"…if I get five minutes to myself, I would rather have a glass of wine than go to get a Pap smear done…"

GIPPSLAND PRIMARY HEALTH NETWORK
CANCER SCREENING RESEARCH

Report of qualitative research

25 June 2019

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EXECUTIVE SUMMARY

The Gippsland Primary Health Network (GPHN) commissioned MMResearch to conduct a program of qualitative research to assist in developing approaches to address low cancer screening rates in the region.

The aim of the research was to explore knowledge, attitudes, behaviours, motivators and barriers with respect to each of the cancer screening programs, cervical, breast and bowel cancer screening, with the specific aim of identifying opportunities for encouraging screening behaviours.

The research design comprised a program of fourteen group discussions with 80 participants, segmented by age, sex, and screening participation. Participants were recruited to the research if they were not up to date in at least one of the cancer screening programs, with separate groups for each of the programs. The discussions in each group focused primarily on the screening program that the participants were not up to date with, but also included discussion of other cancer screening program as appropriate for age and sex of the group. All research sessions were recorded and transcribed, and the data was thematically analysed for this report. This project was granted ethics approval by the Latrobe Regional Hospital Human Research Ethics Committee.

SUMMARY OF KEY FINDINGS

The following is provided as a summary of the findings of the research, documenting the key issues identified for each of the screening programs, and the themes that emerged when comparing responses across the three programs.

Bowel Cancer Screening

- Awareness and perceptions of bowel cancer were strongly associated with the NBCSP itself, with exposure to the kit communicating that bowel cancer was an issue for the population. For some, close personal association with incidences of bowel cancer, through family and friends, also communicated that bowel cancer was reasonably common.
- However, people were not aware of how common bowel cancer is, reporting that it does not have the same profile as breast, prostate or skin cancer. Consequently, perceptions of personal susceptibility to bowel cancer were low, and this affected perceptions of the need to screen.
- Increasing people's knowledge about the incidence of bowel cancer, especially in relation to other cancers that they already have concerns about (breast, prostate and skin cancer), was a key factor in prompting them to consider that they should treat screening for bowel cancer at least as importantly as they treat testing for other cancers.
- Bowel cancer is believed to be quite a serious disease, with the treatment understood to have severe implications on a person's life and lifestyle. Familiarity with bowel cancer was often associated with cases of late diagnosis, radical treatment and poor prognosis. These experiences contributed to a reluctance to find out about a bowel cancer diagnosis.
- Of those who had not completed the NBCSP kits, some rejected it immediately, while others put it aside and have not subsequently gotten around to completing it. The latter group had typically not

decided not to do the test, but had not prioritised it sufficiently to act. This group appears to offer the greatest opportunity to change behaviour through messages that enhance understanding of the importance and benefits of screening.

- Barriers to bowel cancer screening included factors associated with:
  - The kit – Distastefulness and embarrassment about the procedure;
  - The kit – Complicated procedure and instructions;
  - Health attitudes – priorities and perceived susceptibility;
  - Health attitudes – attitudes of avoidance and fatalism; and
  - Screening beliefs – poor appreciation of the role and benefits of population screening, including the perception that one would experience symptoms.
- There was no sense of urgency associated with bowel cancer screening or with completing the kit. The information included with the kit did not create a sense that it needs to be done in a hurry, as evidenced by the number of participants who reported putting the kit aside for weeks, months or even years.
- Other than receiving the kits, participants experienced few reminders or prompts to participate in the screening program. There was some awareness of a CCV campaign that had launched during the time of the fieldwork, but otherwise, they did not experience any promotion of the issue in mass media, local media or social media, and few mentioned that the topic was raised by their health professionals.

Breast Cancer Screening

- Breast cancer has quite a high profile in the minds of women, associated with its prominence in the media and the close personal connection many women have with breast cancer.
- Breast cancer was regarded as a serious disease with potentially severe consequences, although it was understood that developments have improved treatment outcomes so that it was now considered more of a treatable cancer.
- Despite awareness of its commonness, several factors mitigated perceptions of personal susceptibility to breast cancer. Most importantly, there was a common belief that the main predictor of breast cancer was having a family history. Consequently, not having a family history of breast cancer was cited as a reason for not needing to participate in breast screening. There is a definite need to promote messages that counter this belief.
- The main barriers to participation in the breast screen program included factors associated with:
  - The procedure – unpleasant and painful;
  - The procedure – concerns about radiation;
  - The procedure – convenience of locations and bookings;
  - Health attitudes – priorities and perceived susceptibility;

  - Health attitudes – attitudes of avoidance and fatalism; and
  - Screening beliefs – poor appreciation of the role and benefits of population screening, including the perception that one would detect a lump if it was cancer.

- There is limited awareness that the breast screen program is only promoted as a free service to women over fifty, and little understanding that the test is less valuable for younger women due to factors associated with breast tissue density.
- Past experiences of mammograms affect future participation. Several participants reported having had a mammogram many years ago, when they were in their twenties and thirties, and found the experience to be so uncomfortable that they have not returned. These women have not received anything to communicate that the procedure might be different for them now, or that the equipment or operators might have changed in the meantime.
- Despite breast cancer being recognised as having a high profile in the community and the media, participants could not recall any mass media campaigns promoting breast screening in recent years.
- Participants also commonly reported that breast screening was not consistently mentioned by their doctors. Several mentioned that having had reminders from their GP in the past had been an important prompt to booking in for a mammogram.
- Amongst those who were not up to date with breast screening, several reported not receiving reminder letters, suggesting that there may be a need to review the reminder process in terms of whether there are any gaps, and whether the existing communications are effective.
- There was some recall of the BreastScreen Victoria Mobile Unit, although a general perception that this was not as available as it had been in the past. Greater access to this service is likely to be an effective component of overcoming barriers related to convenience and to the quality of the service.

Cervical Cancer Screening

- In contrast with breast and bowel cancer, cervical cancer was believed to be rare, and as such was not high on people's radar of diseases to worry about. While some reported having had abnormal cells detected in past Pap tests, few knew of anyone who had developed cervical cancer. As such, women did not rate their personal susceptibility to cervical cancer as high.
- The Pap screen program was recognised as having been operating for a long time, however, it was evident that many women did not understand that the Pap test was a screening test for cervical cancer. Rather, numerous misunderstandings existed about the Pap test being for a range of gynaecological and sexually transmitted conditions. To some extent, these perceptions were related to their experience that prompts to have a Pap test in the past had been associated with sexual issues, pregnancies and gynaecological symptoms.
- The issue of HPV and its link with cervical cancer was raised during these discussions. While there was some awareness, very few were confident in their knowledge around these issues. Participants wanted to know more about issues, such as:

- Is cervical cancer only related to sexual activity? And if so, what do these changes mean for those who are no longer sexually active?
- Is the vaccine 100% effective? And related to this, do those who have had the vaccine need to continue with Pap testing?
- How does HPV affect men, and should men also be regularly tested for HPV?
- Why is a five-yearly testing regime more effective than the current two-yearly regime?

- The poor awareness and understanding of these issues suggest that there is a substantial need for detailed and effective communication about HPV, the vaccine and its impact on cervical cancer and the cervical cancer screening program. It will be very important in the transition to HPV screening to create clear and simple communications about the changes, and to ensure that these changes are consistently communicated through direct messaging to women as well as through messages from health professionals.
- The issue of self-testing was raised unprompted in several groups. Participants believed that self-testing would overcome many of the barriers they experienced to participating in the cervical screening program.
- The main barriers to participation in the cervical screening program included factors associated with:
  - The procedure – unpleasant, embarrassing and uncomfortable;
  - The procedure – skills and relationship with a health practitioner;
  - Health attitudes – priorities and perceived susceptibility;
  - Screening beliefs – poor understanding of the purpose of the Pap test.
- The overwhelming sense from these groups was that, because they would prefer not to think about Pap tests, if they did not experience any blatant external cues to action, then they simply avoided it. Consequently, these women felt that they would only undergo a Pap test if it was suggested by a GP, if they were reminded by a letter and / or if they were prompted by social marketing.
- However, women who are not up to date with Pap tests commonly reported not receiving reminder letters, suggesting that there may be a need to review the reminder process in terms of whether there are any gaps, and or whether the existing communications are effective.
- Some suggested that on-line booking system or a smart phone app, where they were able to specify that they wanted to attend for a Pap test, would help them to overcome barriers associated with talking about the procedure.

Local issues that contribute to low cancer screening rates

- A range of factors associated with the provision of health care services in the Gippsland region were believed to affect cancer screening rates, including health care resources generally, and specific issues related to general practitioners.
- The main concern was the difficulty of receiving care from a GP with whom people could develop a long-term therapeutic relationship. Many participants reported that GPs did not stay in the area for

long, and / or that it was difficult to see the same GP even when making a booking at their regular clinic.

- This was thought to especially affect cervical cancer screening, where trust was considered to be fundamental. Women raised specific concerns in relation to Pap tests with respect to a lack of female GPs and the difficulties they experienced in communicating with some GPs that they felt were exacerbated by the intimacy of the procedure.
- The lack of continuous care by a practitioner was believed to affect whether people were reminded to take part in all screening programs.

CONCLUSIONS & RECOMMENDATIONS

This research was designed to explore the factors that contribute to people's participation in screening for breast, bowel and cervical cancer, for the purpose of providing insights for the development of approaches that will encourage participation in these screening programs.

What does this research tell us about participation in cancer screening?

- An overarching theme of this research was that the concept of cancer screening is not well understood or sufficiently appreciated to overcome the barriers to participation.
- The concept of population screening was found to be quite complex and somewhat antithetical to many people's approach to their personal health.
  - Participants reported that they usually acted on their health if they believed they were at risk of a disease and/or if they were experiencing symptoms.
  - This was reinforced by their experience that health tests were typically recommended by health professionals for diagnostic purposes (i.e., in anticipation of a positive result).
  - However, participation in screening requires people to act independently of these usual triggers, and the typical outcome of a screening test is a negative result for a condition that a person does not necessarily believe that they might be at risk of.
  - This is compounded by the tests themselves being experienced to varying degrees as unpleasant, uncomfortable, embarrassing and / or inconvenient.
  - Consequently, there is often not a sufficient internal driver for people to screen, so that external drivers become critical.

What needs to be done to improve cancer screening rates in the region?

Taking into account the findings across all three of the screening programs, factors that affect participation include a combination of:

1. Perceptions of susceptibility to each of the cancers.
2. Awareness and experience of each of the screening tests.
3. Personal health attitudes and beliefs.
4. Being reminded to screen.

1. Addressing perceptions of susceptibility will require different messages for each of the cancers. For example:
   - Bowel cancer – to increase understandings of how common bowel cancer is compared with breast and prostate cancer.
   - Breast cancer – to educate women that not having a family history is not a reason to go un-screened.

- Cervical cancer – to educate women about who needs to be screened, especially in the context of the changes to HPV testing.

2. Addressing barriers related to each screening test will also require different messages for each of the screening programs, for example:
    - Bowel – develop and promote simpler instructions.
    - Breast – communicate advances in the technology, the process and the operators since the early days of mammograms.
    - Cervical – consideration needs to be given to whether the misunderstandings about the Pap test need to be corrected.

3. There are opportunities to affect behaviours across all three screening programs by addressing health attitudes and beliefs that affect how people balance their decisions with respect to the barriers & benefits of screening. To achieve this, consideration needs to be given to a combination of approaches, including:
    - Developing attitudes to health that place disease prevention as a high priority (in the context of existing illnesses and caring for others).
    - Improving understanding that the benefit of screening in terms of early detection and treatment.
    - Consideration will need to be given to the development of messages that seek to achieve these aims, including messages about:
        - The benefits of screening – that screening can detect these cancers before symptoms are experienced (e.g., that the FOBT detects microscopic blood that you won't see, that the mammogram can detect lumps smaller than you will be able to feel).
        - The benefits of screening – that early detection means simpler, more effective treatment, and is the best way to avoid the more drastic and severe forms of treatment for these cancers.
        - Health attitudes and priorities– that the long term benefits of screening outweigh the short term discomfort of the procedures.
        - Health attitudes and priorities – that it is as important to look after yourself as it is to look after everyone else.

4. There are opportunities to affect behaviours across all three screening programs by developing approaches to ensure appropriate and timely reminders. The strategy will need to develop approaches that more effectively prompt and remind people about the screening programs, taking into consideration:

- That broad social marketing approaches will be required, including a combination of mass media, local media, social media. The more prompts and reminders people are exposed to, the more they will be encouraged to screen.
- An aim of communications should be to normalise participation in cancer screening through stimulating conversations about cancer screening.
- Further consideration needs to be given to the effectiveness of existing communication programs, including:
  - Invitation and reminder letters – Are these getting to people? If so, are they communicating effectively?
  - GPs and GP clinics – Do reminder systems exist? Are they being used? What is the role of the GP, the Practice Nurse and others in promotion of cancer screening? What barriers and challenges do GPs and GP clinics face with respect to promotion and delivery of cancer screening programs?

BACKGROUND

The Gippsland Primary Health Network (GPHN) commissioned MMResearch to conduct a program of qualitative research to assist in developing approaches to address low cancer screening rates in the region.

The aim of the GPHN Population Based Cancer Screening Program is to develop a range of sustainable, evidence based and best practice activities to impact population-based breast, bowel and cervical screening programs to increase the likelihood of people to screen for cancer throughout their life.

Certain objectives of the GPHN Cancer Based Screening Program are of direct relevance to this research, including:

- Increase whole of community awareness of population-based bowel, breast and cervical screening programs.
- Target breast cancer screening rates for women aged 50-74 years living in Churchill Moe and Morwell towards the State average.
- Target bowel cancer screening rates for men aged 50 living in Latrobe City towards the state average.

In the process of designing this research, we were mindful of the fact that there are three different cancer screening programs, each with different target audiences, different regimes and different protocols for participation. Consequently, to provide sufficient insights and guidance, this research project needed to comprise three separate components, one for each screening program. While the research was designed to look for overlapping opportunities with respect to the outcomes, it was also evident that there is a need to look at each of these screening programs separately in order to identify those opportunities.

There are numerous stakeholders in the local area who are influential in the provision of services that will encourage participation in the three cancer screening programs, and we acknowledge that the views of these stakeholders should be sought with respect to the findings and recommendations of this research.

Cancer screening in the Latrobe Valley

Information related to each of the screening programs, and key data related to each of the cancer screening rates in the Latrobe Valley is summarised below.

Bowel cancer

The target audience for the National Bowel Cancer Screening Program (NBCSP) is men and women aged 50-74. People in this target audience are invited to participate in this program with a kit mailed out to them by the Commonwealth government. The program began with a five-yearly interval, and is being changed to a two-yearly interval, which will be fully rolled out by 2020.

Bowel cancer participation rates in Latrobe City were lower for:

- Males;
- 50 year olds (compared to 55, 60, 65 or 70 year olds); and
- Residents of the Moe and Morwell SA2s, compared to the rest of Latrobe City.

Breast cancer

The target audience for breast cancer screening is women aged 50-74. Women in this age range are invited to participate in a two-yearly mammogram screening program through BreastScreen Victoria.

Breast cancer screening rates in Latrobe City were lower for:

- Women aged 70-74 years (compared to women aged 50-69 years);
- Women in Moe, Morwell and Churchill postcodes compared to the rest of Latrobe City;
- Aboriginal and Torres Strait Islander women and women who speak a language other than English at home.

Cervical cancer

With the recent change of this program to a five-yearly regime of screening for Human Papilloma virus, the target audience for cervical cancer screening is women aged 25-74.

Cervical cancer screening rates in Latrobe City were lower among:

- 20-24 year olds and also among 65-69 year olds.

Research Objectives

The purpose of this project was to provide insights that will inform the development of strategies and communications to encourage cancer screening. The overall aim of the research was to explore knowledge, attitudes, behaviours, motivators and barriers with respect to each of the cancer screening programs, cervical, breast and bowel cancer screening.

Specific issues that were explored included:

- Awareness of each of the cancers, including:
  - Knowledge and perceptions of incidence;
  - Knowledge and perceptions of seriousness; and
  - The impact of knowledge and awareness on screening behaviours.
- Perceptions of susceptibility to each of the cancers, including
  - Identification of factors that affect perceived susceptibility; and
  - The impact of perceived susceptibility on screening behaviours.
- Awareness of the screening programs, including:
  - Awareness of the recommended screening regime;
  - Understanding of the process of screening;

  - Perceptions of the value of screening; and
  - The impact of awareness of the screening programs on screening behaviours.
- Exploration of attitudes to and experiences of screening:
  - Experiences of screening, and how these have affected subsequent screening behaviours;
  - Motivations for screening;
  - Barriers to screening.
- Exploration of perceptions of existing strategies and programs aimed at encouraging screening:
  - Response to recent social marketing campaigns.
  - Role of health professionals in encouraging screening programs.
  - Exploration of other influencers.

RESEARCH APPROACH

The research design comprised a program of 14 group discussions, with a total of 80 participants.

Target audiences

In determining the most appropriate approach for this research, we were mindful of the fact that there are essentially three separate programs of research (one for each of the screening programs), each of which has a different target audience.

- Cervical cancer screening – Women aged 25-74
- Breast cancer screening – Women aged 50-74
- Bowel cancer screening – Men and women aged 50-74

The only audience segment that overlaps these programs are women aged 50-74, for whom all three screening programs are relevant, hence a substantial emphasis of the sampling was on this group.

Sample and Segmentation

Factors taken into account for segmenting the sample included:

- **Screening program** – the research was segmented to enable exploration of each of the different screening programs. This was achieved through separate groups of men and women and through age segmentation, as follows:
  - Men aged 50-75 – bowel cancer
  - Women aged 25-49 – Cervical (HPV) screening

  - Women aged 50-74 – Cervical, Breast, Bowel screening.

- **Screening status** – participants recruited to the research were 'under-screened' for the cancer screening program of relevance to their age/sex segment. Under-screened included:
  - **Never screened** – invited, but not participated in the screening program.
  - **Lapsed screeners** – have participated at least once in the nominated screening program but were overdue for their next participation (for breast and cervical we defined this as being at least a year overdue).
  - A mix of never and lapsed screeners were recruited.
- Note that the women aged 50-74 are the target audience for all three cancer screening programs. Hence, for this target audience we conducted multiple groups, with the criteria for each group being about underscreening for one program only (i.e., there were 3 groups of 50-59 year old women, with one group who identified as under-screened for breast cancer, one group who identified as under-screened for bowel cancer and one for cervical cancer).

The table below provides a summary of the sample segmentation we have proposed.

	Men	Women		
Age	**Bowel**	**Bowel**	**Breast**	**Cervical**
25-34				2 group
35-49				2 group
50-59	2 groups	1 group	1 group	1 group
60-74	2 groups	1 group	1 group	1 group

Group discussions

A discussion guide was developed based on the research objectives, and after detailed consultation with the GPHN project team. This discussion guide was used by the group moderator to prompt conversation amongst the participants, to steer discussion to the topic areas to be covered and the specific questions of interest within each topic area. Given the sensitivities of some of the issues to be discussed, we matched the sex of the moderator with that of the group for the cervical and breast screening groups. Some of the bowel screening groups were co-facilitated. Both of our moderators have extensive experience conducting group discussions on the topic of cancer screening.

Given the issues identified as important for exploration in this research (knowledge of each of the cancers; perceptions of severity and personal susceptibility to these cancers; awareness of the screening programs; barriers to participation; perceptions of the efficacy of the screening programs; and prompts to action), the research questions were designed around the Health Belief Model. The discussion guides were developed to facilitate conversation around the factors that feed into this model of health behaviour.

Recruitment

Recruitment was coordinated by a professional research recruitment agency. The process comprised a mix of methods, beginning with an email to a sample of the agency's database of people who live in the Latrobe Valley, and who have previously expressed their interest in participating in market and social research. This was supplemented through advertising (local media and social media) and snowballing techniques. We recruited between six and nine participants for each group, with response rates returning a total of 80 participants. Participants were paid an incentive to cover time and expenses.

Group facilities

The groups were conducted in facilities in local hotels in each of Traralgon and Morwell. All research sessions were audio-recorded for the purposes of analysis.

Analysis and reporting

With the permission of participants, all research sessions were recorded. The recordings were transcribed and analysed using a thematic analysis approach, with themes developed from the research objectives and emergent trends from the data. The thematic content analysis approach involved the following steps:

- Reading a sample of transcriptions to identify key themes and subthemes;
- Preparation of a coding guide based on these topics;
- Reading each transcript and coding responses according to theme and subtheme. During this process, specific quotes were identified as illustrative of the breadth of findings;
- Writing a descriptive analysis that covers the breadth of findings, and identifies the relative weight of issues within each theme and subtheme; and
- Preparing a narrative report of all issues.

A sample of quotes has been included for illustration purposes, with a reference to the group in which the quote was made in terms of sex, age group and the screening status that the group was recruited on the basis of (Bo=underscreened for bowel cancer, Br = underscreened for breast cancer, Cx=underscreened for cervical cancer).

It should be noted that these quotes are not necessarily representative or reflective of segment differences, rather, they are included to illustrate and provide context and language to the findings of the group discussions.

While this report is an accurate reflection of the attitudes of participants, the limitations for generalising qualitative research should be acknowledged.

Ethics approval

This project was granted ethics approval by the Latrobe Regional Hospital Human Research Ethics Committee (Reference number 2018-22).

DETAILED FINDINGS

As the content of discussion related to each of the three cancer screening programs was quite different, the findings are presented separately for each program.

Within each of the three cancer screening topics, the findings have been documented with respect to the following key areas:

- Knowledge and awareness of the cancer, including perceptions of incidence, severity, risk factors and personal susceptibility.
- Knowledge and experience of the screening program, including awareness, perceptions of accuracy and perceived benefits.
- Factors affecting participation in the screening program.
- Prompts to participation in the screening program.

Documentation of findings for each of the screening programs is followed by sections on:

- Responses to the 'Screen for me' social marketing concept
- Perceptions of local issues that affect screening
- Themes common to all screening programs.

BOWEL CANCER SCREENING

The issue of bowel cancer screening was discussed in all the groups of people aged 50-59 and 60-74. Bowel cancer screening was the main focus of discussion in four groups of men who were underscreened for bowel cancer and in two groups of women who were underscreened for bowel cancer. Bowel cancer was peripherally discussed in the 50-59 and 60-74 year old groups of women who were underscreened for either breast (2 groups) or cervical cancer (2 groups).

Bowel cancer – knowledge and awareness

Participants were prompted to discuss their perceptions of bowel cancer. Top of mind perceptions about bowel cancer were commonly associated with the National Bowel Cancer Screening Program (NBCSP) itself, based on reactions to having received the NBCSP kit in the mail. There was some belief that bowel cancer was probably reasonably common and detectable, with participants reasoning that government wouldn't send out free test kits if this was not the case.

> *It must be easily detectable because that's why they send out simple kits apparently, so therefore it must be. I know I'm not great a literature reader on diseases or anything like that, but obviously they send the tests out, it must be easy to detect. (M, 50-59, Bo)*

However, there was a general feeling that bowel cancer was not as important an issue as some other cancers, notably breast or prostate, as it did not have the same profile in the media or in general conversations. Perceptions of the importance of bowel cancer were strongly associated with how much participants had heard about the disease. A common response was that, other than receiving kits from the NBCSP, there was limited promotion of the disease, and therefore it was not as concerning as other cancers that had a higher profile. Those who had a close association with bowel cancer, through family or friends, tended to rate it as a more important issue.

> *My impression is that it is not that common, because I've not seen it and I've got an extended family and circle of friends. (M, 60-74, Bo)*
>
> *There's a handful of bad cancers around you know, and you still think about [bowel cancer] you know, and should you get it checked or whatever, but you don't hear that many statistics you know. (M, 50-59, Bo)*
>
> *I reckon breast cancer is probably, to me, I've heard a lot more about people having breast cancer than bowel cancer, like, a lot, quite a lot, so…it's more common than bowel cancer. (F, 60-74, Bo)*
>
> *My dad died of bowel cancer, so I am scrupulous for the bowel cancer it comes in the box … gotta do that because that was my dad, that is what it comes to. (F, 50-59, Br)*

Top of mind thoughts about the bowel cancer were often related to perceptions of its severity, and these perceptions varied greatly. For some, it was believed to be a severe disease that was either completely life changing or a death sentence. Several people talked about friends or family members who had been diagnosed with bowel cancer, and whose treatment was quite drastic and prognosis poor. They referred to the need for colostomy bags and limiting effects on people's lifestyles as indicating that bowel cancer was a serious disease. It was evident that many of these examples involved late stage diagnosis, although this was not always acknowledged by participants as the determinant of seriousness. As noted subsequently in this report, these perceptions affected some people's participation in the NBCSP.

Painful death. I've known a couple of people that have died from it. (M, 60-74, Bo)

I knew a bloke … and he had it and he had his bowel cut out and had a colostomy bag and all that, and he lasted 18 months after he got the bag. (M, 60-74, Bo)

Well the immediate thought I have is that horrible thought of having this bag arrangement. And yeah, that's a bit awful, you'd almost say, I don't want that, it's a real big issue. (M, 60-74, Bo)

If they get it early enough, they can recover quite well. If not, it can go into your other organs and then you're knackered. You're buggered. (M, 50-59, Bo)

I worked with someone that had bowel cancer, and she was young. She was in her early 30's … She was really crook. And she looked really crook. (F, 50-59, Bo)

The only touching base about bowel cancer that there has ever been in my life is that, that person [who] was diagnosed with bowel cancer, they opened her up to take it out and she died a couple of weeks later. And the point would be? (F, 50-59, Bo)

For others, bowel cancer was believed to be one of the more treatable cancers. To some extent these perceptions were also based on the experiences of family and friends who had been diagnosed with bowel cancer and who had been successfully treated. These participants tended to be more positively inclined towards the benefits of early detection.

Pretty nasty but it is recoverable from. I have a friend … who had severe bowel cancer quite a few years ago and he got all his medicals back, after having a big hunk of bowel cut out too. So it is recoverable. (M, 60-74, Bo)

It's one that can be cured with both surgery and radiation therapy or whatever, unlike a lot of the bone marrow ones. (M, 60-74, Bo)

I've always heard if you catch it early, it's reasonably [treatable] … that's why they send the kits out, no doubt, but why haven't I done it; I can't explain that. (M, 60-74, Bo)

Yeah, I got a feeling it's pretty common but in a lot of cases people are surviving and being treated in different states of degree of surgery required. (M, 50-59, Bo)

They can cut that part of the bowel out can't they, if it's not, I don't know, that's my thought, that I thought they could do that, they can cut part of the bowel out that's affected, and it would be fine after that. (F, 60-74, Bo)

They say that you have got a pretty good chance though if they catch it early with bowel cancer don't, they? (F, 50-59, Bo)

Bowel cancer – Perceptions of susceptibility

Participants were prompted to discuss factors that affected their perceptions of susceptibility to bowel cancer, with responses referring to a combination of perceptions of the incidence of bowel cancer and factors that affected individuals'' perceptions of personal risk.

Compared with other diseases, bowel cancer appeared to be relatively low on people's list of things that might happen to them. Participants reported being concerned about a range of other diseases because of a family history, or because they had symptoms or had already been diagnosed.

While existence of the NBCSP suggested that bowel cancer must be reasonably common, other than those who had a close association with bowel cancer, the disease was not high on participant's personal radar. Those who did rate their personal susceptibility high tended to have either family association or other diseases that they believe might be related to bowel cancer.

Not a lot, I don't know much about it um, yeah, I haven't read much about it, I haven't sort of been in contact with people that have had it so I'm not in conversation with anyone about it. (M, 60-74, Bo)

For me I haven't really thought about it, I haven't dwelled on it, you know I still think I don't know I still feel a bit bomb proof, you know I'm reasonably fit, touchwood I haven't had any issues in that area so, so I tend just to carry on, you know. (M, 60-74, Bo)

It was common for participants to respond that they did not rate bowel cancer as personally important because, unlike other testing regimes, it was never mentioned by their doctors. This issue is discussed in more detail later in this report (Ref: Bowel cancer screening – barriers). As with perceptions of the incidence of bowel cancer, for some, receiving the kit was the only indication they had that this was a disease that they should be concerned about.

It sort of is [something to worry about] actually. Because they've sent this thing. And I'm thinking well, why do they do that? Well, I've had a couple of scares. I've had bladder cancer, which was removed more than ten years ago, I've had a melanoma cut out of my head, I should be worried, I smoke. I should be the one who's bloody well, doing it. (M, 60-74, Bo)

Some participants reported that they did not think about their personal susceptibility to bowel cancer because they did not want to think about negative aspects of health; rather they preferred to focus positively, and believed that this attitude was itself preventive. As documented below in relation to screening barriers (Ref: Bowel cancer screening – barriers), there was an element of fatalism in some of these attitudes, with a belief that they had limited capacity for affecting their own health outcomes. For some, this was a substantial reason for not participating in the NBCSP.

I don't know that much about it, but as I said … unless I think I've got something wrong I'll keep living the way I've been living cos, as I said, if you're gonna get it you're gonna get it. (M, 60-74, Bo)

Oh look, I don't, yeah I'm one of those that … if I don't know it's broken I don't bother getting it fixed. (M, 60-74, Bo)

Notwithstanding this, the general belief that bowel cancer was not as common as other cancers was based on participants experience that they did not otherwise hear much about bowel cancer, especially in comparison with other cancers such as breast, prostate and skin cancer that have a higher public profile.

Throughout these discussions, it became apparent that increasing specific knowledge of the incidence (commonness) of bowel cancer, especially in relation to other cancers that participants already had some concerns about, was a key factor in prompting them to consider that they should screen. In essence, this information was effective because it explained why they should treat bowel cancer as seriously as they treat other cancers for which they are already being tested.

Participants were prompted to discuss their perceptions of the factors that contributed to bowel cancer risk. The main risk factors for bowel cancer were thought to be other bowel diseases, family history, lifestyle, age and gender. There was some awareness that other bowel diseases could be pre-cursors or could increase the risk of bowel cancer. Conditions such as Crohn's disease, diverticulitis and irritable bowel were mentioned.

A reasonably common belief was that there must be a family history association with bowel disease. It was apparent for some though, that this was a general belief about cancer and disease, rather than being a factor that was specifically associated with bowel cancer. Many participants were unsure whether there was an hereditary link with bowel cancer.

> *No is it hereditary, can it be hereditary or not? I don't know whether that can be, a lot of things can be. (M, 60-74, Bo)*
>
> *I would have thought hereditary. (M, 60-74, Bo)*

The most common belief was that bowel cancer was related to diet, with the main factors contributing to bowel cancer believed to be high fast-food and red meat consumption and low fibre consumption. A small number of participants rated themselves as having low susceptibility to bowel cancer because they felt their lifestyle was sufficiently protective: that is, they claimed to eat well and avoid the foods that they believed were associated with bowel cancer risk. However, it was apparent that participants varied substantially in their personal views on this issue, and it was common for participants to report feeling unsure about the exact details of the role of diet. There was also some feeling that it was very difficult for individuals to sort through all the seemingly inconsistent pieces of information they hear about the good and bad of different foods. Given this lack of clarity, the issue of diet did not appear to be a strong barrier to screening.

> *But I'm pretty healthy. I don't go near McDonald's; I don't go near KFC; I don't do none of that shit. I eat healthy. I cook; I do all the cooking at home. (M, 50-59, Bo)*
>
> *Um drinking a lot, they're um not looking after themselves not and basically they're getting obese or whatever. (M, 60-74, Bo)*
>
> *It's because of our diets. We eat too much shit. Too much sugar. Too much fats. Too much red meat. (M, 60-74, Bo)*
>
> *I think sometimes it's got a bit to do with the food that we eat, whether it's got preservatives in it, and things like that. (F, 60-74, Bo)*
>
> *No look I don't worry about it I mean there's the obvious things you can eat well for the best part of your life, fibre and everything and do the best you can, um but no I don't dwell on it, I don't worry about it. (M, 60-74, Bo)*

There was an understanding that age was a risk factor, with participants accepting that the risk of cancers in general became more common as they aged. Some commented that the only people they had known with bowel cancer had been old. The NBCSP also contributed to perceptions of age being a risk, with the kit being sent out at the age of 50 suggesting that this was when the risk of bowel cancer being common began.

> *For me I just thinking people getting into their older years. (M, 60-74, Bo)*
>
> *I always thought that probably, around the 50 years old, if you've had no problems earlier through life, I thought maybe as you get older, your body starts to, like everything, starts to slow down a bit, and it's like we lose our hair, we lose our teeth, whatever, so we start, we are going through an aging process. (M, 60-74, Bo)*
>
> *No, we associate bowel cancer with old age because both our grandparents were in their mid-eighties, both died from it. (M, 50-59, Bo)*

There was some belief that bowel cancer was more of an issue for men than women, although this was not a common belief. This perception was based on a number of factors, including the belief that men have worse diets (ie, eat more meat and less fibre), and that they were less focussed on their health and therefore less likely to get tested early.

Bowel cancer screening – Knowledge and experience

The groups were prompted to discuss the topic of bowel cancer screening, including experiences and perceptions of the NBCSP. To some extent, receiving the kit at age fifty was something of a rite of passage to older age, although some commented that they felt that, at fifty, they were not yet old enough to worry about cancer.

> *Actually, I was like I'm 50 now, so here you go. (M, 50-59, Bo)*
>
> *It was your birthday present. (M, 50-59, Bo)*
>
> *A bit embarrassed about getting it, thinking you know, I'm turning 50 and I'm getting sent a kit to go and poo in, that's not going to be of any real benefit that I thought to me. But I thought it was a bit embarrassing sending it out a middle-aged person, this is like saying you're old this is what's going to happen. (M, 50-59, Bo)*
>
> *It went straight in the bin. I freaked. I turned 50, I read a letter for breast screening, bowel cancer and something else and I immediately rang my mother and went, oh God, I'm going to be dead next year, for Christs sake. (F, 60-74, Bo)*
>
> *I just rang mum and told her I got one in the mail … I was shocked, and she said don't worry about it, everybody gets one when they turn 50 … I thought I was still young, not about 90. (F, 60-74, Bo)*
>
> *You turn 50 and then 'here you go, happy birthday from the Australian Government!' (F, 50-59, Bo)*
>
> *You turn 50, you get your bowel cancer kit, I got a life insurance letter, I got funeral insurance phone calls [laughter] I'm like, I'm frigging 50 not 100 you idiots, it's like dudes just back off. (F, 50-59, Bo)*

While most had at least some degree of familiarity with the NBCSP through receiving the kits, it was common for this to be all they knew of the program at the time. That is, they were aware that people their age had received a kit in the mail that had been sent out by the (federal) government, possibly more than once depending on their age, and that they were supposed to complete the sample and mail it back for testing. However, it was apparent that participants were unsure about the screening program as a whole: they were unfamiliar with how often they would receive the kits, or that they were going to be invited to participate regularly from ages 50 to 74. It was also apparent that some were unsure whether there was any difference between the NBCSP and other bowel cancer tests, such as the one promoted by Rotary or a test given to them by their GP.

When participants were told that the NBCSP is a government program that sends kits out to all Australians every five year, it was apparent that this information made participating in the program seem more important. And when participants were told that the interval was going to decrease to every two years, perceptions of the value of the program and importance of participation increased further, as did intentions to participate. This information raised the importance of participation to the level of other screening programs and regular tests, such as for breast, prostate, cervical and skin cancer.

Participants were prompted to discuss what happened when they received the NBCSP kit in the mail. Amongst those who had not completed the kit, there were two main groups:

1. Those who immediately put the kit aside and have not subsequently gotten around to completing it. This was a very common approach amongst those who have not screened, suggesting that this group provides a substantial opportunity to improve screening rates. While a small number subsequently decided not to do the kit, more commonly, this group reported that they had never made a decision not to complete the test; but that they had not yet decided to complete the test. Some commented that they went back to the kit some time later only to find out that it was out of date. A common issue amongst these participants was that they did not experience any sense of urgency to complete the test. Several of these participants claimed during the groups that they were going to complete the test when they got home after the group discussion.

   I got mine, looked at it, talked to it, filed it, and said, "I'll get back to you!" Filed it as in I put it in my drawer, and it was very funny you say that because the other day when I got the phone call for some reason, I looked for something different. It's still sitting there. (M, 50-59, Bo)

   I think, when I turned 50. That was it. Set it in the study, there for a couple of months, and then put it in the bin! (M, 50-59, Bo)

   I got no great objection to it and I thought yeah, I'll do this one day but it's one of those things that just in the scheme of things gets set aside. Yeah I'll get to that one day and then it sort of disappears out of, off the radar, and ah I did respond and ring back sometime later to the agency but they advised me at that time because of the gap that had occurred the specimen bottles were no longer able to be used. (M, 50-59, Bo)

   Yeah, it just sat on the desk and collected dust, that's I looked at it occasionally and think I should do that then it just gets dismissed … it's not a big pile just something I should do something about one day. Yeah, haven't put a very high degree of importance on it. (M, 50-59, Bo)

   I think that was my thing, just keep them, I might do it eventually, but I never did. (F, 60-74, Bo)

   I don't really know why I haven't done it. It is just sitting there … I have sat it in the toilet to remind me to do it … I still haven't done it. [laughter] So that plan didn't come together did it! (F, 50-59, Bo)

2. Those who rejected the kit immediately. This group tended to offer the strongest and most belligerent opinions about not participating in the screening program, suggesting that they will be the hardest to motivate to change. Their reasons for non-participation, documented in the barriers section of this report, were largely related to distastefulness and complexity of the procedure.

   I think I opened it, whatever, came in a satchel or something like that. So I got that far, and I had a look at the package, and I don't think I'm going any further with this. (M, 50-59, Bo)

   Yeah, I didn't really think twice about it when I got the kit. I just looked at it and thought nah, I'm not doing that. (M, 60-74, Bo)

   Mine went from the letter box to the wheely bin. (F, 60-74, Bo)

As noted previously, receiving the first kit at aged fifty was somewhat of a surprise for some, and it was apparent that their rejection of the kit was at least partly related to it seeming to arrive in their letterbox with no prior warning. These participants did not recall having received a letter prior to receiving the kit.

> *I got the kit when I turned 50 and I was shocked, I think what's this? So, anyway. I think it's in the bin somewhere. (M, 50-59, Bo)*

Amongst those who had rejected the kit immediately, it was common to report that they had not even read the instructions. Several indicated that they had assumed that the process was going to be too complex and/or distasteful, without knowing exactly what the procedure was.

> *I've not read the instructions. (M, 60-74, Bo)*
>
> *I didn't really read them properly no. (M, 60-74, Bo)*
>
> *I didn't open mine. I knew what it was, I didn't quite understand the procedure, but I didn't expect it to be crapping in the bottle, some sort of dip stick or something … I just, I didn't ignore it, it was sitting on the bench and I sort of, made a cup of tea and thought oh shit, I should do something, and one thing led to another and it sat there. (M, 60-74, Bo)*

Bowel cancer screening – Motivators and barriers

Bowel cancer screening – perceived benefits

Participants were prompted to discuss their perceptions of the benefits of bowel cancer screening. The common response was that the value was in terms of early detection, with the obvious perceived benefits of early detection being less invasive treatment, less impact on quality of life, and better survival rates. However, it was apparent that while they could vocalise these benefits, they were not strongly felt as personal reasons for participating in the screening program.

More in-depth understanding of people's perceptions of the benefits of bowel cancer screening are evident in their reactions to the stimulus statements, documented below.

Bowel cancer screening – barriers

Participants were asked to identify the factors that had discouraged them from participation in the screening program. Participants' reports of the barriers tended to focus on factors associated with completing the test kit itself, a range of attitudinal barriers, and barriers related to their appreciation of cancer screening programs.

To some extent, there was not necessarily a single barrier, but a range of factors that contributed to reluctance to participate, reinforcing that the limiting factor was as much attitudinal as procedural.

> *Yeah, I just thought probably because like you know oh god I am getting old now they are sending me all this crap, so I just ignored it and since then I have moved quite a few times and I don't think they know where I live now. (F, 60-74, Br)*

The kit: Distastefulness and embarrassment

The distastefulness of the sample process was typically the top of mind barrier for those who had not screened, and especially for those who rejected the kit straight away. Some mentioned that they did not want to look at, let alone touch their faeces.

How can you put it? I don't really want to reach down and get it. That's about it … Because I know some of my shit really stinks from all the chillies and the garlic, it's just not a place to put your hands. (M, 50-59, Bo)

It's just for me, it seems off, pooing and putting it in a jar, and the stick, it's just wrong. (M, 60-74, Bo)

It's just, the embarrassing part is like, pooing into a little cup thing, you know. (M, 50-59, Bo)

It's disgusting … it's just horrible. (F, 50-59, Cx)

A common response was that storing the sample in the fridge was particularly off-putting. This was more of a problem amongst those who lived with others, and especially those with children. As such this appeared to be more of a barrier at the younger end of the target audience age range.

The first one that I got when I turned 50, um, just glancing through it, you had to store it in the fridge, and that absolutely freaked me out, it disgusted me to the point I haven't gotten over it … Absolutely put me off, to the point where I would, I would do it professionally. (F, 60-74, Bo)

I think it is the idea of having it in your fridge. I mean I had mine and it was in the little thing and it was in the plastic bag then it was in the padded envelope behind something and I still felt gross about it. And that was the only one that I did. I think it sat there for about 7 months; it was just gross. (F, 50-59, Bo)

And it's in the fridge, that is terrifying. (F, 50-59, Bo)

It was evident in responses that participants did not want to talk about doing the test with people close to them, because they were embarrassed. Some even mentioned that they were embarrassed to talk to a GP about the kit. Consequently, for those who were unsure or who found the procedure to be complex, this distaste meant they did not seek any assistance in understanding why and how to participate in the program.

I've got a friend now, a lady friend but I don't want to ask her … Like she's straightforward like me but I hate asking ladies about that kind of thing because I get worked up and I don't know what to say to her and…. Kind of thing. (M, 60-74, Bo)

No, no, no I wouldn't do that [talk to my GP] … I don't know, like an embarrassed kind of thing like that. (M, 60-74, Bo)

The kit: Complicated procedure and instructions

Some mentioned that the process was too complex, with a number of factors contributing to the sense of complexity.

Some claimed that the instructions were too long and difficult to understand. Some claimed that the materials included with the kit make it seem quite scientific, and therefore difficult. Some had an immediate reaction to seeing the collection materials (swabs, test tubes, etc.), believing that this was too complicated for their abilities. Several commented that they did not have the literacy required to read the instructions. Some misunderstood the instructions, interpreting the procedure as more complex than it actually was. Amongst these participants, some suggested that they were not convinced that they would do the procedure correctly and would prefer to be assisted by a medical person. Some suggested that it would be helpful to have a video that explained the procedure.

Nah, if it was in a hospital, I'd say yes but nah, I don't want the chance, because I'm a panic merchant if I do it wrong, what I'm gonna do? Ok? That's what's going through me brain, you think you're alright but are ya alright? Doing it. (M, 60-74, Bo)

Yeah because I can't read or write, and I've got no one there to help me. If it was in hospital, I'd say yes I'd do it. (M, 60-74, Bo)

I looked at the little jar and I thought, what do you mean, hold that there and drop it in? I thought this could end up messy, I thought nah. Throw it in the bin. (M, 60-74, Bo)

I just found them so complicated and because I suffer from … rheumatoid arthritis and just trying to comprehend everything that was just written in it. (F, 50-59, Bo)

Maybe if they use those statistics, and even like a mock demonstration, like some of these ladies hadn't even opened the kit. Just turfed them straight away. So, if you did a mock demonstration on how easy the kit was to use, people might think, oh that's not too bad, I'll do that. (F, 60-74, Bo)

As noted previously, some had assumed that the process was going to be complicated and had not even read the instructions before determining that it was too complex for them.

I didn't get very far into it … I just stuffed the paperwork back into the envelope and stuck it on the desk. I just wasn't in the right frame of mind to read about it and thought I don't need this, and that's as far as I went. (M, 50-59, Bo)

I've never opened the kit, I don't know what's in it, are you actually taking a specimen, or is there a stick or something that you put inside one of your stools and then store that stick, or? I don't, I haven't opened the kit, I don't even know what you do with a specimen kit. (F, 60-74, Bo)

Some reported that the idea of collecting samples over three days made the process seem difficult, and something that they would have to plan well ahead for. Some also commented that they did not use their bowels regularly, and therefore were not able to collect consecutive days' samples.

But what if you don't go! You don't have that many bowel movements? … I have only got half a stomach. I had bleeding ulcers cut out, so I don't go, maybe a couple of times a week. (F, 50-59, Bo)

Several of the participants who experienced complexity as a barrier reported that that they would rather go to their GPs for the test, without understanding that the GP would give them a kit to take home, or appreciating the complications associated with collecting a faecal specimen at the GP clinic.

If the doctors knew that you're over 50 next time you go in, have you opened your test? Have you done this? I would strongly recommend because bowel cancer is the second most, and you'd go 'well, I'm here, I might as well do it. I go to the toilet, and the nurse can scrape it or whatever, and it's done. (M, 50-59, Bo)

Health attitudes: priority and perceived susceptibility

There was a range of health attitudes that acted as barriers to taking part in the NBCSP. These tended to include issues around perceived susceptibility, the priority of different health issues and perceptions of urgency and importance.

For some, having other health issues to deal with meant that they felt unable to prioritise completing the NBCSP kit. This was especially amongst those who reported having a range of more acute health issues themselves or being carers for others whose needs they placed higher than their own.

Yeah, and also, look, personally I got run over by another problem around the same time, which was prostate cancer and ah, had to sort that one out first so. (M, 60-74, Bo)

And so, this last one, probably three years ago I cancelled it because I had a lot of trouble with my wife, so I was more worried about her, than what I was worried about myself. So I just let it go … I'll do it. There's not a problem doing it, but I was just more worried about my wife, than I was worried about myself. I couldn't care less about myself. I was doing that much running around for her, and she was my number one priority. (M, 60-74, Bo)

Yeah I'm more worried about lung cancer. (M, 60-74, Bo)

I got a kit was when I was going through the [breast] cancer treatment and I couldn't cope with finding out that I had bowel cancer. It was just that one thing too much. I was like if I've got bowel cancer that's it. I don't need to know it can just take me. (F, 50-59, Bo)

There was no sense of urgency associated with bowel cancer or with completing the kit. The information included with the kit did not create a sense that it needs to be done in a hurry, as evidenced by the number of participants who reported putting the kit aside for weeks, months or even years. They were not provided with any information at the time of receiving the kit that left them believing that it was not acceptable to put it aside for later. Few were aware when they received the kit that there might be a use-by date with the materials in the kit.

I did get one, I just didn't do it, I think about it like the ads remind me and I think 'yeah I should do that'. But My life is hectic and every time I think 'yeah I'm going to do that', then the shit hits the fan and it just doesn't get done. (F, 50-59, Bo)

As noted in reference to 'Perceived susceptibility', a common reaction amongst those who had not screened was that they did not feel any need to do the test because bowel cancer was not on their list of things to worry about. Most commonly these people reported that this was simply because they heard little about bowel cancer, especially compared with breast or prostate cancer, and therefore had no reason to think that it might be of relevance to them. Some commented that there was no bowel cancer in their family history, so they had excluded it from the health issues that they needed to focus on. And some felt that their lifestyle was sufficiently healthy for bowel cancer to not be a personal concern.

It just felt like you're too young. I felt I was too young for it; that was the view that I had. Nah, everything's right, you're fit and healthy, those sorts of things. (M, 50-59, Bo)

I've been playing cricket for the last 15 years so I don't even think about, you know, I'm fit, I'm healthy. Don't even think about it. (M, 50-59, Bo)

And I'm probably a little bit biased because my wife's homeopath as well, so she's got natural remedies and things like that. We look after our bodies; they will look after us, type thing. (M, 50-59, Bo)

A specific issue that led to a perception of low personal susceptibility for some was not having any symptoms. A common belief was that they would experience symptoms or notice blood in their stool if they had a problem that needed to be checked, and that without this there was no need to do the test.

I consider myself to be reasonably healthy, quite fit for my age, and I tend to think, well I'm not indestructible by any means, but no symptoms and I'm thinking, I'll be right. (M, 60-74, Bo)

I guess in the back of my mind, the thought of a private bodily function, is something that, I think oh well, I've got no symptoms, so I'm not going to put myself through that little drama. (M, 60-74, Bo)

> *With bowel cancer if there's no blood or, the bowel movements are regular, you know I'm thinking well I don't believe I could have it, because there's no symptoms. (M, 60-74, Bo)*

Health attitudes – avoidance and fatalism

Participants also identified barriers associated with their general beliefs about health, cancer and treatments for cancer. This included those who reported that they believed that a diagnosis of bowel cancer was so devastating that they would prefer not to know. Others reported that they preferred to focus on positive aspects of health, and regarded screening tests as giving too much attention to the creation of disease. While neither of these attitudes were especially common, up to one or two people in each group did express such thoughts.

Amongst some, especially the men, there was an attitude of being indestructible. They placed low priority on their health generally, not just in relation to bowel cancer screening, and only visited a health practitioner if something was wrong.

> *Oh, it ended up in the bin at some point. I put it aside and didn't do it. Same as the doctor's visit I tend to only go if I have to, I don't go sort of regularly it's usually if there's an issue. But other than that, I tend not to go to the doctors that much just if I have to. (M, 60-74, Bo)*

> *I'm fit, reasonably fit, I just sort of push it away. She'll be right, bring it on. (M, 60-74, Bo)*

For some, there was a sense of fatalism about cancer and chronic disease generally, and an associated perception that there was little value in diagnosis as the treatment was undesirable and the prognosis was poor. These participants believed that there was little point screening because they did not think anything could be done if bowel cancer was detected. One of the participants who expressed these beliefs reported that his wife had been diagnosed with advanced stage of bowel cancer, and because of the severity of her treatment, he was not interested in finding out whether he might have bowel cancer, as he did not want to have to go through the same experiences as she had.

> *Because once you get it, you've got a time limit. Well they give you a time limit. (M, 60-74, Bo)*

> *I received [an NBCSP kit] and just put it aside and forgot all about it … If I'd had anything like [bowel cancer] I wouldn't want to know … I wouldn't want to know cos I think it changes how people live then, so I'd rather not know so I just haven't. (M, 50-59, Bo)*

> *Yep, for me. If they don't tell me I have it, then I haven't got it. It's a foolish way to think, very foolish. (F, 60-74, Bo)*

> *Yeah, but at the end of the day, I could do the test, and 99% chance it'll come back negative, but it might come back positive too, and if that happens I just don't want to sit there every day and think, which day am I going to be dying? (F, 60-74, Bo)*

> *Well you naturally think that when you get a test that comes back like that, you think, 'oh chemo, oh radiation, oh I'm going to die'… All the things that you have seen that go along with all these, like I am going to lose my hair or… (F, 50-59, Bo)*

> *[I screen for breast cancer but not bowel cancer, because breast cancer is] … less frightening than bowel cancer. (F, 50-59, Bo)*

Screening beliefs: Poor appreciation of screening and its benefits

A range of barriers were identified related to participants knowledge and perceptions of bowel cancer screening. These included a poor understanding of screening in general, a lack of knowledge about

whether other health checks included tests for bowel cancer and concerns about the accuracy of the NBCSP test.

For some, the barrier to participation was simply a poor understanding of screening and its role in preventive health. These people believed that taking a health or disease related test was part of a diagnosis process, and, as mentioned above, if they did not have presenting symptoms that suggested they might have the disease, they were not convinced of the need to be tested.

Associated with this, there was limited knowledge about the specifics of the FOBT as a screening test. Some did not understand that the FOBT could find microscopic blood that was not observable by naked eye, and had believed that they would notice blood in their stool if they had a problem that needed to be tested. Some believed that colonoscopy would be more accurate way to test for bowel cancer, and argued that if they believed they were susceptible to bowel cancer, they should undergo a colonoscopy rather than the FOBT. In the context of these group discussions it was difficult to get these participants to understand that the value of the FOBT was as a screening method to assess whether a colonoscopy was worthwhile, suggesting that this level of health information is quite complex for the health literacy of some in the target audience.

> *You can see [blood] when you poo. (M, 50-59, Bo)*
>
> *I'm questioning if blood's going to be present, you're still not going to find out if it's cancer, you've still got to go off and have a colonoscopy done, so, why muck around with this and just have a colonoscopy. (F, 60-74, Bo)*
>
> *Oh, I'm still for it, just not the kits, I just don't like the kits. (F, 60-74, Bo)*

There was also a sense that the GP clinic would be a better place to be tested, for a range of reasons. Some did not complete the kit because they believed they were already being otherwise tested for bowel cancer in regular health checks with their GPs. They relied on their doctors to test them for whatever they needed to be tested for, and so assumed that bowel cancer would be included if it was important.

> *I do medicals every year anyway and so that often showed if there was a little problem there so if you're aware of things. (M, 60-74, Bo)*
>
> *Well, you go and see your doctor get your blood tests or whatever you need to get, right, which is what I do every 12 months. (M, 60-74, Bo)*
>
> *For me I felt as though it was still too young and those sorts of things. If you're generally going to your GP or something like that, you know your body, too. (M, 50-59, Bo)*
>
> *With that men's health stuff, so you go, they like you to go to the doctor every couple of years to get checked right out, and that's the whole lot done. (M, 60-74, Bo)*

Some reported that they had not completed the kit because they believed the procedure was not sufficiently accurate. Some believed that there should be a more accurate test available through doctors, and suggested that they would have more confidence in the procedure and the results if it was done through their GP. This was not as majorly important issue, and tended to be more commonly expressed by those who talked about other factors that played more of a role in discouraging them from participation in the screening program.

> *But you might be more confident in the results and the tests if you went through the doctor, because then you know you've got a face to face and you know he knows what he's talking*

about. If you sent it off, you don't know if it's your sample that comes back, the results come back. They could've mucked up anyway. (M, 50-59, Bo)

When I turned 60, I found out I'm a high risk for cancer, got my one for my 60th, and still had that thought of, nup, nup, I'd rather have it done professionally … a colonoscopy instead of bowel screening. (F, 60-74, Bo)

The bowel screen, I don't like the idea of the home kit, I worry about how thorough it is. (F, 60-74, Bo)

If they say store it in the fridge, they didn't send me a refrigerated envelope to send it in. So, it's not going to be refrigerated in transit. (F, 60-74, Bo)

I didn't think that it was going to be a very accurate screening because it is only picking up potential blood cells, so if you had haemorrhoids or something then you get a false positive and oh panic, panic, panic so I never bothered because I do have problems with haemorrhoids so. (F, 50-59, Br)

A small number of participants reported having previously received a kit that they were later told was 'faulty'. Some of these people subsequently rejected the screening because they believed it was not likely to be accurate. However, this was unusual, and a more common response was that participants trusted the program, commenting that they did not believe the government would take the trouble of sending out kits to everyone if the test was not backed up by evidence.

But it's also been found lately that the results are … not accurate, but false, some of the results are false because they've come back 'you've got to come back something's not right'. There was somewhere along the process there that wasn't done properly. You're going through that and go 'shit, fuck, what have I done', and then all of a sudden 'you're right, mate, we're all good'. What are you talking about? You dragged me through the mud for the last week and now you're telling me I'm all good? (M, 50-59, Bo)

I'm assuming that it's accurate enough that the government is worth, has deemed that it's worth having a program to use. (M, 50-59, Bo)

If it wasn't accurate, they wouldn't send it all out, would they? You know, you'd think. (M, 50-59, Bo)

You just assume that in the lab they know what they are talking about. And if they give you a result it's right. (M, 60-74, Bo)

Bowel cancer screening – Prompts to action

It was evident during the research that the paucity of prompts to participate in the NBCSP was a substantial reason for low participation rates. As has been documented throughout this research, participants felt that bowel cancer screening did not have the same profile as breast or prostate cancer, and consequently, they did not regard it as important as screening for these cancers. Receiving the kit was the only cue to action that participants had experienced. Further, receiving the kit in the mail did not necessarily communicate that they were being invited into an ongoing, regular program that had the same gravity as cervical or breast screening.

A substantially limiting factor was that participants reported their GPs were not mentioning bowel cancer when they were reminded of being due for other tests, and therefore they did not rate bowel cancer as being as important as heart, blood pressure, diabetes, or other cancer tests. A small number of participants commented that their doctors had pushed bowel cancer screening, and that this did make a difference to them, suggesting that reminders from GPs would be an important component of a strategy to encourage participation.

I don't think the doctors push it enough … Clearly, I'm in the bracket of say from 50 on, so but he's never discussed it. (M, 60-74, Bo)

I don't go to a doctor that often, but anytime I have they've never said anything to me about doing bowel screening. (F, 60-74, Bo)

Like if you got a good, good doctor they'll, each time you go, they'll say "oh you haven't been tested for [prostate cancer] yet" you know. (M, 50-59, Bo)

Well she just tells me that I need to do it, but I have told her why I haven't so… (F, 50-59, Bo)

Oh, because my father had a, it was on our … family history … and so yeah, the doctor really persisted on it that much. (F, 60-74, Br)

When I got the test, I just thought ugh, yeah, like I said, I'll just put it away and I'll do it one day. But just never got around to it. But I had to go to the doctors for something and that's when they said. You need to do this, so I did it. (F, 50-59, Cx)

There was some awareness of recent advertising campaigns promoting the NBCSP, and those who recalled these advertisements reported that they had communicated several important messages: that bowel cancer is common and that doing the test is important. Some noted that they related strongly to the narrative of the advertisement, in which a man is seen putting his kit aside rather than completing it immediately. The Cancer Council Victoria (CCV) advertising campaign had launched during the fieldwork period of this project, and it was evident over the course of the groups that it was being noticed and that these key messages were making a difference to the target audience.

Actually, there's a new series of ads out at the moment saying more people die of bowel cancer than prostate and breast cancer. (M, 60-74, Bo)

Well, from the ads it's pretty bloody common. (M, 60-74, Bo)

The advertising and so on that's been ringing in my ears over the last two or three … saying that it's very, very important we detect it nice and early. Simply because the earlier we get to it, the more chance of life. Whatever it is that they might find, we could knock it on the head. That to me is very appealing. (M, 50-59, Bo)

It's on the radio; it's in magazines; it's everywhere now. (M, 50-59, Bo)

There was one on telly. He opens a drawer, looks at it and he shuts it. Then he pulls it out again … that's like me looking at me. (M, 50-59, Bo)

I think with some, after 50, I think it's every 2 years they send out the test kit now. I saw an ad on tv. (F, 60-74, Cx)

Yeah, well, it does show you what most people do, go, eew, and they put it in the drawer in their bathroom, and then one day they're going through something and they go, oh, I thought I threw that away. (F, 60-74, Cx)

Participants were prompted to talk about where they would expect to see promotion of bowel cancer screening. A common attitude was that they expected more mass media campaigning, especially using TV and radio. Some also wanted targeted media in locations that they frequent, including sports and social clubs, RSL venues and men's shed. Some suggested that the messages should be promoted by prominent (older) media and sports people.

Advertise it more, raise the profile. (M, 50-59, Bo)

Why can't they bring it up on TV or put it on the buses. (M, 60-74, Bo)

Yep go around to the RSLs and all the other clubs around here and put em up on the, yep. (M, 60-74, Bo)

I guess it's what you're involved with, if you're involved in the local footy club and you've got a senior fellow in the club, that's experienced bowel cancer or is on board with all that, then they can talk to people about that. (M, 60-74, Bo)

When you go into some of the pubs here, there's a member swipe card. It comes up with some messages on it that I've noticed. You go 'there's a chook raffle tonight' or whatever it is. There could be some advertising on those sorts of things. (M, 50-59, Bo)

So, if you're targeting the older population, what about neighbourhood houses, bowling clubs, where would they congregate, where would they socialise. (F, 60-74, Bo)

You watch tv and you see everything about skin cancer, and you see things about … breast cancer screening but you never see anything about bowel cancer or other cancers. There needs to be more awareness. (F, 50-59, Bo)

Added to there being little media and advertising promotion about bowel cancer and bowel cancer screening, it was apparent from these discussions that these were topics that were not commonly discussed. Several groups discussed how they had not even spoken with their partners when they received a kit, and were not aware of whether others amongst their family or friends had completed the kit, as this was not something they felt comfortable talking about.

Most of my work colleagues are starting to turn 50 so whether they're getting the kits or not, I don't really know. (M, 50-59, Bo)

I wouldn't have a clue whether a single one of my mates has done it or not, in the same age bracket. (M, 50-59, Bo)

I just don't, like I said, even with my brothers, I just don't go into those conversations. (M, 60-74, Bo)

It's just one of those no go conversations, isn't it? (M, 60-74, Bo)

It's not something a group of blokes would really comfortable sitting around talking about from my opinion. (M, 50-59, Bo)

It's not really something that comes up in conversation, other than, like I said, I got the letter. (F, 60-74, Bo)

Well we had a very short conversation, my wife told me that I should get it done, and I said, I'm not getting it done, end of story, and it went in the bin. So it wasn't really a conversation about it. (M, 60-74, Bo)

Only a small number of people mentioned that they had spoken with family or friends about receiving the kits, and when they had, this tended to motivate them towards participation.

Well, I've got a daughter who does aged care, so she's on my back all the time about getting it done. (M, 50-59, Bo)

I spoke to my wife … she said to me, "Look, do it." She encouraged me to do it. She did. (M, 50-59, Bo)

We had a bit of a chat about this last year … within the umpiring panel (participant was member) … It was just a very brief conversation; didn't go into any details. Someone said, "Got something in the mail again today. I've done this a few times." … It was like, get it done, because he was detected quite early, so that sat in the back of my mind as well. (M, 50-59, Bo)

Only if it has popped up in our lives like … my dad has got bowel cancer, well I might then talk to my friends about, we probably will screen more often, and that conversation. But it is usually an incident that brings that conversation on. (F, 50-59, Br)

Well, my husband was the one that prompted me with the bowel test, because the first one I threw in the bin, and he said to me, look, I'm doing them, what's your problem, why aren't

> *you doing them? He said, you need to have one done. And so, it was actually him talking to me that got me motivated to actually do the next one. (F, 60-74, Cx)*

These observations suggest that one of the factors that might be limiting participation in bowel cancer screening, especially in comparison with other screening programs, is that there is little discussion about bowel cancer or the screening program, and therefore there is little awareness that other people might be taking part in the screening program. It is likely that social norms affect health behaviours, and are especially helpful for overcoming perceptions of distastefulness, confusion and embarrassment associated with the sample collection process. Consequently, this research suggests that consideration needs to be given to strategies that normalise and encourage conversations about the bowel cancer screening program.

> *I have talked to my husband about it, because he needs to be doing it too … He got one when he turned 50. And he turns 55 in July. I think, I have discussed it with him, but not at great length. It's like 'You've got to do that' 'I know I do'. (F, 50-59, Bo)*

> *I think it is the era we are brought up in. You just don't talk about things like that. (F, 50-59, Bo)*

> *You might make a joke at your 50th birthday and you get the present from the Government, you might make a joke about it, but it is not like a deep and meaningful discussion you are going to have. (F, 50-59, Bo)*

> *{if others talked about the kit] … You'd do it more, I think. (F, 50-59, Bo)*

Response to messages

The groups were presented with some statements intended to convey information about the incidence and susceptibility to bowel cancer and the benefits of screening. These statements were not 'tested' as such, rather their use in these group discussions was to provide some insights into the balance and layering of messages that would be required to promote the screening behaviour.

'Bowel cancer is second most common cause of cancer in Australia'

This statement was presented to participants during each group, with discussion prompted around its interpretation and impact.

The information was typically assessed as surprising, with participants commenting that they would have expected to hear more about bowel cancer if it was so common. However, the information tended to be rather limited in its impact, as it did not provide sufficient context for people to relate to. For example, a common reaction was to ask "what is the most common cancer?", and for the subsequent discussion to be overtaken by this question, rather than focussing on bowel cancer.

> *That does surprise me, based on what you hear through the TV channels. I'm a smoker, you hear a whole lot more about smoking. And the second most common, that's amazing. I'm surprised. (M, 60-74, Bo)*

> *I didn't know was about how common it actually was. I didn't think bowel cancer was, I knew there were a couple of other cancers that were pretty common, but, I didn't know that bowel cancer was right up there with them. (F, 60-74, Bo)*

> *Because you don't hear so much about bowel cancer, or people who have got bowel cancer or had bowel cancer. (F, 50-59, Bo)*

> *It's not one of the glamorous ones. (F, 50-59, Bo)*

When the information was presented as 'Bowel cancer is second most common cause of cancer deaths in Australia', its impact was somewhat more powerful, with the emphasis on the bowel cancer causing deaths being taken more seriously. For some, this was a prompt to consider completing the NBCSP kit.

> *I'm going to go home and do it. (F, 60-74, Bo)*

'More people die from bowel cancer than prostate, breast or melanoma'

Responses to this statement suggested that providing comparative information was considerably more impactful than just referring to bowel cancer being the 'second most common'. Participants were surprised by the information because it contrasted with their experience: they heard more about other cancers, and knew more people with other cancers, than bowel cancer.

This statement also reminded some that they did get checked for other cancers, and reinforced that screening for bowel cancer should be at least as important to them as these other screening programs that they participate in.

Hence, this message was valuable because it prompted people to think about the issue of bowel cancer and the importance of screening, and to re-consider their existing beliefs that rated bowel cancer screening as less important than other screening programs.

> *I don't know anyone that's died from bowel cancer. So when you say that statistic I'm sort of shocked and surprised because I know heaps of people with breast cancer, brain tumours, all those other things, younger than me, 30's 40's but none of those, you know, have died from bowel cancer. (M, 50-59, Bo)*
>
> *You hear breast cancer all the time, you know? Jane McGrath, you know, all this sort of stuff, it's all there. If this is worse than that, then why isn't it more upfront? (M, 50-59, Bo)*
>
> *Well women get breast cancer a lot, but they actually have to get checked every couple of years don't they. (M, 60-74, Bo)*
>
> *That one would surprise me because I would've thought breast cancer would be more common than, like more people die from breast cancer cos it's more out there. (M, 50-59, Bo)*
>
> *I knew it was up there, but I just thought breast cancer would be more common. (F, 60-74, Bo)*
>
> *Wow. That's scary. (F, 50-59, Bo)*

'You can have bowel cancer without any symptoms'

While some participants reported being aware of this information, the far more common reaction was that this was news to people, as they had typically believed that bowel cancer would be associated with identifiable symptoms. It was also evident that their prior belief, that they would experience some symptoms if they had bowel cancer, had been used by some as justification for not participating in the NBCSP. Consequently, this information created some concern, addressed an existing barrier to screening, and provided some motivation towards screening.

> *I'm thinking about it now … Well, that you can't see symptoms and that, so anything could be happening down there. (M, 60-74, Bo)*
>
> *I thought that there would have to be blood there to have bowel cancer, but that's not saying that. (M, 50-59, Bo)*

Now you're scaring me, I'm not going to sleep tonight. (F, 60-74, Bo)

I did not know that. (F, 50-59, Bo)

'There is a 90% chance of effective treatment if bowel cancer is detected early'

While there was a general appreciation that early detection would affect treatment outcomes, the specific measure of 90% was new information, and being such a high number was especially impactful. In essence, this statement provided people with an explanation of why the screening program existed, and how it might help them. Consequently, several responded that this information encouraged them towards participation.

Why wouldn't you, it doesn't cost you anything. (M, 60-74, Bo)

I guess knowing that they are shortening the period that they send them out, that costs a lot of money, so there must be a return on that, so, therefore must be effective. (M, 60-74, Bo)

Already heard that. That's commonly enough said, I think. (M, 50-59, Bo)

Yeah, with any cancer. (M, 50-59, Bo)

It's not fully guaranteed but 90 is alright. (M, 50-59, Bo)

I guess it makes you think, you know, it makes me think you're a bit silly not to. (M, 50-59, Bo)

BREAST CANCER SCREENING

The issue of breast cancer screening was discussed in all the women's groups, although it was not a major focus in the groups of women aged under fifty. Two of the groups were specifically recruited because they were underscreened for breast cancer, including one group in each of the 50-59 and 60-74 age ranges. Several of the women in these age segments who participated in the underscreened bowel and underscreened cervical groups were also underscreened for breast cancer. As such, the topic of breast cancer screening was a substantial component of six group discussions amongst women aged over fifty, and a peripheral topic in the four groups of women aged under fifty.

Breast cancer – Knowledge and awareness

Throughout the discussions with women, it was apparent that breast cancer is top of mind when it comes to concerns about cancer. Breast cancer has quite a high profile in the minds of women, because of its prominence in the media and the close personal connection many women have with breast cancer. Interestingly though, amongst those who were not up to date with their breast screening regime, some mentioned that they did not know anyone who had been diagnosed with breast cancer, and compared this with other cancers that they had more close associations with.

I know many people who have breast cancer for instance, unfortunately some people haven't survived, and some people have so it is something close to women's health it's close to my heart anyway, so we care. (F, 60-74, Br)

Only last year one of my nieces was diagnosed with breast cancer. (F, 60-74, Br)

I know a lot of people who have my age, who have had breast cancer and have overcome it, my mum passed away of it, so I know quite a few a people. (F, 50-59, Br)

A girlfriend passed away at 37 … with two young kids, mum passed away at 64, I have got two friends that I can just think of off the tap who have had breast cancer and are in remission, I think it is quite prevalent. (F, 50-59, Br)

My experience is not, I don't know anybody personally that has died of breast cancer, I know heaps of people that have died of pancreatic cancer, bowel cancer, like to me breast is not on my radar at all in people that I have experienced. (F, 50-59, Br)

Generally, breast cancer was regarded as a serious disease, although it was understood that developments have improved treatment outcomes so that it was now considered more of a treatable cancer, and therefore some expressed that they were less fearful about breast cancer now than they had been. Participants believed that breast cancer was fortunate to be the focus of much medical research and development. Notwithstanding, a common concern was about the effect that the treatment for breast cancer can have on quality of life, with common perceptions that the treatment was worse than the disease in terms of impact on well-being and lifestyle. When assessing breast cancer treatment as serious, the notion that one's breasts were a part of one's identity as a woman was an important factor.

I don't find it as scary as I did once because I think there is a lot about cures now days and so I don't react quite like I would have maybe 10, 20 years ago. (F, 60-74, Br)

That it is curable. Caught early enough. (F, 50-59, Br)

As I said, it's not a death sentence. (F, 50-59, Cx)

It's caught early and then you have 80% chance of getting rid of it, but if you leave it too late then your chances are lessened. (F, 50-59, Br)

I feel confident enough in Australia's research … down at Peter McCallum and just hearing so many stories of women, I guess I just feel that it is maybe not a death sentence because just the research and I feel confident. (F, 50-59, Br)

Well I just think of chemo and losing your hair and being sick and all that … I just think you know I have to go all through that yucky, the treatment is worse than the disease. (F, 60-74, Br)

And that unknown too because it is different for every person … I mean for me to lose my hair I would be devastated, you know different parts of the treatment can be different. (F, 60-74, Br)

And I suppose being female, being a woman breasts are part of us and so you are losing part of you. (F, 60-74, Br)

Breast cancer – Perceptions of susceptibility

Participants were prompted to discuss factors that affected their perceptions of susceptibility to breast cancer. This included issues about the incidence of breast cancer in general and issues related to perceptions of risk factors for breast cancer.

There was a general perception that breast cancer was common, associated with knowing women with breast cancer and perceptions that breast cancer issues were commonly reported in the media. To a considerable extent, these perceptions that breast cancer was common contributed to an underlying perception of general susceptibility. However, participants raised a number of factors that they felt mitigated their own personal susceptibility.

Most importantly, there was a common belief that the main predictor of breast cancer was having a family history, and consequently, amongst the women in this research, not having a family history of breast cancer was cited as a reason for not needing to participate in breast screening. Some mentioned that their perceptions of the family history link were based on the celebrity media stories about breast cancer, such as the stories about Angelina Jolie.

Well I personally, we don't have breast cancer in our family, we hardly have any cancers at all. (F, 60-74, Br)

A lot of people do think it has gotta be in the family. (F, 60-74, Br)

Yep, just because of the family, no one else in the family has had breast cancer. (F, 50-59, Br)

I think I have a little bit of a that's not going to happen to me, that happens to other people. I don't have, there is no one in my immediate family that has had any issues with cancer thus far, touch wood hopefully not. Yeah and I am a little bit anti-doctor, so I tend to probably bury my head in the sand a little bit. (F, 50-59, Br)

That film star, and she has the BRACA gene or something so she her breasts off. (F, 60-74, Br)

Another reasonably common belief was that, if they had breast cancer, they would experience obvious signs, such as detectable lumps, that would prompt them to a doctor for tests. Consequently, some believed that, if they had not observed lumps in their breasts, they had no reason to participate in the breast cancer screening program.

I think that's what's one of the little things that had interested me are the signs, you know what are the signs because we don't know and say for instance if you suddenly get a pain in your boob and it lasts for a couple of days you start worrying but it is just a pain, you know

> *and you don't know, do you go get it checked, so actually knowing what signs you need before you worry. (F, 60-74, Br)*
>
> *So, I sort of sit there and I go, umm yeah, I think when I am in the shower and if I feel a lump yeah off you go. But other than that no. (F, 60-74, Br)*
>
> *The slightest little lump for my size I would know it. (F, 60-74, Br)*

A small number of women commented that, as they had previous mammograms with negative results, they believed their personal susceptibility was sufficiently low to not warrant further participation in the screening program.

> *I've had cysts in my breasts. And the first cyst I had removed when I was 18. So I've got multiple cysts in both. Over the years of my life and I've had them, what do you call them… You know, like they put the needle in and such them out? … Biopsy … and they all come back normal. And I've felt that the more they seem to have done that. The more I was getting so I stopped it. I said, 'That's enough.' Because I've had that many done. (F, 50-59, Cx)*

Breast cancer screening – Knowledge and experience

The groups were prompted to discuss the topic of breast cancer screening, including experiences and perceptions of the procedure and awareness of the recommended screening regime. When the topic of screening was first raised, reactions commonly included references to the uncomfortable and painful nature of mammograms, underlying that this was a top of mind concern affecting participation in the breast screening program. This is discussed in more detail in the section on barriers to screening.

There was a reasonable awareness that the recommended breast screening regime was every two years, although some were unsure, and some thought it might be longer.

When asked who the screening program targeted, it was common for participants to believe that mammograms were for women aged 40 and over. While some understood that the free breast screening service was only promoted to women over 50, this was not universal knowledge. Interestingly, this seemed to be something that those in the younger age group were more aware of. A common belief was that the program should be promoted to women of all ages, given that they had heard of women under this age who had developed breast cancer. There was little awareness that the procedure was less effective at detecting breast cancer amongst younger women with denser breast tissue. Participants were unsure of the upper age for the breast screening program, and several women (aged under 74) reported that they had been told by their GP that they no longer needed to be screened.

> *Which makes you wonder because you see all the celebrities and stuff in the news and they're all 30 and 32 and 35. You're like 'why isn't this for everybody if it's affecting people that young?' And they're trying to make it public then why not. (F, 35-49, Cx)*
>
> *I reckon it should be offered to younger people, not just the elderly. (F, 25-34, Cx)*

Several reported having been recommended for a mammogram when they were in their twenties, thirties and forties. Interestingly, several of those who had had a mammogram at a relatively young age, reported that the experience was particularly painful, and that staff had been especially uncaring, which had left them reluctant to screen again subsequently.

Understanding and acceptance of the role of a population screening program such as BreastScreen was somewhat limited. Several participants thought of a mammogram as being a diagnostic procedure, with

a common belief that they would be recommended for a mammogram if they presented to their doctors with signs (i.e., a lump).

I just went because I had a discharge, so that wasn't anything to do with cancer, that was like whoa what's happening here? (F, 50-59, Br)

I thought it was only when you felt you needed it. (F, 50-59, Br)

Participants generally understood that the mammogram shows lumps that need further investigation. However, they varied in terms of whether they trusted the procedure, with some arguing that a mammogram was unlikely to pick up all problems. For a small number of participants, this belief rationalised their avoidance of mammograms.

I know if you have any, any abnormality they can tell right there and then and they will sit you outside, this is what people tell me and call you back in and they will do it again, while you are there so they know. (F, 60-74, Br)

I think what they say is that you have a lump that needs further investigation. (F, 60-74, Br)

What they have there in front of them is accurate, but I don't know whether it can detect every single cancer that may be there. (F, 60-74, Br)

Breast cancer screening – Motivators and barriers

Breast cancer screening benefits

Participants were prompted to discuss their perceptions of the benefits of breast cancer screening. In response to this question, the consistent response was "early detection". And when prompted to identify the benefits of early detection, participants nominated simpler treatment and better prognosis as the main advantages.

If you catch it early you have far greater chance of surviving the cancer. (F, 60-74, Br)

Reading, hearing things you know. (F, 60-74, Br)

To me it is common knowledge. (F, 60-74, Br)

Communication, people do talk about it, it is not put under the mat. (F, 60-74, Br)

However, it was evident during the conversations that, while participants had some awareness that the benefit was in relation to early detection, this did not always act sufficiently to motivate them in their considerations about whether to have a mammogram. It was further evident that barriers to screening tended to come in multiples, with each participant referring to a number of reasons why they had not kept up with the screening regime. This observation suggests that there may be an overall attitudinal barrier, rather than the specific barriers that get mentioned.

No. I honestly couldn't tell you I think it is time, I think it is other things going on in my life, I am a bit of ostrich and stick my head in the sand and that's the idea with a lot of things. (F, 50-59, Br)

Breast cancer screening barriers

Barriers to breast cancer screening included a combination of factors related to the procedure itself, attitudes to health and disease prevention and appreciation of the screening program.

The procedure: Unpleasant and painful

A common barrier was that the procedure was experienced as unpleasant and painful, with participants referring to past experiences as deterring them from further participation in the program. Some mentioned that they had heard about the painfulness of the procedure from others' experiences, and this discouraged them from having a mammogram themselves. Throughout the discussions, a common theme was to ask why the procedure had to be so painful, and why other methods, such as ultrasound, were not used for the screening program.

> *No one wants to go through pain, do they? (F, 50-59, Br)*
>
> *I've never had a mammogram. I am supposed to have them when I am over 50 and I'm 56 and I've never had one. My sister told me that they put her friend through it … pressed [her breasts] flat on the examination table and then they pressed away… my sister couldn't get over it. My friend, she was screaming in pain. And I thought I do not want to ever be tested for breast cancer. So … (F, 50-59, Cx)*

As noted above, some mentioned bad experiences that occurred many years ago (20 or more) and having not gotten up the courage to return since then. Some of these women would have been in their thirties at the time of their previous mammogram, and they claimed to have not received any information since then about changes to the modern procedure or whether it would be different for a woman in her fifties compared with their earlier experiences. There is clearly a need to communicate that modern technology for mammograms and training of staff has improved the experience.

> *And I think the experience I had at Traralgon all those years ago it was pretty painful, and I was just like … surely there is another way other than squashing you all up? (F, 50-59, Br)*

A common attitude was that the painful nature of the procedure was related to breast size, with some claiming that it was painful because they have small breasts and others claiming that it was painful because they have large breasts.

> *But like, my mum finds it extremely painful, do you know what I mean, whether it depends on the size of your breast. (F, 50-59, Br)*
>
> *I have heard that people with smaller breasts it is more of an issue, I have got larger breasts so maybe it wasn't, I don't know, but I hear pain when women talk about mammograms. (F, 50-59, Br)*
>
> *You're in this room and you're starkers from up here, and….it's just uncomfortable, especially when you get someone that comes in and it's… painful for me, I'm a very big lady, and they pull me and push me into position, and they actually hurt me, they pull all my skin, and I end up with bruising and everything from it. (F, 60-74, Cx)*
>
> *For me it is not that easy. (F, 60-74, Br)*

Interestingly, some of those who were up to date with breast screening reported that the procedure was not uncomfortable, suggesting that there is considerable variation in the way women experience the procedure. Some noted that the experience depended a great deal on the person doing the procedure, and that the difference between the skills of practitioners was substantial.

> *It doesn't take long… It's not long. And it's not really, in my opinion, it's not really that uncomfortable for too long as what a pap smear would be. (F, 50-59, Cx)*

You are holding there for maybe two or three seconds. It's not long. So it really, you know, they take it at different angles. But you are literally only there for 2 or 3 seconds. (F, 50-59, Cx)

Look, I have breasts that are about 55 inches, and you know, they weigh a good kilo or so, and so, when they squash it … some nurses are fantastic, other nurses are in a hurry or they're at the end of the day, and they'll just, push it down as hard as they can, and, yeah, as I said, the experience I had in Morwell was just not very good. (F, 60-74, Cx)

So, my first one … was as comfortable as can be. I had a gentle nurse who was doing it… Second time … this one was very rough and yes it was very, very uncomfortable. So the first one was gentle as you could be … from the second experience, yeah, well I won't actually go back to [names hospital], just in case I get that same nurse again. Okay, that sort of says a lot. Like I'll go elsewhere to have it done. (F, 50-59, Cx)

The procedure: Radiation

For a small number of participants, the main barrier was related to concerns about radiation. While these attitudes were not widely held, they tended to be strongly held and voiced by those who did have them. Several women noted that they had a preference for undergoing an ultrasound for this reason.

I don't know I am in two minds … a mammogram I would never have again purely because I have turned Wi-Fi off in my house and I don't have my mobile phone on me and I don't put it in my bra so I don't reckon I should radiate my boobs to see if there is a problem. (F, 50-59, Br)

I have had a whole lot of x-rays in the past and I just think I am at my limit and you are going to squash them and irradiate them to tell me there may be no problem. I don't know. (F, 50-59, Br)

I have read a lot of articles in regards to radiation and other issues that is just like, it may not be correct but I have read articles that said people are actually having radiation on their breasts and then that can actually cause cancer. So, that has had an effect on me … that may not be correct, but that's what I have read and that is one of my concerns. (F, 50-59, Br)

I did read an article … that there is more of a prevalence … of women getting thyroid cancers and there was a possible link to the mammogram screening … I have always been a little bit anti-Western medicine. (F, 50-59, Br)

No, I'm probably not going to get a mammogram because the research that I've read into suggests that they're not *helpful, they're perhaps more detrimental than anything. (F, 35-49, Cx)*

The procedure: Convenience

A substantial barrier to participation in the breast screen program were factors associated with convenience, with this including attributes of the procedure itself and of the venues for undergoing the procedure.

Some talked about the difficulty of having to attend a specific breast screening clinic, which some experienced as not being conveniently located. Some noted the difficulties of booking, and waiting times at the venues. Several participants mentioned the BreastScreen mobile unit, with some questioning whether this still visited the Gippsland area, and some not having known about it. They felt that if the mobile unit was more available, this would help to overcome some of their convenience related barriers.

For some, the main convenience factor was about fitting a mammogram into their lives, especially in the context of work, children, other health issues and caring for other people. As noted below under the

reference to health attitudes, it appeared quite common for women in these groups to be rating their own health care needs as secondary to the needs of others.

> *Convenience … where it is, where you have got to go … you gotta take time out of your day, you have to have the money to pay to get there, is the train close no its not close and then you have to take the car. (F, 60-74, Br)*
>
> *Mate I was doing three jobs, I was going from one job to another and I wouldn't get home until 9 – 10 o'clock at night. You gotta do this! (F, 60-74, Br)*
>
> *I loved the bus, the bus was just so handy … to make it more accessible, easily accessible. Because I know what it was like with the bus being in Leongatha, it was just so good. Even the boss … He said just go, just go up there and make an appointment and just go up there when you need to do it. (F, 60-74, Br)*
>
> *Maybe a lot of women don't go and get them done in this area is because the waiting list to get them done and the places you have to go to get them done are either too far away or you are waiting months and months and months in advance. I go on this from personal experience of past scans and stuff like that. (F, 50-59, Br)*
>
> *Getting more mobile vans around. It would be good if that was breast screening, you said, if they had those ones that. I've seen more of them. Maybe that's the only way in the modern. In the future. People have going to get screened. (F, 50-59, Cx)*

Health attitudes: Priority and perceived susceptibility

Similarly to the issues documented in relation to bowel cancer screening, a range of health attitudes acted as barriers to taking part in the BreastScreen program, which included issues around perceived susceptibility, the priority of different health issues and perceptions of urgency and importance.

Several women mentioned that having a mammogram just never got to the point of being important enough for them to do it. They argued that other life and health issues were always more pressing in their assessment of priorities, and that without direct prompts to action or an obvious reason that might provoke them into screening, it was simply never important enough on their list of priorities. In terms of health issues, several commented that obvious health problems and the existence of acute or chronic diseases tended to get rated as more important than preventive health behaviours such as screening. And for some, this meant looking after others before themselves.

> *Well, look I have known two people that I am very fond of that have died from breast cancer and as I say I am aware of what you should do it … it doesn't worry me to go and have a Breast Screen I just haven't done it. (F, 60-74, Br)*
>
> *Not priority on the list, I concentrate more on what is actually wrong with me now, like how am I feeling now. I have my regular thyroid test and cholesterol and things like that you know that you have after 60 and blood pressure and things like that. I concentrate more on them. (F, 60-74, Br)*
>
> *If there are other medical problems … they would take precedent over going and getting a breast screen if there are other major medical problems … I mean you can end up, as you get older you can end up with a great long list of things wrong, you know and sort of you just gotta deal with what is happening at that moment. (F, 60-74, Br)*
>
> *Yeah, actually, unless it is bothering me. (F, 60-74, Br)*
>
> *I sorta make excuses. I am busy, I am doing this and being a woman and a mum and caring, you are always caring about everyone else, and sometimes you forget about yourself. (F, 50-59, Br)*
>
> *The thing is, I like to know medically the ins and outs of a duck's guts. If something is going on I wanna know everything about it … and when it comes to myself, being a single mother*

of four children and things like that, I expect everybody else to be on board and up with their medical and health stuff. But I am not. (F, 50-59, Br)

As mentioned previously, a barrier for some women was their belief that breast cancer was strongly linked with genetics, and therefore if they did not have breast cancer in their family history of breast cancer, they did not perceive a need to screen.

Health attitude: Avoidance and fatalism

As with the attitudes identified in relation to bowel cancer screening, some also indicated that their general beliefs about cancer and treatments for cancer were barriers to breast screening. Some mentioned that, having watched others go through treatment for breast cancer, they would prefer not to know if they had breast cancer, as they did not want their life to be affected by the diagnosis and subsequent treatment. However, it was apparent that this was less of an issue in relation to breast cancer, with a greater appreciation of the effectiveness of treatment for breast cancers that are found early than had been observed in the conversations about bowel cancer.

If I don't know it doesn't matter, I can just get on with my life. (F, 60-74, Br)

Screening beliefs: Able to detect problems themselves

As noted above, for some, the key barrier was that they would expect to feel a lump if it existed, and so did not regard screening mammograms as necessary.

If I did have anything wrong, I would know about it before. (F, 60-74, Br)

I've never had a mammogram, um, I've checked my boobs myself, and the doctor, but, um, yeah, the mammogram, I always thought if I'm checking, what does the mammogram pick up. (F, 60-74, Cx)

I just don't have boobs and I'm like, 'Yeah, if I knew there was a lump, I'd know'. (F, 35-49, Cx)

Breast cancer screening – Prompts to action

The groups discussed their experience that, while there was a generally high level of awareness of breast cancer and breast cancer screening, they were exposed to limited direct prompts to take part in the breast screen program.

Several participants commented that they could not recall any mass media campaigns targeting breast screening in recent years, and contrasted this with other issues, such as bowel cancer screening or melanoma checking, for which some had seen recent promotions. Interestingly, only one person in these groups recalled having seen local outdoor promotions for BreastScreen.

I have seen the bowel cancer one and all the spot ones, but I haven't seen any ads for come on go and get that squashy thing. (F, 50-59, Br)

You hear about the bowel cancer test and you have your slip, slop, slap for skin cancers. You really don't see anything on TV about you know go and get a breast screen … you really don't see anything except in the news about. (F, 50-59, Br)

There is a couple of placards with … little people stacked up that I have seen around. Probably in the valley and it is like … get your breast screening now or something like that. Yeah, right sure. (F, 50-59, Br)

A common theme was that breast screening was not consistently mentioned by their doctors. Several mentioned that having had a reminder from their GP had been an important prompt to booking in for a mammogram in the past.

> *But you are talking why aren't people going in, you know that could be why because there is not that push for the referral from the doctor to say have you had your check lately, that's all they need to say. (F, 60-74, Br)*
>
> *I think [my GP] did [mention breast screening] a few years ago and said I should be going … that's when I did go have one. (F, 50-59, Br)*
>
> *But to be honest the only reason I had this screen today was because my doctor the one I am seeing now in Traralgon said 'you are going, I am going to put you into have this done', all the blood tests which I have regularly and also she wants to do a cervical, so it was her, it was because of her that I had it. (F, 60-74, Br)*

The issue of reminder letters was raised. Some commented that they received these, while others reported not having done so, or at least not recently. Amongst those who recalled the BreastScreen reminder letters, some felt that the fact that these letters told them that they had already been booked in for a specific time meant they were more likely to attend, and some suggested that this was an approach that other programs, such as cervical screening, would benefit from.

> *I have only received the bowel cancer ones that's all, never received anything about [breast screening]. (F, 50-59, Br)*

Participants were prompted to discuss whether breast screening was a topic that was discussed amongst their family, friends or other social group. On the whole, participants felt that this was not an obvious topic of conversation, although they admitted being less reluctant to talk with others about a mammogram than about bowel or cervical screening. Some mentioned that they would be motivated if screening was discussed more openly amongst their peers, although they admitted that, if the topic was raised, it was usually in the context of the painfulness of the procedure. Some suggested that knowing that friends had undergone a mammogram did encourage them to screen themselves. Some also mentioned that attending a mammogram with a friend was helpful for overcoming some of their barriers.

> *Only if it is something, like my girlfriends only because she had a lump, but other than that no. (F, 60-74, Br)*
>
> *I just think between us, like because women are very open with each other I think maybe opening that dialogue about doing it more often like, I mean if you look at someone like me who has lost their mum, lost a friend, two friends are remission you would think that somebody like me might do something more proactive. (F, 50-59, Br)*
>
> *I bet with a mammogram too. Like I feel more comfortable if I had a friend with me to come out with me and all that. Even if you had done it like, she had already done it. They sort of can tell you everything. (F, 50-59, Cx)*

Participants were prompted to talk about where they would expect to see promotion of breast cancer screening. The common expectation was that there should be more social marketing, including mass media, local media and social media advertising. They also expected more presence of promotional materials in local retail, social and health facilities. As mentioned above, there was strong support for greater presence and promotion of the BreastScreen mobile unit.

I have a fantastic GP for a lot, and he has never mentioned [Breast screening], which is weird because he is so up on everything else so. (F, 60-74, Br)

The mammogram information bus maybe is one way of making that happen. (F, 50-59, Br)

If I am not going to seek it out, then you have to be around theatres or restaurants or at wherever I shop, or wherever I am. (F, 50-59, Br)

I work at the local neighbourhood house and most of well a lot of our demographic is women over 45 to 50 so, my suggestion would be they link with neighbourhood houses and do a program through the Neighbourhood houses. (F, 50-59, Br)

While it was not discussed comprehensively in all groups, some raised the topic of having a dedicated women's health centre, suggesting that this would go a considerable way to overcoming the barriers they experienced in relation to the procedure.

Basically if there was somewhere where it is a bit of women's health where I could go and see the same people there so I could build a relationship of trust with them, so I would go there for a mammogram and just along the corridor there is another door and I go through there and that's where I can talk to someone about it if they have found something and then the next door, just like when I was breastfeeding. It is like you have all these women or people that I can find out information without having to make another appointment here and driving over here, just a bit of women's health centre would be great. (F, 50-59, Br)

Response to messages

The groups were presented with some statements intended to convey information about susceptibility to breast cancer and the benefits of screening. These statements were not 'tested' as such, rather their use in these group discussions was to provide some insights into the balance and layering of messages that would be required to promote the screening behaviour.

'9 out of 10 women who develop breast cancer do not have a family history of breast cancer'

Participants were quite surprised to hear this information. While some had a sense that breast cancer risk was not only about family history, a common perception had been that family history was a substantial determinant. Some mentioned that the family link was emphasised in media reports of breast cancer and by their doctors. A small number of participants mentioned having heard this, possibly through a recent BreastScreen NSW campaign, while it was news for others.

I am shocked. I was actually before you just turned that around, I was about to say I know women are more likely to get it if there is a family history. So, when you turned that I have gone 'Really?'. (F, 60-74, Br)

That is surprising … I just presumed it was more genetics and like with bowel cancer the same, you know if your dad or your grandfather … well then you should get it checked. (F, 50-59, Br)

It's the opposite … those with a history in your family should always get checked. (F, 50-59, Br)

There always is a big push for and even when you go to the doctors, they always say do you have any family history of cancer … so there is this big push on genetics, genetics, genetics. So, I am surprised that that number is so high. (F, 50-59, Br)

They need to push that, because the other types of cancer they push or even heart disease or whatever, they push family and family genetics, so they need to say it. (F, 50-59, Br)

Because most of the time they do push that, if you have this, if someone in your family's had this cancer you should get checked for that cancer. (F, 60-74, Cx)

It's frightening, because I thought one with family history were the ones that at were the highest risk. (F, 50-59, Cx)

Well that's scary to me. I always thought it was like a genetic thing, it runs in the family. (F, 50-59, Cx)

Overall, reactions to this statement demonstrated that it was effective, as it directly addressed a common reason that women used for arguing that breast cancer was not relevant to them, and therefore increased perceptions of personal susceptibility to breast cancer. A common reaction to the statement was that it should be promoted, as it would encourage their participation in breast cancer screening.

'Breast cancer is the most common cancer affecting women in Victoria'

On balance, reactions to this statement suggested that it was not especially surprising information. Participants were typically aware that breast cancer was amongst the most common cancers, and even amongst those for whom it was new information, the statement did not greatly affect perceptions of personal susceptibility. The information was not sufficiently personal and did not address the specific reasons for believing that their susceptibility to breast cancer was low. Rather, it was regarded as a general comment about breast cancer, and not a personal comment that affected an individual's perception of risk or susceptibility. Consequently, hearing that breast cancer was common did little to affect intentions with regard to screening.

I would agree with that but because I don't know a lot about all the other cancers women get. (F, 50-59, Br)

I didn't realise but it doesn't surprise me. (F, 50-59, Cx)

'Breast screening can find cancers before they can be felt or noticed'

This statement did meet with a degree of surprise amongst some of the participants, with several women commenting that they had previously believed that noticing a lump would prompt them to get checked, which was evident in the earlier discussions when this idea was used as a justification for not undergoing breast screening mammograms.

However, for others, this was familiar information that acted more as a reminder of what they already knew or expected about the program, rather than telling them something new that would change their motivation or intention to screen.

On balance, this was assessed as a useful message to be used as a component of a comprehensive campaign, as it promotes the benefits of screening and counters an existing belief held by some that acts as a barrier to screening. Several participants responded that they would, be more likely to screen after hearing this information.

Because our first impression, the most of us think is that you feel your lump or something strange or a symptom of some sort. You don't think that it is that lump that I wasn't sure whether I had breast cancer or a cyst. (F, 60-74, Br)

That needs to be out there to prompt me to definitely go more regularly, because I mean it makes sense doesn't it, the earlier the better. (F, 60-74, Br)

Well I presume that would be right, because of course. (F, 50-59, Br)

You try and have a bit of a feel but honestly if you have biggish boobs you really can't, you know you can't do a proper examination, even the doctors will tell you they can't do a proper examination. (F, 50-59, Br)

It's changed my mind now. Because I'll grin and bear it. It's only for a few minutes. But it could save you for the rest of your life and if there is anything there, they can detect it when it's small. I don't need to worry about it. (F, 50-59, Cx)

'Women who find their breast cancer through Breast Screen are half as likely to need a mastectomy'

Reactions to this statement varied considerably, although it was apparent that it was new information in terms of not having been something that participants had previously given much thought to. For some it was a somewhat self-evident and general statement about the benefits of screening, while for others it communicated a specific message about the benefits of screening. While the issue was not explored comprehensively in these groups, it was also apparent that reactions to this statement prompted as many questions about screening, breast cancer and breast cancer treatment as it gave answers. These observations suggest that communication of this message would be most beneficial in a context that allows more comprehensive explanations, rather than being used as a component of simple motivational messaging.

Well I think it is interesting because obviously it is because they have found it early that you don't have to have a mastectomy. (F, 60-74, Br)

Makes sense because it would be smaller. (F, 50-59, Br)

That info's not really out there. (F, 50-59, Cx)

CERVICAL CANCER SCREENING

The issue of cervical cancer screening was discussed in all the women's groups, with four groups included on the basis of being underscreened for cervical cancer (two groups in each of the age ranges 25-34 and 35-49, and one in each of the age ranges 50-59 and 60-74). The remaining women's groups (two groups in each of the age ranges 50-59 and 60-74) had been selected on the basis of their non-participation in other screening programs, and consequently comprised a mix of participants in terms of whether they were up to date with cervical cancer screening.

Cervical cancer – Knowledge and awareness

When the groups were prompted to discuss their understanding of cervical cancer, it became apparent that this was a disease that they had limited knowledge or experience of, along with some misconceptions. Unlike bowel cancer and breast cancer, only a very small number of participants knew people who had been diagnosed with cervical cancer, and all of the women's groups noted that this was not a topic that was commonly spoken about. Participants had little idea of whether cervical cancer was common, although some noted that as cervical cancer did not have the same public or media profile as breast cancer, they believed that it was likely to be much less common. Consequently, participants acknowledged that they did not know much about cervical cancer.

> *It's not something I've heard a lot about, you hear a lot of people getting sick from, you hear so many people die from breast cancer…so many people die from bowel cancer. (F, 60-74, Cx)*
>
> *Well women seem to be either diagnosed of breast cancer more, or dying of breast cancer more. So it's more heard of. Whereas cervical cancer isn't really. The words not out there for it. (F, 50-59, Cx)*
>
> *It doesn't seem to be as common as what some of the other [cancers] are. (F, 25-34, Cx)*
>
> *I mean it's at the back of your mind, but there's a million other things in front, you know. Looking after your kids. (F, 35-49, Cx)*
>
> *I don't hear people with cervical cancer. I hear of abnormal Pap smears but I don't know anyone that's had it. (F, 35-49, Cx)*
>
> *My aunty died of. They don't know what it started as, whether it was uterine or cervical. By the time they found it, it was everywhere. So, it's like with myself, I should go get checked, I'm being lazy. (F, 25-34, Cx)*

During the group discussions, the issue of HPV and its association with cervical cancer was raised. This included some discussion about the new regime of HPV testing that was replacing the old two-yearly Pap screen program. While it was apparent that some had heard about an association between cervical cancer and HPV, very few were confident in their knowledge around these issues. For several of the women in these groups, knowledge about HPV and its association with cervical cancer was related to information they had obtained when their children had been vaccinated. Some of younger groups noted that they had only heard of cervical cancer in the context of receiving the HPV vaccine when at school. Several others in the groups expressed a considerable degree of confusion during these components of the discussions, and some made references that were clearly incorrect, suggesting that there is a substantial need for more detailed and effective communication about this issue and its impact on cervical cancer screening program.

I didn't really realise that cervical cancer had anything to do with sexual activity to be quite honest. (F, 60-74, Cx)

[I have heard] little bit [about HPV] … I did read a bit of information about it when my daughter got the injection at school. Yeah, it doesn't clearly state how they're all connected. (F, 35-49, Cx)

From what I know, genital herpes can cause HPV, or something along them lines. (F, 35-49, Cx)

Yeah, I'm really confused, I'm sitting here just going, 'What the?' (F, 35-49, Cx)

I didn't know that … I've never had anybody say I must have had HPV, to get cervical cancer. (F, 35-49, Cx)

I did but I think cervical cancer, the only times they were really spoken about for me was like at school, you had to have… needles. (F, 25-34, Cx)

Cervical cancer – Perceptions of susceptibility

In line with the observation that cervical cancer did not have a high profile and the associated belief that it was probably not a common cancer, perceptions of personal susceptibility were also low. In essence, participants had little reason to think of their personal risk of cervical cancer. Some mentioned that they had had early Pap tests that had abnormal cells detected, but that on follow up they were ok and did not associate this experience with perceptions of susceptibility. Only one person across the research reported having known anyone with cervical cancer. Consequently, it was perceived to be a rare cancer that they were unlikely to develop.

I don't stress over that one [Pap tests], whereas I really feel I should have the breast cancer, because we all know we have been close to someone, most of us probably that have had breast cancer, and the bowel cancer. (F, 60-74, Cx)

For me it's the knowledge. I've had a sister in law that's passed away from breast cancer, so personal knowledge and experience with that sort of thing, whereas as you said with cervical cancer, nobody knows at the table who has passed away because of it. (F, 60-74, Cx)

I reckon I would feel more concerned about breast cancer than what I am with cervical cancer. It's like or whether it's spoken more of and out… publicised more than that might be the reason why it's in my head more than cervical cancer. (F, 50-59, Cx)

Yeah, it's not as common as all the other ones … so you kind of go, 'Well it's not going to happen to me'. (F, 25-34, Cx)

Oh, I'd probably go for a mammogram before I go for cervical cancer screening because *I feel like breast cancer is more common. (F, 25-34, Cx)*

It's just not on my mind. Unless I hear I hear of somebody physically being impacted by cervical cancer or something like that I just really don't think about it. (F, 35-49, Cx)

Some commented that because they had had several Pap test results that were negative, they assumed their personal risk was low, and this affected their interest in continuing to screen.

I gave up being concerned about [cervical cancer] really, I thought, you know, the last test, I got probably good results. Nothing bad came back. So I'm fine. So I thought it won't happen, I'll just look for signs. I'll probably end up with bowel cancer or something before I'll end up with cervical cancer anyway. (F, 50-59, Cx)

Ah, the cervical cancer, well, I can see my doctors' point, but I've never had any abnormal smears, why continue to do it at 70? (F, 60-74, Cx)

Some mentioned that they did not rate themselves as being highly susceptible to cervical cancer because they did not have a family history and / or because they were too young to be concerned about this cancer. There was some understanding that cervical cancer, and the associated need for cervical cancer screening, was associated with age. This was reinforced for some participants who reported that they had been told by GPs that they no longer needed to take part in the cervical screening program because of their age or because they were no longer sexually active.

> *I think sometimes I think I'm too young to have it. (F, 35-49, Cx)*
>
> *Yeah, but with cervical cancer you don't really think about it unless, like that family history's there. (F, 35-49, Cx)*
>
> *I haven't had one for about 5 or 6 years, um, I asked my doctor when he did the care plan … and he said, have you ever had an abnormal result, and I said no, and he said oh, well at your age you don't need one. He knows I'm a widow, and he knows I don't have a sex life, so, that's probably why. (F, 60-74, Cx)*

As noted, there was some understanding that cervical cancer was associated with sexual activity, although it was also apparent that this was partly related to the perception that Pap tests were for a range of gynaecological issues and sexually transmitted diseases. Several participants reported that they were no longer sexually active, and that they therefore believed they were no longer susceptible to the conditions that Pap tests were looking for. These women had some understanding that cervical cancer risk was somehow associated with sexual activity, and they consequently absolved themselves from requiring Pap tests. It should be noted that there were some misunderstandings in relation to these issues, in that a reasonably common belief was that Pap tests were a general screening test for a range of sexually related conditions, and not just for cervical cancer.

> *But also, I never had a partner, and I just, I didn't see the point. (F, 50-59, Bo)*
>
> *I probably don't really have to at my age, do I? (F, 60-74, Cx) (69 year old)*
>
> *Yeah, so if you don't have sex at all, do I need to go for a pap smear? (F, 35-49, Cx)*

Some also reported having had a hysterectomy, and therefore no longer being susceptible to cervical cancer or requiring cervical screening.

> *I don't have those bits anymore. (F, 50-59, Bo)*
>
> *I had a hysterectomy and the Gynaecologist said you will never have to have a Pap smear anymore, happy dance. (F, 50-59, Br)*

There was some belief amongst those who had had the HPV vaccine, that they were less likely to develop cervical cancer, contributing to a belief that Pap tests were unnecessary. However, as noted throughout this report, it was also evident that participants were not confident in their knowledge of issues related to HPV, the HPV vaccine and how this was related to cervical cancer and Pap testing.

> *Yeah. But I've had the injections because it was like, 'I'm not going to get cancer now'. (F, 25-34, Cx)*
>
> *Yeah, it's not as, it's a far less likely, maybe where it was a 40% now it's a 5% chance kind of thought. (F, 25-34, Cx)*
>
> *That's what I'm thinking, you know, like where it was a kind of unlikely now it's almost not. (F, 25-34, Cx)*

Cervical cancer screening – Knowledge and experience

The groups were prompted to discuss the topic of cervical cancer screening, including experiences and perceptions of the procedure and awareness of the recommended screening regime. In these discussions it became apparent that, while participant understood that cervical screening was performed through a Pap test, there was a lack of clarity and some misunderstandings about the procedure and its purpose.

Most obviously, there was some misunderstanding of the purpose of a Pap test in terms of what it was testing for. A reasonably common belief was that the test was for a range of gynaecological issues, and not just cervical cancer, with this perception being reinforced in their dealings with their doctors. Several participants reported that when they attended a GP for any gynaecological symptoms or pregnancy related issues, they were recommended for a Pap test. Consequently, it was not surprising that they regarded the Pap test as a general test for the breadth of gynaecological issues. Associated with this, some participants were unsure whether they had been screened, or assumed that they had been when other gynaecological tests were done.

> *I thought it tested other things, but I don't know what it is … Abnormalities, I guess. (F, 25-34, Cx)*
>
> *Actually, I thought that too, like just like your whole inside, like your whole, everything to do with your vagina. (F, 25-34, Cx)*
>
> *It can also just pick up on other things, so as I said, polycystic might show up the growths in there, cysts. (F, 25-34, Cx)*
>
> *So I did check-up and then after the check-up when it came back fine, it's only when I've had the babies that I've felt I've* had *to do it, for that reason. (F, 35-49, Cx)*
>
> *… 26 years ago … there was a post-natal exam. That was the last one. I don't know if that was the checking for cancer or what that was for. (F, 50-59, Cx)*
>
> *I've never had one … unless I've done it when I had a baby? (F, 35-49, Cx)*
>
> *Only ever had one once four years ago, that was after a miscarriage, so I'm not sure. I'm pretty sure they did everything, but I can't really remember. (F, 35-49, Cx)*
>
> *The last time I had a Pap smear would've been about six months after I carried and lost a child. (F, 35-49, Cx)*
>
> *I think it was the doctor if I remember correctly, who had said to me, "Have you had a Pap smear since the birth of your kid or before your kid?" and I said no. He said, "I think you need to have one." (F, 35-49, Cx)*

Independently of these misunderstandings, there was reasonable awareness that they should be having Pap tests every two years from the time they became sexually active. Interestingly, several women reported that they had been prompted by their mothers to have their first Pap test when they first became sexually active, and several women commented that this was the message they had passed on to their daughters.

> *It's just always come up! As soon as you're sexually active you then have to have a test! (F, 35-49, Cx)*
>
> *She's 12 soon … and I said, "You have to have one if you have sex." That's how I was told but it's not necessarily real or true that you have to be sexually active. But she said, "I'm not having sex" and I said great! (F, 35-49, Cx)*

The issue of HPV, the HPV vaccine and how this affected the cervical screening regime was raised in each of the groups. As noted, there was some familiarity with the HPV vaccine and its association with cervical cancer, but participants were not confident in their knowledge and there were some misunderstandings. Awareness of these issues appeared to be higher amongst the younger groups, several of whom had had the vaccine, and some of those whose children had been vaccinated.

Importantly, few were aware that the cervical cancer screening program was changing to HPV testing, or that this meant the screening regime was changing to five yearly. During the groups it became apparent that communication of these changes was quite complex and resulted in some doubt and confusion, with some suggesting that this confusion was detracting from perceptions of the importance of maintaining a screening regime. Some were concerned that a five-yearly regime would be insufficient for finding problems, while others were relieved that they would not need to test as often.

> *The most exciting thing the doctor told me last time she told me I needed one, she said that the testing was going from 2 years to 5 years. Don't know whether that's happened yet or not, haven't been back to talk to her about it. (F, 25-34, Cx)*
>
> *I know that when they were looking at changing it from 2 years to 5 years there was a lot of uproar from women in like, the news threads online, like on Facebook and things like that saying, like 5 years would be too long because if they've got cancer by that time it's way too late to find it. (F, 25-34, Cx)*
>
> *I always thought it was two years, but my last one he went 'you've got up to five years now; it's a new testing system'. (F, 35-49, Cx)*
>
> *Yeah, we've had conversations about it. Everywhere you go, you get told something different. (F, 35-49, Cx)*
>
> *Everyone gets told different information when it's supposed to be something that's solid. I'm wondering why aren't we all getting the same message? (F, 35-49, Cx)*
>
> *[My 25-year-old daughter] … went to the doctor a while ago … the doctor said, "No, you don't need one because you've had the HPV vaccination." (F, 35-49, Cx)*
>
> *Yeah. It's too long. It's not as safe now if they're going to stretch it out to five years, and if you've had multiple partners in that five years, then you've got more risk. (F, 25-34, Cx)*

While issues around the cervical cancer screening program changing to testing for HPV was not fully explored during this research, a range of related issues arose that participants had questions about, including:

- Is cervical cancer only related to sexual activity? And if so, what do these changes mean for those who are no longer sexually active?
- Is the vaccine 100% effective? And related to this, do those who have had the vaccine need to continue with Pap testing?
- How does HPV affect men, and should men also be regularly tested for HPV?
- Why is a five-yearly testing regime more effective than the current two-yearly regime?

These findings demonstrated that it will be very important during the transition period to create clear and simple communications about the changes, and to ensure that these changes are consistently

communicated through direct messaging to women as well as through messages from health professionals.

An issue that arose unprompted across all of the age groups was the notion of self-testing. Participants felt that it could be possible to perform their own swab test, and that this would overcome many of the barriers they experienced to participating in the cervical screening program. Some reasoned that they did this for bowel cancer screening, and therefore believed that it should also be available for cervical screening.

> *Why can't they … send out packages for Pap smears to women like they do for bowel cancer. (F, 60-74, Br)*
>
> *I would rather do that … something that you could do at home, in your own private home, no doctors looking up you. (F, 50-59, Cx)*
>
> *It's such an invasive one. If you could do it yourself. I'd have no problem. (F, 50-59, Cx)*
>
> *If there was a way we could do it yourself, I'd probably support that. If I could do a home test and take it in. (F, 35-49, Cx)*
>
> *Home kits would be good. I see a lot of men have the bowel one, the bowel kits. (F, 35-49, Cx)*
>
> *If you could do it yourself it'd be great. I reckon everyone would be in agreeance that it would be done more regularly. (F, 25-34, Cx)*
>
> *Talking about that, one of my friends in Queensland said her doctor actually gave her a test to do at home. (F, 25-34, Cx)*
>
> *There was this little thing that I had to do when I was pregnant, and you stick your leg up on the toilet seat, and you stick a little swab up there and you poke your cervix. Can't be any worse than, they're touching your cervix, like… I'd do it myself. I'd happily do it myself. I mean, if I can do it when I'm 38 weeks pregnant. (F, 25-34, Cx)*
>
> *I think in all honesty, if there was a home kit, probably just go in the bedroom, sort it out, drop it off when I take the kids to the doctor … drop it in to the pathology place and I'll wait for a call if there's something. (F, 25-34, Cx)*

Cervical cancer screening – Motivators and barriers

Cervical cancer screening motivators

Participants were prompted to discuss their perceptions of the benefits of cervical cancer screening. There was a general understanding that a positive Pap test indicated "abnormal cells", and that this was a prompt to further investigation and treatment if necessary. Several women reported that this had been their experience at some point of their history of Pap testing. There was a general appreciation that this was early detection, and that it contributed to simpler treatments.

It was apparent that these experiences, combined with the belief that cervical cancer was uncommon and the perception that personal susceptibility was low, resulted in participants not having the same level of fear about positive results from Pap tests as they had about positive results from bowel or breast cancer screening. Rather, the benefit of cervical cancer screening was understood to be about avoiding the development of serious diseases such as cervical cancer.

Cervical cancer screening barriers

The groups were also prompted to identify and discuss the factors that discouraged them from keeping up to date with cervical screening. As with the findings for bowel and breast cancer screening, barriers to cervical cancer screening included a combination of factors related to the procedure itself, attitudes to health and disease prevention and appreciation of the screening program.

The procedure: Unpleasant and uncomfortable

The top of mind barrier was that the Pap test procedure was experienced as unpleasant, embarrassing, uncomfortable and/or painful. For some, this was assessed as an inconvenience issue that they just had to get over, while for some others it was the barrier that prevented them from returning for another test.

> *It's a bit unpleasant, but you just do it don't you. (F, 50-59, Bo)*
>
> *Yeah, it's uncomfortable, but it's just doing it. It's that thing that you have to do as a woman. (F, 25-34, Cx)*

The dislike of the procedure included those who experienced it as painful and those who experience it as embarrassing. Based on the women in this research, these experiences ranged from mild forms of discomfort to extreme forms of pain. And it was apparent that this discomfort was exacerbated by many of the other issues documented as barriers, such as the booking processes and the health professionals who took the sample.

> *They are uncomfortable and they are embarrassing. (F, 50-59, Cx)*
>
> *Well last time I had it done, I reckon it depends who does it. And how they do it. Because the last time I had it done [which was 22 years ago], I actually bled and it hurt. And she goes, 'Oh yeah, that would be alright.' But it wasn't alright. Because it was just sore for a few days and the bleeding to me isn't supposed to be normal. I don't think it is anyway. (F, 50-59, Cx)*
>
> *I find them excruciatingly painful … every time. It doesn't matter what doctor does it, it doesn't matter, yeah, when it's done, they're always extremely painful. And so obviously, when you know it's gonna hurt, and you don't get anything fun at the end of it. (F, 35-49, Cx)*
>
> *It's just awkward! … especially if it's a male doctor. (F, 35-49, Cx)*
>
> *Very awkward sometimes. The uncomfortableness … makes you, when you think you've got to go for your test, it's like, 'do I really want to do that again?' (F, 35-49, Cx)*
>
> *I think it's just because I don't like other people looking at my body. I think getting the bottom half of me undressed and then just being out there in the nude for this person that I don't really know, and not having a regular doctor that I'm overly comfortable with, and that doesn't have a thick accent, because I cannot hear very well. (F, 25-34, Cx)*

Some talked about the facilities in the clinics where they were tested not being conducive to feeling safe, especially in the context of such an intimate procedure.

> *I do make excuses … I've had an unpleasant experience, there hasn't been the privacy, um, allowed to me for the pap smear. I've gone into a surgery, um, there's just a basic half a curtain pulled over, and you're just there to display all your worldly goods, and … the other thing is room temperature, because when you're laid bare, and you've got people there, the doctors doing what he/she has to do, it's just an unpleasant experience. It's just not nice. (F, 60-74, Cx)*
>
> *It's just a bit off putting that one … I think it's about the procedure for most women. It's the fear of the procedure and the intimacy of the procedure. (F, 60-74, Cx)*

Well, you know, it isn't very nice, sitting there, laying there. (F, 60-74, Cx)

it's just uncomfortable. Just, I don't like it. Yeah, I just don't like opening my legs, just to…! (F, 35-49, Cx)

I don't like it. I just, I think it's too invasive, it's uncomfortable and some doctors are just really rough and I just can't… But I had the [vaccine], to prevent, so you don't need them. Yeah, I thought I didn't need, but apparently they don't prevent all the cancers. (F, 35-49, Cx)

It was apparent during the groups that concerns associated with the intimacy of the procedure and the feelings of embarrassment and vulnerability were specially an issue for younger women. Further, several of the participants who were mothers of young women in their teens and twenties reported that these were challenging issues for their daughters.

Nobody likes to take their pants off in front of a stranger, like, you know, and I think that, like my 17-year-old foster daughter, she was all like, 'Oh, you know, it's really embarrassing'. (F, 25-34, Cx)

But I think the fear of it is pretty pervasive. My daughter's 24, and when she was 14 she came home from school with her boyfriend and said, 'We want to have sex' … and I said, 'Well, once you're sexually active you have to start having pap smears', so we YouTubed it and yeah, the actual procedure is on YouTube. That put her off having sex for about another 4 years. She thought, 'I'm not ready to go through pap smears'. (F, 35-49, Cx)

I've tried to bring it up with my older daughters … the 22-year old, she said, "That was awkward getting it done." Her results came back fine. The 20-year old she's too afraid to. (F, 35-49, Cx)

Some women reported that they overcame the discomfort and embarrassment by taking someone with them when they went for a Pap test, with examples including mother, daughter, partner and friend.

So I just avoid them. I actually made a friend of mine come in with me and hold my hand during a pap smear just because I couldn't, if I had gone in by myself. (F, 35-49, Cx)

The procedure: The health practitioner

A range of issues associated with the health practitioners performing the Pap test acted as barriers to screening. There was a general understanding that health practitioners differed greatly from each other in their skills in performing a Pap test.

Some talked about having bad experiences with particular doctors in the past that had prevented them from following up for another Pap test, referring to examples where they felt the doctors were not sufficiently skilled in the procedure, which had resulted in pain and discomfort, or sensitive to the intimacy of the procedure.

I think back to the one that I have *had and I was, I think I was maybe 20, 21 or something like that and I actually went with my mum and it was my first one ever and I was like, 'I don't know how to do it'. So she had hers done and then I had mine done. But when, you know how they put the spreader claw thingy, or whatever it is! That actually broke, and it actually snapped back, and so, and left me very heavily bruised. So ever since then I'm kind of like, I don't want to go through that. (F, 25-34, Cx)*

The last doctor I had one with, she didn't seem to know what she was doing. And she had to re-do it straight away. I really didn't feel confident in her abilities. (F, 35-49, Cx)

But yeah, it's daunting after having a really uncomfortable one, but there's some people that just can't seem to do it right, you can feel it and it hurts. (F, 25-34, Cx)

A common theme of this research was that barriers related to embarrassment and unpleasantness of the procedure were exacerbated by not having a regular GP. Several women noted that, given the intimacy of the Pap test procedure, they would prefer to have it done by someone they had developed a level of trust with, which required a long-term relationship with a GP. However, they felt that this had become increasingly difficult in the provision of health care in the local area, with participants commenting that the turnover of GPs and the practices of larger clinics made it difficult to develop relationships of trust with one GP. For some, this lack of trust was exacerbated by not being able to regularly attend a female GP, and for some, the vulnerability was associated with not being confident in their communications with GPs with whom they experienced language barriers. A small number of participants differed, claiming that they felt more comfortable having a Pap test done by a doctor who they did not know, indicating that there were individual differences in these preferences.

> *It's not like the old days where you sort of had a family doctor sort of thing … the doctors change all the time. And so you don't really get to know that doctor. You know what I mean. If you go to a new doctor, you don't know their routine, whether they cover you up or they just leave you sitting there, or you don't know. (F, 50-59, Cx)*
>
> *Yeah, he was my doctor. So absolutely. I had him since I was quite young and he delivered all my kids and everything, so he was the family doctor. And you sort of got to know him … you feel comfortable about going in and talking about anything. But doctors now, If I was to ring and ask for the doctor who I do see, I probably wouldn't get in to see him now. I go to someone else. And I'm not being rude or anything. Half the time you can't understand them. (F, 50-59, Cx)*
>
> *Well I'm not necessarily embarrassed by it, I just don't like for it to be a stranger, I 'd prefer for it to be a regular doctor, but I don't know if any of you guys have had the same experience but whenever I build up a rapport with a doctor they get offered a better job in Melbourne and take off. (F, 25-34, Cx)*
>
> *It just takes me a long time to be comfortable with somebody and when you're going to get undressed in front of them you want to be comfortable. (F, 25-34, Cx)*
>
> *I've just found that I go to the community health centre and there's four different faces next time I go, and then I'm like, 'Well, now I've got to go in for something that's already uncomfortable enough, let alone with somebody that I've never met before, that can't even speak English. (F, 35-49, Cx)*
>
> *I would feel more comfortable if I had the same familiar face when I come through that door and say, 'Okay, you know me', and spread my legs and, let's get it on, that's what I feel like. It's a personal subject. (F, 35-49, Cx)*
>
> *See I'm the exact opposite, I've had the same doctor now for about 6 or 7 years, and I would flat-out refuse to drop my pants in front of him. I'd flat-out refuse to … I think because I see him all the time, 'cos I've got other medical issues and I have to go see him every 4 weeks. (F, 25-34, Cx)*
>
> *I'd prefer someone I've never seen and possibly will never see again, yeah. (F, 25-34, Cx)*

The issue of the doctor's gender was discussed, with the more common attitude being a reluctance to have a Pap test done by male doctor, although a small number disagreed, commenting that they had experienced male doctors as being gentler with the procedure than female doctors. Some noted that these concerns were exacerbated if it was their first visit with a particular male GP. And some pointed out that there were insufficient female doctors in the region.

> *And the fact that he is a male I absolutely adore him; he is just an amazing doctor but yeah, I don't feel happy to have a Pap smear done by him. I don't know why. (F, 60-74, Br)*

I usually ask for a female doctor to do it. Normally they're quite happy. I explain it to them. I say look you know, I prefer a female doctor doing it, is that okay with you. (F, 50-59, Cx)

I find males are better at it because they're more gentle. Females know what you can handle down there, so they're not as gentle as a male I find. (F, 25-34, Cx)

My first ever one I was 19, it was after I had my first baby … I won't say doctor's names, but she, it hurt. She scraped and it really, really hurt, and I waited 10 years till the next one. (F, 35-49, Cx)

I think because he's a male doctor, too, I think I find that always...just that procedure, no, I don't want him doing that. (F, 35-49, Cx)

It always seems to be with a male doctor I've never seen before, and it really makes me uncomfortable. (F, 25-34, Cx)

I always have to see a female if I've got to have it done. It's like a fear, it's makes it very hard, specialist-wise, there's not a lot of female gynaecologists around. I think there's three males at the hospital and one female at the moment. (F, 25-34, Cx)

I've had a male doctor say, I think you should book in with a female doctor for a pap test. You are due, but I don't want to make you uncomfortable. I was like, that's actually pretty courteous. (F, 25-34, Cx)

Some felt that their doctors were reluctant to perform the procedure, and believed they did not bring the issue up for this reason.

I don't think they like doing them, to be honest. From my doctor I got the impression he was just no. I think he wanted to set it up with a female doctor. (F, 35-49, Cx)

It was apparent that the intimacy of the procedure created a range of quite complex challenges. Some of the younger women talked about their fears of being judged by doctors, and that they were reluctant to take off their clothes for this reason. Some mentioned that they were reluctant to have a Pap test if it was suggested at the time of an appointment for a separate issue, as they felt it was something they needed to be prepared for. This was especially in cases where it was the first time they had been to that GP.

Last time I went to a doctor, so I was 20 kilos lighter than what I am now, and he told me I was fat and had to lose 20 kilos. Like, I weigh 120 kilos right now … and I think that's my thing, like I'm not comfortable enough with a doctor to, if someone's gonna sit there, I was 20 kilos lighter than I am now, and he wants to call me fat and say I have to lose 20 kilos, what's he gonna think once I take my clothes off, you know what I mean? (F, 25-34, Cx)

One time I've had a doctor say 'I could do it now', like that, and I was no way … because it's gross. You're not going to do that, see me like that. (F, 35-49, Cx)

I've had a few occasions, where I'm at the doctor and they say, you haven't had a pap smear, can we do it now, and I'm not ready, or I'm seeing a male doctor for the first time, so I'm like, no, I'm fine, and I have to awkwardly exist the doctor. (F, 25-34, Cx)

The procedure: Inconvenience

Complicating these issues with GPs, some mentioned that having to book an appointment for a Pap test was also a factor in their reluctance to screen. They referred to needing to make bookings well in advance because of the lack of availability of their preferred GPs, the challenge of scheduling a convenient time amongst all their other responsibilities, and having to schedule for an appropriate time in their menstrual

cycle. For some, these complications added up to it all being too difficult. These issues were experienced as especially challenging by the younger women, and particularly for those who had young children.

> *I have to find someone to look after kids, and you have to book it in advance, and my roster changes all the time. It has to be a long appointment, and then the appointment might take even longer, 'cause you have to wait and then it's super uncomfortable. You book it in and what if you're on your period, it's too much to deal with. (F, 25-34, Cx)*
>
> *I'm an anxious person. So if it's too far in advanced planning, and in this area, you do have to book your doctor like twenty years in advance, it feels like. (F, 25-34, Cx)*
>
> *It costs more too, if you're not bulk billed, you've got to pay for the longer appointment. (F, 25-34, Cx)*
>
> *The only reason I haven't gone is because I've had the kids, and it's so hard and there's no family around to look after the kids. (F, 25-34, Cx)*

Several of the groups raised the idea of a women's clinic, noting that many of their convenience and discomfort barriers to Pap testing would be overcome if such a facility was available to them. Others suggested that this could also be achieved through dedicated women's health days at their local GP clinics.

> *They need a clinic where you just walk in and everyone lines up and bang, bang. (F, 25-34, Cx)*
>
> *Yes it needs to be, like, okay, women's day, we're all going. Here's the baby- sitter. We've hired someone. We've hired a child educator, they're just going to sit in the room with your kid. (F, 25-34, Cx)*

Health attitudes: Priority and perceived susceptibility

Similarly to the issues documented in relation to bowel and breast cancer screening, a range of health attitudes acted as barriers to taking part in the cervical screening program, which included issues around perceived susceptibility, the priority of different health issues and perceptions of urgency and importance.

As noted, cervical cancer was thought to be uncommon and perceptions of personal susceptibility to cervical cancer were very low. Hence, women did not experience a strong or pressing reason to screen. This, combined with the range of other things they were dealing with in their lives, the reluctance to go to a doctor unless necessary and, as noted below, the lack of prompts to screen, meant that they simply put the issue of Pap tests to the back of their minds and avoided it for as long as possible. In essence, many of the women who were not up to date with cervical cancer screening experience no compelling reason to make Pap testing a priority.

> *I don't know [why I haven't had a Pap test], I think like everything else, I am normally pretty healthy, so I sort of didn't feel the need for it. (F, 50-59, Bo)*
>
> *I am behind in my Pap smear just because I am slack and don't like going to the doctor. (F, 50-59, Br)*
>
> *I would just say its probably about 3 years ago, 3 and a half years ago. Because I've been receiving letters and I keep ignoring them. 'It'll be right! It'll be right! I'll do it eventually'. He [GP] is like, when are you going to go? And I'm like, 'Yeah!'. (F, 50-59, Cx)*
>
> *Well, it doesn't cross my mind. Like I said, it doesn't get advertised, it doesn't, I don't get reminders or anything, like (F, 25-34, Cx)*
>
> *Yeah, I just don't see it as being a big deal … because it's, just something you have to do. (F, 25-34, Cx)*

In this regard, cervical screening was not as frightening as breast or bowel screening, as the barrier was less about avoidance of diagnosis, partly because a positive test was associated with abnormal cells rather than cancer.

> *Yeah. My mother-in-law did when she found out I had abnormal cells. She was like 'you've got cancer!' I was like 'calm down; it's a bad test'. (F, 35-49, Cx)*

Some talked about other presenting health issues being more important than cervical cancer screening. Others talked about having to focus on the health care of their children, partners or parents, and having no time for their own health issues, especially if they were not experiencing problems.

> *With my old doctor … when I was being diagnosed with my diabetes and getting it under control that my doctor just said to me … 'Look, I'm getting prompts here … from Cervical Cancer people. We have to do this'. And I'm going, 'yeah I know but I just want to get better'. So, he said, 'Okay, we'll just concentrate on the diabetes, get you better and we'll go and do it.' So that was my mate, I trusted him. (F, 50-59, Cx)*
>
> *If anything bad came back from it, it's just another little shit to add to the list of shits that I've still got to do. I'm taking care of my family so I haven't got time; I wouldn't do anything about it anyway I don't think. (F, 35-49, Cx)*
>
> *If I got told I had cancer and had to have treatment or anything, blinkers go on, I don't want to know. (F, 35-49, Cx)*

As noted in relation to perceptions of susceptibility, several mentioned that they had had Pap tests in the past, but that after many years of no positive results, they saw no reason to continue with the process. These women felt that cervical cancer was no longer a sufficient risk for them.

> *Actually, I used to get it done all the time and there was just never anything there, so yeah, I sort of like, eventually life takes over and that gets put on the back burner as well. (F, 60-74, Br)*
>
> *When you go through the change of life I think some of those things they just don't enter your head to do. (F, 60-74, Br)*

Screening beliefs: Poor understanding of purpose of Pap test

Associated with the previously reported finding that Pap tests were for a range of gynaecological issues, and not just cervical cancer, some believed that, if they needed to be tested, they would experience symptoms that would prompt them to attend doctor for tests. Further, the perception that Pap tests were for sexually transmitted diseases created a range of barriers, from those who simply did not want to think about these issues through to those who felt they were not personally relevant.

> *See, it's probably stupid, like me thinking oh well, if I've got cervical cancer, I will get some sort of, something will happen down there that will make me go to the doctors. (F, 60-74, Cx)*
>
> *Yeah, that's my opinion. Something will happen down there, or something will fall out, or you know, something will happen. (F, 60-74, Cx)*
>
> *And I think, too, there's been with younger people coming up being taught that HPV then it makes people not want to talk about it because it seems like you're talking about STDs and stuff, and you're putting them away behind your back … everybody's too embarrassed to say it out loud. (F, 35-49, Cx)*

Cervical cancer screening – Prompts to action

The groups were prompted to discuss their experience of the prompts to taking part in the cervical screening program. The overwhelming sense was that, because they would prefer not to think about Pap tests, if they did not experience any blatant external cues to action, then they simply avoided it.

> *I don't really think about it. It's just, kind of like out of sight out of mind, that type of thing. And like everyone said before, you don't see advertisement for it, you don't hear about it a lot, and yeah, it's just one of those things that I just don't think about. (F, 25-34, Cx)*

A common theme across these groups was that cervical screening was not consistently promoted or pushed by health practitioners. Several participants commented that, in their experience, doctors only asked about Pap testing in context of pregnancy. There was also some feeling that doctors were reluctant to conduct Pap tests, which was exacerbated by the systemic factors that resulted in them being not interested in treating anything other than the presenting condition. Hence, women reported that cervical screening was rarely brought up by their doctors when they attended for other health issues. Some of the older women wondered whether doctors were no longer addressing cervical screening with women in their age group.

> *No, doctors don't mention it … I've always had to bring it up. (F, 35-49, Cx)*
>
> *It was only when I was pregnant that they asked. (F, 35-49, Cx)*
>
> *I haven't, I had them … it's probably been about 10 years since I've had one. Um, mainly because it's never actually been asked, and it's never been brought up. (F, 60-74, Cx)*
>
> *Years ago, doctors used to, they'd say you haven't had a pap smear, you haven't had this done, or you need this done. Now doctors go, how quick can I get her out of here? (F, 60-74, Cx)*
>
> *I don't think they really care about the older women. Young ones they might do. But I don't think, once we turn a certain age that they care. (F, 50-59, Cx)*
>
> *But doctors can't seem to focus on more than one issue these days. It's like if you are going for one… I came back for the other thing. If I keep going, you know... 'Today I'll see you for one thing'. If you've got more than one, you come back another day for it. (F, 50-59, Cx)*
>
> *I think unless you go in to a doctor with women problems, they're not going to ask you. (F, 25-34, Cx)*

On the other hand, several participants commented that the main factor that had prompted them to get Pap tests in the past had been reminders from their doctors, with several commenting that they relied on their doctors to inform them about when such tests were necessary rather than keeping note themselves of when they might be due.

> *Yeah, just when I had my last baby, they're just like, 'Oh, when was the last…', I'm like, 'Oh, I've never had one' … she just said, 'Go and get one'. (F, 25-34, Cx)*

The issue of reminder letters was discussed in each of the groups. While some reported that they continued to receive reminder letters, it was common to claim that they were no longer getting reminded by mail. Some acknowledged that they no longer received reminder letters because they had moved house or changed GP, but others were unable to explain why they might be missing out on reminder letters. While some admitted to having thrown out letters in the past, the general attitude was that

receiving a letter saying that they were due for their next Pap test did remind them of the need to screen, and that not receiving such letters made it easier for them to avoid screening.

I've fallen off their mailing list … I used to, I've moved house a few times. Changed GP's. Just changed one GP. But moved house a few times. (F, 50-59, Cx)

Yeah, like I have not received a pap smear test or got anything in the mail since 2011. Like, I have not been reminded about it at all. (F, 25-34, Cx)

It's been about 8 years since I've had a reminder … It was my GP clinic that used to send them … I think they gave up 'cos I used to throw them in the bin and just not respond. (F, 35-49, Cx)

For me I think it's the reminders, bring back the reminders. Keep's people accountable. (F, 35-49, Cx)

Yeah, I have [received letters in the past], and then they just stopped coming. (F, 35-49, Cx)

I actually got one, the last Pap smear I got was because of a letter reminder. (F, 35-49, Cx)

The Pap test reminders were also contrasted with breast screening, in that women admitted that they were more likely to participate in breast screening because the reminder letter booked to attend a specific appointment. While there was not universal agreement, several commented that this approach was effective, claiming that they were more likely to follow up if their session has been scheduled.

The mammograms, they always send you something with an appointment, and I think with that, you can't think I have to ring up, because, if you don't ring up someone else is missing out on their appointment, so it's sort of a commitment, whereas the pap smear you don't. (F, 60-74, Cx)

I don't see why they can't send you out these things, like you said, the breast thing, they send you out the thing so you are due for this, your appointment is this time, you don't have a choice. Everything in life we don't, they boss us around, tell us when we can breathe and when we can't. Why can't they tell us? (F, 60-74, Cx)

Participants across these groups felt that cervical cancer screening was not promoted in the media to the same extent as other screening programs, such as breast or bowel cancer screening. Most could not recall any advertising of Pap tests or the cervical screening program.

I think if it was more out there, as in you know, you see more about it, and heard more about the bad side of it, maybe women might, we go and get everything else, and it's all uncomfortable, and it's all embarrassing. We have babies and it's uncomfortable and embarrassing, you know what I mean. (F, 60-74, Cx)

But they did that with prostate cancer, it was a real taboo subject too, the men never spoke about it, and then they brought that campaign out, and it just seemed to change the whole thing about it … I could see that happening with the pap tests. (F, 60-74, Cx)

I think that cervical cancer gets undetected a lot, because people don't go, because there is no advertising, there is no encouragement. (F, 60-74, Cx)

They advertise breast cancer, they advertise bowel cancer, but they don't advertise cervical cancer. (F, 50-59, Cx)

Not even a sign on the back of the toilet anywhere, you know. (F, 35-49, Cx)

You just don't think about it because you don't see it out there. So if you see a lot of advertisement on it you would think about it. (F, 35-49, Cx)

A small number of participants recalled a previous CCV advertising campaign promoting cervical screening. They claimed that this message and imagery had stayed in their minds as a reminder of the importance of screening, and as a push to overcome their feelings about the test being uncomfortable. Some also reported having seen promotions of Pap tests through social media, and also commented that these reminders did have an impact.

> *All the different women ads, you know with women who are crossing, that you can only see the women crossing their legs feeling awkward and stuff on TV, and, 'Isn't that time to do it'… (F, 25-34, Cx)*
>
> *…in a waiting room. She's got the stockings on, she's like uncomfortable, and they're saying that 5 minutes of uncomfortable is worth whatever, and they're all crossing their legs, that, it's staying in my head. (F, 35-49, Cx)*
>
> *I saw it on Facebook … on a Constance Hall post, they were talking about someone getting cervical cancer … and they were talking about getting pap smears. One lady mentioned 'oh no, it changed to five years'. … I was kind of like, oh shit, that's right. I haven't booked one of them in for a while. (F, 25-34, Cx)*

When discussing the issue of prompts to action, participants admitted that Pap testing was not something they were likely to talk about with other women, except possibly with their daughters or mothers. They felt that the fact that it was such a private issue meant they were less likely to be reminded of the need to keep up to date with screening. Some also mentioned that the association with STDs meant that this was not a topic of conversation. On the other hand, some also noted that it was motivating when they heard that friends were having Pap tests, as this helped to normalise the procedure as well as to remind them of the importance of keeping up to date.

> *It's only a conversation I'd have with my mother, to be honest. (F, 25-34, Cx)*
>
> *But like we were talking about, no-one really talks about it like, you wouldn't talk with your mother or your friends, but I don't, no-one really does that. Why not? Is it a taboo subject? I mean is that why we don't? (F, 25-34, Cx)*
>
> *See I'm one of those people that with my friends I will get right down into the nitty-grittys of my sex life with my friends, no question or anything is off-bounds, but if it comes into sexual health, just the walls go up and I don't know why. (F, 25-34, Cx)*
>
> *Yeah, I think that makes it harder for people to talk about it because it seems a bit taboo and embarrassing or dirty. (F, 35-49, Cx)*
>
> *Yeah, people don't talk about it. I have lots and lots and lots of friends who have had issues, but it's not something that we talk about. (F, 35-49, Cx)*
>
> *My partner's a girl, so I would just say let's just go do it together. We talk about it, and I say, I've got to go do it, get it done. So does she, but we just both put it off, so we can probably just go do it together. Team effort thing. (F, 25-34, Cx)*

There were some suggestions that the process of booking for a Pap test could be made easier, and that this could help to overcome their reluctance, especially if they did not need to talk with anyone during the booking process. Some suggested that on-line booking where they were able to specify that they wanted to attend for a Pap test, or a smart phone app would be useful for this purpose.

> *What about if the Latrobe Community Health or whatever you said it was before, something like that that had an app, that you didn't actually have to go into the doctor and say, 'Hey, I'm here for you to do this, I've got to take my pants off', or for you to ring up and say, 'I need to book in to have a pap test done', if you could book it on an app, 'cos no-one talks to anyone any more, and you could say that's what you're going in there for, when you walk in*

the doctor's, 'Right, alright, lets go, yep cool, you do your thing, I'll do mine'. You don't have to mention the word. (F, 25-34, Cx)

Completely drop the chit-chat. Yep, just straight up, 'I want a pap test', so you book it online, and you go in and you just like, 'Let's go'. (F, 25-34, Cx)

Response to messages

The groups were presented with some statements intended to convey information about susceptibility to cervical cancer and the benefits of screening. These statements were not 'tested' as such, rather their use in these group discussions was to provide some insights into the balance and layering of messages that would be required to promote the screening behaviour. Reactions to this information is documented below.

'At least 8 out of 10 Victorian women who develop cervical cancer, have never had a pap test'

Reactions to this statement were quite varied, demonstrating that it is limited in its capacity to effectively encourage participation in the cervical screening program.

The reference '8 out of 10' was understood to be a high number, and this communicated that there was a risk in not having a Pap test. However, it was evident that some participants did not really understand the statistical reference, with a common interpretation being that it was suggesting that 8 out of 10 women develop cervical cancer. This interpretation commonly provoked disbelief, as cervical cancer was known to be not so common.

Hence, the limitation of this information was that it is interpreted as a message about the incidence of cervical cancer, and does not effectively convey the benefits of screening.

That's pretty drastic. (F, 60-74, Cx)

Well, 8 out of 10, that's just about every second person, well, that's a lot of women, that have ended up with cervical cancer. (F, 60-74, Cx)

…8 out of 10, like I feel like that's a fib, like I'm sure that stat came from somewhere credible, but … I feel like it's more scare tactic, 'cos you know, of the people in this room, there's only one person who knows one person who's had cervical cancer. (F, 25-34, Cx)

The pap tests are obviously quite, they're helping to save lives. (F, 35-49, Cx)

That works. Why is that not on the TV? (F, 25-34, Cx)

'At least 80% of cervical cancer cases in Australia could have been avoided with regular pap tests'

This statement met with a mixed reaction, although on balance it was assessed as having some value in communicating the importance of screening.

The reference to '80%' was recognised as a high number, and the reference to 'could have been avoided' went a considerable way to conveying that Pap tests were effective. As such, the statement communicated that cervical cancer screening should be taken seriously, which had some motivational value. A common response to this statement was that it should be promoted as it explains the benefits of screening and explains that treatment is effective. For some, this message helped to overcome the barriers they experienced and their tendency to avoid the thought that they should have a Pap test.

However, the statement was confusing for some, as they did not understand how Pap tests prevented cervical cancer. For these women to appreciate this message, they also needed to be reminded that early detection means simpler and more effective treatment.

> *It is a big thing isn't it. So, that should be as much on the priority list as bowel cancer, and breast cancer. (F, 60-74, Cx)*
>
> *It does make you think … that I should probably go and get one. (F, 50-59, Cx)*
>
> *It makes me think I should go and get one done, so I could be around a bit longer for my grandchildren. (F, 50-59, Cx)*
>
> *Because we could get it treated and avoid the cancer and it won't ever eventuate to a cancer. (F, 50-59, Cx)*
>
> *That tells me that if you have regular pap tests you will catch it in time … It makes me think I should get a pap test! (F, 25-34, Cx)*
>
> *When … we discovered that if you have regular pap tests you were pretty much guaranteed to be able to catch it and cure it, that would remove almost all of the anxiety about the results for me. Knowing that it could be fixed. (F, 25-34, Cx)*
>
> *That plays on my mind. I know that. So I sink in my chair every time I think about it. (F, 25-34, Cx)*

'Australia is on track to be the first country in the world to eliminate cervical cancer by 2035'

This was new and surprising information that provoked many questions. Participants wanted to know how this could be the case, and what was changing to make this possible.

For those who were aware of the HPV vaccine, there was an assumption that it was related to this. For others, it was apparent during the discussions that they would require a comprehensive explanation of HPV and the new HPV testing approach for them to understand how cervical cancer could be eradicated. Even then, the statement tended to raise as many questions and doubts as provide answers.

Consequently, it was evident in participants' reactions, that this statement did little to prompt individuals towards screening, and potentially has the opposite effect, by communicating that cervical cancer is no longer an issue that women need to screen for. On balance, this statement is not taken as a motivator to participate in Pap testing.

> *Well, how is it going to eliminate it if it's not advertised and people aren't encouraged to go? (F, 60-74, Cx)*
>
> *Well, if this is caused by a sexually transmitted germ, I haven't had sex for 20 years, why should I be getting it? (F, 60-74, Cx)*
>
> *The younger people have come through and had the education. When you sort of think about it, that's another 15 years. We are going to be getting to that point where we are dying. (F, 50-59, Cx)*
>
> *Because, how are they going to eradicate the Papilloma Virus when it's only one strain, when it's only a limited amount of strains that the Gardasil vaccine prevents? (F, 35-49, Cx)*
>
> *I think it's false … I don't think you could eliminate cervical cancer, because cancer is not just caused by one thing … they could eliminate HPV related cervical cancer. I don't think you could eliminate cervical cancer as a whole, unless you were able to eliminate cervix. (F, 25-34, Cx)*

RESPONSE TO 'SCREEN FOR ME' CONCEPT

During the course of this research, a social marketing campaign designed to increase population based cancer screening rates within the local government area of Latrobe was being developed, with the title 'ScreenForMe'. The intention of this campaign was to activate members of Latrobe community to be screening 'community messengers' who will in turn encourage and influence their loved ones to participate in cancer screening.

Given the overlap in timing of the campaign with this research, it was considered expedient to explore people's reaction to the campaign concept. This was not intended as a comprehensive evaluation of the campaign or its materials, rather the discussion was designed to identify top of mind reactions to the campaign concept that could inform the roll out of the campaign. During each of the groups, participants were shown a slide with a version of the 'ScreenForMe' name and some associated symbolic images of families, and prompted to talk about what it meant for them and how it affected their thoughts and feelings about cancer screening. It should be noted that this component of the discussions was towards the end of the groups, so it was following from the detailed conversations about experiences, motivators and barriers to screening, which is likely to have affected responses.

Initial responses to the 'ScreenForMe' name were varied, although it was evident that a common misinterpretation of the name was that it was suggesting that people should screen for themselves. That is, it was commonly interpreted as being a prompt for people to take more care of their own health. Participants typically missed the intended outtake that family members were asking them to screen for the sake of their loved ones. On balance, the notion of taking better care of one's own health was much more motivating than the idea of screening for someone else, as it reflected a central theme of this research, that a substantial limiting factor in cancer screening was the relatively low priority that people place on their own preventive health behaviours.

> *I am just thinking by looking at and if that was the campaign, I would think well actually yeah, I really do need to look after myself a bit better … because I am important. (F, 50-59, Br)*
>
> *It means do it for yourself, not for anybody else. (F, 60-74, Cx)*
>
> *Oh, Screen for me. It's more personalised and just you go get it as Screen for You. (F, 50-59, Cx)*
>
> *Screen for Me, like I'm going to screen for me. (F, 50-59, Cx)*
>
> *I read that as 'value yourself a bit more'. And get yourself screened. That's what I'm working on personally at the moment, valuing myself more. So that worked, but if my 24-year-old daughter's telling me, 'Mum, you really should go get that looked at', yeah, I'll do it when I'm ready. (F, 35-49, Cx)*
>
> *I would've thought screen for me … I don't think the kids are saying it to me. (F, 35-49, Cx)*

When the correct intent of the concept was explained, interest was quite varied. Some felt that it was useful to remind them that their loved ones wanted them to be healthy, and appreciated being reminded that others cared about them. This was more appealing amongst the women in this research, and they most commonly talked about being motivated by their children.

> *Yes, I would do anything for my children and my grandchildren and to keep me alive longer, so I have got great grandchildren. (F, 60-74, Br)*

My daughter even last night she was like mum you need to go to the doctor, and you need to get this and this and this done, yeah, yeah … I hear them and I am a little bit stubborn but yeah, I sort of think yeah, yeah, yeah, I will. (F, 50-59, Br)

Yes, it is appealing to the mother instincts isn't it. (F, 50-59, Br)

Yeah, I'd be happy to have family and my friends pressure me. Definitely, makes me feel like they want me around and yeah. Somebody would care. (F, 50-59, Cx)

I quite often say to people that I have a conversation with, or whatever else, all I say is, all I do is live for my kids and my grandkids, that's just how I go. (F, 60-74, Bo)

I'd be more inclined to do something if my kid was saying 'do it for me'. So it would work. (F, 35-49, Cx)

Well if my child was holding that sign, I'd be like, oh all right, I'll do it for you babe. (F, 25-34, Cx)

For some, the concept was a reminder of the importance of setting an example for their loved ones, especially for their children. The title reminded them that, if they wanted their children to adopt healthy behaviours, they needed to do this for themselves first. These participants felt that the message could contribute to their intentions to participate in the screening programs.

Yeah, I'd do it! Because then you're setting an example. (M, 50-59, Bo)

If [eldest daughter] turned around and said, yep, mum, go and have the bowel test, I'd probably do it. Because she's had her breast cancer. (F, 60-74, Bo)

Amongst those who appreciated the concept, some appreciated that it encouraged them and their families to create conversations about preventative health in general. Some noted that the concept could refer to friendship groups as well as families, and that it could help to encourage conversations amongst friends that would motivate screening.

You know how they have the organ donor campaign, and they say get your family together and talk about that. Why don't we all get together as a family… talk about everything, talk about health as a whole, screening. (F, 50-59, Bo)

My sister … she has told me I am not allowed to die before her, and she is not allowed to die before me either. (F, 50-59, Bo)

I think also a bit of the sisterhood just because we have come together, we are kinda strangers it is like your guilt is kinda I am thinking well you shouldn't, and it is just how women help each other and support each other. (F, 50-59, Br)

The concept was criticised for a range of reasons. Some claimed that it was not effective for them because they would not be motivated to participate in health behaviours by anyone else in their families. A common criticism of the concept was that it was aimed at making them feel bad about not looking after themselves. These participants felt that it was more important for them to recognise that they should be engaging in health behaviours for themselves rather than for someone else, and therefore that the motivation needed to be internal rather than external. This response was especially amongst the women, and can be understood in the context that several of these women had mentioned that the reason they had not kept up to date with their own screening was because they were looking after the health of others (partners, children, parents, etc), and not sufficiently prioritising their own needs. They felt that this message was somewhat nagging and manipulative, which they believed was quite opposed to the self-care attitude that they would need to adopt in order to participate in cancer screening themselves. As

noted above, these participants responded very positively to the notion that they needed to do more to look after their own health.

> *Well I don't have young children so that is not an inspiration so much. (F, 50-59, Br)*
>
> *Make it more of a personal thing, something that you care about yourself. (F, 60-74, Br)*
>
> *The 'me' is wrong, screen for me, screen for yourself. (F, 60-74, Br)*
>
> *Yes, if I'm standing there with my kids, like when they used to come home and say, mum, you have to give up smoking, you're going to die, you know that… 'Oh, piss off'. (F, 60-74, Cx)*
>
> *'Oh, great, another thing telling me I'm a bad mum' … I could see how some people would just be upset by it, rather than educated. (F, 25-34, Cx)*
>
> *We understand so much more than our parents did or their parents did, so just using manipulation or, you know, pulling on heart strings, we don't need that, we can make an informed decision, and we don't have the information. All of us were completely clueless to that HPV. (F, 25-34, Cx)*
>
> *You gotta look after yourself before you can look after others. (F, 35-49, Cx)*
>
> *I find it nagging. I don't personally like people telling me when to get it, I'll do it in my own time, and I find I take longer to do something if they tell me to do it. (F, 35-49, Cx)*
>
> *I think there's enough to feel guilty about and feel ashamed about as it is without being shamed into looking after yourself. (F, 35-49, Cx)*
>
> *I feel like there needs to be more awareness around women not taking care of themselves and not being ok with themselves. Because we always put ourselves last. I think if there was more aim at, it's ok to take care of yourself … that might be easier to digest. (F, 25-34, Cx)*

Participants felt that the concept was motivating them through feelings of guilt, and while this was acceptable for some, others argued that it felt manipulative and would result in them being defensive rather than motivated to participate.

> *For me if it was my kids telling me, they would make me feel so damn guilty, I couldn't lie to them, I would have to do it. (F, 50-59, Bo)*
>
> *I think, it depends on why they want me to … are my kids telling me that I need to look after myself so that I am not a burden on them? Or because they want me around? (F, 50-59, Bo)*
>
> *It feels more like manipulation than information. I think that's trying to, yeah, it's guilting you when we have enough that we're guilted about as mothers, to, you kind of shut off to a certain amount of guilt-tripping. (F, 25-34, Cx)*
>
> *Another job. Like hey, here's another job for your list, mum. (F, 25-34, Cx)*
>
> *It's mum guilt. They're guilting me, that I have to do it because of them. Because if I don't do it, then they're just going to be left without me. (F, 25-34, Cx)*

Some criticised the concept on the basis that it presumes that others know that a person is scheduled for a screening test, which was often not the case because they did not talk about these tests with others. These people suggested that the initial aim would need to be to create conversations about cancer screening amongst family and friends, before this message could be useful.

> *It's interesting to think that if someone saying, 'well do it for me', yet we have all identified that we don't talk about it so how would they? (F, 50-59, Bo)*
>
> *So, for me, like when my husband's old enough for me to say it to him, we don't talk about it anyway, but 'go and do that for me'. How do I approach that? (F, 50-59, Bo)*

LOCAL ISSUES THAT AFFECT SCREENING RATES

The groups were prompted to discuss whether there were any characteristics of the local region that they believed were impacting on their participation in cancer screening programs.

There was some belief that the socio-demographics of the region, referring to low levels of education, high levels of unemployment, welfare dependency and low income, could be associated with lower participation in preventive health behaviours along with somewhat fatalistic attitudes towards health and disease.

> *Because we came here, most of us are ex-miners or whatever worked in the stations and that right, and you battled on regardless of what right. (M, 60-74, Bo)*
>
> *Basically there's a lot of poor in the Valley. (M, 60-74, Bo)*
>
> *Look it's probably a stupid thing to say but it's not a priority, people are just surviving in low economic, you know poor people struggling, just getting through every day that stuff just gets put aside. (M, 60-74, Bo)*

The main issues identified in response to these questions were about the provision of health care services in the Gippsland region, including health care resources generally, and specific issues related to general practitioners. This was obviously more of an issue for women in relation to cervical screening than the other screening programs, although, as documented below, it also affected people's experiences of reminders and prompts to screen.

A common theme was about the difficulty of receiving long-term care from a GP with whom people could develop a therapeutic relationship. Many participants reported that they found it difficult to keep a regular GP and believed that this had implications on their screening behaviours. Some commented that it was common for GPs to stay in the area for only a short time, and therefore that they did not get an opportunity to develop ongoing relationship with a particular doctor. Others commented that they were often unable to attend their preferred GP, even when they booked in at the same clinic.

> *It used to be you always had regular doctors down here, though. Now it's like they're just getting their GP hours down here and move them through as fast as they can. (F, 35-49, Cx)*

Participants believed that an ongoing relationship with a GP would be conducive to participation in preventive health activities, such as cancer screening, as it would ensure that they were appropriately reminded of when they were due for screening tests. They felt that this would make a difference even for those screening programs that did not require attendance at a GP (breast, bowel) as it would mean that they had a health professional who had an overview of all of their health needs. Few participants in this research believed that they had such a relationship with a GP.

A related issue was that participants wanted to see a doctor they were familiar with for some procedures, rather than having to undergo intimate procedure with a doctor they have just met. This was obviously more an issue for cervical screening. And as noted, women in these groups reported a specific difficulty in finding female doctors in the region with whom they could develop longer relationship.

> *I haven't followed up with my doctor, because we can't keep doctors long enough in the valley to get a relationship with them. (F, 50-59, Bo)*

I was getting [Pap tests] done on a regular basis, but over the last 10 years … I have had so many different Doctors … that I just simply forget … You forget about it, yeah, I think it is because you are not seeing a regular constant Doctor who is on your back. (F, 50-59, Bo)

I find, a lot of the problems around the valley too is that how often, and I must admit I've only lived up here fifteen, twenty years, and you struggle to be able to keep a doctor for longer than a couple of years, who wants a different doctor every time you walk in. (F, 60-74, Cx)

We have an enormous turnover of doctors, enormous … and they come up here and they're here for 2 years. (F, 60-74, Cx)

No female doctors down here stay here any longer than 3 months … I've not had a female doctor I've seen stay in the Latrobe Valley longer than, I don't even know *a female doctor that I could give you a name of. (F, 35-49, Cx)*

The information isn't given, and you should be having this or you should have this test or you should have this. (F, 60-74, Cx)

Several mentioned that there was a general shortage of GPs in the area which meant that they would sometimes need to wait for several weeks for an appointment. Some commented that this deterred them from booking as they were unable to plan so far in advance, and others commented that it meant that they only bothered to attend for known conditions, rather than for preventive health behaviours such as Pap testing. Some specifically mentioned that, outside regional centres such as Traralgon, there were even fewer GPs, and that rural areas were not sufficiently serviced.

I came from the Mornington Peninsula where doctors, specialists, everything was just laid on, it was terrific. Came here and we struggled to find a decent doctor. (F, 60-74, Bo)

So, [The BreastScreen bus] is a good thing in some ways especially for regional people, Melbourne people they have lots of things but in regional we don't and there are isolated cases where there is no hospital or no doctor. I mean I have lived in a country town where I had to ring the doctor miles away if I was even sick. (F, 60-74, Br)

But If I go, 'Oh, quick, I need to see a doctor about this', and then I ring a doctor and they go, 'Oh, we don't have an appointment available until the 7th of April, and that's like 2 weeks away, you're like, 'Phh, whatever', you hang up the phone, like you don't try again. (F, 25-34, Cx)

Adding to the difficulties of not having a regular GP, participants felt that the care they were receiving through the GPs they did attend was less than optimal. They talked about systemic factors, such as a lack of time in consultation and the tendency to only focus on presenting problems, as limiting their considerations about preventive health programs.

Several women mentioned experiences where they felt that the GP they attended did not have sufficient knowledge about appropriate testing for cancer screening tests. A specific issue that was raised in almost every group was about feeling that they were unable to communicate with the doctors who they did see because of language issues. Several women commented that this was exacerbated for them in the context of intimate screening tests such as Pap tests, where they felt uncomfortable to have such tests performed by a doctor with whom they had difficulties communicating.

A lot of the times now when you walk into the doctors, you are supposed to know what is wrong with you, you have to ask for what you want, I'm coming here because I don't know what is wrong with me … I don't know what tests are there or what I should be doing or what I shouldn't be doing. And, they say, what would you like done? What are you asking me for? I don't know? (F, 60-74, Cx)

No, because you can't find, I don't know, someone help me out here, you can't find one that speaks English, that you can understand. (F, 25-34, Cx)

But then on the other hand if he is asking you what you think, then you sit there, and you think why am I at the doctor? (F, 60-74, Br)

Unfortunately, no, well my long-term doctor went and kept getting replaced by Indian after Indian. (F, 50-59, Br)

A small number of participants identified a concern that treatment facilities were not sufficient in the local area. This meant that a cancer diagnosis would likely result in time-consuming and expensive trips to the city, and for some, this was a reason to avoid detection and diagnosis.

When people are really unwell it is really hard for them to go down to Moorabbin and have all those scans, like we are getting a PET scan machine locally now, the PET scan is the one that picks up the cancer all over the body but some people are too unwell to go down to Melbourne to have that scan so therefore they either don't go and it progresses. (F, 50-59, Br)

THEMES COMMON TO ALL SCREENING PROGRAMS

This research was designed to explore the factors that contribute to people's participation in screening for breast, bowel and cervical cancer. Taking into account the findings across all three of the screening programs, factors that affect participation include a combination of the following:

1. Knowledge and awareness of cancer.
2. Awareness and experience of the screening tests.
3. Personal health attitudes and beliefs.
4. Being reminded to screen.

Cancer knowledge and awareness

Screening participation was partly related to perceptions of incidence, severity and personal susceptibility to each of the cancers. Bowel cancer was thought to be reasonably common, partly due to the presence of the NBCSP, although there was a common attitude that, unless one experienced symptoms, it was a disease for others to worry about, not me. To some degree, this was because the effects of bowel cancer were thought to be so severe that people were reluctant to find out that they might have the disease. Breast cancer was known to be common, and this was a reason to screen, although not having a family history of breast cancer was a common excuse for those who wanted to avoid screening. By contrast, cervical cancer was believed to be rare, and as such was not really on people's radar of diseases to worry about.

A consistent theme from the discussions was that perceptions of personal susceptibility to a particular cancer contributed to screening for that cancer, for those who understood the value of early detection. However, this did not necessarily translate into screening for other cancers.

> *Once again, I mean it's a bit of a contradiction, because I go once a year, sometimes, for the mammogram, because my mother had breast cancer. (F, 60-74, Bo)*
>
> *You should early screen but yeah I know it, I know that I am slack and I know that I should do it and my father is Stage 4 cancer now, abdominal cancer … he didn't screen and that is why he is Stage 4, so yeah. I have done the bowel test though … I just haven't done the mammogram … I have had the Pap smears and stuff I just haven't done the mammogram. (F, 50-59, Br)*
>
> *Skin cancer I am very mindful of because I just to get so burnt at sport when I was a kid, so I stay out of the sun, I put skin cream on but yeah I don't do the mammogram, I have had a referral for I don't know how long ago, and I haven't done it. (F, 50-59, Br)*
>
> *Definitely [up to date with breast screening], because both the grandmothers died from breast cancer. So, I keep it up. (F, 60-74, Cx)*

Given these differing levels of knowledge and awareness, and the separate influence of perceptions of susceptibility for each cancer, addressing issues about each of the cancers in a manner that encourages screening will require different and separate messaging for each screening program.

Screening awareness and experiences

Screening participation was also partly related to factors associated with the screening tests. The issues were somewhat different for each of the screening programs, as each test is quite different, involving different procedures, different environments and different degrees of engagement by the person. The bowel screening test is done at home, being a somewhat complex procedure that some experienced as distasteful. The breast screening test involves booking a visit to a screening unit (mobile or hospital) and many experienced the mammogram to be uncomfortable or painful. The cervical screening test requires booking a visit to a doctor, and was experienced as intimate and embarrassing, which was complicated by misunderstandings about the links between cervical cancer, HPV and sexual activity.

Consequently, addressing people's needs with respect to the barriers associated with the screening process would require a different strategy and a different set of messages for each screening test.

> *Look I have always pretty much kept up with the Pap smears because I don't have a major issue with that, it is just a non-invasive. (F, 50-59, Br)*
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> *[Why do you have a mammogram, but not a Pap test?] Well, I think that the procedure isn't as bad, you know, it isn't, it isn't really an internal thing, is it, you know. (F, 60-74, Cx)*

Health attitudes and beliefs

When considering the impact of people's health attitudes and health beliefs on participation in cancer screening, there were considerable overlaps between the three cancer screening programs. These included:

- Limited understanding of the concept of cancer screening
- Low priority placed on health, and especially on preventive health behaviours

Participants in this research typically expressed quite poor understandings of cancer screening, with a common perception that the tests being discussed were diagnostic tests, and demonstrated limited understanding of the concept of population screening. This had several consequences that were observed to limit participation in cancer screening programs, including:

- Fear of diagnosis – a common theme amongst those who avoided screening was that they did not want to find out that they had a particular cancer. Some had watched friends and family members go through cancer treatments, and wanted to avoid having to go through the same processes themselves. They talked about the treatments being worse than the cancers. For these people, screening was perceived as a step towards a diagnosis of cancer.
- Poor understanding of the benefits of early detection – an associated theme was a poor understanding that the main benefit of screening was that problems could be detected and treated before they became cancers, meaning simpler treatment and better prognosis. Forefront in some people's minds when they thought about screening tests was what will happen if they get a positive result, with little consideration given to the more likely outcome of a screening test being a negative result.
- Belief that symptoms will be experienced if tests are needed – a common attitude, especially in relation to bowel and breast cancer, was that they would know if they needed to be tested,

because they would experience signs or symptoms. Participants were limited in their understanding that the FOBT could detect microscopic blood that they would not be able to see, or that the mammogram could detect lumps that were smaller than what they could feel. To some extent, the limitation associated with this barrier was interrelated with the poor understanding of early detection, in that participants did not genuinely appreciate the value, in terms of effectiveness of early treatment, of detecting potentially problematic signs prior to these becoming noticeable symptoms.

> *When I was turning 50, I made up my mind I am going to go and have a full physical. Just get everything done. Everything. And I haven't done it yet! [laughter]. But yeah, I should just be getting it done. But I'm sort of scared of the results because I lost my partner to cancer and then my daughter. He had thyroid cancer and my daughter got thyroid cancer. So, I really should be … it's like. Yeah, I still haven't done it. (F, 50-59, Cx)*
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> *I am probably scared to know the results because my dad died of skin cancer. (F, 50-59, Cx)*
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> *It's also too like if I was to find out that if something is wrong. It's the, it doesn't stop there, it's more testing, more this, more everything … the treatments. … I'm thinking of cancers in general. If I was to find out that I had something. Like it's cervical cancer or either breast cancer. It's just doesn't stop there. (F, 50-59, Cx)*
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> *If they tell me I have it, I had to go and have a biopsy. I know the process. I've seen, like with a thyroid. I've seen the long process and everything. It's just. (F, 50-59, Cx)*
>
> *If I'm going to have cancer, I'd probably be a mess, I'd rather just enjoy my life and then one day just drop dead, like. (F, 25-34, Cx)*
>
> *Everyone I've known that's found out they've got cancer have gone. But people that have had cancer that didn't know, they've lasted a while, so it's good not to know. (F, 35-49, Cx)*

A substantial barrier to participation in all of these screening programs was the low priority people placed on their own health, and especially on behaviours associated with preventive health. While they would attend a doctor for a variety of reasons: if they experienced something wrong, if they had an ongoing condition that required medication, or if someone they loved or cared for was sick; a very common attitude was that giving time and energy to dealing with a condition that, as far as they knew, they did not suffer from, was not worthwhile in the context of all the things they were concerned about in their lives. The cancer screening programs that were the subject of this research were part of this, along with a range of other health issues. These attitudes demonstrate that the benefits of early detection and early treatment are not rated as sufficiently high to encourage behaviour, and suggest that messaging around the benefits of screening should be developed and promoted.

> *See, you don't have enough time to sit there and go, oh, what about me? I might have this. (F, 60-74, Cx)*
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> *Some people are probably just like me, they're just slack, they just don't want to be fixed so they don't go to the doctors and find out. I mean, I have to admit, to the point where Huntington's is in my family, so many of my aunties and uncles, my aunty, my dad, my nan have all died from Huntington's, where it's disgusting, um, I've never got tested, I wouldn't get tested. (F, 60-74, Cx)*
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> *I'm not just going to make a doctor's appointment and say, 'Well, I think I'm due for a pap smear, do it'. So, it's just… I'm too busy to, I only go to the doctor if I'm really sick and I really need to, and then I walk in there, I tell them what's wrong with me, give me a script and I walk out! (F, 35-49, Cx)*

I think there's sort of a problem too that a lot of people sort of, their minds aren't on themselves, their minds are paying the bills, going to work, looking after the kids, there's other things that are more pressing than taking care of yourself. (F, 35-49, Cx)

It's like going to the dentist. We all don't want to do it until we have to. A bit more physically in pain to go make ourselves go to the dentist. Pap smear's just...if I get five minutes to myself I would rather have a glass of wine than going to get a Pap smear done. (F, 35-49, Cx)

Throughout these discussions, attitudes of avoidance and perceptions of fatalism were common amongst those who were not up to date with cancer screening. As noted above, in relation to understanding of population screening, some simply preferred not to know whether they might have cancer, and so avoided screening. Some also believed that they could not afford the time or energy that having cancer would mean, and therefore preferred not to find out. And it was apparent in these conversations that participants had found a way to make these seemingly irrational attitudes make sense to them.

I don't like to know about things. I'd rather it just knocks me off. (M, 60-74, Bo)

It seems to be more cases that people tend to die quicker once they know [they have cancer]. (M, 50-59, Bo)

I've had five kids, that I've brought up, so I was on my own, I didn't have time to get sick and be thinking about oh, I might have this or I might have that, because if I've got something mate, my world ends. I've got five kids, who's going to take them. Who's going to look after them, who's going to help me? (F, 60-74, Cx)

The following conversation between a participant and the moderator highlighted the complexity that goes behind people's fear of receiving a cancer diagnosis, and shows how these fears impact on participation in screening …

P: I just don't want to do [the NBCSP kit]. Like, my dad suffered from cancer for so long, but I just don't…

M: You don't want to find out?

P: Yeah, he went through so much treatment.

M: For bowel cancer?

P: No, just for skin cancer.

M: So, cancer's a bit of a scary word for you and you'd rather not know? Is that what I'm hearing?

P: Yep. (F, 50-59, Cx)

Interestingly, at the end of these groups, a common reaction to the conversations was the idea of 'It's time for me to start looking after myself better'. It was apparent for these participants that a consequence of the group discussions was a realisation that they were not doing some of the things they could be doing to maintain their health, and participation in these conversations left them with an understanding of the value of following up with screening behaviours. For these participants, the conversations had shifted the balance from being about their avoidance or dislike of the testing procedures, to an appreciation that the potential benefits were greater than they had been acknowledging.

That we should get screened for stuff even though we don't want to. (F, 50-59, Bo)

That all our excuses are really pathetic. (F, 50-59, Bo)

I have to start looking after myself. I have two young *kids … that if something happened to me, if I die, like, I could get hit by a bus tomorrow. I can't prevent that, but this I* can *prevent. I have to start, I have to start what I can change – change, where I can't, just let it go. (F, 35-49, Cx)*

Prompts to action

It was evident throughout these group discussions that a key determinant of participation in cancer screening was exposure to prompts to action, and it was evident that participants often required multiple prompts before they took action.

Prompts to participate in cancer screening took a number of forms, including:

- Invitation and reminder letters;
- Mention and referrals by GPs and other health professionals;
- Social marketing campaigns, including mass media and targeted local and social media; and
- Discussions with friends and family.

While participants were adamant that receiving messages through any one of these channels of influence might not make a difference to whether they screened or not, the discussion highlighted that when they received similar prompts across several different channels, they were likely to pay attention and consider the priority they placed on screening.

A common theme from the discussions with women was the belief that invitation and reminder letters for breast and cervical screening programs were not received to the same extent as they had been in the past, with several commenting that they no longer received any reminders. Whether women are not receiving reminders or simply ignoring them, these observations suggest that there is a need to evaluate the existing letters programs to determine whether there are any gaps in these reminders. And, if letters are being sent, there is a need to evaluate their effectiveness for gaining attention and for communicating the importance of screening.

Another common theme from these discussions was that GPs were not promoting cancer screening programs. The discussions suggested that the reasons might be different for each of the screening programs. Participants suggested that bowel cancer screening was seldom mentioned by GPs, except possibly for those who were in higher risk categories, such as having family history or related conditions. While some women suggested that their GPs were reminding them about breast screening, this did not seem to be consistent. Participants talked about a range of factors that they felt acted as barriers to their GPs consistently and regularly promoting cervical screening. It was apparent that some of these issues were systemic, in that they were related to time available in consultations and the tendency to deal with presenting issues rather than preventive health. The findings of this research suggest that consideration needs to be given to GPs experiences of the promotion of these cancer screening programs, and, if appropriate, to develop approaches that will facilitate GPs to talk about cancer screening with their patients.

A consistent theme of this research was that participants believed they were not exposed to advertising campaigns that promote cancer screening as much as they had been in the past. There was some awareness of the recent Cancer Council Victoria campaign promoting the NBCSP, which was on air during the research, but there was little recall of other campaigns through either mass media, local media or

social media recently. Some recalled previous campaigns for breast screening and cervical screening programs, including the CCV 'Uncomfortable' campaign that has not aired for many years. Across the groups, participants felt that social marketing campaigns did affect their participation in cancer screening as they brought the issues to the front of their mind, educated them about the cancers and the programs, left them feeling that these cancers were common and that they might be susceptible, and reminded them of the benefits of screening. Without social marketing prompts to action, other reminders (such as letters and GP recommendations) were experienced in isolation, while advertising campaigns told them that the cancer screening programs were for all people, creating a sense of screening as being the norm. These observations suggest that there is a need to develop social marketing campaigns, using mass media, local media and social media, to promote cancer screening and encourage participation.

Associated with the notion of normalising cancer screening, a common theme of this research was that people did not talk much about these cancer screening programs, except in the context of discussing negative aspects of the programs, such as their dislike, distaste or embarrassment with the procedures. On the other hand, it was apparent during this research that the more participants talked about the screening programs, the more they overcame some of the barriers related to dislike, distaste and embarrassment. Finding out that others were doing the tests went some way to encouraging people to overcome their own resistance, and to prioritise their own health needs over their reluctance to test. The women's groups in particular frequently talked about the impact that knowing friends were having their mammograms and Pap tests had on their own motivation to screen. These observations suggest that consideration should be given to approaches that encourage discussion of screening amongst peer groups, and that normalise participation in the screening programs.

We gratefully acknowledge the men and women from across Gippsland who participated in this research.

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