer input occurs at both the governance and service delivery levels.

## Risks

- High participation rates may not be achieved without involving consumers to ensure communications and the screening process are appropriate and effective.
- Inequities in screening uptake may persist without involving relevant communities to ensure the screening programme is acceptable.
- Failing to involve relevant consumer groups may undermine confidence in the NBSP.

## Chapter recommendations

1. A consumer engagement plan should be developed for the NBSP, covering all levels of the programme and maximising opportunities for co-design.
2. A reference group of consumers, family and whānau should be established to provide oversight and influence at the governance level of the NBSP.
3. DHBs should liaise with existing regional cancer consumer groups and cancer non-governmental organisations to source consumer input, particularly at service delivery level, as a way of taking account of local issues and needs.

## 11. Comparing the New Zealand pilot with other pilots

The New Zealand pilot was largely comparable with the pilot programmes undertaken in Australia and the United Kingdom 5–10 years earlier. The New Zealand pilot was large, targeting almost 200,000 people (50–74 years) in Waitemata DHB. By comparison, the Australian pilot targeted 60,000 people (aged 50–74 years) while the UK pilot targeted almost 128,000 people (aged 50–69 years).

Both the Australian and UK pilots used a faecal occult blood test (FOBT) as the screening test. However, they differed in the technologies they used: guaiac FOBT (gFOBT) was used in the UK and immunochemical FOBT (iFOBT or more commonly known globally as FIT) in Australia, like the New Zealand pilot. The UK mode of selecting the population for invitation differed from the Australian and New Zealand pilots as well. Briefly, the UK worked from GP lists and GPs removed cases they felt were not suitable for screening, whereas Australia and New Zealand used health databases designed to capture all age-eligible people.

The UK also had a different method of offering FOBT. In response to evidence-based strategies developed in Australia and elsewhere, New Zealand was the first country to use pre-invitation letters and active follow-up of priority populations. Moreover, the UK pilot used highly selected and monitored colonoscopy providers while Australia and New Zealand used a usual-care model across public and private systems. While it is essential to bear in mind these and other differences when comparing programmes, it is possible and informative to compare them.

### Pilot purpose, expectations and evaluation findings

The purpose of the New Zealand pilot evaluation was 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.<sup>45</sup> Appendix 7 provides a comparison of the outcomes data reported by the three pilots.

Both the UK and Australian pilots identified areas needing improvement and systems that needed to be developed to better meet the needs of national roll-out. For both, these took the form of a substantial list of 'lessons learned'. They expected that the pilots would not be perfect and would need to subsequently address the lessons learned in the pilots when progressing to national roll-out. Likewise, the New Zealand pilot evaluation report includes information on issues that arose during the pilot and areas for improvement.

### Effectiveness

**Participation**, a measure of the proportion of the population willing to do the screening test, is a crucial aspect maximising the population benefits of a screening programme. In the New Zealand pilot, participation was judged to be satisfactory at 56.9 percent for the prevalence round (round 1). However, in parallel with the UK and Australia, lower rates were seen in certain subgroups of the population according to age, ethnicity, gender, familiarity with English language, and socioeconomic and education status. The UK participation rate

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<sup>45</sup> Litmus et al. 2016. *Final Evaluation of the Bowel Screening Pilot: Screening rounds one and two*. Wellington: Ministry of Health.  
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(58.5%) was similar to New Zealand's, while in Australia the participation rate was lower (45.4%). Operational differences in the test offer and engagement in testing as well as publicity partly explain the different rates.

**Colonoscopy uptake**, the willingness to undergo colonoscopy following a positive screening test, was highest in New Zealand at 85.6–88.1 percent, depending on the screening round. This compares with 55 percent in Australia and 80.5–82.8 percent in the UK. However, in Australia data collection was incomplete and, since the programme has rolled out, the rate has exceeded 80 percent.

**Colonoscopy quality**, as judged from the completion rate, was said to be 97 percent in New Zealand, a little higher than in Australia (87–89%). This measure was not specifically reported in the UK.

**Adverse event rates**, for perforation with or without polypectomy and for bleeding after colonoscopy, were either slightly higher or similar to those of the Australian pilot. These were not documented for the UK, or with accuracy in the Australian pilot, although they have been reported subsequently as they are crucial outcomes for monitoring.

The **number of people with cancers detected** was 265 over the two rounds of screening, with more being found, as would be expected, in the first round. Screening programmes typically find about two cancers per 1,000 screenees, as was seen in New Zealand (2.8 cancers per 1,000 in round one and 1.4 per 1,000 in round two). Furthermore, the number of cases diagnosed at stage I (or A) was double that otherwise expected, pointing to a strong likelihood of a reduction in mortality. In addition, the pilot found and removed advanced adenomas from 1,435 people. This has the potential to reduce the incidence of bowel cancer.

A desirable shift in stage at diagnosis was observed for both Australia and New Zealand. This strongly supports the fact that screening programmes will have a beneficial effect on cancer mortality.

Appendix 7 shows additional comparisons of other outcome measures between the three pilot programmes. It must be recognised that the way these outcomes were measured was not always the same and one needs to be careful not to over interpret any apparent differences.

In regard to effectiveness, the New Zealand pilot evaluation report concluded that the results were satisfactory and met objectives and that, in moving forward, measures of effectiveness should be monitored. These conclusions were comparable with those reached in the Australian and UK pilots.

## **Cost**

Cost-efficiency in New Zealand was assessed by accepted international standards but it must be recognised that resultant judgements are particular to a country and its health system. In New Zealand it was concluded that screening would save costs in certain scenarios, the very best outcome that could be hoped for. Cost-effectiveness was confirmed in both Māori and non-Māori populations, despite differences in participation rates and detection of cancers.

The Australian pilot was judged to be cost-effective to the same order of magnitude as the New Zealand pilot, but cost-saving was not evident for Australia. This measure was not initially reported for the UK.

## **Equity**

Equity is crucial in the context of public health structured programmes that seek to benefit all eligible members of the population. The New Zealand pilot identified inequities that paralleled those seen in other countries. It was concluded that, based on these observations, efforts needed to be made to reduce inequities in the future by strengthening the focus on inequity. The pilot evaluation report provided considerable detail on how this might be done. Australia and the UK made similar observations and decisions to strengthen the focus on reducing inequities.

Adequacy of population coverage is also an equity issue. For all three pilots it is clear that actual coverage was uncertain, either as reported in their evaluations or identified by subsequent events. In the UK, coverage was dependent on GP lists, with GPs able to identify and withdraw people considered unsuitable for screening. Therefore, actual coverage in the UK was unclear. In Australia, the registry was considered to be 94 percent accurate and subsequent considerations have not challenged that. In New Zealand, coverage was reported as 97.5 percent, which would mean it was similar to Australia. However, subsequent information about issues with the screening register (see chapter 7) suggest this figure is not accurate and an additional equity issue might exist in New Zealand that warrants attention.

## **Safety and acceptability**

A comprehensive range of measures of safety and acceptability was assessed in the New Zealand pilot. These measures were also points of focus for the UK and Australian pilots although reporting was more comprehensive in New Zealand for measures of colonoscopy quality.

**Safety** in New Zealand included governance, quality standards and improvement processes, data collection and workforce demands. The processes undertaken to provide colonoscopy services were understandably different from the UK and Australian pilots due to the different health care systems, approaches to offering FOBT and provision of colonoscopy.

It was recognised in New Zealand that improvement in most safety measures is desirable and needs to be addressed going forward. However, none of the safety issues was of sufficient concern to recommend a halt to the screening roll-out. Again, this was similar to the observations made and conclusions reached in the UK and Australian pilots.

However, it is important to single out colonoscopy workforce issues, as capacity to undertake timely colonoscopic verification of positive test results is a crucial event in the screening pathway. A delay in access to timely colonoscopy might fail to detect or delay detection of cancer. Wait-times can provide a perspective on workforce challenges.

In the New Zealand pilot, 95 percent of people with a positive FIT had a colonoscopy carried out within 11 weeks. It was not possible to clearly compare this with Australia and the UK due to differences in the way it was reported. However, some commented on variability in wait-times in some settings in New Zealand (Appendix 8) and were concerned about what

might happen as the programme is rolled out. In the future, it is important to comprehensively consider capacity of a sufficiently-skilled workforce.

**Acceptability** to the public and providers at the various stages of the screening programme was monitored closely in New Zealand and Australia. It was found to be acceptable to most eligible invitees. The level of acceptance was even higher among providers. However, barriers to participation for Māori and Pacific peoples need to be addressed. Both Australia and the UK also identified specific subgroups needing special attention and decided on planned efforts to be incorporated into roll-out timelines.

## 12. Learnings for other national programmes

The NBSP offers a number of learnings that the Ministry of Health can use to support the design and roll-out of further national health programmes (not just screening programmes). These learnings are presented using the New Zealand Triple Aim for Quality Improvement (Figure 4).<sup>46</sup>

### Improved quality, safety and experience of care

A programme should have robust and clear project management, QA and governance oversight to manage risk and to enable shared learning and knowledge transfer.

Government IT projects, and health IT projects especially, need to be acutely mindful of the consumer at the end of each process or decision, and should apply suitable rigour according to the scale of risk.

Strong QA controls should operate at national and local levels, allowing for reasonable flexibility for localised solutions for implementation.

When establishing a pilot, consider sustainability and roll-out, ensuring these are scoped and planned for from the outset. Accept and expect pilots to reveal learning opportunities for improvement which should be built into broader roll-out. Planning for pilots should be mindful of political terms and funding cycles to ensure timelines will not be affected by changes in leadership.

### Improved health and equity for all populations

Māori, Pacific and consumer expertise should be involved at all stages of a programme's development and implementation. This will assist in working towards equitable health outcomes. Additionally, there is a Treaty obligation to ensure involvement of Māori expertise.

Efforts to improve health literacy need to be culturally appropriate and locally tailored, recognising the important role of health professionals in communicating health knowledge effectively.

Figure 4: New Zealand Triple Aim for Quality Improvement



### Best value for public health system resources

Ensure clinical governance and appropriate leadership seniority presides at all levels of the programme, including for health IT projects. All programmes should have clear line of sight to senior levels of management within the Ministry of Health.

<sup>46</sup> [www.hqsc.govt.nz/assets/Core-pages/\\_resampled/resizedimage326297-triple-aim-April-2013.png](http://www.hqsc.govt.nz/assets/Core-pages/_resampled/resizedimage326297-triple-aim-April-2013.png)  
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Programme teams should foster strong, functional relationships and build a culture of trust to enable a positive learning environment across all organisations that are involved and impacted.

Ensure the workload associated with developing business cases for large-scale programmes is properly resourced and does not impact adversely on programme implementation.

Programme directors, managers and sponsors should encompass the strengths of the wider government sector, seeking out and being willing to receive advice from other experts, both within the organisation and beyond.

# Appendix 1: Terms of Reference – Independent Assurance Review for National Bowel Screening Programme

## Background

The National Bowel Screening Programme (NBSP) commenced in July 2017 with a staged roll-out starting in Hutt Valley and Wairarapa District Health Boards (DHBs) for men and women aged 60 to 74 years following a six-year Bowel Screening Pilot (the Pilot) at Waitemata DHB.

The Ministry is currently on track to implement the NBSP by the end of the 2020/21 financial year:

- Hutt Valley and Wairarapa DHBs commenced screening on 17 July 2017.
- Waitemata DHB transitioned from the pilot to the NBSP on 1 January 2018.
- Southern and Counties Manukau DHBs will commence screening by 30 June 2018.
- The remaining 15 DHBs are scheduled to implement the NBSP between 1 July 2018 and 30 June 2021.

The primary objective of the NBSP is to reduce the mortality rate from bowel cancer, by diagnosing and treating bowel cancer at an earlier, more treatable (and less costly to treat) stage and to identify and remove pre-cancerous advanced adenomas (polyps) from the bowel before they become cancerous.

Implementing bowel screening is a complex process with a number of operational, technical and clinical dependencies, such as facilities, equipment, business processes, information technology and staffing. Roll-out of the NBSP is reliant on the ability of each DHB to provide clinically safe and appropriate services.

## The Review

The Minister of Health is seeking assurance through an independent review about how well positioned the NBSP is for successful delivery, what changes might be required and what the Ministry of Health can learn to support the design and roll-out of further national initiatives.

The impetus for the review is the identification of issues associated with the Bowel Screening Pilot Information Technology System (BSP) and operational processes that resulted in eligible participants not being (re) invited during the pilot which, for some eligible participants may have led to a delay in their bowel cancer diagnosis.

The review will explore why some eligible participants did not get (re) invited, and how the lessons learned from the operation and implementation of the pilot to NBSP can be applied to ensure a safe and successful roll-out.

## Purpose

To provide assurance that the NBSP is positioned for a successful roll-out, the review will:

Provide assurance on the NBSP governance, operational management and resourcing and recommendations for any changes as required, including:

- an in-depth review of the BSP and associated operational processes to provide advice and assurance on its functionality to support the NBSP in the initial roll-out phases (DHB 1–8) and as the programme continues to be rolled out.
- assurance and evidence based recommendations about the transition from the Pilot to the NBSP, including the high level design of the National Screening Solution as a fit for purpose system.
- assurance and evidence based recommendations on the protocols and policies for operationalising the NBSP, ensuring they are robust and fit for purpose.
- assurance that a population health screening approach is embedded in the programme and those responsible for operationalising the NBSP have the tools, resources and expertise to do so.
- assurance that the planning and implementation processes to ensure DHBs are able to effectively plan and manage increased capacity requirements, including workforce, facilities, equipment and information and communication technology to safely implement the NBSP within the projected roll-out timeframes.

### Scope exclusion

A clinical review of the evidence that supports the introduction of a population based bowel screening programme. The benefits and harms of bowel screening at a population level have been evidenced through international clinical evidence and New Zealand based evaluations of the Pilot and are outlined in the August 2016 programme business case.

### Review personnel

The Health Quality and Safety Commission (HQSC) will provide expert project management and secretariat support to the review team to ensure timely delivery of the findings.

Professor Gregor Coster will lead the review team that includes Dr William Rainger, Professor Graeme Young and Dr Mary Seddon.

Additional reviewer(s) with particular areas of expertise can be appointed to support the Lead reviewer.

The review team will also include input from a Public Health Medicine Specialist to provide expertise on population health systems and the impacts of these systems on the quality and safety of the roll-out with a focus on future improvements.

### Review process

The reviewers will review relevant documentation, held by the Ministry and DHBs relating to the Pilot and the Programme, which will include information relating to the pilot operated by Waitemata DHB and Argonaut (BSP provider), including:

- The Programme and Implementation business cases for the NBSP
- The independent system and process review already undertaken on the issue (2018)
- Sapere research group review of round 1 and 2 of the Bowel Screening Pilot (2016)
- Accenture external information technology report (2016)
- EY information technology report (2017)
- Gateway review (2017).

The reviewers may interview former and current Ministry and DHB staff and any other persons as required.

The reviewers will also undertake further investigation and talk with representatives of other agencies (including the Treasury, Government Chief Digital Officer and Ministry of Business, Innovation and Employment) as necessary.

In addition to the matters set out under the Purpose, the reviewers may provide advice on any other matters arising in the course of the review.

#### Engagement and communications strategy

A Communications strategy will be developed by HQSC, in consultation with the Ministry of Health and the Minister's office to support the review.

#### Deliverables

The lead reviewer will provide a written report to the (Acting) Director General of Health, setting out their evidence based findings, and recommend any actions or improvements to policies, processes and practices as a result of the findings of the review. The evidence on which the findings are based will also be included in the report.

The reviewers will also include interim updates on progress as required to the (Acting) Director-General of Health.

The (Acting) Director General of Health will consider the findings of the review and based on this the Ministry will develop an action plan for implementation, as part of the on-going roll-out of the NBSP.

It is anticipated the review will take six-to-eight weeks.

#### Issues, conflicts and risk resolution

Issues and potential conflicts or risks will be identified and documented by review members and escalated to the HQSC as identified.

#### Travel and expenses

The HQSC will manage remuneration (within the rules stipulated by State Service Commission), travelling allowances and expenses for review members where these are not already addressed as part of the terms of appointment.

## Appendix 2: Review panel members

Professor Gregor Coster CNZM, PhD, FRNZCGP (Panel Chair)

Professor Coster is the inaugural Dean of the Faculty of Health at Victoria University of Wellington, appointed in 2017 to establish the new faculty, including new undergraduate and postgraduate programmes, and to advance research and translational activities in health. He was Professor and Head of Department of General Practice and Primary Health Care at the University of Auckland for 10 years, subsequently becoming Dean of Graduate Studies for that university.

He has chaired two district health boards and been deputy chair of PHARMAC, the commercial entity responsible for national purchasing of New Zealand's pharmaceuticals. He was a board member of the Accident Compensation Corporation and in 2018 retired as Chairman of WorkSafe New Zealand. He is a general practitioner with 40 years of professional experience. He has chaired national organisations including the Royal New Zealand College of General Practitioners and District Health Boards New Zealand.

Dr William Rainger MPH, FAFPHM, FNZCPHM

Dr Rainger is an experienced public health medicine specialist with a background in health services management. He has been involved in previous audits or reviews of the Cervical Cancer Screening Programme (2005) and the Breast Screening Programme (2012). He was the founding president of the New Zealand College of Public Health Medicine (2008–2011) and he is the director of Hygieia Consulting Ltd.

Dr Mary Seddon MBChB (dist), MPH, FRACP, FRACMA

Dr Seddon graduated from Otago Medical School and holds fellowships in general medicine, public health and medical administration. Her interest in quality improvement started during a Harkness Fellowship at Harvard Medical School and she has worked in this area for the last 15 years. She has been involved in major patient harm reduction programmes in medication safety, infection prevention, patient falls and pressure injuries. Dr Seddon has recently returned to New Zealand after three years in Australia, where she was in an executive leadership role for West Moreton Health. Her portfolio included clinical governance, innovation, research and education. She currently runs her own consulting company, Seddon Healthcare Quality Ltd.

Professor Graeme Young AM FTSE FAHMS AGAF, MB, BS (Melb), MD (Melb), FRACP.

Professor Young is a Matthew Flinders Distinguished Professor and Professor of Global Gastrointestinal Health at Flinders Centre for Innovation in Cancer, part of the College of Medicine and Public Health at Flinders University, Australia. He has an international reputation, especially in the broad field of colorectal cancer and its prevention and colorectal epithelial biology, having been an active researcher for over three decades in screening test technologies and their translation into clinical practice and public health programmes. He has advised health authorities in Australia and a number of countries around the world,

including New Zealand, the United Kingdom, Canada, the United States and the Netherlands, on aspects of prevention of colorectal cancer.

## Appendix 3: Glossary

Adenoma	A tumour that is not a cancer (if left, a certain proportion of adenomas will develop into cancers).
Bowel perforation	A hole in the wall of the gastrointestinal tract that can in rare circumstances occur as a result of colonoscopy.
Clinical governance	<p>A framework through which organisations are accountable for continually improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish.<sup>47</sup></p> <p>This definition is intended to embody three key attributes:</p> <ol style="list-style-type: none"><li>1. recognisably high standards of care</li><li>2. transparent responsibility and accountability for those standards</li><li>3. a constant dynamic of improvement.</li></ol>
Consumers	Patients and their families and whānau who have had personal experiences in the health and disability system. The term also includes those who might use health and disability services in the future. As members of the public, they have a right to have input into services. <sup>48</sup>
Consumer engagement	A process where consumers of health and disability services are empowered to participate in decisions about the treatment, services and care they receive. It is most successful when consumers and clinicians demonstrate mutual respect and active listening and have confidence to participate in full and frank conversation. Systems that support consumer engagement actively seek input from consumers and staff at all levels of an organisation. <sup>49</sup>
Corporate governance	The mechanisms, processes and relations by which organisations are controlled and directed.
Corporate Centre	Three central agencies – the State Services Commission, The Treasury and Department of Prime Minister and Cabinet – work together as a ‘Corporate Centre’. The Corporate Centre takes an active role across the sector and provides system-level coordination, a clear focus and strong leadership. The Corporate Centre uses the three

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<sup>47</sup> Scally G, Donaldson L. 1998. Clinical governance and the drive for quality improvement in the new NHS in England. *British Medical Journal* 317: 61–5.

<sup>48</sup> Health Quality & Safety Commission. 2015. *Engaging with Consumers: A guide for district health boards*. Wellington: Health Quality & Safety Commission. URL: [www.hqsc.govt.nz/our-programmes/partners-in-care/publications-and-resources/publication/2162/](http://www.hqsc.govt.nz/our-programmes/partners-in-care/publications-and-resources/publication/2162/) (accessed 4 July 2018), p 7.

<sup>49</sup> See footnote 49.

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	agencies' respective strengths and collective expertise to support the state sector to deliver better outcomes for New Zealanders.
Disease-specific mortality	Deaths caused by a particular disease (e.g. bowel cancer).
National Health Index (NHI)	A database that assigns a unique identifier to every person who uses health and disability support services in New Zealand.
Polyp	A growth that protrudes from a mucus membrane.
Positivity threshold	The threshold for a positive test, ie, the amount of blood detected in a participants screening sample that triggers a positive result. The NBSP has set this threshold at 200 ngHb/ml.
Priority groups / populations	The priority populations for the NBSP include Māori, Pacific peoples and individuals living in high deprivation areas (decile 9 or 10).
RShiny app	Interactive tool used to analyse data from the NBSP register.
Stage	The extent of a cancer in the body. Staging is usually based on the size of the tumour, whether lymph nodes contain cancer and whether the cancer has spread from the original site to other parts of the body.
Surveillance colonoscopy	A colonoscopy undertaken because of a family history of cancer, a personal past history of neoplasia or a genetic syndrome, including a polyposis.
Symptomatic colonoscopy	A colonoscopy undertaken as a consequence of a person presenting with symptoms that may be linked to colon pathology (eg, bowel cancer, ulcerative colitis, polyps, other).

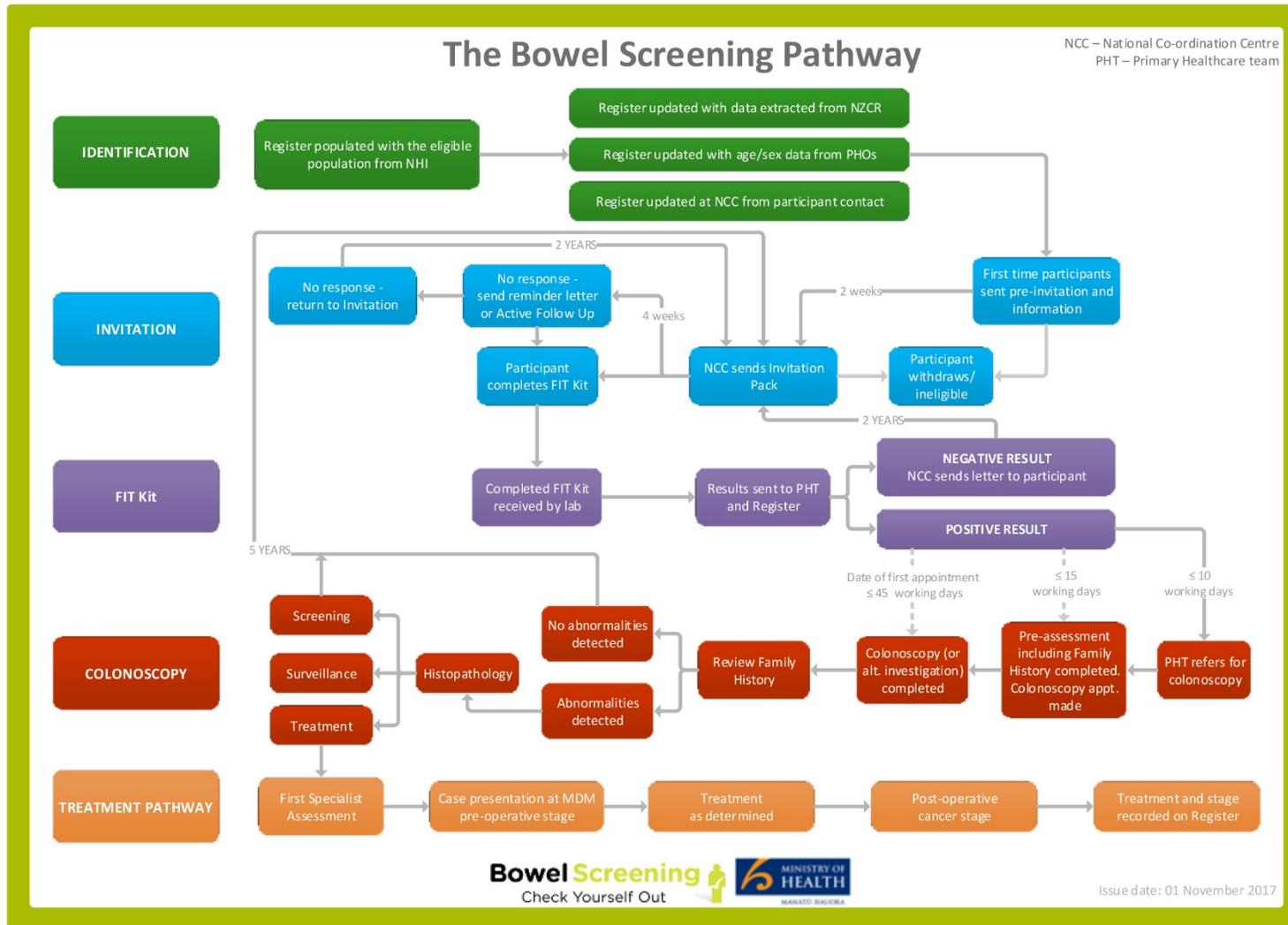
## Appendix 4: Interviewees

Person	Role	Organisation
Dr Malcolm Arnold	Gastroenterologist, Chair, National Endoscopy Quality Improvement Programme	Bay of Plenty DHB
Professor Ian Bissett	Surgeon, Chair of the National Bowel Cancer Working Group	The University of Auckland and Auckland DHB
Dr Ashley Bloomfield	Chief Executive	Ministry of Health
Professor Barry Borman	Associate Director and Epidemiologist	Centre for Public Health Research, Massey University
Ann Buckley	Data Manager, Bowel Screening Pilot	Waitemata DHB
Ann-Marie Cavanagh	Chief Technology & Digital Services Officer	Ministry of Health
Stephanie Chapman	Programme Director, NBSP	Ministry of Health
Dr John Childs	Chair, Bowel Screening Advisory Group	Auckland DHB
Janine Cochrane	Service Manager, NBSP	Southern DHB
Pania Coote	Executive Director, Māori Health	Southern DHB
Associate Professor Sue Crengle	Public Health Physician, GP and Medical Advisor to Bowel Cancer NZ	Otago Medical School
Fiona Cundy	Project Lead, NBSP	Wairarapa DHB
Associate Professor Sarah Derrett	Public Health Physician and sits on the Executive of Bowel Cancer NZ	Otago Medical School
Dr Joanne Dixon	Chair, National Screening Advisory Committee	Canterbury DHB
Michael Dreyer	Group Manager, National Digital Services	Ministry of Health
Chris Fleming	Chief Executive	Southern DHB
Nicola Giblett	Regional Manager of the Central Region Bowel Screening Regional Centre	Hutt Valley DHB
Stuart Godwin	Principal Advisor System Assurance	Department of Internal Affairs
Professor Des Gorman	Executive Chair	Health Workforce New Zealand
Helen Gower	Former Principal Advisor, BSP	Ministry of Health
Eddie Gray	Manager Technology Initiatives, NSU	Ministry of Health
Tofa Gush	Director Pacific People's Health	Hutt Valley and Wairarapa DHBs
Davin Hall	Principal Advisor, Health	The New Zealand Treasury
Ross Hewett	Laboratory Manager	LabPlus
Dr Jason Hill	Clinical Director, NBSP	Southern DHB

Sophie Hochschild	Project Manager	Homecare Medical, NCC
Dr Debbie Holdsworth	Chair, Bowel Screening Pilot Steering Group	Waitemata DHB
Dr Mike Hulme-Moir	Clinical Director, Bowel Screening Pilot	Waitemata DHB
Dr Chris Jackson	Oncologist, Medical Director Cancer Society	Southern DHB
Angela Johnson	Service Delivery Manager	Homecare Medical, NCC
Karen Kempin	Charge Nurse Manager and Nurse Endoscopy Trainee	Southern DHB
Lisa King	Senior Advisor Investment Management and Asset Performance	The New Zealand Treasury
Astrid Koornneef	Group Manager, NSU	Ministry of Health
Paul Lambert	CIO and Programme Director	Homecare Medical, NCC
Jill Lane	Director, Service Commissioning	Ministry of Health
Dr John McMenamin	Primary Care Advisor	National Bowel Cancer Working Group
Scott McWilliams	Data and Quality Manager	Waitemata DHB
Dr Allan Moffitt	Clinical Director, ProCare	University of Auckland
Dr Peter Moodie	General Practitioner	Karori Medical Centre
Dr Jane O'Hallahan	Clinical Director, NSU; Chair Clinical Oversight Group	Ministry of Health
Carolyn Palmer	Manager, Health	The New Zealand Treasury
Dr Susan Parry	Clinical Director, NBSP; Chair, Colonoscopy Assurance Group	Ministry of Health
Maree Pierce	Implementation Manager, NBSP; Chair, Sector Deployment Steering Group; Chair, National Coordination Centre Operational Governance Group	Ministry of Health
Sukhin Rai	AOG Senior Strategy and Investment Advisor, Service and System transformation	Department of Internal Affairs
Associate Professor Deborah Read	Epidemiologist	Centre for Public Health Research, Massey University
Toby Regan	Manager, Information, Quality and Equity, NSU	Ministry of Health
Dr Bronwyn Rendle	Public Health Physician, NSU	Ministry of Health
Natalie Richardson	Service Group Manager	Hutt Valley DHB
Associate Professor Deborah Rowe	Chair, Māori Monitoring and Equity Group	Te Whare Wānanga o Awanuiārangi
Dr Peter Sandiford	Public Health Physician	Waitemata DHB
Nick Saville-Wood	Chief Operations Officer	Lakes DHB
Dr Nina Scott	Public Health Physician	Chair of Te Ahuru Mowai, National Māori Cancer Leadership Group
Dr Kerry Sexton	Clinical Lead, NSU	Ministry of Health

Mathu Shanthakumar	Biostatistician	Centre for Public Health Research, Massey University
Dr Andy Simpson	Chief Medical Officer	Ministry of Health
Andrew Slater	Chief Executive	Homecare Medical, NCC
Dr Maelan Tagelagi	General Practitioner, GP Liaison for Bowel Screening Pilot	Waitemata DHB
Gary Thompson	Māori Consumer Advisor	Māori Monitoring and Equity Group
Gaye Tozer	Programme Manager, Bowel Screening Pilot	Waitemata DHB
Arati Waldegrave	Policy Analyst	Department of the Prime Minister and Cabinet
Dr Russell Walmsley	Chair of Endoscopy Governance Group for New Zealand	Waitemata DHB
Dr Maree Weston	Colorectal Surgeon and Co-Clinical Director, NBSP	Counties Manukau DHB

# Appendix 5: NBSP interim service delivery model pathway



## Appendix 6: NBSP roles and responsibilities

The following information is taken from the Ministry of Health's *National Bowel Screening Programme – Service Delivery Model for National Coordination Centre*. It describes the roles and responsibilities of each of the organisations that are responsible for the delivery of the NBSP.

### Ministry of Health National Screening Unit

The Ministry's NSU has the overall responsibility for the delivery of the NBSP, and is responsible for identifying the eligible population to be invited to the programme. The NSU essentially acts as the agent of the eligible population, with the NCC being responsible for ensuring participants progress through the screening pathway in a timely and safe way.

The NSU is also responsible for providing quality standards, clinical guidelines and governance to the programme, and monitoring the quality and safety of the programme including diagnostic and treatment outcomes.

The NSU will be the business owner for the NSS, with the Ministry's Technology and Digital Solutions team managing the technology solution.

### The National Coordination Centre (NCC)

The role of the National Coordination Centre (NCC) will be to coordinate the participants' national bowel screening pathway, acting as a safety net for participants across the pathway and maximising participation for eligible people.

The NCC will be responsible for central coordination, mail house functions, contact centre and data quality and management. Specific to the bowel screening pathway, and in-line with the NCC quality standards and service agreement, the NCC will be responsible for:

- inviting participants on to the NBSP pathway
- tracking participants along the pathway from end to end, ensuring no participant fails to progress to the next stage within the required timeframe
- ensuring each participant receives a definitive outcome.

As part of their service, the NCC will also provide:

- contact centre operations, through which the NCC will be the public face of the NBSP
- mail house services including stock management
- Data quality management in the BSP+ IT system
- support for the DHBs set up and implementation - NCC will be involved in training DHB super-users in the BSP+ system, and involved in readiness testing and assessments
- equity, through active follow up on priority populations where they did not respond to an invitation to the programme
- quality improvement (QI) by participating in QI and service improvement initiatives and achieving the NCC Quality Standards

- monitoring of participants' progress through the pathway, KPIs and targets for coordination functions.

#### FIT Laboratory

The FIT laboratory is responsible for analysing the FIT samples returned by participants and providing the results to the NCC and their designated Primary Healthcare Practitioner (where known).

#### Bowel Screening Regional Centres (BSRC)

There will be four regional Bowel Screening Regional Centres (BSRCs) across New Zealand:

- Northern Regional Centre – led by Waitemata DHB
- Midlands Regional Centre - led by Healthshare
- Central Regional Centre – led by Hutt Valley DHB
- Southern Regional Centre – led by Southern DHB

The BSRCs will have four key roles:

- Supporting the DHBs in their region in their planning and establishment of bowel screening, particularly in the areas of quality and clinical expertise, and assist the Ministry in ensuring consistency in roll-out of the National Bowel screening Programme.
- Provide clinical leadership to their region to ensure consistent, safe and high quality screening, diagnostic and histopathology services at each DHB.
- Ensure that there is a regional equity plan which is developed in collaboration and consultation with all DHBs and stakeholders in their region.
- Provide overview of the performance of DHBs in their region against the Interim Quality Standards, monitor regional quality and safety performance and identify and support opportunities for quality improvement with the NBSP in their region, and in conjunction with the Ministry.

Note that the information above is provided for context only, as the BSRCs are not part of this Service Delivery Model.

#### District Health Boards (DHBs)

The DHBs are responsible for:

- outreach post Active follow up on 'Priority Population' participants who do not respond to an Invitation
- managing pre-assessment processes for participants with a positive FIT test result
- managing the 'Failsafe pathway', when referrals have not been received by day eleven of a positive FIT result being received
- managing colonoscopy booking and performing colonoscopies for participants with a positive test result
- confirming histology and reporting of histology results through local laboratory arrangements

- managing referrals to treatment, surveillance and the NZ Familial Gastrointestinal Service, as required based on the outcomes of BSP Screening
- managing data capture in the BSP+ IT system in the Colonoscopy and Treatment stages of the pathway
- contact management for PHO, providing support and education to PHOs and Primary Healthcare team on their role.
- organising community initiatives to raise awareness and increase participation, especially among priority groups.

For further information on the roles and responsibilities of the DHBs please refer to the DHB SDM document.

### Primary Care

Primary Health Organisations (PHOs) and general practices play a fundamental role in the Bowel Screening Programme.

Key input from the PHOs and general practices for the Bowel Screening Programme includes:

- PHOs make a subset of their patient enrolment data available for the purpose of enhancing a district-wide register of the eligible population, and to enable the patients' Primary Healthcare team to be informed of their patients' screening results. The participant's designated Primary Healthcare Practitioner, including GP or NP (if known) is identified on the Consent Form sent to the participant with the FIT kit and Invitation Letter.
- The Primary Healthcare team may provide an additional tier of recruitment through opportunistic discussion.
- Primary Healthcare teams who access patient reminder systems may also see that their patient has not participated and can initiate discussions about the programme at the time of a consultation.
- The Primary Healthcare Clinical team inform participants of a positive result and where appropriate refer them to the local DHB Endoscopy Unit for colonoscopy pre-assessment within 10 working days of the receipt of the result at the practice.
- Studies suggest this arrangement is likely to increase patient compliance with further diagnostic investigation and treatment if necessary.
- The Primary Healthcare Clinical team also inform the local DHB Endoscopy Unit by means of an 'Information' Referral, where the participant has elected to be treated privately or to not continue with the programme.
- PHOs and Primary Healthcare centres collaborate with DHB's for communications and community engagement activities by having posters and information leaflets available in Primary Healthcare centres and including information about the Programme in their regular email updates to practices - and their newsletters.
- Those participants that have a family history of bowel cancer or have had extensive inflammatory bowel disease will be encouraged to speak with their Primary Healthcare Clinical team, as they may have an increased risk of bowel cancer. These participants should still complete a bowel screening test but may subsequently be assessed for surveillance rather than screening follow up.

## Appendix 7: Comparison of data reported in the final evaluation report of the New Zealand Bowel Screening Pilot, with data available for the Australian and UK pilots

To facilitate comparison of the key outcomes measured in each of these pilots, data has been drawn from reports of the Australian and UK pilots and added to the table (Table 13 of Appendix 5) reporting pilot monitoring indicators for the New Zealand pilot.<sup>50</sup> The data reported below for the UK and Australian pilots has been extracted from the pilots so as to be as close as possible to the outcomes reported for New Zealand. However, both collection and calculation methods differed, approaches to inviting people differed, data was not always complete (especially pathology outcomes in Australia), and definitions varied such that care should be taken in interpreting any large differences between the pilots. These differences have not been addressed in detail as it is not necessary for the purposes of this report.

Note that the New Zealand Ministry of Health developed a detailed set of monitoring indicators to monitor and evaluate the progress of the pilot. For the pilot monitoring indicators, go to: [www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/bowel-cancer-programme/bowel-screening-pilot/bowel-screening-pilot-results#bspindicators](http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/bowel-cancer-programme/bowel-screening-pilot/bowel-screening-pilot-results#bspindicators).

**Table A1: Reporting the New Zealand Bowel Screening pilot monitoring indicators for Round 1: 1 January 2012 to 31 December 2014 and for Round 2: 1 January 2014 to 30 September 2015 (from Table 13 of Appendix 5), and adapted to include summary findings of the same or similar measures in the Australian and UK pilots**

No	Indicator description	Evidence	Target	New Zealand	Australia <sup>51</sup>	UK <sup>52</sup>
1	Overall participation	This is the % of people with a final iFOBT result (positive or negative) out of all those eligible invited by the programme, for the first and second screening round.	60% for first screen (Round 1)	Round 1: 56.8%  Average for Round 2: 53.4% Where Round 2 was first screen: - Aged in or moved in: 44.4% - Did not respond or unsuccessful in Round 1: 23.5% Where Round 2 was second screen: 83.2%	45.4% (39.9–57.5% in the 3 regions). More women (47.4%) than men (43.4%). Participation was higher for the two least disadvantaged quartiles. Participation appeared to be lower for Aboriginal and Torres Strait Islander people compared with the general eligible population, and for people who spoke a language other than English compared with English speakers.	58.5% first round, 52.1% second round.  Uptake varied with gender, age, and level of deprivation.
2	Coverage	This is the % of eligible people in Waitemata DHB region <sup>53</sup> who were invited to participate	>95%	97.50%	56,907 invited (full population registry)	127,746 invited (GP filtered).

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		during the first screening round.			94% correctly linked to registry address.	
3	Time to colonoscopy as at December 2015	This is the % of people whose time between the laboratory receiving a positive iFOBT to having a colonoscopy carried out was within a specified target (excludes people who decline colonoscopy performed privately).	95% <11 weeks	95%	Median 30 days.	Increases in workload were noted (14–28%) while wait-times were increased from 40 to 140 days.
4	Proportion of individuals with a positive screening test undergoing colonoscopy or CT colonography	This is the % of screened people with a positive iFOBT result who have had a colonoscopy or CT colonography through the programme, or have a date booked for a colonoscopy.	>90% undergo colonoscopy or CT colonography	Round 1: 88.1% (95.1%) <sup>54</sup> Round 2: 85.6% (93.3%) <sup>52</sup>	1,273/2,308 positives = 55% but this was an underestimate due to data collection deficits given the usual-care model. Of documented GP referrals for testing in positives (which corrects for the deficits), 93.4% were referred for colonoscopy and 1.8% for other tests.	80.5% first round and 82.8% second round.
5	Colonoscopy completion rate as at September 2015	This is the % of completed colonoscopies (reaching the caecum).	Acceptable >90% Desirable >95%	Round 1: Approximately 97% Round 2: Approximately 97%	Males 97.3% (86.9% adequate) Females 94.2% (88.8% adequate)	Quality was felt to have been improved but no objective data was reported.
6	Colonoscopy complication rate for perforation or bleeding	This is the number of people requiring admission to hospital for an intermediate or serious adverse event related to perforation or bleeding	<10 per 1,000 colonoscopies	3.3 per 1,000 <sup>55</sup>	??	??

<sup>50</sup> Litmus et al. 2016. *Final Evaluation of the Bowel Screening Pilot: Screening rounds one and two*. Wellington: Ministry of Health.

<sup>51</sup> Australian Government Department of Health and Ageing. 2005. Screening Monograph No.6/2005. *The Australian Bowel Cancer Screening Pilot Programme and Beyond: Final Evaluation Report*. Australian Government Department of Health and Ageing.

<sup>52</sup> Weller D, Coleman D, Robertson R, et al. 2007. The UK colorectal cancer screening pilot: results of the second round of screening in England. *British Journal of Cancer* 97: 1601–1605.

<sup>53</sup> For this indicator, the number of eligible people in the Waitemata is defined as those people residing in the Waitemata DHB region, aged 50–74 years based on 2013 census data sourced from Statistics NZ.

<sup>54</sup> This figure includes those who have cancer found through a colonoscopy undertaken privately.

<sup>55</sup> This number was calculated on the expected number of adverse event rates reported in the UK Bowel Cancer Screening Programme Quality Assurance Guideline for Colonoscopy and based on the fact the 7 out of 10 pilot participants proceeding to colonoscopy are identified to have had a lesion.

		occurring within 30 days of colonoscopy, per 1,000 of those who had a colonoscopy during the first and subsequent screening rounds.				
7	Colonoscopy complication rate for events other than perforation or bleeding	This is the number of people requiring admission to hospital for other intermediate or serious adverse events not related to perforation or bleeding occurring within 30 days of colonoscopy, per 1,000 of those who had a colonoscopy during the first and subsequent screening rounds.	No agreed international standard	0.3 per 1,000	??	??
8	Positivity rate	This is the % of people with a positive iFOBT during the first and subsequent screening rounds.	6–8% for first screen (Round 1)  No agreed target for Round 2	Round 1: 7.5%  Average for Round 2: 5.9% Where Round 2 was first screen: - Aged or moved in: 5.2% - Did not respond or unsuccessful in Round 1: 8.5%  Where round 2 was second screen: 5.5%	9.0%	First round 1.59%. Second round Test positivity was 1.77%, (unusual but due to low sensitivity of this technology)
9	Colorectal cancer (CRC) detection rate	This is the number of people diagnosed with any CRC per 1,000 screened with an iFOBT result available for the first and subsequent screening rounds.	1.8–9.5 First screen (Round 1) per 1,000 (Range from population screening programmes with iFOBT)	Round 1: 2.8 cancer per 1,000 (3.1 per 1,000) <sup>56</sup>  Round 2: 1.4 cancer per 1,000 (1.6 per 1,000) <sup>53</sup>	69 cancers (PPV 3.8%) in those where data was ascertained. PPV for both cancer and advanced adenoma = 19.2%	Round 1: 1.35 cancers per 1,000. Round 2: Detection rate for cancer was 0.94 per 1,000, while detection rate of all neoplasia was 5.67 per 1,000.
10	Colorectal cancer (CRC) stage at diagnosis (including polyp cancers)	This is the TNM staging for CRC detected at the first and subsequent screening round. In cases where more than one staging was given for an individual, only the most serious staging result is included. For cancers found through public colonoscopy.	No agreed international standard	Stage 1: 47.6%  Stage 2: 21.6%  Stage 3: 22.9%  Stage 4: 7.9%	37.8 vs 19.6% (ACPS, programme detected vs outside the programme)  21.3 vs 28.5  30.7 vs 26.1  3.1 vs 12.2	One quarter stage C or D but more detailed staging was unclear.

<sup>56</sup> This figure includes those who have cancer found through a colonoscopy undertaken privately.  
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11	Advanced adenoma detection rate	This is the number of people diagnosed with any advanced adenoma (villous or tubulovillous or, high grade dysplasia or, greater than or equal to 10 mm in size) per 1,000 screened with an iFOBT result available for the first and subsequent screening rounds.	No agreed international standard	Round 1: 15.5 per 1,000 Round 2: 7.5 per 1,000	176 advanced adenomas	??
12	Adenoma detection rate	This is the number of people diagnosed with any adenoma per 1,000 screened with an iFOBT result available for the first and subsequent screening rounds.	13.3–22.3 per 1,000 (Range from population screening programmes with iFOBT)	Round 1: 36.2 per 1,000 Round 2: 23.2 per 1,000		Round 2: 5.73 per 1,000
13	Positive predictive value of iFOBT for cancer	This is the % of people with a malignant outcome in those having a colonoscopy for the first and subsequent screening rounds.	PPV Cancer first screen 4.5%–8.6%	Round 1: 4.3% (4.4%) <sup>53</sup> Round 2: 2.9% (2.9%) <sup>53</sup>	3.8%	Round 2: Positive predictive value for cancer 5.3% vs 8.5% in Round 1. For both cancer and neoplasia 32.1% vs 38.8% in Round 1.
14	Positive predictive value of iFOBT for advanced adenoma	This is the % of people with any advanced adenoma in those having a colonoscopy for the first and subsequent screening rounds.	No agreed international standard	Round 1: 24.0% Round 2: 15.3%	PPV for <b>both</b> cancer and advanced adenoma = 19.2%	
15	Positive predictive value of iFOBT for adenoma	This is the % of people with any adenoma in those having a colonoscopy for the first and subsequent screening rounds.	PPV adenoma first screen 9.6–40.3%	Round 1: 56.1% Round 2: 47.7%		
	Cost-effectiveness.			Estimated to be <b>cost-saving</b> (not just cost-effective) with quality adjusted life year (QALY) gains. Cost per QALY was –\$1,344. Considered to be cost-effective even when entire age range was included or when just Māori were considered.	For a target population aged 55–74 years, at the pilot participation rate of 45.4%, the estimated cost per additional life year saved is \$24,000. For a target population aged 50–74 years, at the pilot participation rate of 45.4%, the conservative estimate of cost per additional life year saved is \$20,000.	

Note: Unless otherwise stated, these figures do not include people who have exited the programme and had private colonoscopies, or adenomas and cancers detected through them. Unless otherwise stated, all indicators are based on the European Guidelines for Quality Assurance in Colorectal Cancer Screening and Diagnosis.

*The indicators were developed using recommendations and standards set out in the European Guidelines for Quality Assurance in Colorectal Cancer Screening Diagnosis, and the United Kingdom Bowel Screening Programme Quality Assurance Guidelines for Colonoscopy.*

## Appendix 8: Endoscopy Governance Group for New Zealand – Quality Assurance Standards for units and individual colonoscopies

Unit standards		Individual colonoscopist standards	
Standard 1	Endoscopic facilities	Standard 1	Experience of colonoscopist
Standard 2	Personnel/list composition	Standard 2	Process of consent
Standard 3	Equipment	Standard 3	Intra-procedural techniques
Standard 4	Quality of care	Standard 4	Electronic report content
Standard 5	Administration of medication	Standard 5	Delivery of report to patient
Standard 6	Clinical quality	Standard 6	Performance and audit
Standard 7	Safety	Standard 7	Continuing endoscopic medical education
Standard 8	Comfort		
Standard 9	Quality of the procedure		
Standard 10	Quality of patient experience		
Standard 11	Aftercare		
Standard 12	Ability to provide feedback to the service		
Standard 13	Audit		
Standard 14	Education		