National Bowel Cancer Screening Program

PRIMARY HEALTH CARE

ENGAGEMENT STRATEGY

2016-2020

A strategy to reduce the incidence of, and mortality from, bowel cancer by engaging the primary health care sector to encourage and guide participation in the National Bowel Cancer Screening Program.

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# Executive Summary

The goal of this strategy is to reduce the incidence of, and mortality from, bowel cancer by engaging the primary health care sector to encourage and guide participation in the National Bowel Cancer Screening Program (the Program).

Primary health care providers/general practitioners (PHPs) have indicated support for playing a central role in bowel cancer screening in Australia. Evidence suggests that greater involvement by PHPs in encouraging and supporting participation in the Program is required to complement the Program’s direct mail method.

This strategy aims to provide a consistent national vision, and guide the implementation of measures, to better engage PHPs in the delivery of the Program. It was developed by the Department of Health in consultation with state and territory governments, the Cancer Council Australia, the Royal Australian College of General Practitioners, the Australian College for Rural and Remote Medicine, the Australian Primary Care Nurses Association and the Australian Association for Practice Management.

It identifies the following five broad priority areas for action:

1. Working in partnership to engage PHPs
2. Professional development and information for PHPs on the Program
3. Practice tools and resources
4. Working with PHPs to promote equitable access to the Program for under-screened groups
5. Efficient register and reporting systems.

A National Action Plan has been developed to detail the actions and timeframes associated with each priority area, focusing on areas requiring national coordination and action.

The Department of Health has overarching policy development and program implementation responsibility for the Program and will lead the implementation of this strategy and the action plan in consultation with the Program’s advisory group.

# Introduction

This strategy aims to:

* guide the implementation of measures by the Department of Health to better engage Primary Health Care Providers/General Practitioners (PHPs) in the delivery of the Program; and
* provide a consistent national vision to better engage PHPs in the Program, without constraining the development of tailored solutions by individual organisations.

This strategy has been developed by the Department of Health in consultation with state and territory governments, the Cancer Council Australia, the Royal Australian College of General Practitioners, the Australian College for Rural and Remote Medicine, the Australian Primary Health Care Nurses Association and the Australian Association for Practice Management. It details objectives for PHP engagement and priority areas for action. The priority areas have been informed by Australian and international evidence on bowel cancer screening and the important role of PHPs in supporting bowel screening programs.

The Department of Health has overarching policy development and program implementation responsibility for the Program and will lead the implementation of this strategy. This will be done in consultation with the Program’s advisory group and individual states and territories where relevant. The Department of Health has developed a national action plan, which will be reviewed every year, detailing the actions and timeframes associated with each priority area. It focuses on areas requiring national coordination and action. This will include developing tools and resources that complement existing work and can be utilised by states and territories and non-government organisations in their work to engage PHPs in the Program.

# Background

The Program commenced in 2006 as a Commonwealth program, in partnership with state and territory governments. Eligible Australians are invited by mail to complete a immunochemical Faecal Occult Blood Test (FOBT) in their own home and mail it to the Program’s pathology laboratory for analysis. Following the Australian Government’s 2014-15 Budget announcement of a $95.9 million additional investment into the Program, its expansion is being accelerated, and by 2020 all Australians aged between 50 and 74 will be invited to screen every two years.

The goal of the Program is to reduce the morbidity and mortality from bowel cancer by actively recruiting and screening the target population for early detection or prevention of the disease.

The objectives of the Program are to:

* achieve participation levels that maximise the population benefit of early detection of bowel cancer in the target population;
* enable equitable access to the Program for men and women in the target population, irrespective of their geographic, socioeconomic, disability or cultural background, to achieve patterns of participation that mirror the general population;
* facilitate the provision of timely, appropriate, high quality and safe diagnostic assessment services for Program participants;
* maximise the benefits and minimise harm to individuals participating in the Program;
* ensure the Program is cost effective and maintains high standards of program management and accountability; and
* collect and analyse data to monitor participant outcomes and evaluate Program effectiveness.

The Program model (direct mail) is the most common method for recruitment used in bowel screening programs around the world and research strongly supports direct mail as an effective recruitment method. [[1]](#endnote-1) However, there is also good evidence that PHP involvement in the screening process is an important factor in achieving good participation rates. See Appendix A for a review of the evidence for recruitment models.

Research undertaken by Ipsos-Eureka in 2010 for the Department of Health found strong evidence that people are more likely to participate in bowel screening if they receive information from their PHP. [[2]](#endnote-2)

A review of the Program in 2012 by KPMG noted a lack of awareness of, or trust in, the Program by some PHPs and recommended promoting PHP endorsement of screening and providing targeted communication and information packs for PHPs. [[3]](#endnote-3)

The Biennial Screening Working Group (BSWG) (discontinued in December 2015) was established to advise the Department of Health on policy and program issues around the expansion of the Program to a biennial screening interval. Increasing the role of PHPs to encourage participation in the Program was one of the priorities of the BSWG.

State and territory governments have implemented, or are planning, a range of strategies to engage PHPs in the Program. Activities include qualitative research into PHP attitudes, development of jurisdictional strategies, development of resources, delivery of information sessions and practice audit tool projects.

# Policy Context

The Program is evidence-based and operates in accordance with the [*Australian Population Health Screening Framework*](http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/16AE0B0524753EE9CA257CEE0000B5D7/$File/Population-based-screening-framework.PDF). The Framework was endorsed by the Australian Health Ministers’ Advisory Council in 2008 and includes key principles for the implementation and management of screening programs. Key principles which relate to PHP engagement include the need for evidence based strategies for recruitment and ongoing participation; efficient use of resources; and professional development and training to support the workforce.

The *National Bowel Cancer Screening Program Policy Framework for Phase Four* covers the phased implementation of biennial screening from 2015 to 2020. The Framework identifies increasing participation in the Program as a key focus in Phase Four, including by supporting the role of PHPs in encouraging participation.

The expansion of the Program will bring it into line with the National Health and Medical Research Council (NHMRC) Clinical Guidelines[[4]](#endnote-4) which recommend faecal occult blood testing at least every two years for people over the age of 50 who are at, or slightly above, average risk for bowel cancer (about 98% of the population).

The Royal Australian College of General Practitioners [*Guidelines for preventive activities in general practice*](http://www.racgp.org.au/your-practice/guidelines/redbook/) (The Red Book) is a synthesis of evidence-based guidelines from Australian and international sources and provides recommendations for everyday use in general practice. The Red Book recognises the critical role of GPs in maximising participation in screening and managing participants with a positive test.

The [*European Guidelines for quality assurance in colorectal cancer screening and diagnosis*](http://www.kolorektum.cz/res/file/guidelines/CRC-screening-guidelines-EC-2011-02-03.pdf) 2010*,* recommend PHPs involvement in the implementation of organised screening programs and the process of conveying information to people invited to screen.

# Participation in the Program

The Program is still maturing with the phased implementation of biennial screening from 2015 to 2020. Since the inception of the Program in 2006 to June 2014, over 2.5 million Australians have been screened. In the two year period from 2013 to 2014 the participation rate was 37%. For those receiving their second or subsequent invitation after participating previously, the re-participation rate was 74%.

Participation was lower for men, those living in remote and very remote areas and people with the lowest socio-economic status.

There are some limitations with the measurement of the Program’s participation rate. To be accurate, participation rate calculations should exclude people from the denominator who are not eligible to participate. This includes people who have a previous diagnosis of bowel cancer; symptoms or illness precluding screening; had a colonoscopy in the previous five years or completed any FOBT kit in the previous two years. Currently, none of these groups can be reliably excluded so all invitees are included in the denominator.

An analysis of MBS data shows that 8.4% of people who were invited to participate in the Program over three years from 2010 had claimed a colorectal surgery item (including colonoscopy) in the 2 years prior to their invitation.

A Victorian survey in 2011-12 also found that 28% of people who acknowledged receiving a National Bowel Cancer Screening Program test in the mail did not complete the test because they had already completed another bowel test. [[5]](#endnote-5) This research indicates that a significant proportion of older Australians might be participating in bowel screening outside of the Program in consultation with their PHPs.

A review of the Program in 2012 by KPMG noted that stakeholder views on the participation rate varied. Some felt the rate should be closer to 50 or 60%, based on the United Kingdom bowel cancer screening program and the Australian BreastScreen and cervical cancer screening rates. However, others maintained that rate was excellent given the Program’s level of maturity. Participation rates in countries using this model vary greatly from 20% in Croatia to over 50% in England, Scotland and New Zealand (pilot).

It is anticipated that participation in the Program will increase naturally as more people are biennially screened, noting that the participation rate for second time or subsequent invitees was 74%. However, increasing participation remains key priority for the Program, consistent with the Program objectives. Strategies to address low participation rates in under-screened groups are particularly important to ensure equitable access to the program regardless of an individual’s geographic, socioeconomic, disability or cultural background.

Improving bowel cancer screening participation rates and reducing disparities in under-screened groups is important to reduce bowel cancer morbidity and mortality. This PHP Engagement Strategy is one of a number of measures the Department of Health is progressing to increase participation. Others include:

* the “A Gift for Living” communications campaign launched in April 2015, with a second phase in March 2016, with positive evaluation results;
* better targeting of invitations (excluding those who have recently had a colonoscopy claimed through the MBS);
* an alternative screening pathway for Aboriginal and Torres Strait Islander people, including the screening kit being offered in primary care services; and
* a National Cancer Screening Register to support the expansion of the Program.

# Current Situation: PHPs Role in the Program

PHPs play a pivotal role in the Program. They are well placed to increase participation in the Program and play a key role in ensuring that participants progress through the screening pathway. PHPs also advise the Australian Government on a range of clinical and program delivery issues, including through representation on Program committees.

An overview of the Program participant screening pathway and a flow chart is at Appendix B. PHPs’ role within the screening pathway is to:

* encourage those who are sent a screening test and for whom the test is clinically relevant, to participate;
* assess those with a positive result and refer them for further examination as clinically indicated, for example a colonoscopy;
* indicate whether a patient referred for colonoscopy is a Program participant to assist with reporting to the Program Register;
* notify the Program Register of referral/non referral for colonoscopy or other bowel examination for participants with a positive result;
* manage individuals identified as being at increased risk of bowel cancer in accordance with the National Health and Medical Research Council (NHMRC) Guidelines; and
* inform individuals at average risk that the NHMRC Guidelines recommend screening at least once every two years from the age of 50.

Currently GPs are actively involved in managing patients with a positive test and organising referral for colonoscopy. However, there is opportunity for much greater PHP involvement in the screening process, in particular identifying eligible patients, discussing the Program with patients and if appropriate, encouraging screening (through the Program if eligible or alternative method if not eligible).

The National Cancer Screening Register, which will commence operations for the National Bowel Cancer Screening Program on 20 March 2017, will support PHPs in their clinical decision making regarding their patients participation in the Program. PHPs will be able to interact with the Register, for example they will be able to bring forward or suspend an invitation for a patient. The functionality of the new register could be used to support the opportunistic provision of Program kits by PHPs to select population groups to complement the overall mail out model. The feasibility of this approach will be considered by the Program in the future.

# Evidence for Expanding the PHP Role

A comparison of 20 bowel screening programs internationally concluded that a mixed method, multi-level approach is likely to maximise bowel screening rates. This includes making information about screening broadly available, ensuring that the opportunity to screen is readily accessible at the population level and engaging PHPs in the screening process. [[6]](#endnote-6)

Research has consistently demonstrated that a recommendation from PHPs to screen for bowel cancer using an immunochemical FOBT is an important motivator for participation.[[7]](#endnote-7), [[8]](#endnote-8) ,[[9]](#endnote-9) PHPs involvement in conveying information to people invited for screening has been shown to improve awareness of the risk of bowel cancer and the benefits of screening, and to increase confidence in the screening method. Evidence suggests that PHP involvement in an individual’s decision to undergo screening is the strongest predictor of participation, in particular, for less educated people.[[10]](#endnote-10)

Involvement from PHPs could assist people from culturally and linguistically diverse groups to overcome identified barriers to screening such as language, lack of confidence in ability to complete the test, and fatalistic views about cancer.[[11]](#endnote-11)

Four small jurisdictional pilots that involved Indigenous primary health care services offering the Program kit to Aboriginal and Torres Strait Islander people were conducted between 2008 and 2011, resulting in small increases in participation. The evaluation supported integrating bowel cancer screening into Indigenous primary health care services by health workers offering the kit and providing education, support and follow-up.

# Barriers & Facilitators to PHP Engagement

Australian PHPs have indicated support for a playing a central role in bowel cancer screening and highlighted the need for more education and training.[[12]](#endnote-12) Understanding the current barriers and facilitators to PHP involvement in the Program is important to determine what support is required to facilitate an expanded role for PHPs.

It is important that PHPs trust that the immunochemical FOBT is an effective test for use in population bowel cancer screening in order for them to support the Program. Surveys of Australian GPs in 1980s and 90s reported that only 35-55% of GPs believed the FOBT was an effective test for screening [[13]](#endnote-13) and found that concern about false positive rate was a key barrier to GPs supporting FOBT screening. [[14]](#endnote-14) Subsequent surveys of Australian GPs’ attitudes towards bowel cancer screening using the FOBT demonstrate that support for the test has increased over time. [[15]](#endnote-15),[[16]](#endnote-16),[[17]](#endnote-17),[[18]](#endnote-18)

Research conducted in 2010 on behalf of the Department of Health found GPs generally reported positive impressions of the Program, with 83% of the 272 GPs surveyed having recommended participation to patients.[[19]](#endnote-19) Those who had not recommended the Program did so for medical reasons such as having already planned or conducted another screening test or having a high risk or symptomatic patient, and only 3% reported reasons that related to the Program itself (e.g. not believing the test was accurate or thinking the patient would struggle with the instructions).

While the current GP approval rate is unknown, it is likely that lack of approval by some GPs at least partly influences decision-making by some people who choose not to participate in the Program.[[20]](#endnote-20)

Qualitative research was undertaken in Victoria in 2014 and Queensland in 2015 into the attitudes of GPs to bowel cancer screening and the Program. [[21]](#endnote-21), [[22]](#endnote-22) It found that barriers to supporting participation in the Program include that some GPs:

* do not feel part of the Program and feel that their expertise with patients and their role in influencing health behaviours has not been considered in the program design;
* have high awareness of the Program but less knowledge of how it works (eligible age cohorts; screening intervals; how to do the test);
* are reluctant to raise bowel cancer screening with patients who do not initiate this conversation themselves;
* focus on identifying high risk patients or those with possible symptoms;
* have doubts about the reliability of the FOBT and concerns about its’ acceptability with patients; and
* have a preference for colonoscopy due to the ability to immediately diagnose and to treat polyps and perceived patient preference.

Other reported barriers to Australian GPs supporting bowel cancer screening include lack of time, confusing screening guidelines, lack of remuneration and lack of interest.[[23]](#endnote-23)

The qualitative research in Victoria and Queensland also suggests that colonoscopy is over-used as a screening tool. It is evident that GPs are referring some patients at average risk for colonoscopy. This is contrary to the NHMRC Clinical Guidelines which recommend FOBT testing at least every two years for people over the age of 50 who are at, or slightly above, average risk for bowel cancer. Over-use of colonoscopy is problematic as it exposes patients to the potential harm associated with colonoscopies and places extra demand on services.

The Victorian research identified a number of factors that would facilitate PHP involvement in the Program. These included: financial incentives; training delivered through professional bodies with professional development credits (group information sessions, on-line programs and clinic based programs); patient record prompts for patients at eligible ages; resources to promote the Program in clinics; and a supply of kits for the clinic either for distribution or demonstration.

Other factors that are known to motivate GPs to support FOBT screening include being provided with information on the prevalence of bowel cancer; effectiveness of screening (reduction in mortality and morbidity); test effectiveness (proportion of false positives and false negatives) and test characteristics (non-invasive and simple/quick).[[24]](#endnote-24), [[25]](#endnote-25)

# A Team Approach to Bowel Cancer Screening

Practice Nurses, Aboriginal and Torres Strait Islander Health Workers, Practice Managers and other non-clinical staff all have an important role in supporting bowel cancer screening activities. A team approach can increase efficiency by utilising the skills of all practice staff and reducing time pressure on GPs. For example, there is evidence that counselling and reminding patients to screen by non-physician PHPs is an effective approach to increase participation. [[26]](#endnote-26) Practice administrative staff play a key role in setting up practice level systems to support screening.

The Practice Nurse Incentive Program provides incentive payments to practices to support an expanded and enhanced role for nurses working in general practice. Practice Nurses could be supported to be responsible for writing to eligible patients to encourage participation in the Program, undertaking risk assessments, demonstrating the kits, undertaking screening audits on practice records and completing forms for the Program register.

# Working with the Primary Health Care Sector

Working with PHPs to encourage uptake of new initiatives needs to take into account the environment in which PHPs work. A major barrier to the implementation of preventative activities in general practice is the limited time available in the context of the work to be done.

Evidence suggests that the greatest barrier to optimal prevention in general practice is not lack of knowledge but the lack of a systematic and integrated approach such as recall and reminder systems. [[27]](#endnote-27)

The time pressures and structural barriers faced by PHPs need to be taken into account when developing specific strategies to increase their involvement in delivering the Program. Limited time also needs to be considered in determining the best way to communicate and engage with PHPs.

# Primary Health Networks

Primary Health Networks (PHNs) work with general practitioners, other primary health care providers, secondary care providers and hospitals to facilitate improved outcomes for patients.

Screening for bowel cancer is a national headline performance indicator for PHNs which will encourage PHNs to engage with PHPs to increase their involvement in the Program.

Ideally, PHNs should be able to access local level data to monitor performance against the screening indicator. Access to data is expected to be further improved with the implementation of the National Cancer Screening Register.

# The Strategy

## The Goal

The goal of this strategy is to reduce the incidence of, and mortality from, bowel cancer by engaging the primary health care sector to encourage and guide participation in the National Bowel Cancer Screening Program.

## Objectives

The objectives of the strategy are to:

* Support PHPs to incorporate bowel cancer screening activities into standard practice.
* Increase PHPs’ trust in, and endorsement of, the Program.
* Increase PHPs’ involvement in encouraging participation in the Program, where appropriate.
* Support PHPs to effectively support Program participants along the screening pathway.
* Support PHPs to manage patients in accordance with evidence based guidelines on the early detection of bowel cancer.

## Priority Areas

Five broad priority areas for action have been identified to support the strategy’s objectives. It is important to note that state and territory governments have already commenced work in a number of these areas.

### Working in Partnership to Engage PHPs

Better engagement of PHPs will require working in partnership with a number of organisations. Organisations with a key role to play include the Royal Australian College of General Practitioners, the Australian College for Rural and Remote Medicine, the Australian Primary Health Care Nurses Association, the Australian Association for Practice Management, Primary Health Networks, state and territory health departments and the Cancer Council Australia. Engaging with these key primary care stakeholders will be important to harness support and guidance for implementation activities.

Engaging with other stakeholders that can influence PHPs bowel cancer screening advice to patients such as colonoscopists (Gastroenterological Society of Australia) and private health insurers (Private Healthcare Australia) will also be important.

The [*Choosing Wisely Australia*](http://www.choosingwisely.org.au/) initiative facilitated by NPS Medicine Wise encourages clinicians and consumers consider and discuss what care is truly needed by identifying unnecessary tests, treatments or procedures that may cause harm. This campaign is an avenue support PHPs to recommend bowel screening is accordance with evidence based guidelines.

### Professional Development and Information for PHPs on the Program

Evidence suggests that PHPs require information to increase their knowledge, confidence and awareness of bowel cancer screening and the Program, including the evidence base.

Consistent messages need to be provided to PHPs from a range of channels about:

* the effectiveness of the Program in reducing bowel cancer mortality and morbidity[[28]](#endnote-28),[[29]](#endnote-29);
* the NHMRC guidelines, in particular that FOBT is recommended for people over 50 who are at, or slightly above average risk (about 98% of the population);
* the effectiveness of a GP recommendation to encourage participation in screening;
* how to assess risk levels;
* the effectiveness of the Program test (proportion of false positives and false negatives)1,[[30]](#endnote-30); and
* the test characteristics (non-invasive and simple/quick).

Information could be delivered to PHPs through a range of mechanisms including training with professional development credits, information sessions, presentations at conferences and communication via editorials/articles in relevant publications and newsletters (hard copy and on-line). Where possible, training needs to be linked to existing on-going professional development mechanisms.

### Practice Tools and Resources

Practice level supports that promote an integrated and systematic approach to screening are key to facilitating PHP involvement in screening. For example, practice software reminder systems to prompt PHPs to have a discussion about bowel cancer screening have been shown to significantly improve screening rates. [[31]](#endnote-31),[[32]](#endnote-32) Approaches which involve summarising data on practice software systems and providing feedback to PHPs on their screening performance also have a positive effect on screening participation rates. [[33]](#endnote-33)

Bowel cancer screening tools and resources could be developed, or where available promoted, to support PHPs to identify eligible patients, conduct bowel screening risk assessments and where appropriate encourage participation in the Program and support patients through the screening pathway.

### Promoting Equitable Access to the Program for Under-Screened Groups

Research suggests that Indigenous Australians and people from culturally and linguistically diverse backgrounds would benefit from support from health professionals to increase their participation in bowel cancer screening. [[34]](#endnote-34)

The Department of Health engaged Menzies School of Health Research (Menzies) in June 2015 to develop consumer resources and PHP training materials to support the screening kit being offered to Aboriginal and Torres Strait Islander people by PHPs. In 2017, an alternative pathway pilot will commence in 50 Indigenous primary health care services.

A review of the Program in 2012 by KPMG noted that a similar alternative pathway might be worth exploring for other under-screened groups, such as people from culturally and linguistically diverse and lower-socioeconomic backgrounds. [[35]](#endnote-35)

### Efficient Register and Reporting Systems

There are some limitations and weaknesses with National Bowel Cancer Screening Register which prevents the Program from adequately supporting health professionals, including PHPs. This includes a reliance largely on paper-based reporting from forms that need to be filled in by hand by health professionals.

In the 2015-16 Budget the Australian Government announced the development of a National Cancer Screening Register (the Register) that will support the renewed National Cervical Screening Program and the expansion of the National Bowel Cancer Screening Program. The Register will provide a single cost-effective service, to collect and report screening data, and inform timely clinical decisions for both screening programs.  The Register will commence operations for the National Bowel Cancer Screening Program on 20 March 2017.

The Register features will include a single participant record, streamlined reporting and connection to the *My Health Record* to enable participants and health professionals to provide, update and receive information. GPs will be able to identify their patients’ eligibility for screening to encourage participation and to support clinical decision making regarding their patients participation in bowel cancer screening. PHPs will be consulted on the Register’s supports for electronic reporting, including linkages to existing clinical information systems to remove the time consuming paper-based reporting.

# Monitoring Progress

Monitoring progress in meeting the objectives of this strategy will be measured by a range of mechanisms, including attendance by PHPs at training and information sessions; interactions by PHPs with the National Cancer Screening Register; and Program participation.

# Conclusion

PHPs have indicated support for playing a central role in bowel cancer screening in Australia. Evidence suggests that greater involvement by PHPs in encouraging and supporting participation in the Program is required to complement the Program’s direct mail method. This strategy provides a consistent national vision for the work being undertaken by a number of government and non-government organisations to better engage PHPs in the Program.

# Appendix A

## Literature Review: Evidence for Recruitment Methods

### Direct Mail Method

The direct mail method of recruitment or direct mail as part of a combined model of a program is the most common method for recruitment used in bowel screening programs around the world[[36]](#footnote-1). Participation rates vary greatly from 20% in Croatia to 70% in Finland. Much of the evidence available to support the direct mail method is based on the success of these screening programs.

A recent Australian study by Courtney R, et al[[37]](#footnote-2) found that mail-based strategies with FOBT invitation can achieve participation rates of 51-59%, with increased participation evident in two studies that had adopted pre-notification prior to the screening invitation.

A study by Logan et al (2012)[[38]](#footnote-3) looked at the take up of the United Kingdom Bowel Screening Program after the first million tests were sent out by direct mail (prior to 2008). The Program model was deemed to be successful with a participation rate of over 50%. The UK Program offers screening by FOBT every two years to people aged 60 to 69. This is being extended to cover people up to the age of 75. Currently, people over 70 can request a screening kit by calling a toll-free phone number. One off screening by flexible sigmoidoscopy is currently being piloted in selected regions for people turning 55 years of age.

In the Australian context, the Bowel Cancer Screening Pilot Final Evaluation Report[[39]](#footnote-4)found that the direct mail of invitations from a central register would be an effective primary mechanism for invitation and distribution of FOBTs in a national program. However, this method of recruitment requires a consumer to have a fixed address. People without a fixed address require an alternative distribution mechanism.

A recent study by Roosbroeck et al (2011)[[40]](#footnote-5), concluded that inviting people by direct mail and including a test kit resulted in a much higher participation rate that by inviting people through a PHP (52% compared to 28%). The pilot was undertaken in Belgium in 2009 and involved the invitation of over 19,000 people.

A study by Hoffman, R.M et al (2011)[[41]](#footnote-6) utilising New Mexico’s Veterans’ Affairs Health Care System (database) showed that a delivery model based on using an electronic health record to identify eligible patients and then directly mailing them gFOBT kits might be a more efficient method for achieving colorectal cancer screening than a usual care model that relied on an office visit to implement screening. The delivery model supports a population-based approach to implementing screening and then monitoring utilisation and outcomes.

A study by Levy, B.T et al[[42]](#footnote-7) found that mailed iFOBTs plus educational materials improved colon cancer screening rates in Iowa research network (IRENE) practices. Mailing FIT kits with easy-to-understand educational materials improved attitudes toward screening and dramatically increased bowel screening rates among patients who were due for screening in a practice-based research network, ie these people were not recorded in their medical practice as having completed a practice recommended bowel screening test.

A recent study from Belgium invited around 19,500 people aged between 50 and 74 years to participate in colorectal cancer screening[[43]](#footnote-8). Of these, around half were direct mailed a FOBT kit and the remainder were sent a letter inviting them to visit their PHP to collect a FOBT. The overall participation rate was 42.1%. 52.3% of people who received the kit in the mail returned the completed test compared to 27.7% of those who were invited to visit their PHP.

An Italian randomised population study by Rossi et al (2011)[[44]](#footnote-9) trialled direct mailing of FOBTs to two groups, people due for rescreening and people who were previous non-responders to their invitation to collect a test from a health clinic. The study concluded that the direct mailing of FOBTs modestly increased participation.

A survey undertaken by Ipsos Eureka in 2011 on behalf of the Department shows that 88% of NBCSP participants surveyed (9 in 10 people) would prefer a kit to be mailed directly to them.

In terms of cost-effectiveness, a study by Sequist TD et al[[45]](#footnote-10) determined mailing of FOBT kits to be cost-effective with the results showing a higher uptake of screening by those mailed a FOBT kit than those who did not receive a FOBT kit by direct mail (44% compared to 38%).

There has been a substantial amount of research into the results of direct mailing FOBT kits in targeted population screening for colorectal cancer compared to other recruitment strategies such as the collection of a FOBT kit from a health centre, or a telephone intervention. All of the studies reviewed confirm that the existing model of recruitment in the NBCSP is consistent with the best available evidence, that is, direct mailing of FOBT kits is an effective method of recruitment for colorectal cancer screening in a targeted population based screening program. The evidence suggests that this model is suitable for people with a fixed address, which accounts for approximately 99.5%[[46]](#footnote-11) of the Australian population.

### Direct Mail Method with Additional GP Involvement

There is substantial evidence that the preferred mechanism for receiving health messages is from a person’s PHP or health professional. It has been shown that people who are prompted by their PHP to discuss and consider bowel cancer screening are more likely to be involved in such a program (Harris et al., 2000[[47]](#footnote-12)).

A recent article in Practical Gastroenterology[[48]](#footnote-13) reviews 20 established bowel screening programs and outlines recruitment methods used in international bowel screening programs. The article concludes that a mixed method, multi-level approach that reduces structural barriers to screening (e.g., make information about screening broadly available and ensure that the opportunity to screen is readily accessible at the population level), employs personally tailored contacts with persons in target populations, and engages primary care providers in the screening process is likely to be the most effective approach to maximizing bowel screening rates.

Research undertaken by Ipsos Eureka in 2011, on behalf the Department of Health, identifies that people would be more likely to participate in bowel screening if they received information from their PHP.

The Bowel Cancer Screening Pilot Final Evaluation Report[[49]](#footnote-14) found that the direct mail of invitations from a central register requires a consumer to have a fixed address. People without a fixed address require an alternative distribution mechanism.

The *European Guidelines for quality assurance in colorectal cancer screening and diagnosis, European Commission, First edition, 2010*, recommend that PHPs should be involved in the implementation of organised screening programs and should be involved in the process of conveying information to people invited to screen.

A study by Christou et al (2010)[[50]](#footnote-15) found that the NBCSP is not reaching many Indigenous Australians in the target group, with factors contributing to sub-optimal participation including how participants are selected, the way the screening kit is distributed, the nature of the test and comprehensiveness of its contents, cultural perceptions of cancer and prevailing low levels of knowledge and awareness of bowel cancer and the importance of screening. The study recommends modifications to the current program to facilitate access and participation by Indigenous and other minority populations.

A survey undertaken by Worthley et al in 2006[[51]](#footnote-16), questioned the reason for non-participation in a screening initiative. The survey identified that further involvement of a person’s PHP in the screening process may encourage participation.

Zajac IT et al[[52]](#footnote-17)2010, investigated the effect of general practice and PHP endorsement for FOBT based screening. Associating recent contact of a PHP or practice with an invitation to screen was shown to achieve better participation and re-screening than an invitation from a certralised register. The study found that increased participation can be achieved by practice endorsement alone without requiring actual PHP involvement.

### Direct Provision of FOBT Kits by PHPs

Other than the evidence mentioned above about PHP engagement in a screening Program, there is limited literature that supports a model which requires a person to obtain their FOBT from a particular source (rather than by direct mail).

Several countries (Korea, Israel, Italy, Japan and Canada) currently operate a model similar to this, ie mailed contact to encourage screening. Most of these models require a person to collect a test kit from a local health clinic or their PHP. Participation in these programs is low (between 10 and 30 per cent)[[53]](#footnote-18).

*Case study – Ontario, Canada[[54]](#footnote-19)*

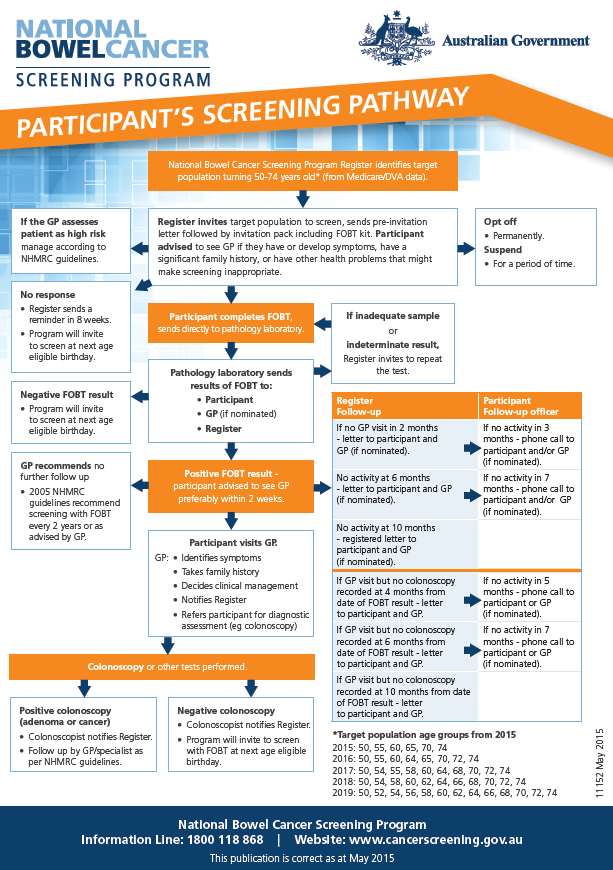
Ontario runs the ColonCancerCheck Program. PHPs are the first point of contact and undertake a risk assessment on eligible patients aged 50-74 to assess their risk for bowel cancer. Those assessed at average risk are provided with a FOBT kit to complete at home. PHPs are responsible for ordering FOBT kits and managing stock. The FOBT kit used has a three year expiry date. People who don’t have PHP can obtain a kit from a pharmacy. PHPs are encouraged (with financial incentives) to contact eligible patients, using a prescribed method, to make an appointment do discuss bowel screening. In 2010/11, the ColonCancerCheck Program had a participation rate of 30%. A rate of 47% was calculated for people over due for screening (via any method). While many lessons can be learned from the Ontario Program, the low participation rate does not indicate support for a program design of which PHPs are the first point of contact.

# Appendix B

## The Screening Pathway

The major components of the pathway are:

* Identification of eligible population: The Program Register identifies eligible age cohorts from the Medicare/DVA data.
* Pre-invitation: Direct mail from the Register is the primary means utilised by the Program of recruiting eligible people. Eligible people receive a pre-invitation letter to participate in the Program, two weeks prior to receiving the test kit.
* Invitation: Eligible people receive a test kit by mail and are encouraged to return the completed test to the Program pathology for analysis.
* Invitation reminder: If the participant does not return the iFOBT they are sent a reminder letter eight weeks after the invitation date. If an iFOBT is not returned the participant is invited to screen at the next eligible age.
* iFOBT Pathology analysis: Contracted pathology laboratory analyses the iFOBT samples and sends result to the participant, the nominated GP and the Program Register.
* Negative iFOBT Result: If the patient receives a negative iFOBT result, the result notification advises that it is recommended that they rescreen in two years’ time.
* Positive iFOBT result: If the patient receives a positive iFOBT result they are advised to visit their GP within two weeks. The GP (if nominated) is also informed of the iFOBT result. The GP can then discuss the results and appropriateness of a colonoscopy or other investigative procedure with the patient and refer the patient on where appropriate.
* Positive iFOBT result follow-up: If there is no follow up recorded on the register at eight weeks post positive iFOBT, the participant and the GP (if nominated) are sent a reminder letter by the Register. A further letter is sent at 6 months. The Participant Follow-up Function (PFUF) also contacts the participant and the GP (if nominated) by phone if there is no activity at three months and then at seven months.
* Positive diagnostic result follow-up: If a GP visit is recorded in the register, but no colonoscopy visit is recorded the participant and GP are sent letters by the Register at four and six months. The PFUF also contacts the participant and the GP (if nominated) by phone if there is no activity at five months, and then at seven months.
* Diagnostic assessment – usual care: Once referred by a GP, the participant undergoes further diagnostic assessment, usually a colonoscopy, as part of usual care health services within their state or territory.
* Positive diagnosis: If the participant is diagnosed with bowel cancer or adenoma following colonoscopy or other procedure, their outcome is recorded by the Program Register, and they are discharged from the Program. Further treatment, care and surveillance are provided within the usual care health system.
* Negative colonoscopy diagnosis: If the patient receives a negative colonoscopy result, it is recommended that they rescreen with an iFOBT in five years’ time. Unless a program participant identifies that they do not wish to participate further in the program, they will be invited to rescreen at the next eligible age.



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