



Australian Government

Department of Health and Ageing

BOWELCANCERSCREENING 

PILOT PROGRAM
An Australian Government Initiative

Screening Monograph No.3/2005

The Australian Bowel Cancer Screening Pilot:

Outcomes of the National GP Workshop

24 August 2004

Record of Outcomes:

**Bowel Cancer Screening
National GP Workshop**

24 August 2004

This report was prepared by the Screening Section, Targeted Prevention Program Branch, Australian Government Department of Health and Ageing.

© Commonwealth of Australia 2005

ISBN 0 642 82815 6

Publications Approval Number 3772

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part may be reproduced by any process without prior written permission from the Commonwealth. Requests and inquiries concerning reproduction and rights should be addressed to the Commonwealth Copyright Administration, Attorney-General's Department, Robert Garran Offices, National Circuit, Barton ACT 2600 or posted at <http://www.ag.gov.au/cca>

Requests for additional copies of this report should be addressed to:

National Mailing and Marketing
11 Tralee Street
Hume ACT
Phone (02) 6269 1000
Fax (02) 6260 2770

Table of Contents

Purpose.....	5
Background	5
Introduction.....	6
Key Issues / Themes for consideration	6
Opportunities for GPs	6
Pathway issues	7
Quality improvement – consultations and referrals	7
Training and support for GPs.....	8
Data transfer and interface with a National Screening Register	8
Interface and referral arrangements	8
Role of Divisions of General Practice and State Based Organisations.....	8
Role of other key players (Practice staff and nurses, Cancer Councils).....	9
Access & equity	9
Attachment A: Discussion paper prepared by North East Valley Division of General Practice May 2004.....	10
Attachment B: Bowel Cancer Screening National GP Workshop – Syndicate Group Discussion Topics	27
Attachment C: List of participants at Bowel Cancer Screening National GP Workshop 24 August 2004	30

Outcomes Paper: Bowel Cancer Screening National Workshop to discuss issues for General Practice 24 August 2004

Purpose

The purpose of this paper is to:

- record issues discussed by General Practitioners (GPs) and representatives of key GP stakeholder and professional groups at a workshop (the Workshop) held on 24 August 2004 on issues for general practice should a national bowel cancer screening program be introduced in Australia;
- inform the overall evaluation of the Pilot undertaken by Healthcare Management Advisors (HMA) on behalf of the Department of Health & Ageing (the Department); and
- inform the Australian Government's consideration of whether to introduce a national bowel cancer screening program.

Background

In the 2000-2001 Budget, the Australian Government announced that it would invest \$7.2 million over four years to improve knowledge about the early detection of bowel cancer through the Pilot. In the 2004-2005 Budget, a further \$7.5 million was allocated to continue work undertaken in the Bowel Cancer Screening Pilot and support investigation into the benefits and logistics of establishing a national bowel screening program. Evaluation of the Pilot will be finalised in November 2004, after which time the Australian Government will consider the possible introduction of a national bowel cancer screening program.

During the course of the Pilot, general practitioners within the Pilot sites and on the Pilot working groups identified a range of issues which should be addressed, not only in the context of a potential national bowel cancer screening program, but also to ensure that service provision in general is of the best standard achievable in terms of quality, consistency, accessibility and appropriateness.

In May 2004, the North East Valley Division of General Practice prepared a discussion paper drawing on feedback from GPs involved in the Pilot identifying core issues for general practice that need to be addressed in the context of implementation of a national bowel cancer screening program. This is at Attachment A. A list of syndicate group topics, including issues/questions to be considered, was developed with reference to this paper and is at Attachment B. These documents were sent to all workshop participants in advance and informed discussions on the day. A list of workshop participants is at Attachment C.

Introduction

This paper's focus is on identifying issues for general practice, including individual GPs, Divisions of General Practice, State-Based Organisations (SBO's) and peak GP bodies¹ should a national bowel cancer screening program be introduced in Australia.

Workshop participants provided feedback on the following range of topics:

- opportunities for GPs should a national bowel cancer screening program be introduced in Australia;
- barriers and enablers to GP participation in a national program;
- quality improvement (QI)– consultations and referrals;
- training and support for GPs, including the most appropriate delivery mechanisms and media;
- data transfer and interface with the National Screening Register;
- screening pathway issues;
- interface and referral arrangements – including with pathology and colonoscopy services, hospital or day facilities and specialists;
- role of Divisions and State Based Organisations;
- role of other key players (for example, practice staff and nurses and Cancer Councils); and
- access and equity (provision of culturally appropriate services to Aboriginal and Torres Strait Islander (ATSI) and Culturally and Linguistically Diverse (CALD) groups, provision of services to disabled groups and people living in rural and remote areas.

The key issues or themes that emerged throughout the workshop are outlined below.

Key Issues / Themes for consideration

A number of issues raised in discussions at the workshop require further consideration should a national bowel cancer screening program be introduced. These issues are identified below and may require formation of collaborative committees or the undertaking of projects prior to possible implementation of a national bowel cancer screening program.

Opportunities for GPs

Participants articulated that in the event of a national bowel screening program there were many opportunities for GPs including:

- GP involvement in population health activities at a primary care level;
- a greater public health focus as a practice level;
- improved, integrated, patient care through a GP led holistic and pro-active approach to health care;

¹ These peak, or professional bodies, include the Australian Divisions of General Practice (ADGP), Royal Australian College of General Practitioners (RACGP), Australian Medical Association (AMA), Australian College of Rural Remote Medicine (ACRRM) and the Rural Doctors Association of Australia.

- strengthening of the primary health care relationship between GP and patient;
- continued promotion and recognition of the integral role of the GP in ensuring appropriate referral to cost effective services;
- refreshing or reinforcing GP knowledge about the incidence of bowel cancer and the importance of screening;
- building linkages and partnerships with other health service providers such as specialists, hospitals, Aboriginal Medical Services and local and State health authorities;
- developing partnerships/networks with Divisions of General Practice, SBO's, consumer groups and Cancer Councils; and
- further exploring the role of practice nurses and support staff in reducing GP work load.

Pathway issues

All groups represented at the workshop support the Pilot pathway (central invitation and Register arrangements) and the critical role of GPs within the pathway. Some further work is needed to develop more effective mechanisms or processes to deal with the following issues:

- the requirement to nominate a GP, when the person does not have a usual GP;
- distribution of Faecal Occult Blood Test (FOBT) kits to persons without a fixed address, in particular ATSI groups;
- provision of timely access to GP and specialist services, particularly in rural and remote communities; and
- duty of care and consent issues.

Quality improvement – consultations and referrals

Workshop participants strongly supported the development of national standards/protocols for bowel cancer screening, derived from the National Health and Medical Research Council (NHMRC) guidelines, supported by an ongoing education/training program for GPs linked to Continuing Professional Development (CPD) points. Both the national standards and training program should be centrally developed and distributed by a well recognised organisation and/or accredited by peak bodies, such as the relevant Colleges, Divisions and government.

There was also agreement of the critical role of appropriate and timely feedback or reports to GPs from the Register in supporting quality consultations and referrals. Reports should also enable comparison of individual data to State and/or national data. This was seen as key to the engagement of GPs in the screening program, including encouraging compliance with national standards/protocols, adherence to the NHMRC guidelines and adoption of best clinical practice.

Support was also voiced for mechanisms to ensure GPs receive feedback from specialists on clinical outcomes and surveillance. This was seen as critical in supporting quality in consultations, referrals and practice according to NHMRC guidelines (or any others developed for any possible national program).

Training and support for GPs

Participants agreed that prior to implementation of a national program, key information should be made available to, and through, peak GP stakeholder groups so that GPs are more ready to participate in a national program.

Participants supported an integrated approach to training that explores cross-program synergies. There is a huge opportunity to streamline training, education and on-line support tools (on-line professional development and use of clinical software) to support GPs in undertaking a range of prevention activities, not just bowel cancer screening, for example, smoking, nutrition, physical activity, diabetes, asthma, mature age health checks and chronic disease initiatives.

There is a need to identify the professional bodies that could provide leadership to oversee and guide the identification of training needs for GPs and practice staff, assist in development and implementation of training plans or programs, and identify the optimal method for delivering these programs within an approved national screening program.

Education and training materials need to be succinct, aimed at the practice level, targeted to common scenarios (eg reasons for patient consultations) and should make use of both paper and electronic formats to cater for different practice arrangements.

There was strong support for national information campaigns for consumers and GPs that are aligned in terms of key messages and logically sequenced (i.e. GP campaign first). These will assist in raising consumer and GP awareness about the incidence of bowel cancer, the importance of screening and reinforce and encourage involvement in a screening program.

Data transfer and interface with a National Screening Register

Strong support was voiced for improvement of data collection and transmission arrangements for a possible national program, in particular electronic capture and transmission of data to the Register and other health service providers (electronic referrals). Further exploration of the feasibility of using standardised software and the options available is required.

Interface and referral arrangements

There was support for the idea of a preferred provider list so that GPs can refer program participants to accredited service providers who have agreed to adhere to program protocols and standards. This will require consultation with the relevant colleges.

It was agreed it was important to develop national protocols/standards for obtaining consent to colonoscopy. Obtaining such consent should be the responsibility of the specialist/proceduralist and be obtained during a pre-consultation visit. This will require consultation with the relevant Colleges.

Role of Divisions of General Practice and State Based Organisations

It was agreed that further exploration is needed of the best role/s for key GP stakeholder and professional groups (national bodies, State Based Offices, Colleges, Australian Medical

Association, Cancer Councils etc.) to support GP participation in a possible national program. Additional work is also needed on the most efficient and effective funding model to support these bodies in performing these roles.

Role of other key players (Practice staff and nurses, Cancer Councils)

It was agreed it was critical to support and explore options for further involvement of practice/support staff to assist in reducing the administrative workload for GPs. A whole of practice approach to screening is the preferred option. This will require collaboration between the relevant colleges (both medical and nursing).

Access and equity

Participants also emphasised the need for early engagement with key stakeholders to explore models of service delivery to meet the needs of demographically and geographically diverse populations, ATSI, CALD and disabled groups.

**Attachment A:
Discussion paper prepared by
North East Valley Division of General Practice
May 2004**

Circulated to participants in a National GP Workshop held 24 August 2004,
University House Canberra

To inform discussion of issues for General Practice should a National Bowel
Cancer Screening Program be introduced in Australia



BOWEL CANCER SCREENING

Pilot Program

Implications for a National Program DISCUSSION PAPER – Updated August 04

Introduction

The North East Valley Division of General Practice (NEVDGP) prepared this discussion paper in May 2004. In this updated version members of the Victorian Implementation Committee have provided additional comment. The original idea was to provide input into the design of the qualitative evaluation of the GP experience of the BCSPS auspiced by the Department of Health and Ageing. The document provides a detailed analysis of the Pilot Program from the General Practice perspective. It includes a mixture of specific feedback, comment and recommendations based on all of the information we have gathered throughout the Pilot Program. It is hoped that these will inform improvements for a national program.

A successful national program requires both the provision of services and co-ordination between these services. Both these aspects should be included in the evaluation of the Pilot program.

GPs have direct experience with all parts of the Pilot pathway and interface with:

- 1) Pilot participants;
- 2) pathology services;
- 3) HIC Register; and
- 4) colonoscopy services.

They are involved in both clinical and administrative roles within the Pilot pathway and have an ongoing duty of care to and relationship with their patients after the register has discharged its duty of care. For this reason, as well as commenting on the GP experience, we have also included our impression of other aspects of the Pilot pathway (services and systems).

The overall response of GPs to the Pilot is positive. Our impression is that the majority of GPs involved in the Pilot welcome an organised National Bowel Cancer Screening Program as they recognise the extent of morbidity and premature mortality from bowel cancer in the community. This document focuses specifically on the detail of the problems experienced and issues raised by the Pilot.

GP role

Communication and workload issues

The communication pathways within the Pilot were extremely comprehensive and served a number of needs including:

- patient care;
- register functioning (including safety net procedures);
- data collection (research for establishing the viability of a National Program);
- epidemiological information;
- clinical practice (quality improvement); and
- screening tool (family history and symptoms).

The comprehensive and multiple functions served by the communication processes throughout the screening pathway gave rise to a high volume and burdensome amount of paperwork for GPs.

GPs are very focused on direct patient care and support in principle what is necessary to promote quality care.

- Any facet of the Pilot that is seen as meaningful patient care is not experienced as an excessive increase in workload. If the activities do not seem meaningful they become burdensome and are not necessarily completed.
- A significant part of the GP communication related to the transfer of duty of care from the register to a GP.
- GPs experienced the notification process (i.e. GP Assessment Forms) as cumbersome because of the additional functions being served by these forms.
- We recognise the paperwork for the Pilot program is more detailed than would be required for a national program. Paperwork for a national program needs to only contain information that is necessary for patient care and a functional register.

The Participant Details Form (PDF) functioned as a screening tool with respect to self reporting of symptoms and family history. Gathering this information could be thought of as the *sensitivity* of the test and the process generated a high number of *false positives* because the information was acted on regardless of whether or not the family history or symptoms information was clinically significant (*See discussion under "Duty of Care"*).

The function of the PDF as a screening tool has not been evaluated. This function (ensuring that people with family history or symptoms see their GP) may better be served by a public education campaign.

Recommendations:

- **That the data collected on all forms are reviewed with the aim of:**
 - **clarifying the purpose of the information gathered and its relevance to a national program; and**
 - **simplifying notification processes and minimizing GP workload.**
- **That the Pilot safety net procedures be reviewed and those relevant to the management of positive FOBT be retained.**
- **That those Pilot safety net procedures concerned with the clinical management of family history and symptomatology be omitted.**
- **That questions asking about Risk Assessment (Family History and Symptoms) be deleted from:**
 - **Participants Details Form; and**
 - **GP Assessment: Not Referred for Colonoscopy Form.**
- **That public promotion of the screening program include:**
 - **a recommendation that people with strong family history or symptoms see their GP;**
 - **a definition of strong family history; and**
 - **messages that bowel cancer is common and that most cases are caused by diet and lifestyle factors.**
- **That information in the Invitation to Screen includes a recommendation that people with strong family history or symptoms see their GP and that this is reiterated in the Notification of Results letter.**
- **That the dual functions of the General Practice: Referred for Colonoscopy Form (medical referral and register notification) are separated so that the register only receives information relevant to maintenance of a screening program.**
- **That there is one GP Assessment form with an item indicating Referred or Not Referred for Colonoscopy.**
- **That consideration is given to the development of referral forms that allow for inclusion of adequate information for referral processes including space for free form written information as well as patient and GP contact details.**
- **That, with respect to referral for colonoscopy, clinical information is not communicated to the Register and is contained only within the referral letter. This includes co-morbidities, medications, past history, concerns about anaesthetic risk, etc.**
- **That an option for electronic notification (including lodgement) is available for GPs.**

Clinical Practice and recruitment of GPs to a Bowel Cancer Screening Program

The NEVDGP's impression is that most GPs are committed to a high level of patient care and do not necessarily link this to the processes required by a screening program. For example, if the GP does not value the maintenance of a register as adding to the health care of their individual patients they are less likely to adhere to screening program protocols.

For some GPs a tension exists between the perception of the individual good and the public good. One of the strengths of general practice is its responsiveness to individual patient needs which some experience as at odds with the running of public health programs.

Many GPs reported the issue of patients within the region but outside the Pilot cohort (age and postcode) requesting FOBT. There was some tension because many of these people fitted within the NHMRC guidelines target population for screening.

The Division played an important role in clarifying three issues:

- that the Pilot was not a clinical trial but was testing the feasibility, acceptability and affordability of population based screening for bowel cancer by FOBT;
- that this Pilot was not a open access service but a program testing the feasibility, acceptability and affordability of a publicly funded program; and
- Medicare does not currently rebate bowel cancer screening by FOBT.

GPs' participation in a screening program is influenced by a number of factors including:

- i Awareness of:
 - the prevalence of bowel cancer;
 - clinical management of bowel cancer; and
 - clinical guidelines.
- ii Attitudes to:
 - screening programs in general;
 - register requirements of GP;
 - FOBTs as a screening tool for bowel cancer;
 - clinical guidelines; and
 - Government initiatives.
- iii Adherence to guidelines in clinical practice.

If GPs are to be successfully recruited to a national screening program, it is absolutely essential that the guidelines for the Screening Program are congruent with the NHMRC guidelines. This will maximise GP education opportunities and ensure that GPs are not being asked to operate outside best practice guidelines. The need for consistency with NHMRC guidelines will be further highlighted as public awareness about bowel cancer issues increases. (*See later discussion "Market Issues"*).

Recommendations:

- **That the Screening Program and the NHMRC guidelines are congruent.**
- **That strategies to enhance GP participation in a national program include:**
 - **education about current clinical issues relating to screening and management of bowel cancer;**
 - **education about the management of people over 75 years and under 50 years of age;**
 - **promotion of accepted guidelines reflecting “best practice” (NHMRC); and**
 - **recruitment to the public health aspects of a screening program including the importance and function of the register.**
- **Given the potentially high level of public awareness about bowel cancer generated by a national screening program it is important to support a national education program for GPs that addresses the issues of management of people with:**
 - **a Family History of bowel cancer (particularly establishing clinical significance);**
 - **symptoms suggestive of bowel cancer;**
 - **a recent FOBT; and**
 - **a recent history of colonoscopy.**

Referrals for colonoscopy

It would be expected that a screening program would generate increased demand for colonoscopy. GPs have reported increased colonoscopy referrals. The range of explanations for this include

- **increased identification of people with recognised clinical indications for colonoscopy (i.e. positive FOBT, significant family history and significant bowel symptoms);**
- **increased reporting of family history and symptoms (Participant Details Forms). Some of these will be significant and some will not however this raised awareness has increase anxiety for patient (risk of bowel cancer) and GP (medico-legal concern);**
- **lack of confidence in FOBT /screening processes compared with a more definitive/diagnostic test; and**
- **GPs being targeted by marketing from private colonoscopy services promoting colonoscopy as the first line screening test (undermining FOBT screening and playing on GP medicolegal concerns).**

In the Australian health system GPs are recognised as gatekeepers in terms of access to specialist health services. In the context of colonoscopy services this role includes ensuring appropriate referral of patients for colonoscopy thus protecting the patient from unnecessary colonoscopy (with all the attendant risks) and ensuring appropriate use of public funds.

Ease of making a referral (effectiveness of paperwork etc)

- GPs have reported problems with the paperwork (GP Assessment: Referred for Colonoscopy) as outlined above. Often the forms were not used and consequently tracking of Pilot participants was confounded.
- In the Melbourne Pilot all preferred providers had a separate referral process for Pilot participants and not all staff were aware of the Pilot. This resulted in some Pilot participants moving through the system without being identified and in some GPs experiencing such confusion that they opted to refer privately. Our impression is that the Pilot paperwork was less likely to be used with private referrals.

Access (timing, waiting lists, systems issues etc)

- GPs have reported the importance of ease of access for colonoscopy services (both waiting time and processes of referral).
- GPs reported cynicism about the ability of a national program to provide access to timely colonoscopy services in the public sector given the current waiting lists for symptomatic patients. For example, currently a person, outside the Pilot cohort, with a clear clinical indication for colonoscopy can wait for up to twelve weeks in the Public system, compared to a Pilot participant who has access to colonoscopy within three weeks.
- Within the Pilot Program, GPs highly valued the guaranteed access to colonoscopy services for participants of the program. Within a national program, adequate provision of colonoscopy services will be essential to ensure timely access for any accepted clinical indication including positive FOBT.

Knowledge of services

- It was important that GPs were familiar with the range of providers both within the Public and Private sectors.

Choices and consequences of preferred providers vs private providers

- If the colonoscopist does not return the Notification paperwork to the Register, the GP will receive a letter from the Register stating that the patient has not had colonoscopy.

Recommendations:

- **That community education includes promotion of the value and effectiveness of FOBT as a screening tool and the role of the GP in clinical assessment and referral for colonoscopy.**
- **That there is adequate provision of colonoscopy services so as to ensure timely access for any accepted clinical indication including within a screening program.**
- **That the referral process is streamlined.**
- **That there is an urgent national review of the conditions for publicly funded colonoscopy (possibly with a view to regulation) to reduce unnecessary colonoscopy within and outside a screening program.**
- **That an effective mechanism be put in place to ensure that publicly funded colonoscopy complies with the NHMRC guidelines.**

- **That the formal national evaluation undertakes interviews with Pilot Program colonoscopy service providers (including the specialists and nurse managers of the program) as they can provide specific input into considerations about service needs within a national program.**

Duty of care issues

Many GPs voiced concerns about issues relating to duty of care.

- By collecting information about Risk Assessment (family history and symptoms) the register assumes a wide-ranging responsibility that leads to complexity in the discharge of its duty of care. The information gathered may be incomplete and clinically unreliable and complicates the pathways leading to increased administrative workload, uneasiness about the correct placing of duty of care and unnecessary cost.
- Including Sedation Risk/Anaesthesiology Class on the GP assessment form creates confusion about the GP's role and therefore duty of care. GPs are familiar with including information on comorbidities, past medical history, drugs, allergies and a current physical examination. Many GPs are not prepared, or feel very uncomfortable being asked to make a Sedation Risk assessment believing this is better addressed at a pre-admission clinic. GP Assessment Forms could provide an opportunity for GPs to provide relevant patient information to assist in a pre-admission clinic making an appropriate Sedation Risk assessment.
- Current Safety Net procedures require notification of a GP consultation to discharge the register's duty of care (after three attempts the register discharges duty of care) for positive FOBT, family history and/or symptoms. Within the Pilot pathway the duty of care rests with the Register until it is discharged to a GP or the Participant. The Register (safety net) requires that the participants have a nominated GP (this field is a mandatory field on the Participants Details Form). However, participants may nominate a GP who has neither knowledge of nor a medical record for them. This nominated GP is then the recipient of all communication from the register thus transferring the duty of care to the GP. There is widespread unease amongst GPs about the duty of care for these patients. Further:
 - i This information may come to the GP with limited participant details being provided thus making it difficult to establish contact;
 - ii GPs may have closed their books to new patients.
- The GP/participant relationship is important in providing optimal quality of care. However it also recognises that asking participants to nominate a GP and having this field mandatory does not necessarily reflect an established relationship between GP and participant. Whilst the safety net is less effective when a participant does not nominate a GP public education about the benefits of seeing a GP for positive FOBT, strong family history and/or symptoms may more appropriately address this issue.
- As a publicly funded health program the aim is to invite all people in the appropriate age group to screen for bowel cancer. Whilst equity of access is essential it is equally important to ensure that people's right to choose (to do the test or not, to have a GP or not

and to seek treatment if required) be respected. By people making their own choices, they retain responsibility for their own care. Clarity around duty of care issues could be addressed by a public/GP education campaign rather than by complex safety net procedures.

- The safety net procedures currently include notification of colonoscopy report and histopathology to the register. Colonoscopy service providers are not required to provide this information to the referring GP. This raises an issue of duty of care for the participant's GP if they are unable to assess appropriate ongoing management for their patient following the colonoscopy procedure. Whilst communication between the colonoscopy and/or pathology service provider and the referring GP is assumed best practice, in reality this may not occur.

Recommendations:

- **That safety net procedures need to be reviewed to identify:**
 - where current procedures have worked smoothly and effectively;
 - where current procedures have not worked well; and
 - how to effectively target safety net procedures in a national program to ensure that duty of care issues are met while maintaining a reliable and effective screening pathway.
- **That Risk Assessment (Family History and Symptoms) is omitted from the Participant Detail Form (see discussion above).**
- **That the "Nominated GP" field no longer be a mandatory field for the Bowel Cancer register.**
- **If the Nominated GP field is to remain mandatory then the Participants Contact Details must be provided to the GP nominated by the participant.**
- **That regardless of whether or not the participant has nominated a GP, the letter advising the participant of a positive FOBT include a recommendation to consult a GP.**
- **That education of the general public and GPs include promotion of the importance of seeing a GP for positive FOBT, strong family history and/or symptoms.**
- **That pre-admission clinics be a requisite part of the colonoscopy Pathway.**
- **That colonoscopy services be required to communicate the results of the colonoscopy (colonoscopy and histopathology reports) to the referring GP. Any recommendations about future management made by the colonoscopist should be included in information provided to the GP.**

Model of delivery of Pilot screening program

GPs from the Pilot are now experienced in a variety of models of population health screening programs and are well placed to provide feedback about the model of delivery for a National Bowel Cancer Screening Program. Those GPs who gave the Division feedback directly about the Pilot have indicated that they support the model of delivery of the screening program (sending invitation directly to participant) because they did not want to be involved in the distribution of FOBTs.

However, there are some communities that have found the model difficult to implement. The model of distribution could be looked at from a number of perspectives (including GP, CALD and ATSI).

There may be value in considering some flexibility in distribution models for some specific communities. For example, some health practitioners, such as GPs with a high number of patients from culturally diverse backgrounds, or ATSI health workers could provide FOBT kits to participants who may have discarded those sent in the mail.

In the Pilot project FOBT kits are bar coded and cross-referenced with participant details from Medicare data etc. However, it cannot be assumed that the FOBTs are actually completed by the participant to whom they are sent. If a number of models of distribution were used, there may be value in using name/address/date of birth information for identification rather than bar codes. The ATSI and CALD discussion papers, provided by the working groups, address these issues further.

The current model of distribution relies heavily on a high level of literacy. The information contained within the myriad of literature (including FOBT instructions) supplied to the participants is not always clear and consistent.

Recommendations:

- **That the formal GP evaluation addresses the question of “model of delivery”.**
- **That there should be a review of all participant communication and information to ensure that:**
 - **the reading level of all written materials is set at Year 8 level or below (where possible) ensuring that simple messages are conveyed without compromising the meaning;**
 - **the content is consistent with other public education messages;**
 - **any actions that the participant is required to undertake are clear; and**
 - **any messages about assessing family history and symptoms are clear (currently they are not well understood by participants).**

Practice issues

The Division recognised that a number of activities could fall to practice staff and consequently provided Practice Staff with training in some aspects of the Pilot program. GP Practices varied in their use of practice staff (managers, reception staff and practice nurses) in activities associated with the Pilot.

Recommendations:

- **That the formal GP evaluation addresses the impact of the Pilot on practice staff.**
- **That a National Bowel Cancer Screening Program should include GP education about the effective use of practice staff.**

CALD issues in General Practice

The Victorian Pilot site had a number of GP clinics that service CALD populations. GPs did report longer consultations required for older CALD participants. GPs highlighted a number of issues relating to CALD participants including:

- Difficulties in access to information about the Pilot in the appropriate language;
- Participant Details Form only in English;
- Difficulties in access to interpreters during the consultations – often GPs rely on family members for interpretive services (which is not considered best practice for working with CALD groups); and
- Differing cultural beliefs about cancer and fear of screening tests.

See further discussion under “Model of Delivery of Pilot screening program”

Recommendations:

- **In the event of a National Program consultation would need to be with both peak representative bodies, and regional health services to tailor culturally appropriate models of delivery.**
- **National Screening Program should include GP education around accessing TIS and options for using interpreters.**
- **National Screening Program should include GP education around cultural beliefs around cancer.**

Aboriginal and Torres Strait Islander issues

Because of the diversity of Aboriginal and Torres Strait Islander communities across Australia the experiences gathered in the Pilot will be insufficient to fully inform a national program with respect to Aboriginal and Torres Strait Islander communities. There is a large body of work that documents the difficulties and issues involved in health service delivery including screening in Aboriginal and Torres Strait Islander communities. Given the burden of morbidity and premature mortality experienced by the Aboriginal and Torres Strait Islander populations, a national bowel cancer screening program would need to fit within existing frameworks such as the National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003 – 2013 (prepared July 2003). These frameworks focus on the determinants of health.

See further discussion under “Model of Delivery of Pilot screening program”

Recommendations:

- **A national Bowel Cancer Screening Program works within the existing frameworks for Aboriginal and Torres Strait Islander community health.**
- **In the event of a National Program, consultation would need to be with both peak representative bodies, such as NACCHO, and regional health services to tailor locally appropriate models of delivery.**

Pathway, Register and HIC issues

- The screening pathway is relatively complex requiring a high level of administrative input. There is a lot of information gathered by all of the forms (PDF, GP Assessment), the forms are complex, there is a large number of different letters triggered at different points in the pilot pathway to both GPs and Participants and there is a significant cost associated with these.
- GPs reported confusion between the functions and phone numbers for the Participant and GP Helplines. Additionally GPs reported difficulty in finding the appropriate contact details for the Helplines, Register etc. To address this problem the Division supplied GPs and Practice Staff with stickers detailing relevant contact information. However these were provided to GPs very early in the Pilot program, often before GPs had seen a Pilot Participant and required the information, and could not be found when they were needed.
- GPs reported inconsistencies in the information provided by the HIC General Public Helpline and the literature provided in the GP Resource Kit.
- Information provided by the General Public Helpline was in English. A non-English speaking participant who rings the Helpline will be advised, in English, to contact the Translating and Interpreting Service who then ring the Helpline and have a 3-way conversation.
- Community education campaigns have generated concern and questions in the general public. National Helpline currently responds only to administrative questions about the Pilot and then directs participants to other sources for clinical support (eg: Cancer Council Victoria or GP).

Recommendations:

- **That a National Helpline should have the ability to address both administrative and clinical issues.**
- **That all supporting resources and services provide consistent information.**

Support

There was a range of supports available to GPs :

- Division – helpdesk, practice visits, information sessions, training sessions, news update;
- website(s) BCSPP, CCV, NHMRC, NCCI;
- GP info kit; and
- other

Recommendation:

- **That the formal GP evaluation addresses the usefulness of each of the available supports.**

Recommended key informants for a comprehensive GP evaluation

We recommend the use of key informant interviews/focus groups as the preferred evaluation method. Key informants should include representatives of the range of settings and a range of attitudes/interests as listed below:

- small (single) Practice;
- large GP Practice;
- medium GP Practice;
- CALD Practice/ Practices with ATSI patients;
- non-CALD Practice;
- CHC GPs;
- GP who is/was enthusiastic about Screening for BC and the Pilot;
- GP who is/was not enthusiastic about Screening for BC and the Pilot;
- GP with a large number of patients who are in the BCSPP cohort;
- GP with minimal number of patients who are in the BCSPP cohort; and
- GP Practice Staff

Divisions of General Practice

There were four phases of Divisional involvement within the Pilot:

1. Preparation for Pilot including:
 - a. attending GP Workshop (Feb 2002);
 - b. establishing links with key stakeholders in Victoria (including Implementation Committee);
 - c. planning for Divisional role and activities;
 - d. developing Familiarisation presentation;
 - e. involvement with Education and Communication Task Group; and
 - f. appointing Project Officer.
2. Engaging and Familiarising GPs and Practice Staff with the Pilot including:
 - a. distribution of GP Resource Kits (including FOBT sample kits, Stickers);
 - b. practice visits; and
 - c. CPDs for GPs and Practice Staff.
3. Supporting the Pilot Implementation including:
 - a. dedicated Project Officer and GP Consultant;
 - b. Division Helpline for GPs and Practice Staff;
 - c. monthly news update to Divisional membership;
 - d. ongoing Implementation Committee meetings and liaison with Cancer Council, state Health Department;
 - e. supporting public engagement campaign;
 - f. inter-site communication and co-ordination; and
 - g. participation in Pilot workshops (Canberra).
4. Evaluation including:
 - a. planning a comprehensive GP evaluation;
 - b. interdivisional discussion re GP evaluation;
 - c. preparation of Discussion Papers (Colonoscopy, GP Evaluation, Implications for a National Program); and
 - d. one-to-one evaluation interviews with GPs.

We recognise that a lot of the work the Division was involved in was particular to a pilot program:

- the program was new;
- GPs were unfamiliar with Bowel Cancer screening;
- geographical boundaries and age specification that determined access to the Program; and
- difficulties experienced with the trial notification, register and safety net procedures.

In a national program with simplified notification, register and safety net procedures and the ability to undergo national education campaigns (both GP and general public) the intensity of Divisional support may be reduced.

Divisional involvement in a national program would be simplified with:

- comprehensive and consistent information for GPs in resource kits, CPDs and register helpline;
- national education campaign (GP and general public) re:
 - bowel cancer;
 - the benefits of FOBT as a screening tool; and
 - the benefits of a register;
- dedicated staff at Divisions who understand above; and
- training resources for Divisions.

Recommendations:

- **That in the national evaluation Divisions should be asked about:**
 - **communications between the Divisions and other Stakeholders (as listed below);**
 - **what was required to enable the Pilot to work from a Divisions perspective (see our issues raised in this paper);**
 - **what sort of communications would be needed in a National Program with a focus on both Communication Processes and Content?**
 - **workforce issues – with respect to planning and implementation for the Pilot and implications for a possible National Program;**
 - **other issues (unexpected issues and outcomes).**
- **Key Stakeholders for Divisions' evaluation:**
 - **GPs, Pilot Site Divisions, Local Cancer Councils, Dept. of Health and Ageing, State Health Departments.**

Colonoscopy services

Workforce

This is a primary health care initiative and not all of the colonoscopy workforce is familiar with this as framework for professional practice. Workforce planning needs to consider:

- i quality of technical expertise (safe colonoscopy);
- ii quality of patient care (dedicated services that provide advice and support as required bearing in mind that raising the spectre of cancer generates significant morbidity irrespective of the outcome of further procedures); and
- iii quality of systems (with respect to co-ordination of services, communication, etc.).

A National Bowel Cancer Screening Program could increase the appropriateness of colonoscopy referral so that there is a shift from inappropriate use of colonoscopy as a screening tool in low risk patients to those who fall within the accepted NHMRC guidelines for requiring colonoscopy. If this shift in resources occurs many of the workforce and colonoscopy service funding issues could be addressed.

Other issues

- i impact of Pilot on usual access to colonoscopy (waiting lists);
- ii appropriateness of paperwork (GP Referral, colonoscopy reports etc);
- iii issue of recruiting providers to program. Any screening program of this nature necessitates documentation to maintain register as crucial part of running program (issue of familiarity/ commitment to public health ethos);
- iv ethics of providing easier access for people on a screening program compared with those from symptomatic population; and
- v consider how some Pilot processes may differ from usual (non-Pilot) colonoscopy service to identify positive models of care.

Recommendations:

- **That some detailed evaluation be undertaken to ascertain the experiences of colonoscopy service providers in each of the sites.**
- **That models of colonoscopy service delivery be explored for development of a National Program.**
- **That models of patient care in colonoscopy services be reviewed to look at developing guidelines/criteria for service delivery.**

Market issues

The Division is aware that some private Colonoscopy providers have been marketing colonoscopy as a screening procedure to both GPs and the general public. Similarly Pathology services are promoting their products by providing FOBTs to GPs. In both cases these services are being provided independently of any commitment to a public screening program and the associated register processes. This has implications for:

- overservicing;
- regulation; and
- participation in an organised national screening program.

There is an increasing amount of ad hoc and often inappropriate (according to NHMRC guidelines) screening activities occurring related to the increasing awareness of bowel cancer and the market forces at play.

Recommendations:

- **That there is a need for immediate and ongoing education that addresses the following issues for:**
 - **General Public:**
 - **FOBT as an effective and safe screening tool for asymptomatic people;**
 - **and**
 - **NHMRC Guidelines for FOBT and Colonoscopy**
 - **General Practitioners:**
 - **FOBT as an effective and safe screening tool for symptomatic people;**
 - **NHMRC Guidelines for FOBT and Colonoscopy; and**

- relationship between the types of FOBT tests available, the sensitivity of the test and the implications for patient management
- That at the commencement of a National Program the Register must be able to take into account:
 - the history of screening and diagnostic activities people have undergone (FOBT, colonoscopy); and
 - those people who are having ongoing surveillance
- That public education campaigns address the importance and value of:
 - an organised screening program;
 - a screening register; and
 - FOBT as an appropriate screening tool that helps to determine when and if you should have a Colonoscopy.

Originally prepared by:

Ms Alison Elliott (Project Officer), Dr Mira Kapur, (GP Advisor), Dr Mary Belfrage (GP Advisor)

North East Valley Division of General Practice

May 2004

Updated Version prepared August 2004

With input from the Victorian Implementation Committee

**Attachment B:
Bowel Cancer Screening National GP Workshop –
Syndicate Group Discussion Topics**

Syndicate Group 1

TOPICS	ISSUES/QUESTIONS TO CONSIDER
1. Quality improvement – consultations and referrals	<ul style="list-style-type: none"> • What is needed to support and encourage GPs to comply with national quality protocols (eg the NHMRC guidelines)? • What sort of streamlined processes could be applied?
2. Training and support	<ul style="list-style-type: none"> • What support materials and training programs are required to assist GPs to participate in a possible national screening program? (eg Helpline/s, printed materials, practice visits, link to CME points) • What sort of streamlined processes could be used in the delivery of the materials and training? <ul style="list-style-type: none"> ○ What about in rural and remote areas? ○ What existing infrastructure could be used in the delivery of these training and support programs?
3. Data transfer and interface with the national screening Register	<ul style="list-style-type: none"> • What tools could be put in place to simplify and support the role of GPs? (eg, electronic interface, use of Medical Director or similar IT program) • What issues will influence provision of data to the Register and others? • To what extent can we rely on electronic data transfer? What barriers might we face with this?
4. Pathway issues	<p>Central to the pathway in the Pilot was the decision to distribute FOBT kits directly to the public.</p> <ul style="list-style-type: none"> • Given what you have heard about the success of this approach in the Pilot sites: <ul style="list-style-type: none"> ○ What are the pros and cons of distributing kits to the public through general practitioners or another means?

	<ul style="list-style-type: none"> ○ What recommendation would your group make for how kits should be distributed for a national program? Why? ○ How does the structure/model of the Bowel Cancer Screening Pilot perform, relative to other screening programs?
--	--

Syndicate Group 2

SUGGESTED TOPICS	ISSUES/QUESTIONS TO CONSIDER
1. Interface and referral arrangements – Pathology and Colonoscopy Services, Hospital or Day Facilities, Specialists	<ul style="list-style-type: none"> ● What arrangements will need to be put in place to streamline processes for GPs? (eg streamlined referral and consent processes, timely access to colonoscopy for screening participants) ● In what ways can/should the public be communicated with in order to assist in streamlining processes/consultations with GPs?
2. Role of Divisions	<ul style="list-style-type: none"> ● What role should Divisions and State Based Organisations play in supporting GPs should a national bowel cancer screening program be introduced? (eg coordination/liaison, practice visits, information sessions, training, regular updates, helpdesk) ● What funding and resourcing will be required to support roll-out of mobilisation strategies by SBOs/Divisions? ● How can we expect these supports to best be delivered? Who should deliver them?
3. Role of other key players	<ul style="list-style-type: none"> ● What roles could practice staff and nurses perform to relieve the pressure on GPs? (eg completion of forms, transfer of data to Register, contact/follow-up of patients, assistance in smooth referral to colonoscopy) What would be required to support and facilitate them in taking on these roles? ● What role can/should the Cancer Council, or similar organisation, play in relation to mobilising and supporting GPs? What would be required to support and facilitate them in taking on these roles?

<p>4. Access & equity</p>	<ul style="list-style-type: none">• How can provision of culturally appropriate models of service delivery be supported for CALD and ATSI groups?• How can provision of appropriate models of service delivery for disabled persons be supported?• What support materials and training are required for GPs? (eg use of TIS, cultural awareness, including cultural barriers to screening and discussion of cancer)• What arrangements are needed to address issues in rural and remote areas?
-------------------------------	---

Attachment C:
**List of participants at Bowel Cancer Screening
National GP Workshop 24 August 2004**

Name	Representing
Dr Fiona Millard GP, Mackay Division of GP	Mackay Pilot site (Mackay Division of General Practice)
Dr Linda Foreman The Cancer Council, SA (former Clinical Advisor to AW & ASDGP)	Adelaide Pilot site (parts of Adelaide Southern & Western Divisions of General Practice)
Dr Helen Parry GP Advisor, ASDGP	
Ms Alison Elliott Program Officer, NEVDGP	Melbourne Pilot site (part of North East Valley Division of General Practice)
Dr Mira Kapur GP Advisor, NEVDGP	
Dr Wayne Clapton Medical Director/Manager SA Cancer Registry Department of Health, SA	State & Territory Governments (in States with Pilot sites)
Mr Rory Wilby Program Manager Prevention & Cancer Screening Department of Human Services, VIC	
Ms Jennifer Muller Director Cancer Screening Services Unit QLD Health	
Ms Alison Peipers Cancer Education Programs	The Cancer Council Victoria
Ms Rebecca Russell GP Education Officer	

Name	Representing
<p>Professor Finlay MacRae Gastroenterologist The Royal Melbourne Hospital VIC</p> <p>Professor James St John Gastroenterologist Senior Clinical Consultant National Cancer Control Initiative, VIC</p> <p>Dr Chris Stevenson Cancer Screening Project Health Registers and Cancer Monitoring Unit Australian Institute of Health and Welfare</p>	<p>Bowel Cancer Screening Pilot, Monitoring & Evaluation Steering Committee (MESC)</p>
<p>Dr Charles Guest Deputy Chief Health Officer Population Health Division ACT Health</p> <p>Mr Ross O'Donoughue, for Dr Denise Robinson NSW Health Department</p> <p>Dr John Carnie Director Disease Control & Research Branch, & Deputy Chief Health Officer Department of Human Services, Victoria</p>	<p>State & Territory Government representatives, Australian Screening Advisory Committee</p>
<p>Ms Julie McCormack National Manager, QA & CPD</p> <p>Dr Peter McGuire Chair, QA&CPD Committee Coordinator, GP Vocational Education Centre</p> <p>Ms Margo Field National Partnerships Development Advisor, gplearning team</p>	<p>Royal Australian College of General Practitioners (RACGP)</p>
<p>Dr Richard Heah GP, Work Health Clinic</p>	<p>Australian Medical Association (AMA)</p>
<p>Mr Mark Elliott Senior Policy Officer</p> <p>Ms Rachael Yates Senior Policy Officer</p>	<p>Australian Divisions of General Practice (ADGP)</p>

Name	Representing
Ms Susan Stratigos Policy Advisor	Rural Doctors Association of Australia (RDAA)
Ms Susan Webster Divisions Consultant	General Practice Divisions Victoria
Ms Kate White Cancer Screening Projects Dr Dilip Dhuphelia GP, Toowoomba QLD	Queensland Divisions of General Practice
Dr John Crimmins GP and GP Educator ANSWD Dr Susan Harnett Chairman and Program Manager, Bankstown Division of GP Ms Shanelle Sloan Program Manager, Population Health Riverina Division of GP	Alliance of NSW Divisions of General Practice
Dr Tuck Meng Soo GP, ACT Division of GP	ACT Division of General Practice
Dr Karen Moller GP, Perth Central Coastal Division of GP Dr Crystal Cree GP, Pilbara Division of GP Dr Revle Bangor-Jones GP, Canning Division of GP	Members of WA Divisions of General Practice
Ms Rebecca Dadds Senior Project Officer	Cancer Institute NSW
Mr Wayne Kinrade Director, HMA	Bowel Cancer Screening Pilot Evaluator, Healthcare Management Advisors (HMA)
Ms Ann Porcino Facilitator	RPR Consulting