



Australian Government

Department of Health and Ageing

**BOWELCANCERSCREENING** 

PILOT PROGRAM  
An Australian Government Initiative

## Screening Monograph No.2/2005

# A Qualitative Evaluation of Opinions, Attitudes and Behaviours Influencing the Bowel Cancer Screening Pilot Program:

Final Report

August 2004

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Attitudes and Behaviours Influencing the  
Bowel Cancer Screening Pilot Program

**FINAL REPORT**

**Bowel Cancer Screening Pilot Monitoring and Evaluation Steering Committee**  
**August 2004**

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ISBN 0642 82812 1

Publications Approval Number 3769

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Reports on the Bowel Cancer Screening Pilot were coordinated by the Bowel Cancer Screening Pilot Monitoring and Evaluation Steering Committee with support from the Screening Section, Targeted Prevention Program Branch, Australian Government Department of Health and Ageing. This report was prepared by Woolcott Research Pty Ltd.

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# 1

## Executive Summary

### 1.1 Background

**This qualitative study was conducted in order to assess attitudes, opinions and behaviours that influenced participation and non-participation in the Bowel Cancer Screening Pilot Program conducted from late 2002 to mid 2004. It was a part of a full evaluation of the Pilot, and it was to provide input from the perspective of the general population within the target age groups from each of the Pilot areas, as well as some feedback from GPs from those areas.**

The Pilot involved the distribution of self-administered FOBT kits amongst people aged 55 to 74 years, in Mackay and in specific post codes of Melbourne and Adelaide, and it was to act as a test study, to inform decisions about a possible national roll out of a screening program at a later date.

The research study involved consumers who had received the material and who had decided either to participate or not, for various reasons. A specific component of Aboriginal and Torres Strait Islander (ATSI), South Sea Islander (SSI) and culturally and linguistically diverse (CALD) people were included in the study, in order to ensure any activities adopted in the future were inclusive of their needs, and a sample of GPs were also included.

This report details the findings of the qualitative study, with this executive summary outlining the key findings, along with conclusions and recommendations.

### 1.2 Objectives

**The key objectives of the study were to, as described above, assess the relevant attitudes opinions and behaviours that influenced participation in the Pilot, along with reactions to the Kits and the test material, and the context surrounding participation.**

Amongst the general public, including the CALD, ATSI and SSI kit recipients, the more detailed objectives included:

- the level of awareness and knowledge surrounding bowel cancer and screening generally;
- overall reactions to the Pilot and the way it was conducted;

- the process of consideration and actions taken once aware of the Pilot including key triggers and barriers to participation, and exploration of any cultural or language issues amongst CALD, ATSI and SSI recipients;
- detailed evaluation of the content of the invitation pack and the material in it; and
- suggested improvements to the program if it were to be conducted on a national level.

Amongst GPs the main objectives were:

- to examine reactions to their involvement in the program;
- to obtain feedback on, and satisfaction with, the model of delivery of the program, both from their own and their patients' perspective; and
- to collect any feedback they had regarding improvements if the program were to be conducted at a national level.

### 1.3 Research design

**The research was conducted as a large scale qualitative exercise, combining mini group discussions and one on one in depth interviews amongst specific target groups in each of the Pilot areas.**

#### *General population*

Participants and non participants were recruited at random from within each Pilot geographic area as follows:

- a series of 8 mini groups was conducted amongst participants;
- a series of 6 mini groups and 7 face to face in depth interviews were conducted amongst non participants; and
- 4 face to face in depths were conducted amongst participants who had been referred on for a colonoscopy.

The group discussions were split equally between males and females, and same sex mature moderators were used to ensure open discussion.

#### *Culturally and linguistically diverse, Indigenous and South Sea Islander participants and non- participants*

A series of 60 in depth interviews were conducted amongst people from CALD, ATSI and SSI backgrounds in the Pilot sites, with the language and cultural groups chosen for each of the sites based on the 2001 Census data.

The languages covered included Cantonese (Melbourne), Vietnamese (Adelaide), Italian and Greek (Melbourne and Adelaide), and Aboriginal and Torres Straight Islanders and South Sea Islanders in Mackay.

Culturally specific researchers conducted the interviews, and roughly equal numbers of males and females were included.

### ***GPs within the Pilot sites***

A broad selection of GPs operating in the pilot sites were included, with a total of 20 telephone in depths, and 6 face to face interviews, all conducted by appointment at appropriate times for them.

## 1.4 Detailed findings

### ***Overall attitudinal trends***

There were some overarching differences in attitudes and knowledge regarding health issues generally, and cancer specifically, observed between males and females, participants and non participants, the pilot areas, and CALD, ATSI and SSI people, which had some bearing on levels of participation and likelihood to screen.

In summary, those who participated in the Pilot tended to be people who were confident, and in control of their own health. They appeared more informed about health issues, and more inclined to talk openly about the testing procedure, sometimes even joking about it. Non participants on the other hand were more likely to be suffering from other illnesses, and to be less informed and more reluctant to confront and discuss health issues.

Females were in the main more proactive and aware than were males, and they had played a part in encouraging their partners to be more interested in their health and in adopting preventative behaviours.

In Mackay, there was a higher awareness of the Pilot and more open discussion of it in a social sense, and this impacted to some degree on participation. This could be attributed to the more controllable publicity and media within a regional centre such as Mackay, along with a general propensity for people in regional areas to pick up on special activities, and view them positively as being inclusive, because they feel they are sometimes left out of city based health or social programs and activities.

Whilst to a degree the CALD, ATSI and SSI people were influenced by the same variables as the general consumers, it was clear that issues around English language competency and literacy were highly relevant for these people.

Support networks also had a definite impact on participation as a result of the literacy and language needs, with family and friends, GPs and health and community workers playing an important part in helping recipients of the Kits understand what was required.

ATSI and SSI people were generally less proactive and less likely to take control of their health compared to other groups, depending heavily on community health workers to raise issues with them.

Overall however there were no significant cultural taboos evident around the topic of bowel cancer and screening amongst any of the CALD language groups or Indigenous participants included in the research.

### ***Pre-existing knowledge and attitudes toward bowel cancer***

It was very clearly evident that bowel cancer is still a relatively low profile cancer, with often erroneous beliefs associated with it. It was not seen as one that was talked about much, and no celebrities were known to have openly been featured as having it, unlike some other cancers, so it was therefore thought to be quite rare.

Despite that, it was also one of the most *feared* forms of cancer, being thought to be particularly deadly once discovered, or leading to a very poor quality of life.

This concern can prompt some people to screen, but others are disconcerted by the fear, preferring not to think about it or face up to something like screening because “it is better not to know”.

There was also a perception that it is mainly a male disease (which led some females to believe it was unlikely to affect them), or a disease that just strikes late in age (65+), or only those with a family history. Some also believed it would be easily identifiable through observable symptoms.

GPs had, it appeared, been quite active amongst this age group in encouraging those with family history or any symptoms at all to undertake colonoscopies.

Levels of awareness did not vary dramatically by language group, but it did seem as though CALD people were less familiar with the concept of “do it yourself” health checks such as the FOBT, being more likely to rely fully on the GP or Doctor to conduct any screening or check ups. For many CALD participants the GPs were respected and viewed as “experts”, and in many cases the responsibility for health care was deferred to the GPs, with the FOBT kit often taken to them for advice. If the GP advised on participation in screening, they were more likely to do it.

Amongst Indigenous and South Sea Islander research participants, knowledge and awareness was much lower than amongst other groups, and several had difficulty in distinguishing between bowel cancer and other cancers. They tended to talk about “checking your insides” with little understanding of the process. Once again the community health sector had been influential in encouraging other screening, for example through the “Well Women Check” program in Mackay, and it was imagined that bowel cancer screening would be included in that sort of initiative.

### ***The role of Government***

Regardless of whether people participated in the pilot or not, it was definitely seen to be the role of Government to inform the population about health, and to provide options which could assist the community to effectively manage their health.

The majority were very much in favour of a Government initiated bowel cancer screening program, seeing it as a real benefit to the population. If such a program were to go ahead, most felt that it should be supported by mass media and advertising, ideally with a celebrity involved to normalise it and bring it out into the open.

Both CALD and Indigenous groups were also extremely positive about the concept, feeling grateful to have been involved and included. The ATSI people in particular were more likely to view the program as an example of the “government caring about me and the health of my community.”

### ***Reactions on the receipt of the pilot pack and how it was used***

Reactions to receipt of the invitation pack varied according to pre-existing attitudes toward health and the perceived need for preventative behaviours, as well as the levels of awareness about the Pilot and what it involved.

Those who did participate in the Pilot were more likely to have noticed and picked up on publicity about it before they received the material, and so it did not come as a surprise to them. They reacted positively, and tended to discuss it with friends, building up a feeling amongst themselves that it was a normal thing to participate in.

Non participants however were less likely to have noticed or remembered publicity and were more likely to be surprised by it.

Some were embarrassed about it being seen in their letter box, and they were less likely to want to discuss it with friends or family, and therefore had no social support or influence to encourage them to participate.

For some, receipt of the kit was a reminder of the loss of a friend or partner through cancer, and some also found the amount of material in the pack was off putting and complicated looking. As a result there was a proportion who immediately threw the pack away, without looking at it in any detail.

Amongst those from culturally and linguistically diverse backgrounds, those with less knowledge of English were more likely to put the Kit aside, or to seek help from a third party, such as family members, or, as mentioned, the GP. There was limited recognition of the presence of the web site, or the phone Helpline.

Some Indigenous and South Sea Islander people either could not recall having received the Kit, or had thrown it away, seeing it as too complex and difficult to digest, particularly if

literacy was an issue. Importantly however, after discussing the testing in the research, some were disappointed they had not conducted it or tried to find out more.

### ***The decision making process and the role of the information pack***

The decision about whether to proceed with the test or not was primarily influenced by a range of prior attitudes and beliefs about bowel cancer and the role of screening, and to some extent the material contained in the Kit was irrelevant to that decision, except amongst those who were undecided.

That is, there was a continuum of attitudes, with at one end a segment who were already aware of bowel cancer and the role of screening in providing positive outcomes. These people were already proactive in managing their health, and likely to have taken the test regardless of what the accompanying material was like. The brochure and letter served to reinforce existing attitudes, and they therefore read it in depth.

At the other end of the scale were those who were clearly unwilling to confront the issue of cancer at all, with a deeply fearful attitude. They were more likely to have “thrown the material in the bin”, or some had glanced briefly at the materials, but not taken in any detail. It was clear these people were not processing the material rationally, and no amount of facts or detail would persuade them.

In the middle were a group who tended to feel they probably should participate, but who were reluctant for various reasons, and often came up with excuses for putting it aside till later. The material and perceived ease of the test did have influence on this group, whilst some looked for further support from the GP to confirm their decision.

For some CALD people, a lack of English skills had a clear impact on the extent to which the material was looked at in any depth, and if they did not receive help from a family member or GP, they were unlikely to proceed further. Some had been quite alarmed by receiving the material and seeing the word “cancer” without being able to understand the whole thing.

Some were reluctant to call the 1300 number for translation because they were concerned about the quality of translations.

Indigenous and South Sea Islander people were also affected by literacy levels, and they, unlike CALD respondents, were less likely to bother family members with questions, or ask others for support. It was only after a health worker suggested it to them that they took any action.

### ***Participation triggers and barriers***

As discussed, prior positive attitudes toward preventative health measures and bowel cancer were the most powerful motivators regarding participation or non participation, combined with a range of other elements including *triggers* such as:

- belief in the efficacy of screening in preventing death from the disease;
- social acceptance and encouragement to take part in a screening program;
- a desire to ensure the best quality of life possible into old age, often motivated by involvement in grandchildren and the community;
- a belief by males that bowel cancer is more common for them;
- family history of bowel cancer; and
- perceived ease of use of the screening kit and its components, particularly compared with colonoscopy.

As mentioned, CALD people often required further encouragement from the GP, and for ATSI and SSI people, the intervention of community health workers in encouraging people to test to “obtain peace of mind”, and “check out what is happening on the inside” was important.

Particular barriers to participation included:

- fear of finding something, and that leading to a certain death, or poor quality of life... *“it is better not to know”*;
- having no visible symptoms;
- a general lack of social support, a feeling of loneliness in facing it;
- no family history “we are a heart family, not a cancer family”;
- the test format itself, and a preference to be removed from it altogether, i.e. have a colonoscopy where the GP handles it all;
- physical problems in collecting the samples;
- doubts about the efficacy of an FOBT, using just a “smear”; and
- the presence of other illnesses and a general inability to cope with yet another process.

Amongst those from culturally and linguistically diverse backgrounds language was a significant barrier, along with the general barriers described above. Some were overwhelmed by the size of the kit and the amount of information in English, whereas others assumed it would not be relevant to them because it was not in their language. Sometimes family members, such as children were embarrassed about explaining the detail. Several said that if the information had been sent to them in their own language they would have participated straight away.

For Indigenous and South Sea Islander people there was less awareness of bowel cancer related issues, and therefore less understanding of the purpose of the kit and the screening process.

### ***Reactions to the specific materials in the kit***

There were no issues or problems identified with any of the material, apart from the language and literacy issues already discussed.

The main criticism was that there was a lot to read which was daunting for those less committed, and the HIC letter, and the Dietary and Activity booklet were felt to be extraneous to a degree, the HIC letter because there were no concerns about privacy, and the booklet because it was not providing any new information and was not relevant to the completion of the screening.

The presence of family history details on the participation form were expected, but did confirm the notion for some that only those with family history are at risk.

The letter and the information booklet worked well, with the statement of fact about numbers who die each week on the letter in particular causing impact.

There were pros and cons associated with each test type, the DEPEND test appeared more complex initially, but was thought to look more like a “real” test and people liked the paper collection sheet, whereas the INFORM kit was thought to be easy to use with friendly approachable instructions. Some had doubts about the efficacy of the small smear from this test type.

Those from culturally and diverse backgrounds definitely felt there was too much information present in the kit, and there was a strong preference for bilingual information to be sent with it. They were happy with the translated information they were shown in the interview, which had been taken from the materials shown on the bowel cancer screening pilot website.

The Indigenous and South Sea Islanders had few comments about the specific materials, an indication of their general lack of engagement with them until prompted by a health worker.

### ***GPs reactions and feedback***

Overall, the reactions of the GPs included in the research were very positive. They believed a screening program would be very beneficial for the community, particularly in relation to Bowel cancer which has few early symptoms.

### ***Administration***

Most thought that the program had been well designed and implemented, and they indicated that they were generally happy with the workload and administration, particularly given the staggered nature of the distribution of kits.

Payment for completion of forms was seen as a good incentive, particularly given the number of forms they complete which they are not compensated for.

There were however suggestions for improvement including:

- participation numbers on forms, to save time in trying to find this number;
- difficulty in telling the referral forms apart (they suggest colour coding);
- the need for extra space for extra comments; and
- the inclusion of the contact details of the register and Helpline to save time in looking these up.

Reactions to the idea of electronic forms were extremely favourable amongst some, provided they were compatible with Medical Director. Some found reconciliation of payments difficult and suggested a specific item number be provided.

### ***The referral process***

Reactions to the referral for colonoscopy process were mixed, and some felt waiting times had been excessive.

They felt the implications of this for a national rollout had potential to be quite serious if specialists were not available, or if there was not an ability to move high-risk cases through more quickly. There were also concerns about whose responsibility it was to follow up on when the colonoscopy was to take place.

### ***Duty of care***

Most GPs included in the research were comfortable with their duty of care under the screening program, assuming that it would remain with HIC until the patient consulted them with regard to the program. Most suggestions regarding this generally centred around public education and communication encouraging patients to consult their GP, or a GP if they did not have a regular doctor.

### ***GP education***

There were mixed reactions regarding the amount of information GPs had received regarding the Pilot, from HIC and the Divisions.

GPs in the research talked about having received a “huge” file of information that made them initially believe the work load would be complex and onerous, when in practice it was not.

They did not believe they needed much information about bowel cancer, rather that the information should focus on the administration, and on the efficacy of the newer testing procedure.

### ***Patient response***

GPs found patient response had been positive, particularly after receiving encouragement from the GP. There was however strong support for the need for a public awareness campaign, to build the social acceptance of the FOBT as a normal easy procedure, and to help educate people about bowel cancer screening.

GPs felt that people who were without a fixed address would be disadvantaged, particularly some ATSI people in Mackay, and they also felt that people with poor literacy and English skills had found the information packs too complicated and therefore inaccessible. They again suggested supplementing the information in the packs with targeted TV, Radio and other media activities.

# 2

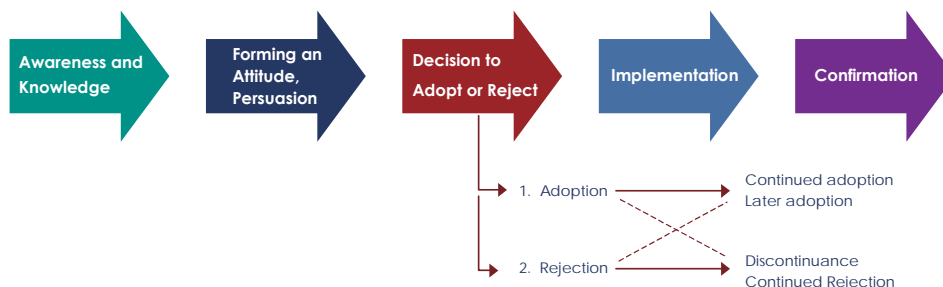
## Conclusions and Recommendations

### 2.1 The general population

Overall the Pilot was very positively received and applauded as an important Government initiative. However, whilst it reportedly has achieved a relatively high level of participation amongst the target groups, the research findings suggest that this will not be increased dramatically in a National roll-out, without a public information campaign to set up the context of the screening offer. That is, to inform and create attitudinal change toward Bowel Cancer and the impact of Screening.

The model below describes how different messages would be required via various channels at the different stages in the decision making process, starting with the setting up of a firm background of awareness and knowledge initially surrounding bowel cancer and its prevalence, then moving through to education about screening and FOBTs, to build on the social acceptability of them as a normal process, and to increase awareness of their ability to detect signs early.

The distribution of the kits along with meaningful support material then has a more receptive audience and background in which to operate, and the assistance of GPs and other health professionals can be used to further persuade and educate, with reminder kits and or letters working as a prompt. Promoting the program with GPs and community health workers prior to the commencement of a national program would improve the success of the program, considering the important role health professionals have with this age group and amongst CALD, ATSI and SSI communities.



The information and messages required at the various stages in the decision making process would include:

### ***Awareness and knowledge***

If the aim of a national rollout is to increase participation levels above those achieved in the Pilot, there will need to be some activity, ideally via mass media such as television, magazines or print, that will educate the broader community, and the target age group in order to raise the profile of bowel cancer, and to correct some of the perceptions that people have which may inhibit their propensity to screen.

Most would expect this to utilise some sort of celebrity testimonials, as the feeling is this technique works well to create attention and communicate that no one is immune from the disease.

The key facts which would need to be communicated would include:

- the prevalence of bowel cancer, that it is not a very rare disease, that males and females can suffer from it, that it does not just strike older (65 plus) people, that it can be present without noticeable symptoms, and it is not necessarily only found amongst those with a family history; and
- reassurance that it is not a death sentence if picked up early on.

### ***Forming an attitude, persuasion***

To ensure the right attitudinal context for receipt of the kit, the knowledge and awareness needs to be built on with persuasive elements, including:

- the existence of in home screening (ie the FOBT);
- the ease of use and benefits of FOBT;
- that screening is a part of controlling your own health and destiny, and that it can ensure a good future life with family and grandchildren;
- that screening is a “normal” process that everyone does, that it may not be the most pleasant but it is OK to laugh about it; and
- there is support available from GPs or other health professionals if anyone has misunderstandings about it.

### ***The decision to adopt or reject***

Once the background is set up, then the Kit and the presentation of the material needs to act as a further prompt to decision making, particularly amongst those who are still wavering or procrastinating.

The ideal invitation pack would therefore contain:

- the clear introductory letter, containing brief details about privacy and the HIC involvement;
- the booklet with information details for further reference; and
- the kit itself.

That is, we do not believe the HIC letter, or the red booklet are necessary.

Each kit has pros and cons, with the “ideal” kit containing:

- the Inform brushes and instructions;
- the Detect sheet for the toilet; and
- reassurance that the “smear” test obtained with the brushes is efficacious and reliable enough.

### ***Implementation and confirmation***

GPs and the Helpline must be available to assist people who have difficulties in implementation, and obviously follow up results notification is important in confirming to people the purpose of the test and its usefulness.

## **2.2 Culturally and linguistically diverse and Indigenous people**

One of the major barriers to participation amongst CALD and Indigenous people was the lack of awareness. The lack of understanding of bowel cancer-related issues, and of the benefits of preventative measures and early detection caused some anxiety and confusion among participants, often leading to a passive rejection of the FOBT rather than active consideration. Amongst those who completed the FOBT, many required support, encouragement or endorsement from GPs and health workers because they lacked confidence in their ability to self-screen and complete the test correctly.

### ***Knowledge and awareness raising***

As with the general population the research suggests that awareness-raising activities need to start with basic information about bowel cancer itself, that it is something that can affect everybody. Once this is understood the community is in a better position to receive and understand information about the fact that it is something that can be managed or prevented through early detection and regular screening.

Once screening is positioned as a strategy to maintain health, rather than detect or confirm illness, the community will be more empowered and better equipped to engage with the idea of self-screening.

The Aboriginal Community Health Service in Mackay currently runs 'Well Women' checks, where breast and cervical screening are positioned as a normal part of regular health checks. There is an opportunity to provide information to health workers such as these, so that this can be imparted to patients as part of routine health checks.

### ***Advertising and promotion***

While not all participants were exposed to the promotional activities and advertising relating to the Pilot, for those who were aware of it stated that to some extent it allayed their anxieties, and positioned the Kit as something that was relevant and appropriate for them.

It is important that promotional activities begin prior to the Kit arriving in the mail. This will assist to curb fears about being specifically targeted because 'something is wrong', and in some cases creates positive anticipation about the Kit's arrival.

In a national rollout of the FOBT screening program, strategies that include GPs, community health organisations, ethnic and Indigenous media and community organisations are likely to be very effective in reaching the target audience:

- **GPs:** The use of GPs in promotional activities is likely to be highly effective. Many of the CALD participants looked to their GP to sanction the program, and to support and encourage their participation. It is recommended that bilingual GPs be used in ethnic media strategies as a way of endorsing the program. It is recommended that consideration be given to developing a question and answer-style format for these communications, particularly in ethnic radio;
- **Community health:** The community health sector is very important for reaching both Indigenous and South Sea Islander communities and newly arrived migrants. The research showed that when people were made aware of the Kit prior to it being sent in the mail (either by media, posters or community discussion), or when a health worker reminded them about the program, this had a positive impact on their decision to complete the FOBT;
- **Ethnic and Indigenous media:** Ethnic and Indigenous media are important mediums for the delivery of information about the FOBT. This is important not only because it provides an avenue for the delivery of information in languages other than English, but again positions the screening as relevant to the individual. It also improves the awareness of the FOBT in the wider community, which is especially important in the CALD communities where family members are often being asked to provide support and assistance in understanding the nature, purpose and process of screening; and
- **Community organisations:** Community organisations, particularly social aged-groups were an effective medium for providing information about the FOBT. They also stimulated community discussion and awareness of self-screening related issues. It is recommended that this strategy be continued in a national rollout.

A number of Indigenous and South Sea Islander people also suggested community information sessions as a way of improving levels of participation in the program. It was suggested that these be coordinated through Indigenous health services by an Indigenous or South Sea Islander health worker. The need for separate sessions for men and women was identified. The CALD participants did not consider this segregation necessary.

### ***Translated information***

One of the other barriers to participation raised was the lack of translated information provided directly to participants.

While the logistical difficulties of providing translated information directly to participants is acknowledged, the provision of a simple statement in a range of languages such as “*Important information about your health ... see inside for details*” displayed in a prominent position in the Kit (perhaps on the back of the envelope) may encourage people to either seek out information in a translated format or ask for assistance to understand the material.

It is also recommended that the use of GPs, community health organisations and community information sessions as conduits for translated information be considered.

### ***More intensive support for Indigenous Australians***

Many of the Indigenous and South Sea Islander participants completed the FOBT after being encouraged, reminded or supported by health workers that were known to them.

Given the literacy issues and disempowerment in many Indigenous communities in Australia, strategies to assist to health workers to provide the necessary support to community members need to be considered, such as home visits, information sessions, etc.

### ***Messages***

Given the process of self-screening is a new one to many people, and one that people are not necessarily confident about, messages should emphasise the process as well as sell the health benefits of participation. It is recommended that the following messages be promoted:

- the FOBT is simple, easy and requires little effort;
- it can be administered by an individual with no medical experience, and does not require assistance from a health professional;
- results can be read successfully from a very small amount of sample;
- the FOBT has been endorsed by GPs;
- the fact that completing the FOBT is free of charge;
- the Australian Government should continue to be promoted prominently.

## 2.3 General Practitioners

Overall the GPs included in the research were very positive about most aspects of the Pilot and its administration.

They also confirmed the need for a public awareness campaign, to assist in educating people about bowel cancer and the need to screen, and to suggest people talk to their doctor about any doubts they might have.

In addition, there were some issues regarding the administration that needed some attention, including:

- participant numbers on forms;
- space for additional information on the forms;
- colour coding of referral/non referral forms; and
- specific item numbers to assist in payment reconciliation, and electronic forms.

Some GPs had concerns about waiting times for colonoscopies, and suggested that there would be a need to have a system for prioritisation of certain cases if specialists were not going to be available.

GPs also felt that much of the material they had received about bowel cancer and screening generally was not required and the volume of material suggested the Pilot process was going to be a complicated one. They therefore felt it should be simplified considerably, although they do require details about the newer FOBTs because they had had some doubts about the efficacy of previous tests.

They also confirmed the need for translated material and simple information for CALD and Indigenous participants, as well as the provision of the option for more transient people to pick up a test if needs be from health or community centres.

### 3.1 Background

**This study was conducted in order to assess attitudes, opinions and behaviours that influenced participation and non participation in the Bowel Cancer Screening Pilot Program conducted from late 2002 to mid 2004, to assist in the evaluation of the Pilot, and in further planning for a possible national approach.**

Colorectal cancer (bowel cancer) is the second most common cause of cancer related death in Australia with a one in seventeen lifetime risk for males, and a one in twenty six risk for females of being diagnosed with the disease by the age of 75 years. Due to the lack of symptoms until later in the disease, survival rates can be significantly improved by strategies targeting the prevention and early detection of it.

In an effort to improve knowledge about the early detection of bowel cancer, the Australian Government allocated funds in the 2000 Budget to develop and administer a Bowel Cancer Screening Pilot Program (the Pilot).

The Pilot involved the distribution of self-administered faecal occult blood test (FOBT) kits, along with various pieces of associated information, among people aged 55 to 74 years in three chosen areas and specific postcodes in Mackay, Adelaide and Melbourne. By encouraging people to screen, and providing specialist referral for those individuals who tested positive, the Pilot was a trial of a program which would have the aim of improving bowel cancer outcomes, by identifying many cancers before symptoms might prompt investigation and diagnosis.

As there was currently no bowel cancer screening program or community awareness campaign at a national population level, the Pilot was to act as a test study, to inform decisions regarding the possible national rollout and fine tuning of the program. The overarching purpose of the Pilot was therefore to provide the Government with feedback to assess the feasibility, acceptability and cost effectiveness of a possible national program in the future.

In order to assess the outcomes of the test program, an extensive evaluation of all aspects of the Pilot was conducted. In addition to other evaluative activities, this included the qualitative investigation of the attitudes, opinions and behaviours of consumers invited to participate and of GPs involved in the program.

This document contains the detailed report of the findings of that qualitative exercise conducted by Woolcott Research, in partnership with Cultural Perspectives.

The study included: a general population component including participants and non-participants; a culturally and linguistically diverse (CALD), Aboriginal and Torres Strait Islanders (ATSI) and South Sea Islanders (SSI) component of participants and non-participants; and some GPs from Pilot areas. These three segments of the population, that is mainstream consumers, CALD, ATSI and SSI consumers and General Practitioners are reported on separately in this document, with an executive summary which pulls the findings together and provides conclusions and recommendations based on the results at the front of the document.

## 3.2 Objectives

**The fundamental purpose of this study was to provide input into the evaluation of the effectiveness of the Bowel Cancer Screening Pilot Program in encouraging screening for bowel cancer, by sensitively exploring the attitudes, opinions and behaviours that influenced participation and non participation, and investigating the perceptions of the program and its methods and communication material amongst those involved.**

For the purposes of the research, consumers were defined as people living in the postcode catchment area of the three Pilot sites aged 55 to 74 years, who were invited to participate in the Pilot program.

Amongst **consumers** (mainstream, CALD, ATSI and SSI), the key areas of investigation included:

- feedback on the awareness and knowledge of, and consideration given to, bowel cancer screening, *before* receiving the invitation kit, i.e. had the Pilot only acted as a trigger for those who already had a high propensity to test, or had it served to educate and persuade more generally;
- overall reactions to receipt of the invitation pack which included exploring:
  - immediate reactions;
  - perceived positives and negatives;
  - how recipients processed the material (ie. did they read it straight away, did it prompt discussion, did they put it away for later, or just throw it out);
  - other sources of information about cancer and screening, and about the Pilot in particular;
  - the amount of social and community comment;
  - spouse/family impact;
  - cultural issues (CALD, ATSI and SSI); and
  - any other activity related to the program that influenced their response.

- the process of consideration and actions taken in response to awareness of the Pilot:
  - reasons why consumers decided to participate (motivators and triggers);
  - reasons why consumers did not participate (concerns and barriers – going beyond the rational excuses such as “lack of time” to also identify emotional factors);
  - how long did it take to consider the program and decide whether to participate, and
  - what action was taken.
- detailed evaluation of the content of the material, and reactions to particular components such as:
  - the letter;
  - the HIC privacy reassurance;
  - the FOBT kit (differences between the two test kits);
  - risks of the FOBT procedure and the acceptability of those risks;
  - use of personal data on the register, and
  - management of test results including receipt of results and the coordination of further testing.
- finally, suggested improvements to the program were explored, particularly relating to the provision if conducted on a national level.

Among **GPs** who were involved in the Pilot the key objectives included:

- examining reactions to their involvement in the program. This involved exploring issues such as:
  - perceptions of the processes guiding the program;
  - opinions on their personal role in the program including aspects such as time required, administration and payment, referral to other service providers and their interactions with patients, and
  - views on any issues the program might pose for Aboriginal, South Sea Islander and culturally and linguistically diverse (CALD) groups.
- obtaining feedback on, and satisfaction with, the model of delivery of the program;
- investigating perceptions of the strengths and weaknesses and possible barriers to participation of the program, especially with respect to the GP population; and
- obtaining any feedback they had relating to improving the provision of the program on a national level.

Discussions with the clinical and project staff involved in managing the implementation of the Pilot were also conducted at a Pilot workshop session prior to the research, with the objective of gaining insight into any relevant location issues.

### 3.3 Research design

The research design implemented amongst each of the key segments is outlined below:

#### ***General population in the pilot sites***

The general population component of the study was conducted utilising mini group discussions (4-5 people per group) and in-depth interviews.

This combination of methodologies was chosen because of the sensitive nature of the subject, and previous research we have conducted on the issue which suggested that some people will find it confronting to discuss some elements in a large group. Recruitment was conducted by age and gender, with random recruiting in post codes within each of the pilot sites.

This component of the study included:

- 8 mini groups – participants (part affinity);
- 6 mini groups – non-participants (part affinity where possible);
- 4 face to face in-depths, participants referred for colonoscopy; and
- 7 face to face in-depths – non participants.

The groups and depths were conducted in locations within or close to the Pilot areas to encourage involvement, and they were suitable venues for aged people.

This component of the study was split as follows:

	PARTICIPANTS				NON-PARTICIPANTS			
	MINI-GROUPS, PART AFFINITY		IN-DEPTHS REFERRED FOR COLONOSCOPY		MINI-GROUPS, PART AFFINITY (IF POSS.)		IN-DEPTHS	
	Male	Female	Male	Female	Male	Female	Male	Female
<b>Mackay</b>								
55 – 64	1	1					1	
65 – 74				1			1	1
GP's								
<b>Adelaide</b>								
55 – 64	1		1	1	1	1	1	
65 – 74	1	1				1		1
GP's								
<b>Melbourne</b>								
55 – 64	1	1	1		1	1		1
65 – 74		1			1		1	1
<b>TOTAL</b>	<b>4</b>	<b>4</b>	<b>2</b>	<b>2</b>	<b>3</b>	<b>3</b>	<b>4</b>	<b>4</b>

### ***GPs and stakeholders***

Amongst GPs from within the Pilot sites, a number of telephone and face to face in-depth interviews were conducted, at times appropriate for them as follows:

- 20 phone in-depths with GPs (6 in Mackay, 7 each in Adelaide and Melbourne); and
- 6 face-to-face in-depths with GPs (2 in each pilot site).

Note: GPs who participated in the Pilot were recruited from lists provided by the Department. The GPs were recruited to ensure a spread across large and small practices – with small practices being defined as those with 1 – 2 GPs and large practices being those with 3 or more GPs.

Practices with patient groups including Aboriginals, South Sea Islanders and CALD groups were included in the research. GPs who were involved in previous research into the Pilot were not excluded from the research. Stakeholder consultations were conducted at a workshop in Canberra where those involved in each of the sites met to discuss issues and outcomes and with some telephone follow-up.

### 3.4 Culturally and linguistically diverse, Aboriginal and Torres Strait Islander and South Sea Islanders

The methodological approach used for the CALD and ATSI component was a series of in-depth interviews. While group discussions bring a range of benefits, particularly related to understanding personal and group behaviour and providing an environment for free and open debate and discussion, they also have limitations where the issues being discussed can be deeply personal and sensitive. This is especially true for Indigenous, South Sea Islander and CALD communities.

The language and cultural groups included in the evaluation were selected using the 2001 ABS Census data relating to the size of the language other than English groups in the pilot sites. In total 60 depth interviews were conducted as follows:

	PARTICIPANT	NON-PARTICIPANT
Aboriginal and Torres Strait Islanders	Mackay 8	Mackay 7
Cantonese	Melbourne 5	Melbourne 2
Vietnamese	Adelaide 1	Adelaide 2
Italian	Melbourne 3	Melbourne 3
	Adelaide 3	Adelaide 3
Greek	Melbourne 3	Melbourne 3
	Adelaide 4	Adelaide 1
South Sea Islanders	Mackay 7	Mackay 5

Roughly equal numbers of men and women in each of the above segments were included in the sample.

Bilingual interviewers conducted the fieldwork with the CALD groups in Melbourne and Adelaide, and Indigenous and South Sea Islander researchers conducted the relevant research in Mackay. Interviews were conducted face-to-face, although the participants were given the option of participating via the telephone if this was preferred for confidentiality reasons, however this proved unnecessary as all took up the face-to-face option.

# 4

## Detailed Findings

### 4.1 Mainstream consumers

#### 4.1.1 Overall attitudinal trends

**Before discussing the findings in detail, it is worth commenting on some broad trends in attitudes and behaviours which were observed between the participants and non participants, and between males and females in the group discussions, and which had some bearing on reactions to the Pilot and to screening.**

Whilst the study was a purely qualitative exercise, and therefore not designed to accurately measure these trends, they did appear to be relatively consistent across most of the groups, and across the three Pilot areas, and we therefore have some confidence in including them in our findings.

There were also some minor attitudinal and behavioural differences evident in Mackay compared to the city test sites, and these are discussed at the end of this section.

#### *Participants and Non-Participants*

In observing the general demeanor and lifestyles of the people in the participant groups compared to the non participant groups, those in the participant groups appeared to be somewhat more informed, involved and “in control” of their health and the management of it.

That is, they tended to be more likely to spontaneously talk about the need to keep fit, eat well, and have check ups, and they were more upfront in discussing and even joking about health issues per se. This tendency was most evident amongst the female participants, but some males were also like this, often however having been encouraged by their wives to take more interest and adopt certain behaviours.

Participants were quite **proud** of the fact that they were taking positive steps to do what they can to prevent any illness, and as mentioned, they talked about taking “control” of their lives to ensure they have a good future with each other and with their families.

The non-participant group members were, it seemed, generally less able to cope with some aspects of everyday life, and they were more likely to be suffering from other illnesses, or

minor disabilities, or some even described themselves as being a bit “depressed” about their health and life generally.

They tended to be more reluctant to confront and talk about health issues, and were relatively uncomfortable within the groups when the discussion started to focus on cancer, bowels and screening.

### ***Males and Females***

Whilst there were some clear exceptions, in general the females tended to be more open and knowledgeable about health issues, and they appeared to be more likely to visit the GP more regularly than the males.

Some of the males, and particularly those in Mackay who had more of a country “rugged” male persona, admitted openly that they relied on their partners to manage health matters for them to some degree, and to push them into looking after themselves or going to the doctor when they otherwise would not deem it to be necessary.

Prior to receipt of the Pilot material, the males were less likely to have listened to or picked up on any promotional activity regarding suggested behaviours or pre-emptive measures such as screening for cancer, unless their GP had actually raised the subject with them, or a close friend had suffered, bringing the issue to a more personal level.

### ***Pilot Areas***

The group discussions in the Melbourne and Adelaide Pilot sites were very consistent in reported awareness, attitudes and behaviours regarding the Pilot, however we did observe a higher level of local awareness and social discussions in Mackay, compared to the bigger city sites.

Other research we have conducted would suggest that activities such as the Pilot are more visible and noteworthy to residents of “contained” regional centres such as Mackay, because they feel that they often miss out on social and health services and support and therefore should take advantage of it when it is offered.

There had also been greater media activity in Mackay which had more impact overall. On the downside however, we had greater difficulty in recruiting non-participants to the groups in Mackay and they tended to immediately refuse to be involved, definitely not wanting to discuss the issue further at all, despite incentives, etc.

We could hypothesise that this may be a reaction to a greater level of social “pressure” on participation that had been created in the area, leading to some of the non-participants feeling possibly guilty or irresponsible about their decision and therefore reluctant to come out and discuss it further.

#### **4.1.2 Pre-existing knowledge and attitudes toward bowel cancer**

It was very clearly evident from the discussions in the groups that bowel cancer is still a relatively low profile cancer, with varying levels of knowledge about it, and often erroneous beliefs associated with it.

Unlike many other sorts of cancers, such as breast cancer, prostate cancer and brain tumors, no celebrities were known to be attached to bowel cancer in a publicity sense, and there were no special appeals, awareness weeks or advertising campaigns that people were aware of. It is therefore seen to be a *rarer* cancer than those mentioned above.

In addition, it focuses on a part of the body that was not generally discussed or talked about openly, and therefore although many have known of someone who might have it, they might simply refer to it as “cancer”, or even “stomach cancer” rather than being specific about it.

Despite it not being so top of mind, it was however one of the most feared cancers, and the feeling was that it was a very “final” cancer...that is, more likely to lead to death relatively quickly, or to a very poor quality of life. The thought of having to live with a colostomy bag, and to have to possibly depend on someone else for much of your personal daily care was particularly frightening for men.

Whilst this fear could act as a prompt to screen for some, it was also a deterrent, with some feeling that given the perceived finality of the disease they would rather not know if they had it until absolutely necessary.

There was also a perception that bowel cancer is more of a male disease, and some females therefore felt they were unlikely to suffer from it, and many felt that it really only strikes at an older age (65 to 70 plus).

Bowel cancer was strongly associated with people with a family history of the disease, which also could deter some people from screening if they did not have that history, and it was also believed to be relatively easily identifiable through obvious symptoms such as pain, bleeding or changes in bowel habits.

Some GPs had clearly been quite active amongst this age group to encourage those with a family history or with any symptoms to undertake colonoscopies, however it was generally as a result of the patient raising the issue during a consultation on another issue, rather than a proactive suggestion from the doctor.

### 4.1.3 The perceived role of government

Regardless of whether people participated in the Pilot or not, it was definitely seen to be the role of the Government to inform the population about health and to provide options which could assist people and encourage them to effectively manage their health, particularly as they get older.

Most in the groups were very positive about the Government's work to date in promoting issues such as breast cancer screening, immunization etc, and in encouraging people to take part in what is being offered, provided it was conducted in a manner which is not too overbearing or pushy, and that it does not make people who do not participate for various reasons feel out of place.

Most wanted to feel that they could make their own choice about these matters, and not be railroaded into participation if they were not entirely committed.

The majority were very much in favour of the concept of a Government initiated bowel cancer screening program, with some of the participants in the Pilot also aware that as a "free" service it offered a real benefit to the community which otherwise would have to be paid for by individuals participating. These people were aware that alternative FOBT kits had been available from GPs or pharmacies in the past and that these had to be purchased.

Most had very clear preconceptions about how any communication or educational campaigns should be conducted, basing their views on the general patterns of advertising for breast cancer, prostate cancer, diabetes and other illnesses, where celebrities have been used as spokespeople.

It is felt that the use of celebrities is very effective in signaling that "*anyone*" can get these diseases no matter how famous one is, or how much money one has. It also brings the topic more out in the open if celebrities are prepared to talk about it on television and in other media.

### 4.1.4 Initial reactions to the receipt of the pilot kit

**Given that those who participated in the Pilot and those who did not had different pre existing attitudes toward health and preventative behaviours, they tended to react quite differently on initial receipt of the kit through the mail.**

#### *Participants*

The participants were more likely to have noticed and picked up on publicity that had been conducted in their area about the Pilot and how it was being conducted, so many of them were already expecting the material and it did not come as a total surprise. They had particularly noticed local paper advertising and editorial discussion, with those in Mackay in particular

being more aware, citing other activity in addition to local papers such as shopping centre stands and television, as well as word of mouth to some degree.

Those with a predisposition to participate reacted quite positively when they received their kits. They felt it offered them an easy solution to an issue that some of them had already considered doing something about, or those who had not previously considered screening received the kit with a “why not” reaction.

Participants were much more likely to have mentioned the Pilot to their friends, and discussed it more openly, building up the feeling amongst themselves that it is a socially acceptable and responsible thing to participate in, and that “everyone” is doing it. Some participants were quite jocular about the kit and the use of it, reporting how they and their friends had been having a bit of a laugh about it.

There was also some awareness amongst participants of FOBT kits having been available in the past, through club related activities (Rotary/golf etc).

As mentioned, those in Mackay were a little more likely to be expecting the kit, with even reports of the postman handing it to people personally with a comment about it.

Other research we have conducted in regional areas would suggest that this heightened awareness is not uncommon, with the combination of more focused media and the greater propensity for regional people to pick up on public opportunities and programs being offered to them.

For the participants, privacy was not an issue. That is, they did not feel uncomfortable about being targeted or mailed to in the Pilot. They accepted it was happening for all over 55 year olds in their area and had no problem with that.

### ***Non-Participants***

Non participants were, as mentioned, less likely to have noticed or remembered any publicity or local activity surrounding the Pilot, and therefore claimed that the material came as something of a surprise to them, a bit “out of the blue”.

Because of this, some raised concerns about receiving the kit, commenting that it was a large and noticeable envelope with what appeared to be a lot of material in it which was a bit off putting.

Some were also a little embarrassed being seen receiving it, because of the mention of “bowels” on the front, and because of the feeling that “everyone” (for example in a block of units with rows of letter boxes) will see the envelope sticking out and will know what the recipient is doing with it, and they felt this was an invasion of privacy.

Amongst the non-participants there was also a reluctance to talk about it amongst friends or even to partners, and therefore there was no social support or influence at play. In that sense it emphasized a feeling of aloneness for the people who were on their own, and they therefore did not want to spend much time thinking about the test or being involved in it.

For some the receipt of the kit and the focus on cancer was an unpleasant reminder of the loss of friends or family to the disease, and whilst this could be a prompt to the positively predisposed, to the more reluctant it caused them to want to switch off from the material and dispose of it quickly to eliminate that reminder.

The non-participants also were more likely to question why they had been particularly chosen for the Pilot, because they had not read about the criteria for inclusion, and they did not necessarily get to read the introductory letter or booklet, often having rejected the material and thrown it all away without having looked at it in any depth.

#### **4.1.5 The decision making process**

The manner in which people processed the material once they received it, and the extent to which they read it and considered it in any depth, was primarily influenced by a range of prior attitudes and beliefs about bowel cancer and the role of screening, and to some extent therefore the material itself was irrelevant to the decision to participate, except amongst those who were more undecided as to their view.

There appeared to be a continuum of attitudes and knowledge regarding the subject of bowel cancer and screening and this in turn impacted on the willingness to become involved in participation in the Pilot.

At one end of the spectrum were a group who were already somewhat aware of the detail surrounding bowel cancer and of the role of screening in providing positive outcomes in cancer treatment. These people were already proactive in taking control of their health and adopting a preventative kind of approach.

This segment were always going to participate in the Pilot given the opportunity, regardless of what the material was like, or the type of kit offered.

For this group the material such as the brochure and the letter served to reinforce their attitudes, and provide important detail on how to go about participation, and they tended to read it in depth.

At the other end of the scale were a segment who were clearly unwilling to confront the issue of cancer at all, particularly if they were on their own, with a deeply fearful attitude toward the outcome of any screening or testing process.

This segment were more likely to report that they “threw the envelope in the bin” without even looking at it. Some had glanced at the material, but often looking at the details and becoming aware of it had aroused more fear than they had previously, and they therefore then rejected the concept and ignored the testing option.

Essentially those at this end of the continuum were not processing any of the information provided rationally, and so no amount of detail or factual background would impact on their

decision making or change their mind about screening because they were reacting at a very emotional level.

Whilst this was a qualitative exercise and we cannot therefore estimate the sizes of these segments within the overall population, anecdotal feedback on the recruitment of the non participants would suggest that many of those who would not come to the groups also fell into this segment, being very unwilling to come out and discuss any aspect of their feelings or reasons for rejection of the Pilot.

In the middle of the continuum however was a group who tended to feel they probably *should* participate in the Pilot, but who felt reluctant about it for various reasons and who tended to procrastinate about it.

This group tended to just glance at the material, and some picked up on particular elements which had a motivating effect, such as the number who die each week from bowel cancer as quoted in the letter.

This non-committed segment had a tendency to put the material and the kits aside for “later”, coming up with practical reasons or excuses for why they could not complete the test immediately, such as the perceived difficulty of the kit itself, or holidays, or minor physical problems such as stiffness or arthritis.

Some did try the test and thought that they had failed the first time they did it and did not send it in, feeling doubtful that they had conducted it properly and concerned that it therefore would be inaccurate.

The material itself and the perceived ease of conducting the test (combined with social acceptance and pressure) did therefore have some impact on this middle wavering segment and it is important that what is provided works to the fullest in that regard.

Some of the procrastinators also indicated that they did raise the subject of the Pilot with their GP, and that the GP had encouraged them to participate and this had prompted them into it.

The receipt of reminder letters and or kits had acted to prompt a small proportion of the non participants, or those who had tried and failed to try again.

#### **4.1.6 Participation triggers and barriers**

##### ***Triggers and Motivators***

**As discussed in the previous section, for a high proportion of the more positive participants the most powerful trigger to participation was the pre-existing attitude and desire to screen along with the commitment toward doing whatever is necessary to ensure good health. The provision of the kit therefore was simply a convenient means and an opportunity to easily exercise control over one’s health and future wellbeing.**

Building on that however, elements tended to come into play, and these included:

- the level of understanding and belief that a screening process and the resulting interventions where necessary can successfully prevent the disease spreading. It would seem that case studies and testimonials by other sufferers have been successful in communicating this for other cancers, and this has “rubbed-off” to some degree on reactions to the Pilot;
- a general widespread social acceptance of the process of screening as being a normal health measure for all people of a certain age, and one that can be spoken of relatively lightheartedly and even joked about;
- a belief in the notion that by taking action one can help to ensure a good quality of life into old age, without being dependent on anyone, where one can ensure a future with the family and grandchildren, and that a relatively fatal disease can be dealt with early on and controlled;
- many men felt that bowel cancer was particularly threatening for them and therefore they were easily convinced that the FOBT is a means of getting to it early and avoiding the impact of it;
- the belief in the need to undertake a range of specific and regular preventative health measures as one ages, including screening where possible for a range of cancers, as well as tests for heart disease, diabetes etc. GPs were having some influence educating in that regard, and females were reportedly talking their partners into consulting their doctors more than they might otherwise;
- a family history of bowel cancer had prompted some to participate because they felt they might be more at risk, and finally; and
- reactions to the physical components of the screening kit and the perceived ease of use of it had acted to prompt some who knew about the alternative of colonoscopies and the preparation involved for that to process.

*Note: there were particular pros and cons associated with each of the different types of kits tested as discussed later in this report.*

### **Barriers**

The belief that cancer, and particularly bowel cancer, is a serious and often fatal illness did prompt some people to participate in the Pilot to ensure they catch it early, *however* it could also result in a powerful fear of screening and of subsequently finding a problem.

Some people felt that once it has been found and identified then “it is all downhill from there”, and they therefore preferred not to know. These people tended to talk about friends or family who had been diagnosed with bowel cancer as a result of a colonoscopy and had died within six months of screening. They had seen no real evidence of the positive outcomes of screening, and therefore believed that “its better not to know”. Some of the older people thought that it was too late for them anyway, and had a fatalistic attitude “ *if it is going to happen it will*”.

In addition to the general attitudes and beliefs above, there were a range of other issues which appeared to be acting as a deterrent, including:

- being of the opinion that they were “healthy”, with no visible symptoms;
- the belief that because they had no family history of bowel cancer they would not suffer from it, for example, “we are a heart family, not a cancer family”;
- a general feeling of mild depression and a lack of social support, no one to confide in or discuss the Pilot with, combined with a reluctance to talk about bowels and cancer;
- the test format itself, for example the need to use it over two days which meant storing the first sample somewhere, the thought of putting the sample in the mail, the perceived complexity of the test, and the degree to which the instructions were clear;
- a preference to be totally removed from the sample collection process...that is some people expressed a preference for a colonoscopy versus an FOBT, because with a colonoscopy it is “all left to the Doctor to deal with”;
- some people had definite physical problems in collecting samples, such as arthritis and mobility difficulties like sore shoulders or backs, which prevented leaning down to, collect the sample, and they were very reluctant to involve anyone else to help in this process. Others (females) were concerned because they could not control the passing of urine and therefore felt they would contaminate the sample, and for males bleeding hemorrhoids seemed to be another concern amongst a relatively high proportion;
- the presence of other illnesses and the stress of dealing with those made some people reluctant to take on what they perceived to be the stress of dealing with yet another health issue;
- some felt that the testing was an “intrusive process”, whereas something like a mammogram was more of an external test, which one can get “over and done with” in one session, and some non-participant women said they would participate in a mammogram for that reason, but would not do the FOBT;
- doubts about the efficacy of the FOBT also deterred some who would prefer to go straight into a colonoscopy where one could be more certain of accuracy. They were put off by the “smear” concept and could not understand how a small sample could possibly be an accurate predictor. One or two in the groups had in fact been prompted by receipt of the kits to go straight to the GP and ask for a colonoscopy, without participating in the Pilot; and
- Finally, there were a group who described themselves as “*gunners*” that is, they always procrastinate over many activities, but they claimed that they were “*gunner*” do the test at some stage, they just hadn’t got around to it, and needed to be pushed and reminded several times before they would.

#### **4.1.7 Reactions to the specific material in the kit**

Overall there were no real issues or problems identified with any of the material provided with the test kits, with the only criticism being that there appeared to be a lot of information and bits to read, which resulted in some people being a little overwhelmed, leading to the information and the tests being put aside by some and left until later when they might have more time.

As mentioned also, there was a segment who did not read any of the material provided, instead tending to throw it all out straight away as a result of their negative pre-existing attitudes regarding screening and bowel cancer, rather than as a result of anything contained in the kits.

Reactions to the individual components included:

##### ***The Envelope***

The envelope was generally thought to be fairly innocuous but clear in what it was referring to, although as previously discussed some people did not like the overt mention of “bowels” on the front, and the large size of the envelope resulting in it sticking out of the letter box for everyone to see. The outside of the envelope looked fairly “Governmenty” and therefore official, which was seen as the right approach for a National Pilot program such as this.

##### ***The Letter***

The letter was the one piece of communication in the envelope that was most likely to be read by both participants and non-participants. It therefore acted as the main piece of communication about the Pilot, and it was believed to be clear and to the point in that regard.

The opening statement about the number of people who die each week from bowel cancer was seen as very powerful, and a quite confronting fact, which was a motivator for some of those already predisposed or not committed to participation, but which caused some non participants to switch off from further reading because they did not want to deal with it.

Overall the letter was felt to be clear and to the point, and easy for all to understand and the use of the persons name as an introduction was also positive.

##### ***The HIC Letter***

At best, group members had just glanced at the HIC letter. It was seen as a fairly unnecessary component of the kit, because privacy, and the source of the names and addresses was not of great concern to either participants or non participants. Most simply assumed it had come from “government” lists, and they were perfectly comfortable with that, although one or two had thought it must have come through the Doctor, or a hospital, or some other register.

Given the lack of concern, it was felt that this HIC information did not need to be provided on a separate sheet of paper in so much detail, but could instead be included in the main letter with a small mention only.

### ***The Participation Form***

The participation form was seen as very straightforward and predictable, easy to understand and fill out, and it caused no alarm or concern. Again it was just seen as a normal government form, and not too detailed or difficult.

The need to fill out the details of any family history however tended to confirm the view that bowel cancer is much more likely to occur amongst those with this family history, which can encourage those without that history to believe they will not be affected and that they perhaps need not bother with the test.

In addition, the mention of symptoms such as “unexplained tiredness” can cause some alarm, as everyone in this age group could think of times when they have suffered from this.

### ***The Information Booklet***

Participants found the information booklet to be a very useful source of information with most finding something in it that they were unaware of or that clarified something for them. It confirmed and strengthened their propensity to take part.

It did not however work to particularly change the minds of any non participants, they tended not to read it in any detail, just glancing through at best, because many had already made up their minds and had no real interest in finding out more. The undecided also did not tend to initially read this booklet in detail, and these people were more likely to be prompted by other external factors such as social discussion or local advertising. They did however tend to return to it and read more once they had become more positive about participation.

### ***The Dietary and Activity Guidelines Booklet***

The information in this booklet was felt to be quite interesting and well laid out, however most people felt it was not telling them anything particularly new or different, and it was information that many in the groups felt they were getting from a range of other sources such as magazines, Sunday papers, radio etc.

It was felt to be somewhat extraneous to include in the context of the Pilot material when there was already plenty to read.

## **4.1.8 Reactions to the testing kits**

Each of the two kits sent out had positives and negatives associated with them, concerning either initial reactions prior to use, or actual in use issues, with the “ideal” kit emerging as a mixture of elements from each.

### ***The Detect Kit***

This kit looked more like a “proper” medical test to many of those who received it, and this provided a sense of confidence in it as being reliable and accurate. It looked to be more substantial to those who received it, and the test tube sampling suggested that the sample taken would be uncontaminated and large enough to allow for accurate diagnosis.

The idea of the paper collection sheet was seen as a practical help in trying to collect the sample, with some men actually squatting above it on the ground which they thought worked well.

On the negative side however the instruction leaflet in this kit tended to detract from the more official feel of it, as it was felt to not look particularly professional, being a single typed piece of paper, and the whole kit had discouraged some of the less committed non participants because they thought that it looked too complicated, fiddly and difficult to use.

There were also some concerns also about having to urinate first, before collecting the bowel samples, because some women cannot manage to do each separately. They therefore did not think they should participate because their samples would be contaminated.

### ***The Inform Kit***

An important positive for the Inform kit was the manner in which the instructions had been depicted. They were found to be really easy to follow, with the illustrations helping to provide the detail in a very friendly and approachable manner.

The manner of collection of the samples was also seen as an easy process, with less close contact with the stool required. People with hand mobility problems found the long brushes quite easy to manipulate.

In a perceptual sense however some group members felt that the kit was not immediately recognisable as a kit, because of its slim envelope like shape, and no really clear labelling. Some had initially thought it was just another component of the information material.

Others had concern about the efficacy of this test which just required a “smear” on the card. They could not envisage how a test could be accurate without a more substantial sample.

Those who had used the Detect kit felt that they preferred the paper collection sheet, as they felt this would make it easier to get to the stool.

There were also some details in the instructions for this kit which made some people worry whether they would conduct the test properly, such as the need to ensure there was no “blue” in the toilet and that it was quite clean.

## 4.2 Culturally and linguistically diverse, Indigenous and South Sea Islander participants

### 4.2.1 Overall observations

The first point to note with regard to the CALD, Indigenous and South Sea Islander research findings is that they suggest that there were no significant cultural taboos around the topic of bowel cancer and obtaining faecal samples to screen for bowel cancer among any of the language groups and Indigenous participants included. The research did however naturally select people who were more comfortable with this topic, so there is a bias towards those who are prepared to discuss these topics.

However, in all of the discussions participants did not suggest that this is a topic that is culturally inappropriate to discuss with others, and indeed many talked about discussing the test with family, friends, and health professionals and in community information sessions and gatherings. The level of comfort in discussing bowel cancer and the test varied amongst individuals, as some people felt embarrassed or squirmish while others were quite open, and this did not appear to be a cultural factor.

The majority of the people involved in the research were very positive about the Bowel Cancer Screening Pilot and identified the benefits of early detection and preventative measures, and there were no concerns expressed that this was an inappropriate approach for receiving material of this nature. There were no obvious differences across the different target groups. The research suggests that the dominant motivators that drove participation and non-participation included personal experience (having a family member/friend who had bowel cancer), levels of confidence, access to support networks, and access to information in a language that people were familiar with.

The individual reactions to the invitation to participate in the pilot program varied across the research, but in the main the responses tended to vary depending on their personal experiences, their support networks or level of community engagement and their access to information in a language they are familiar with. As well, there were considerable variations depending on how pro-active people were generally about their health, and the level of control people perceive they had over their health as with the General Population.

For those who felt more “in control” of their health, the reactions to the pilot program were very positive and these participants were eager to participate. These participants tended to be more pro-active with regards to their health, and were more likely to understand why they were receiving the kit, the benefits of screening and were less likely to feel anxious, fearful and confused about the process. Those who had other health concerns, or who felt less confident with their level of knowledge and understanding of health matters, were less likely to participate, although some sought assistance and advice from family, friends, health professionals or health workers.

For others who received, but did not actively seek, this support (more likely to be the Indigenous and South Sea Islander participants), decisions to participate were based on this advice. Those who were more isolated are less likely to have access to support, and therefore the research suggests these people would be less likely to participate in a screening program.

There was a noticeable difference in response from the Indigenous and South Sea Islander participants compared to those from culturally and linguistically diverse backgrounds. Indigenous and South Sea Islander participants were less pro-active with regards to their health, and were also less likely to take control in managing their health. As well, health workers were an important source of support and encouragement, rather than GPs and family, and these participants were more connected to the community health sector than to GPs.

### ***Differences for participants and non-participants***

Non-participants tended to be less confident than the participants, and hence had more reservations about the test, their ability to do the test, and the outcomes. Many talked of being overwhelmed with the amount of material when they initially received the kit, with the initial response being *“Where do I begin with all this material?”*

It is also worth noting that the non-participants had lower levels of English competence, and this clearly has an impact on level of confidence and also ability to manage such a large amount of information in English. This is clearly a significant group when we are targeting those aged over 55 years, and it will be important to support the invitation packs with information distributed through community networks and the media so that those with lower levels of English know what to expect and can be empowered to respond to the invitation.

As well, for those with lower levels of English language skills, there were concerns that they did not understand the materials accurately, and this appeared to further reduce their levels of confidence and hence reduced their likelihood to complete the FOBT. The concerns about not understanding the material referred not only to the information in English, but also to the translated material, as there was a level of mistrust about the accuracy of translations.

Issues around English language competence and literacy in English are highly relevant for CALD, Indigenous and South Sea Islander target groups.

Aside from the limitations with regards to information provided in English, several of the non-participants were concerned about the test itself. These concerns tended to relate to not being comfortable mailing samples, or a lack of confidence in the accuracy of the test. This latter point was not only questioning the efficacy of the testing process, it also reflected a lack of confidence in their personal ability to administer it correctly.

There was a perception that the test should be administered by doctors and other health workers, and there was a sense that they were not confident in the results of a self-administered test.

## 4.2.2 Pre-existing knowledge and attitudes toward bowel cancer

### *Those from culturally and linguistically diverse backgrounds*

Everyone included in the research was aware of bowel cancer, but the level of understanding was limited and generally varied depending on personal experience. While there were a few individuals who had relatives or close friends who had experience of bowel cancer, the majority had limited personal experience. In these cases people were unable to articulate the risk factors, symptoms and outcomes associated with it. The research also found that the levels of awareness did not vary by language background, or by participation in the bowel cancer screening pilot, as the changes tended to be dependent on personal experience and level of engagement with their own health. The research also suggests that levels of knowledge were lower among CALD, Indigenous and South Sea Islander participants than those from the mainstream community.

The table below shows the general findings when discussing levels of awareness and knowledge prior to participation in the pilot program. As can be seen, there were few differences in the levels of knowledge, although non-participants had a less detailed knowledge of risk factors and family history, and were less likely to have spoken to others about bowel cancer. Interestingly, the majority of females included in the research had participated in other screening programs, namely breast screen and cervical screening, and this was true for those participants and non-participants of the bowel cancer pilot. It appeared that the bowel cancer screening created more anxiety among participants than the breast screen and cervical cancer screening programs.

While generally the perception was that the community was not very knowledgeable about bowel cancer, a few of those being interviewed felt that the level of awareness in the community was growing.

#### **Levels of awareness for participants and non-participants:**

Participants	Non-participants
Most were aware of cancer across the language groups, although a few had close family/friends who had experienced bowel cancer and these participants had greater levels of knowledge. Vietnamese participants had lower levels of knowledge.	As with participants, most were aware with a few having greater levels of knowledge because of personal experience.  Very limited understanding of family history and risk factors.
General perception was that “in our community” levels of awareness of bowel cancer are very low.	General perception was that “in our community” levels of awareness of bowel cancer are very low. For the Chinese community it was also thought that newly arrived migrants are more likely to be superstitious about talking about cancer.
More likely to have spoken to family and friends about bowel cancer.	Less likely to have spoke to others about bowel cancer.

This aspect of the research also emphasised the important role that health professionals play for those from culturally and linguistically diverse backgrounds, and it was clear that for many GPs are respected and viewed as the clear experts, and that in many cases responsibility for health care is deferred to GPs in favour of individual responsibility.

*“When we worry about our health we go to see the doctor and ask for a general health check.”*

*“The majority of the community do not think of these kind of screening programs.”*

The research suggests that in most cases people are reactive rather than proactive with regards to their health, and that the most trusted source of advice are GPs. This needs to be considered when developing strategies that target people from culturally and linguistically diverse backgrounds. In particular it is necessary to demonstrate the importance that GPs place on such screening programs while also minimising the need for personal contact with GPs to complete the bowel cancer screening. It appears that the CALD participants view the ‘do-it-yourself’ health checks as a new idea, as there is a level of resistance to taking personal control and limited levels of confidence in their ability to control the process.

### ***Indigenous and South Sea Islander participants***

Indigenous and South Sea Islander participants had far lower levels of awareness and knowledge of bowel cancer than the CALD and mainstream community participants, and several had difficulty distinguishing between bowel cancer and other cancers. Similarly, many found it difficult to articulate the risk factors and symptoms associated with bowel cancer. For those who had completed the FOBT knowledge levels were still relatively low, and when discussing the process talked very generally about it as *“checking your insides”*, with little detail on the nature of the test. There were a few participants where polyps had been identified in the FOBT, and these people did not understand the follow-up treatment, initially assuming they had bowel cancer.

As discussed earlier, knowledge levels and to a lesser extent participation in the bowel cancer screening program varied depending on the level of control people had over their individual health, and how pro-active they were in this regard. The Indigenous and South Sea Islander participants were less pro-active about their health compared to the CALD and mainstream samples. Many CALD participants who received the kit took it to a third party, usually their GP or sometimes family members. For the Indigenous and South Sea Islander participants many had thrown the kit away or only responded once the health worker approached them about the test.

This presents significant challenges for conducting a national rollout as the need for support from the community health sector is significant, and this will be difficult to guarantee in a national program.

This research also highlights the significance of the community health sector (both health workers as well as GPs within the community health sector to a lesser extent) among the Indigenous and South Sea Islander people included in this research.

While not all participants had gone through the community health sector, many of the participants had, and the support offered by the community health sector was significant in Mackay.

As well, Indigenous women talked about the ‘well women check’ offered through the community health sector, and that this includes breast and cervical screening, and that it would be appropriate to also include bowel cancer screening in this program.

### **4.2.3 Role of Government**

The research found that the fact that the screening program was being delivered by Government was clearly identified and perceived positively. The general impression that this created was that it is a serious issue, and that people are “lucky” to be given the opportunity to participate in such a program. This was true across the board, with Indigenous and South Sea Islander and CALD respondents reacting positively to the government screening program, and some even expressing gratitude for the screening program.

*“The Australian Government would not invest all this money and time mailing out information and do-it-yourself kits unless it was a significant problem.”*

*“It seemed to create a sense of urgency in relation to testing and also stimulated greater awareness.”*

*“Since I received the letter, my attitude changed. I thought it must be serious otherwise the Government would not plan to spend a lot of money on this program. It had a positive effect on me.”*

*“This is an exciting event. It is a good thing for the government to do. It is better to prevent than try to cure the disease later. This will save tax payers’ money and save a lot of family sorrows.”*

The research also found that Indigenous and South Sea Islander participants were more likely to view the screening program as an example of the “*government caring about me.*” The perception from the pilot program for many of the Indigenous and South Sea Islander participants was that this pilot is an example of the Government “caring” about the health of their community, rather than interpreting it as a sign that bowel cancer is a significant problem in the community (this latter interpretation was more likely to be identified among the CALD participants).

### **4.2.4 Initial reactions to receipt of the kit**

#### ***Those from Culturally and Linguistically Diverse Backgrounds***

As mentioned, the initial responses to the Kit varied depending on whether people had been exposed to promotional information about the Bowel Cancer Screening Pilot and on levels of English language competence. Many of the Chinese and Greek participants in Melbourne had

seen or heard the media promotion prior to receiving the Kit, and this enhanced their level of understanding and limited the level of concern about the kit.

Indeed a few of the Chinese respondents were anticipating the Kit, and had checked their postcode to make sure they were included in the pilot area. Italian and Vietnamese respondents were less likely to have seen any promotion prior to the kit arriving and tended to be a little confused and concerned on receipt of the kit that they were specifically targeted because of concerns about their health. It is worth noting that that subsequent media activity, and discussions with family members and GPs allayed these concerns.

Generally, those who had seen the promotion prior to receiving the Kit were more likely to complete the FOBT. This research does not provide feedback on the impact of the communication strategies targeting the different language groups, as it is impossible to assess this through qualitative research. However it clearly identifies the importance of supporting any rollout with significant media activity to encourage participation and minimise any anxiety in the community.

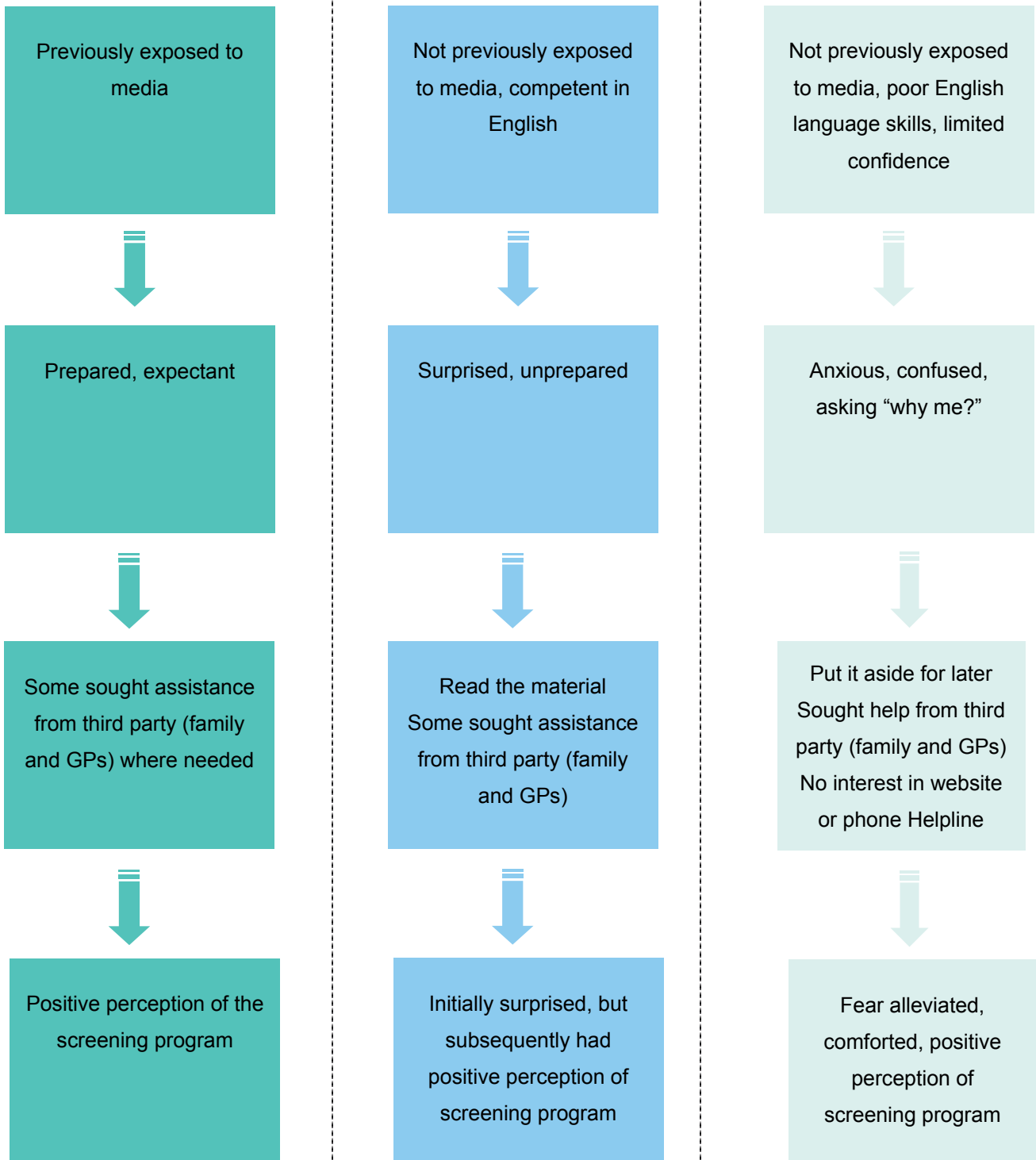
Aside from the impact of prior knowledge on initial reactions, the other difference depended on level of English language skills. Not surprisingly, those with lower levels of English language skills were more likely to put the Kit aside, and many asked for assistance from a third party to help them understand the information. Family members often gave this support in the first instance, and also GPs. There was limited interest in the website or the phone Helpline number as there was some concern about the quality of the translations, and it was felt that to use the Telephone Interpreter Service (TIS) it is necessary to have some English language skills to be able to navigate the system.

The diagram below summarises the initial reactions of recipients depending on their level of media exposure and their English language skills. As the following diagram shows, for many of those who had not been exposed to information about the pilot program prior to receiving the kit in the mail, there were reasonably high levels of concern when they first received the Kit. This was often heightened when they were not able to allay these fears immediately because of limitations in reading the information in English.

Those who had been exposed to information about the screening program prior to receiving the Kit were positively predisposed to the program and the material reinforced these perceptions (column one). For those who had no previous exposure to the program before receiving the Kit, responses varied depending on their English language skills. For people who were able to read English (column two), while they were surprised and unprepared initially, this uncertainty was addressed by the materials themselves, as well as from a third party where preferred. On the other hand, for those with no previous exposure to the program and limited English language skills (column three), receipt of the Kit generated feelings of anxiety, and these could not be allayed until help was sought from a third party.

As the diagram shows, for most participants the end result was a positive perception of the program, but the journey for those with limited English and no previous knowledge was longer and more anxious.

## Reactions to the receipt of Pilot Kit



The following quotes also demonstrate the range of initial responses to the receipt of the Kits:

*“When I received the Kit I opened it straight away, but then I couldn’t understand it because the reading materials were in English. Eventually I found a few lines in Vietnamese on the bottom part of a multilingual page. That helped me to understand how to do the test, and then I took it (the Kit) to my doctor.”*

*“I asked my daughter-in-law. She explained a few words to me in Vietnamese, then I put it aside – I didn’t see this was a need for me.”*

*“When I see the words bowel cancer, I don’t want to associate with that, cancer is a serious illness. I didn’t want to open the pack, I put it aside.”*

*“Why was it addressed to me? There might be something wrong with me.”*

### ***Indigenous and South Sea Islander participants***

There were differences in initial responses among those who completed and those who did not complete the FOBT.

As with the results for the CALD respondents, those who completed the FOBT were more likely to have seen the promotion prior to receiving the kit. In Mackay they talked about the television commercials and promotions in the shopping centre, and a few said that they were “*waiting for it*”. These participants did not identify the promotion as specifically targeting Indigenous or South Sea Islander people, but saw it as relevant as it was targeting the Mackay community. There was a perception among a few that Mackay was “*lucky to be chosen*.”

As you would expect, those who completed the test were more likely to be literate, and few of these had expressly asked others for support. However, several had been encouraged by health workers to participate.

There was also some hesitancy in discussing the test with family, as several said that they did not want to worry their family with details of the test. This is different to the CALD sample, where those who did the FOBT were more likely to talk about the test with their family, health professionals, and to a lesser extent, friends.

For non-participants, several did not recall receiving the Kit at all, and these people had lived at the current address for several years, suggesting that it would have been received. Others remembered the kit arriving, but at the time threw the kit away as they found it too difficult to digest. Interestingly, the Indigenous and South Sea Islander non-participants were far less likely than the CALD respondents to have actively sought assistance, and while the community health sector has a significant influence, this needs to be driven by the health sector itself, rather than by community members.

It is also worth noting that a number of people regretted not completing the test once they had spoken to a health worker or after they had seen promotions about the pilot program. For this research itself, several of those who did an interview as non-participants (that is, they had not completed a test) were interested in being involved. The Indigenous researcher then contacted

the HIC to request Kits for these individuals. This process itself also indicates the level of support necessary among the Indigenous audience, as it was necessary for the researcher to negotiate the system and request the Kits on behalf of the individual community members.

#### **4.2.5 Triggers**

Amongst a number of participants the perception existed that the FOBT provided an opportunity to participate with little effort, and to have some control over the process. This was seen as a motivator for participation in the program. These participants tended to be better able to understand the English materials sent to them, and appeared to be more health savvy generally.

A number of participants felt that the fact that the FOBT was free was a motivator for participation, and a few believed that screening of this nature usually attracted a fee if administered by a physician.

Exposure to promotional activities and advertising regarding the FOBT also acted as a trigger for many participants, with some expecting to receive the materials as a result of the activity. For others it allayed anxieties that they were “at risk” because the FOBT had been addressed to them.

It should be noted that across the research the appeal of the process, (i.e. the fact that the FOBT was seen as easy to use, private and sent directly to the participant), was just as much a motivator for participation as the perceived health outcome of the screen.

#### ***Those from culturally and linguistically diverse backgrounds***

A number of participants mentioned consulting their GPs about the FOBT information and process. For many, the endorsement of the process by their GP provided the necessary impetus to participate. For others however, their GP’s explanation that participation in the screening program was voluntary actually acted as a deterrent to participation.

Participants in all the language groups appeared to defer responsibility for health decisions to GPs, and in many cases the notion of self-screening was quite new and something that they were not necessarily comfortable or familiar with, (“*the technique looked like a nursing job*”). In these cases consultation with their GPs generally provided the necessary confidence to participate in the program.

Participants who attended community information sessions about the FOBT in their own language found them very useful, particularly with regard to improved awareness of bowel cancer related issues and the benefits of preventative measures such as the FOBT.

The media and promotional activities that participants were exposed to before receiving the FOBT Kit helped to raise awareness of the program, and to contextualise the Kit after it arrived. In a few cases it generated a sense of ‘privilege’ about being situated in a pilot area.

The information contained in the Kit that directed people to translated information did not generally act as a trigger for participation, and this information was only actively sought out in one case.

### ***Indigenous and South Sea Islander participants***

Amongst those Indigenous and South Sea Islander participants who were more pro-active about their health than others, the television advertising and shopping centre promotion played a greater role in supporting the decision to participate in the FOBT screening. In most cases where participants recalled the promotional activities, the local content was noted and helped to position the FOBT as ‘something that is relevant to me’. However, as mentioned, these participants tended to be more health savvy generally, and the value of the advertising was in identifying the FOBT as an opportunity to obtain ‘peace of mind’ with little effort and at no cost to the individual. These participants tended to have some knowledge of bowel cancer issues, and the advertising and promotion was of less value in raising awareness of bowel cancer related issues generally.

For those who were less literate or less knowledgeable about bowel cancer issues, contact and encouragement from Indigenous and South Sea Islander community health workers was perhaps the most important trigger for participation. Indeed discussions with these participants suggested that they probably would not have participated otherwise. The reasoning for this more likely stems from lack of involvement and engagement with their own health, as opposed to an active decision not to participate.

For those who spoke of completing the FOBT because of an opportunity to attain ‘peace of mind’, most did not clearly articulate a deep understanding of the benefits of screening and tended to use phrases such as “*make sure nothing is wrong*” and “*checking out what is happening on the inside*”.

As with the CALD participants the ease of the process and general peace of mind was articulated more strongly than the preventative benefits of screening such as avoiding illness and early detection.

### **4.2.6 Barriers**

There were a range of barriers to participation identified that generally stemmed from fear and a lack of knowledge/awareness of the issues. A number of non-participants spoke of not engaging with the Kit because of a desire not to know about the issue, and in particular how it might relate to them.

*“When I see the words ‘bowel cancer’ I don’t want to associate with that. Bowel cancer is a serious illness. I don’t want to open the pack, I put it aside.”*

Others expressed a belief that screening of this nature was both valuable and important, but decided not to participate because they had no symptoms, and therefore felt it did not concern them. There were some cases where people actively encouraged or supported their spouse's participation, however decided not to participate themselves.

*“My husband participated straight away. He encouraged me many times to take part. He had a problem and requires an annual check up. I thank the government for having this plan for preventing cancer.”*

There were only a few instances where participants elected not to participate because the process of collecting and sending samples was seen as unpleasant, unhygienic or inappropriate.

However there was a perception that this type of test should be completed with the assistance of a physician. This related to a lack of confidence in their own ability to correctly complete the FOBT rather than a perception that self-testing was an inappropriate form of screening.

### ***Those from culturally and linguistically diverse backgrounds***

For those from CALD backgrounds language was a significant barrier to participation. There were several aspects to this. A number of participants received the Kit and were overwhelmed by the size and nature of information in English, and simply put it aside. Others assumed it was not relevant to them because the information was in English. Some asked family members to translate it for them, with various outcomes. For some, being made aware that participation was not compulsory was enough to make them decide not to take part in the pilot. In a few cases, the family member who translated the information (usually an adult child) was uncomfortable explaining the process for collecting the sample, which again resulted in a decision not to participate. In cases where the family member was neutral about the project, the person for whom they were translating often took this as a directive that they were not required to complete it.

A few participants did not want to “bother” their family, so did not ask anybody to translate the information for them. Across the research participants showed very little initiative in seeking out translated information. Many did not see the information in the Kit as relating to the availability of translated information. Amongst those who did, in all but one case this information was not sought out in either written form or through the telephone interpreter service. There was no interest shown in web-based information in English or otherwise.

It was therefore the case that unless a person felt comfortable enough asking somebody to help them understand the materials, they were unlikely to seek to understand the materials at all. This was despite the fact that the Kit was addressed to them.

There were a number of cases where participants indicated that had information been sent directly to them in their own language, they probably would have participated. It should be noted though that some participants did not feel confident about the quality of translated

information and had a preference for bilingual information so that translated information could be cross-checked against the English information.

### ***Indigenous and South Sea Islander participants***

For the Indigenous and South Sea Islander research participants similar barriers existed, however lack of awareness of bowel cancer related issues and lack of engagement with their own health tended to be accentuated in many participants. Literacy issues proved to be a significant barrier for a number of participants, and it was clear that many were unable to comprehend the pack and simply put it aside or threw it away.

Fewer Indigenous participants mentioned asking a family member or friend to help them understand the Kit, and there seemed to be less community discussion generally about the program than was suggested by the CALD participants. As discussed above, a direct approach from an Indigenous or South Sea Islander health worker was often the catalyst for participation. However it should be noted that participants did not actively seek out advice from health workers in the same way that many CALD participants consulted their GP.

There seemed to be much less awareness of the bowel cancer related issues among the Indigenous participants. For some non-participants even after an explanation of the Kit was given, it was clear that some still struggled to understand the nature and purpose of the screening. A few people who completed the FOBT and required follow up colonoscopies or treatment for polyps were unable to clearly articulate the nature of the follow up treatment, and in a few cases assumed that they had had received treatment for cancer.

There were no cultural barriers identified in relation to the FOBT, or toward self-screening. While a few women were embarrassed by the thought of the process, there was no evidence to suggest this 'shame' was embedded in a cultural taboo.

### **4.2.7 Reactions to materials**

Participants were shown the FOBT Kit and asked to comment on it as an overall piece, as well as its individual components.

In general, participants certainly had no major issues with the Kit in terms of tone or accessibility, although many commented that there was too much information and certain pieces were extraneous. Very few participants read all of the material contained in the Kit. As would be expected, many of the CALD participants displayed a strong preference for information to be available in their own language.

Amongst both the CALD and the Indigenous research participants, no concerns were raised regarding privacy and they were unconcerned about being identified for the pilot through the Health Insurance Commission, or about copies of their results being forwarded to their GP:

*“How could they do these things otherwise?”*

*“This is related to my life, so I would like my GP to know.”*

Given this, it was very common for participants to consider the HIC letter to be an unnecessary component of the FOBT Kit, and something that could be referred to briefly in the introduction letter.

Other comments in relation to the components of the Kit included:

- the **introduction letter** was clear and easy to understand, and the most likely component of the Kit to be read and recalled;
- the **participation form** was simple and easy to understand, and what participants would expect with a Kit of this nature. No issues in relation to the provision of personal details were raised; and
- the **booklet** was more likely to be glanced at than read closely. Those who read it found the information clear and easy to understand and a good source of information. Amongst those who did not read it, no concerns were raised about the quality or presentation of the information.

Both CALD and Indigenous and South Sea Islander participants considered the **‘Dietary Guidelines’ booklet** a bit unnecessary, with a number commenting that the information contained in it was ‘commonsense’. A few of the CALD participants suggested included culturally specific foods in translated content.

The fact that the **Australian Government** produced the FOBT Kit was both clear and acceptable to participants. Indeed, the prominent positioning in relation to government was seen positively and gave credibility to the Kit.

The fact that very few issues were raised in relation to the Kit and its components is probably indicative of the way in which the research was conducted, that is, depth interviews rather than group discussions. Group discussions create more of an environment where participants’ thoughts and ideas are more likely to be stimulated by the opinions of others.

### ***Those from culturally and linguistically diverse backgrounds***

As mentioned previously, a number of participants (both those who completed the FOBT and those who did not) felt there was too much information contained in the Kit. Although this in itself was not raised as influencing a decision about whether or not to participate, it nonetheless did make the process more difficult for some people.

*“...overwhelming ... too many details about bowel cancer. It was difficult to know what to send back and what to keep”*

There was a strong preference noted for bilingual information to be sent directly with the Kit, the lack of which was seen as the single most important barrier to understanding or engaging with the Kit. As discussed participants were not proactive about seeking out translated information, and in some cases were reluctant to ask even family members to interpret it for them.

When prompted about the reference to translated information in the Kit, a number had not seen this reference, and commented that it should be displayed more prominently in the Kit.

Amongst those who had noted the reference to the existence of translated information, only one acted on this and sourced the written information. There was little interest in either the 1300 telephone number or in web-based information.

The CALD research participants were shown the translated information as a part of the interview, and none raised any concerns about the quality of the information in terms of tone, length, language used or accuracy of translation.

### ***Indigenous and South Sea Islander participants***

The Indigenous and South Sea Islander participants generally had fewer comments about the components themselves, which is indicative of their lower level of displayed engagement generally. Those who completed the FOBT generally felt the information was adequate, simple and easy to understand. Those who did not complete it were often completely overwhelmed with the information and did not engage with the contents of the Kit at all.

### ***Reactions to the tests – ‘Inform’ and ‘Detect’***

Those who completed the FOBT were generally pleasantly surprised by the ease of the process, and only a few comments were made with respect to the test itself.

The ‘Inform’ Kit was generally seen as compact and slim with user-friendly instructions and diagrams. The ‘Detect’ Kit was more likely to be seen as bulky, and appeared more like a clinical test than the ‘Inform’ Kit. The instructions and diagrams were generally seen as more ‘technical’.

Despite the fact that participants generally found the process of completing the test surprisingly simple, it is worth noting that many still wanted reassurance from their GP that they were following the correct procedure.

*“[It was] simple and easy to understand. The method of collecting samples is fine, but I still need to see my doctor.”*

## **4.3 General Practitioners**

### **4.3.1 General reactions to the pilot**

As mentioned previously, one of the main objectives of the research amongst GPs was to obtain feedback on how they felt the national provision of the program could be improved. However, it should be noted that overall reactions to the program were extremely positive.

When prompted, GPs were generally able to think of some limitations of the program and provide suggestions for improvement or finetuning, but these concerns were not top of mind reactions.

Top of mind reactions instead tended to focus on the value of the pilot. GPs were unanimously favourable towards the idea of the Government taking such an active role in encouraging preventive medicine. They believed that bowel cancer screening was very important as prevention and early detection were the keys to beating the disease.

Many noted that as bowel cancer is generally asymptomatic in the early stages in their experience people often feel that any changes are normal and ignore them. They consequently believed that the program was of great benefit to the community, particularly as it was free to access. Comparisons were often made with BreastScreen and the cervical screening campaign, and bowel cancer screening was seen as an important addition to these programs. They were therefore happy to be involved in what they felt was an organised response to the serious threat of bowel cancer – a program that could save lives.

Most also felt that the Pilot had been well designed and implemented. Their initial reactions indicated that they were generally happy with the workload and administration, communication, their duty of care, and the effectiveness of the tests. The general view was that while there were a few issues that needed to be ironed out before national implementation, that overall the program was working well.

#### **4.3.2 Reactions to their involvement in the program and the administration of it**

Again, initial reactions to the administration required of them and the subsequent effect on their workload were positive among GPs. The increased workload as a result of the Pilot was not seen as onerous. They were also quite happy with the administration involved as it was part of a program they saw as meaningful and important. In addition, the payment for completing the forms was seen as an incentive – particularly as they had so much paperwork that they were not compensated for.

Most GPs in the research felt that effort had been taken in the development of processes and forms to make the administration as easy as possible. Further, most felt that as their dealings with patients regarding the Pilot had been spread over an extended period, that they were not overloaded with too many patients at any one time.

When prompted on ways that the administration could be further streamlined, GPs were able to come up with a number of suggestions for improvement. Almost all mentioned that the forms lacked the participant number. Initially, a number had spent time trying to find out this number when completing the forms which was seen to be a waste of their time. Eventually, they tended to leave this field blank, so it was seen to be an unnecessary item. Some even worried if failing to complete this item meant they would not receive payment as they had not filled in the form correctly.

Another issue identified with the forms was the difficulty in telling the referral and non-referral forms apart – many suggested that the forms be colour coded to overcome this confusion, or simply be combined, with the option to tick a box to indicate whether it was for referral or non-referral. In addition, it was recommended that the forms should include a section with additional space where they could provide information deemed necessary such as medication history and notes from the medical examination.

A final recommendation for form design was that the contact details of the Register and the Helpline should be included on the forms to save GPs from having to look elsewhere for this information.

Reactions to the idea of electronic forms were extremely favourable. Most felt that this would be much easier and consistent with the way they were doing the rest of their administration, but they noted that the forms would have to be compatible with Medical Director in order to prevent double handling. It was suggested though, that paper forms should be retained, at least for a transition period, for non-computerised surgeries.

Some were also confused by the system of payments. They found it difficult to reconcile payments as the procedures did not involve any mechanism to list which patients they had seen in relation to the program. So while they received a list of patients for whom they were receiving payment, they had no systems in place to detect if any patients were missing from this list. Specific item numbers were offered as a suggestion to overcome this problem.

While many GPs were happy to take on some responsibility for following up their patients, they believed that this should be in addition to the follow ups from HIC. It was clearly seen that HIC would have the ultimate responsibility for reminders.

There were a variety of reasons for this. It was seen as easier and more logical for HIC to be responsible for follow up, as they have access to all the necessary information. In fact, GPs believed that if it was left solely to them to follow up patients, then those people without a nominated GP would be left out. It would also be impractical for GPs to undertake initial follow up (to encourage patients to complete the FOBT in the first place) as they were unlikely to be aware of when the kits were received, and they may also not necessarily be aware of which patients had listed them as their nominated GP. Further, most felt that it was more forceful if the Register followed patients up – patients would be more likely to feel like it was something they had to do.

### **4.3.3 Reactions to the referral process**

Overall, reactions to the referral for colonoscopy process were mixed. This was clearly seen as an area that would need to be considered before the screening program could be implemented on a national basis to ensure that there would be enough specialists to cope with the greatly increased demand for colonoscopies.

Many believed that the waiting times for colonoscopies had been excessive during the Pilot. They felt there had been insufficient specialists to deal with the numbers coming through the Pilot and that the colonoscopists were overloaded. This situation was seen as a particular concern due to the anxiety it caused for patients.

Positive test results, particularly those that could indicate a serious disease like bowel cancer, were clearly concerning for patients, and any delay in finding out what these results indicated was seen to be very upsetting for patients.

Others believed this was less of a problem due to the ability to rush urgent patients through. That is, if a patient had other indicators of bowel cancer as well as positive FOBT results, such as family history or other clinical signs, they were able to move them up the queue. These GPs were therefore reasonably comfortable with the waiting times as they felt they were able to manage their patients' expectations by letting those who had to wait for longer know that the risk their positive test result meant bowel cancer were low. Some others believed that while this ability to rush cases through was relatively positive, that even greater ability to prioritise the queue was required.

Others also noted that despite the issues with waiting times that the Pilot had provided better access to colonoscopies through the public system than had previously been available, which was of benefit to the community.

In terms of the ease of the follow up and referral process for those requiring colonoscopies, this appeared to work well and was not seen as burdensome.

There were, however, some reports of results going missing and of GPs not being notified of results. In these cases GPs had to call the Helpline to chase results. Care must be taken with these findings, however, as they may not be representative due to the qualitative nature of measurement.

There were concerns over whose responsibility it was to ensure the completion of the referral process. Some believed that there was no system in place to confirm when requests for colonoscopies had been received. They felt they would be more comfortable if the referral process included some form of check so they would know that the referral had been received, rather than just hearing from the patient if there was a problem.

#### **4.3.4 Perceptions of duty of care**

Most GPs were comfortable with their duty of care under the screening program. The general belief was that the duty of care would remain with HIC until a patient consulted them regarding the program. There were, however, some changes that were suggested that could further clarify this.

These suggestions generally centred around the communications for the program encouraging patients to consult their GP (or *a GP* if they did not have a regular doctor). Firstly, patients receiving positive FOBT results who had not nominated a GP should be encouraged to

consult a GP. Secondly, while patients with a nominated GP who tested positive were advised to consult their GP, a timeframe was not specified. A timeframe of a couple of weeks was suggested. Finally, a public education campaign highlighting the importance of early detection of bowel cancer was seen as essential in encouraging patients to screen, and where necessary, to visit their GPs.

GPs were conscious of the need for CALD people in particular to ask their GP for confirmation about issues such as the screening process, and they were happy to provide this reassurance where necessary.

#### **4.3.5 Reactions to GP education on the program**

There were mixed reactions to the information that the GP's had received regarding the Pilot from HIC and the Divisions. There was in fact a common perception that too much information had been provided on the program prior to its commencement. This related to both the workings of the Pilot and bowel cancer generally.

In relation to the former, a number of GPs had been concerned about their role in the program and the time involved, after attending an information session. They talked about having received a "huge" file of information to read which gave them the impression that the administration would be highly complicated. It was only after the Pilot started that they realised that the administration was in fact not difficult or overly involved. Some recommended that the information packs given to GPs be greatly reduced with only one or two pages outlining the process. Many actively found general education on bowel cancer to be unnecessary as this was basic information that they had learned in medical school.

Although many GPs believed that in general they had received too much information prior to the Pilot, there was one aspect of the education that they had found particularly useful. It was seen to be essential that all GPs were made aware of the value of the particular FOBTs used. While some had been aware that new more efficacious tests had been developed in the last five years, others had questioned the value of the tests.

Perceptions of the tests depended on "what articles they had read". They therefore felt that education from the Divisions early in the Pilot on the effectiveness of the tests in detecting cases of cancer and saving lives was important. A number also found feedback during the Pilot on how the program was working and how many cases had been picked up was useful in reinforcing the value of the screening tests.

#### **4.3.6 Reactions to patient response to the program**

**GPs generally found patient reactions to the program to be positive. Many noted that while some patients had been initially reluctant to participate, that often this hesitation was replaced by positive reactions after talking to others who participated and finding out how easy it was. People came to feel it was acceptable or even feel left out if they had not participated.**

Most felt that they were able to encourage reluctant patients to participate, although they noted that only people who were at least considering participation were likely to consult them in relation to the program.

A number mentioned that some patients felt excluded if they fell outside the target age range. Some felt that in the national roll out there should be a broader age range included, or at least the capacity for them to be able to include other patients on request.

While there was a reasonable understanding of the need to impose age restrictions in the Pilot, GPs felt this would be less acceptable in the “real” program.

Overwhelmingly, a public awareness campaign was seen as crucial to the success of the national roll out. They believed that the public needed more information on the prevalence of the disease in order to be more aware of the importance of screening. Without an awareness of how common the disease is, people are likely to think if they have no symptoms there is no need to screen. Many recommended that campaigns like that used for BreastScreen would be of great benefit. Others mentioned that posters behind toilet doors like those used for cervical cancer screening would be a good way to communicate with the public on the issue.

#### ***Patients without fixed addresses***

Some concerns over access to the screening test for those without a fixed address (particularly in Mackay) were raised. It was believed that this group, which largely comprised of Indigenous people and people of lower socio-economic status (particularly homeless) were not receiving the kits.

One GP mentioned that while in the beginning of the program, GPs had been able to notify the register of patient changes of address, that this had been stopped for privacy reasons. However, it was seen that this would stop disempowered groups who would not be likely to contact the register to obtain kits, from participating in the program.

To overcome this problem in the national roll out, it was suggested that some mechanism to allow GPs and/or health workers to advise HIC of patient addresses should be incorporated. If this was not possible for privacy reasons, then an alternative means of obtaining kits (such as directly from GPs or through health centres or community centres) should be considered.

#### ***Patients with language/literacy issues***

Some felt that the information packs (in both English and the translated versions) were in language that was too complicated for people with limited literacy skills and CALD groups. They suggested that the material would be confusing for people who have limited literacy skills and limited knowledge of biology. In order to make the program more accessible to those who would find any written material difficult, it was suggested that the information in the packs needed to be supplemented with press, radio and TV campaigns.