Adherence to Rescreening for Colorectal Cancer with Faecal Occult Blood Testing

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Abstract

This thesis aimed to describe and predict adherence to Faecal Occult Blood Test (FOBT) rescreening recommendations in South Australia. Specifically this thesis aimed to determine the relevance of social cognitive variables for explaining variations in rescreening adherence. FOBT screening for colorectal cancer (CRC) is recommended every one to two years for those over the age of 50; reductions in incidence and mortality from CRC are dependent on continued compliance with these guidelines. Whilst there has been substantial research on factors associated with initial screening participation, there has been very little research conducted on how to encourage rescreening adherence (i.e., continued participation in annual or biennial screening offers). The few studies that have examined predictors of rescreening have, to date, limited their exploration to demographic and health systems factors. This thesis aims to determine the relevance of the inclusion of behavioural factors previously associated with initial screening (i.e., social cognitive variables) for explaining rescreening and also to explore potential new predictors of rescreening not previously examined in CRC rescreening research.

The thesis used a sequential, mixed-methods research design to address the aims. Three separate studies, one qualitative and two quantitative, were used to explore predictors of adherence to FOBT rescreening. The three studies are presented as three separate papers in the thesis. Study one used 17 semi-structured interviews to explore rescreening participants’ past experience with FOB testing. Exploratory thematic analysis was used to determine factors relevant for inclusion in a subsequent questionnaire. The questionnaire was then administered to 4000 potential participants
within the target age range for FOBT screening (50-75 years) in South Australia. Study two analysed questionnaire data to determine associations with stage of readiness (intention) for rescreening. Following survey completion, respondents (survey response rate of 49%) were provided with three annual offers to screen with FOBT. Data collected during the questionnaire phase were used to identify variables predictive of rescreening adherence. Univariate and multivariate modelling were used to determine associations with intention and adherence.

Results of study one revealed that many of the factors previously associated with initial screening (e.g., perceived barriers, benefits and social influence) were associated with rescreening. However, specific barriers, for example, maintaining a screening routine, were identified for rescreening. In addition previous screening experience appeared to influence attitudes toward future participation i.e., improved participants self-efficacy with regard to future participation and reinforced the perceived benefits of participation.

Study two found that almost 30% of prior screeners were non-adherent with rescreening. Social cognitive (self-efficacy, perceived barriers and benefits, social influences, implementation intentions) and demographic/background variables (age, knowledge, and health insurance coverage) were associated with rescreening intention. Conversely, in study three, only few social cognitive variables (perceived barriers, self-efficacy and response efficacy) were marginally associated with screening adherence across three rounds of screening. The demographic variables gender, insurance and marital status better differentiated patterns of adherence. When a measure of satisfaction with prior FOBT screening was added to the multivariate models in study three, none of the social cognitive variables significantly predicted adherence.
Satisfaction with prior screening substantially increased rescreening intention and adherence by 13% and 42% in studies two and three respectively.

Results of the thesis indicate that although social cognitive variables differentiated intentions to rescreen, when demographic variables and satisfaction with prior screening were held constant, social cognitive variables did little to predict rescreening adherence. Satisfaction with prior screening was an important predictor of both rescreening intention and adherence. Exploration of the factors contributing to satisfaction with screening may provide an important opportunity to modify and improve screening services to encourage rescreening. Several demographic variables were also found to have a substantial impact on intention and adherence. An investigation of how these demographic and background factors interact with social cognitive variables may allow for greater tailoring of messages to encourage rescreening.
Declaration

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Chapter four, paper two:


Amy Claire Duncan

Signed: 

date:
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List of Abbreviations

BHS- Bowel Health Service

CRC- colorectal cancer

FOBT- faecal occult blood test

FS- flexible sigmoidoscopy

HBM- Health Belief Model

MHLC- Multidimensional Health Locus of Control

NBCSP- national bowel cancer screening program (Australian)

NBCSPP- national bowel cancer screening pilot program (Australian)

NHMRC- National Health and Medical Research Council

RCT- randomised controlled trial

SCT- Social Cognitive Theory

TPB- Theory of Planned Behaviour

TTM- Transtheoretical Model of Behaviour change

PMT- Protection Motivation Theory
Chapter One- Introduction

Preamble

This chapter provides an overview of Colorectal Cancer (CRC) incidence and mortality, disease epidemiology and suitability for population screening. The chapter also outlines the available options for CRC screening with a particular focus on Faecal Occult Blood Testing (FOBT) in an Australian context. FOBT rescreening is defined. Rates of rescreening adherence and the limitations and measurement issues associated with obtaining and analysing rescreening adherence are also discussed. The final section of this chapter reviews the small body of literature currently available on CRC rescreening and concludes with some suggestions for future research.

Colorectal Cancer Epidemiology

CRC is the third most commonly diagnosed cancer in males, and the second in females worldwide, with an estimated 1.2 million new cases, and 608,700 CRC related deaths reported in 2008 (Jemal et al., 2011). Rates of CRC incidence are two to five times higher in developed countries than developing countries with the highest rates found in Australia, New Zealand, Europe and North America (Jemal, et al., 2011). The most recently available Australian data show that in 2007 there were 14,300 new cases of CRC reported, and 4,047 deaths, accounting for 13.1% of all reported cancers and 10.1% of all cancer deaths (Australian Institute of Health and Welfare, 2011).

Colorectal cancer is a malignant (cancerous) tumour that begins in the bowel; like all cancers, it can spread to other parts of the body such as the liver or lungs, in its more advanced stages (A. B. Benson, 2007). The majority of colorectal cancers start in the wall of the large bowel and develop from benign (non-cancerous) lesions known as
adenomas or polyps (Leslie, Carey, Pratt, & Steele, 2002). Disease onset is usually asymptomatic, and the development from adenoma to carcinoma can take up to five or ten years (Rozen, Young, Levin, & Spann, 2006). Treatment options for CRC include surgical removal or resection of polyps/cancers, chemotherapy and radiation (A. B. Benson, 2007). Treatment success ranges from 90% for cancers detected at the early, localised stages to 10% for late stage metastatic cancer (Haggar & Boushey, 2009). The improved treatment outcomes available to those with early stage CRC makes it an ideal candidate for early detection screening methods.

Several factors have been identified as increasing the risk of CRC. For example, a family history of CRC in one or more first degree relatives, has been consistently linked to a higher than average risk of developing CRC (Haggar & Boushey, 2009). Familial cancers can be aggressive, developing at a younger age and often progressing at a much faster rate (Lynch & de la Chapelle, 2003). Irritable bowel conditions such as ulcerative colitis and Crohn’s disease have also been linked with a higher than average risk of CRC (Haggar & Boushey, 2009). Genetic testing and/or specialist surveillance is recommended for those above average risk for CRC due to the increased likelihood of cancer incidence (Lynch & de la Chapelle, 2003). Colorectal cancers arising in these circumstances however, only account for between 15% and 20% of all reported cases (Rozen, et al., 2006) with the majority reported amongst the average risk population.

Amongst those considered to be at ‘average’ risk for CRC lifestyle factors including diets high in fat and low in fibre, smoking, heavy alcohol consumption and physical inactivity, have all been associated with increased CRC incidence (Haggar & Boushey, 2009). Whilst CRC affects both genders, the average lifetime risk of CRC has been shown to be slightly greater for men (1 in 8) than women (1 in 11) (Australian
Institute of Health and Welfare, 2011). Reports also show sharp increases in incidence of CRC from the age of 50 onwards (Haggar & Boushey, 2009).

**Screening for Colorectal Cancer**

**Definition of screening**

Screening refers to the systematic use of a test in an asymptomatic population in order to identify those who show indications of disease (World Health Organisation, 2012). The World Health Organisation has outlined several principles for screening; these principles form the basis of the majority of decisions concerning the development of organised screening programs. Originally written in 1968 (Wilson & Jungner, 1968), and revised in 2008, the guidelines are as follows;

1. Screening programs should respond to a recognised need
2. The objectives of screening should be defined at the outset
3. There should be a defined target population
4. There should be scientific evidence of screening program effectiveness
5. The programme should integrate education, testing, clinical services and programme management
6. There should be quality assurance, with mechanisms to minimise potential risks of screening
7. The programme should ensure informed choice, confidentiality and respect for autonomy
8. The programme should promote equity and access to screening for the entire target population.
9. Programme evaluation should be planned from the outset
10. The overall benefits of screening should outweigh the harm

(Anderman, Blancquaert, Beauchamp, & Dery, 2008, "Synthesis of emerging screening criteria proposed over the past 40 years," Box 2.)

There is substantial evidence that CRC is a major public health problem (Jemal, et al., 2011). Due to the substantial amounts of time spent in an asymptomatic and curative state, CRC is a perfect candidate for population level screening (Haggar & Boushey, 2009; Lieberman, 2010). The objectives of screening for CRC are twofold; firstly

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1Screening tests differ from diagnostic tests which are used to confirm the presence of disease amongst those showing disease symptoms.
screening aims to reduce incidence of CRC by the detection and removal of precancerous adenomas, and secondly to reduce mortality from CRC through detection and treatment of colorectal cancers (Australian Cancer Network Colorectal Cancer Guidelines Review Committee, 2005). A strong evidence base has been used to differentiate those at average from those at above average risk for CRC (Lynch & de la Chapelle, 2003) and to determine suitable screening guidelines for each (Levin et al., 2008). Several tests are available to screen for CRC and many countries have organised population screening programs including Australia, the United Kingdom, many European Countries, Japan and parts of the United States and Canada (V. S. Benson et al., 2008). There is a strong body of evidence to support both the population benefit and cost effectiveness of a variety of screening methods for CRC, these are outlined below.

**Screening tests for Colorectal Cancer**

There are two main categories of screening tests for CRC; stool based tests and structural colon examinations (endoscopic screening) (Lieberman, 2010). New screening technologies such as computer tomography colonography and stool DNA testing have emerged in recent years, however to date there is insufficient evidence of their efficacy at a population level (Lieberman, 2010). The focus of this thesis is on stool based testing as this is the primary screening method recommended for average risk individuals in Australia (Australian Cancer Network Colorectal Cancer Guidelines Review Committee, 2005).

**Faecal occult blood testing for colorectal cancer (stool based screening).**

A Faecal Occult Blood Test (FOBT) is a screening test designed to detect occult (not visible to the human eye) traces of blood in stool. There are two main types of FOB tests, guaiac based FOBT (gFOBT) and immunochemical FOBT or FIT (Faecal
Guaiac FOBT screening tests are not specific to human blood therefore consumption of certain foods, for example red meat, prior to testing can increase the likelihood of false positive test results (Lieberman, 2010). Immunochemical tests are specific to human blood and therefore do not have any dietary restrictions (Lieberman, 2010). Although both are currently accepted screening methods there has been greater public (Cole, Young, Esterman, Cadd, & Morcom, 2003) and professional (van Roon et al., 2011) support for FIT in recent years. There are several commercially available FOBT screening tests and a variety of different sampling methods. Screening with a FOBT is performed at home, therefore it is not physician directed; samples are then sent away for testing. Despite some reported aversion to the screening method (Cole et al., 2011; Reeder, 2011) there is evidence that FOBT screening is acceptable to the population (Clavarino et al., 2004; Salkeld, Solomon, Short, & Ward, 2003).

FOBTs are not diagnostic tests for CRC. FOBTs are designed to identify who is more likely to have colorectal neoplasia (precancerous adenoma or cancer), the presence of which is later confirmed with diagnostic methods (i.e., colonoscopy). In practice, those testing positive on an FOBT are 20 times more likely to be diagnosed with colorectal neoplasia than those who test negative (Young & Allison, 2009). Those presenting with visible bleeding, a sign of later CRC are not advised to use FOBT screening as FOBTs have been found to have low specificity for detecting later stage cancers (greater than ten millimetres in diameter) (Lieberman, 2009).

Those who test negative for occult blood in a FOBT are recommended to continue screening at recommended intervals. In Australia, screening with FOBT is recommended for the average risk population aged 50 and over at least once every one to two years.
(biennial screening) (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005). These guidelines are consistent with the evidence base for FOBT screening (see below); however several countries, including the United States, have recently updated their screening guidelines to recommend annual FOBT (Levin, et al., 2008).

The evidence base for screening recommendations and the efficacy of FOBT for reducing both incidence and mortality from CRC comes from several large randomised controlled trials (Hardcastle et al., 1996; Jorgensen, Kronborg, & Fenger, 2002; Mandel et al., 1993; 2000). These trials report between 15% and 33% reductions in mortality and significant reductions in incidence amongst those allocated to screening compared to controls. Studies were conducted over screening and follow-up periods of 10-13 years. Screening intervals were biennial (Hardcastle, et al., 1996; Jorgensen, et al., 2002; Mandel, et al., 1993) and/or annual (Mandel, et al., 1993). Results support the use of either annual or biennial screening intervals, however in a comparison of the two screening intervals, Mandel et al. (2000) reported that whilst both were associated with decreased CRC incidence, these differences were only statistically significantly different from controls amongst those receiving annual screening.

These trials achieved between 38.2% and 59.7% complete (i.e., participation in every screening offer) compliance with FOBT, and high levels of compliance with follow up diagnostic testing (i.e., colonoscopy) of approximately 95% (Hardcastle, et al., 1996; Jorgensen, et al., 2002; Mandel, et al., 1993; 2000). Most importantly, greater reductions in mortality were observed for those who adhered to all screening tests compared to those that did not (Hardcastle, et al., 1996). The evidence of population benefit from
FOBT screening is therefore dependant on levels of adequate complete annual and/or biennial adherence as well as compliance with diagnostic testing.

In a review of the literature concerning the cost effectiveness of population screening with FOBT, Lansdorp-Vogelaar, Knudsen and Brenner (2011) found FOBT screening to be cost saving compared with no screening, in all reviewed analyses. A comparison between the different types of CRC screening tests available also showed FOBT screening to be the most cost effective screening method, compared with structural colon examinations, as long as the test used is of high specificity to detect CRC (Lansdorp-Vogelaar, et al., 2011). However, although FOBT screening has been found to cost less than colonoscopy screening, colonoscopy outperforms FOBT screening in numbers of life years saved (Sonnenberg, Delcò, & Inadomi, 2000). This is not a direct reflection on the efficacy of the screening method but rather on rates of compliance with annual or biennial screening; higher compliance, better efficacy because of enhanced yield (Sonnenberg, et al., 2000). The efficacy of FOBT to reduce incidence, mortality and cost is therefore highly dependent on high levels of ongoing compliance.

*FOBT screening in Australia; the National Bowel Cancer Screening Program.*

When the data for this thesis were collected, the Australian government provided free FIT screening to those turning 50, 55 and 65 in any given year (Australian Government Department of Health and Ageing, n.d-b). This program began in August 2006 following the success of a pilot program undertaken between 2002 and 2004 that was designed to test the feasibility of FOBT screening (Bowel Cancer Screening Pilot Monitoring and Evaluation Steering Committee, 2005). Screening via the National Bowel Cancer Screening Program (NBCSP) began in August of 2006 with initial screening offered to those aged 55 or 65 years and repeat screening offered to all previous pilot
invitees. Participation rates for those invited to screen in 2008 (2010 supplement data) was 41% (Australian Institute of Health and Welfare and Australian Government Department of Health and Ageing, 2010), well below initial targets of 70% (Bowel Cancer Screening Pilot Monitoring and Evaluation Steering Committee, 2005). The staggered roll-out of the program to selected age groups was designed to ensure that other health services, including colonoscopy providers, would be able to cope with anticipated increases in demand (Australian Government Department of Health and Ageing, n.d-b).

Shortly after the first draft of this thesis was completed the Australian government announced additional funding for the NBCSP as part of the 2012-2013 Federal Budget (The Commonwealth of Australia, 2012). The program will receive $49.7 million dollars to extend FOBT screening to those aged 60 and 70 years old from 2015. This extension will ensure 5-yearly FOBT screening for all Australians between the ages of 50 and 70. This approach is contrary to the substantial evidence base that recommends at least biennial participation in screening for population reductions in incidence and mortality (Hardcastle, et al., 1996; Jorgensen, et al., 2002; Mandel, et al., 1993; 2000). There is little evidence to suggest any benefit from one time screening participation (Kafrouni & Kwon, 2011; Lieberman, 2010) and none to indicate that the current five year screening interval will have any population effect. Whilst the 2012-2013 budget announcements included plans for the gradual roll out of biennial screening from 2017 to select age groups, it is estimated that the program will not be fully implemented until 2034 (The Commonwealth of Australia, 2012). It is therefore important that research programs identify ways of encouraging compliance with
screening programs (such as the NBCSP) and ways of encouraging participation within the period between the five year offers.

There are several options for obtaining FOB tests in Australia outside of the NBSCP. FOBTs can be purchased through non-government organisations such as The Cancer Council Australia, community organisations such as Rotary Health Australia, pharmacies and FOBT manufacturers. Screening tests can also be obtained through General Practitioners (GPs) or online (e.g., Bowel Cancer Australia, 2010). The average cost of an FOBT is $37.50 (Bowel Cancer Australia, 2010; Enterix, n.d) however some local organisations, for example Cancer Council South Australia, offer subsidised testing (between 15 and 20 dollars)(Cancer Council South Australia, 2012).

The data for this thesis were collected independent of the NBCSP. As highlighted above, at the time the data for this thesis were collected, the NBCSP was not offering biennial screening at a population level. The data utilised in this thesis were obtained by providing three FOB screening tests, on an annual basis, to a defined study population. Detailed Information on these screening offers and the study population are provided in chapter two.

**Structural Colon Examinations (Endoscopy).**

Endoscopic tests are also available for CRC screening; these include colonoscopy and flexible sigmoidoscopy (FS). Both procedures are performed by a doctor or specialist, require bowel preparation and dietary restrictions in the days before screening and are consequently significantly more onerous than FOBT utilisation. Flexible sigmoidoscopy uses a flexible scope to examine a portion of the bowel (about 50-60cms) whereas colonoscopy inspects the full bowel and is the preferred way to
diagnose CRC (Saunders, 2003). Both colonoscopy and FS have been shown to reduce effectively mortality from CRC (Atkin et al., 2010; Forde, 2006), however to date, the evidence to support colonoscopy screening is based on cohort or case control studies and has not yet been examined at a population level (Lieberman, 2010).

Screening recommendations for average risk individuals in Australia are once every 5 years for FS, however nationally funded programs to support FS are not yet available (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005). Colonoscopy screening is not recommended for average risk individuals in Australia (Levin, et al., 2008). Colonoscopy is the recommended surveillance for those above average risk, or is the recommended follow up test to be completed when significant adenomas or other signs of CRC are detected in other screening tests (e.g., FOBT) (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005). Colonoscopy is therefore the crucial final step on the screening pathway to determining the presence of colorectal cancers (Lieberman, 2010).

Nationally funded programs to support colonoscopy are not currently available in Australia. Whilst FOBT screening in the NBCSP is free of charge, those testing positive do incur additional out of pocket costs associated with follow up diagnostic examinations. Medicare Australia does subsidise the cost of diagnostic or therapeutic (removal of polyps) colonoscopy. Additional out of pocket costs incurred by the patient vary substantially depending on the type of test performed (i.e., the extent to which the bowel is examined) and where the test is performed (i.e., public or private sector). When this thesis was completed, in 2012, colonoscopy with complete examination of the bowel with or without biopsy in the public sector incurred an out of pocket cost of 278 Australian dollars (Australian Government Department of Health and Ageing, n.d-a).
Colorectal Cancer Rescreening

The previous sections outlined the evidence base for FOBT screening for CRC. Although FOBT screening has been found to be both cost effective (Lansdorp-Vogelaar, et al., 2011; Pignone et al., 2011) and efficacious in reducing CRC incidence and mortality (Hardcastle, et al., 1996; Jorgensen, et al., 2002; Mandel, et al., 1993), achieving these outcomes is dependent on consistent compliance with repeated screening every one to two years. This requirement for compliance at recommended levels highlights the importance of moving beyond an understanding of variables influencing initial uptake to a focus on the variables that predict rescreening (i.e., the maintenance of screening behaviours enacted at the recommended interval).

Definition

For the purposes of this thesis rescreening is operationalised as participation in more than one consecutive FOB screening tests in accordance with screening guidelines. Most of the literature on participation in FOBT screening is concerned with the variables that influence participation in a single screening opportunity, sometimes referred to as ‘initial’ screening (Beydoun & Beydoun, 2008; Kiviniemi, Bennett, Zaiter, & Marshall, 2011). In the present study single/initial screening is operationalised as the number of people who participate in a single opportunity to screen with FOBT. These participants then form the denominator for calculating the proportion of the population who rescreen (i.e., reparticipants) in subsequent screening opportunities. In this thesis those who do not participate in any screening are called non-participants. Those who participate in initial screening offer(s) but then decline subsequent ones are described as having ‘dropped out’ of, (Dossaert, Boer, & Seydel, 2003) or relapsed (Prochaska, Velicer, DiClemente, & Fava, 1988; Rakowski, Dube, & Goldstein, 1996) from, screening.
Rescreening or reparticipation represent the desired behavioural outcome whereas relapse or drop out represents the target behaviour for improvement.

Throughout the literature, and consequently, this thesis, the term adherence is used to describe participation in screening in accordance with screening guidelines. As is explained in more detail in the following sections, there are multiple different tests that can be used to screen for CRC, similarly the guidelines as to how and when these tests should be used varies between countries. It is therefore important to acknowledge that whilst the term ‘adherence’ is often the general term used to describe the behaviour of participating in screening tests, the decision to participate in screening is ultimately a choice that depends on risk classification and individual preferences.

**Rescreening Rates**

Few studies within the CRC screening literature have examined rates and predictors of rescreening. Ongoing searches of several major data bases (Scopus, PubMed, PsychInfo) pairing ‘colorectal cancer and screening’ with the terms; repeat, rescreen, compliance, adherence, maintenance, interval, continued, and regular, conducted between 2008 and 2012, and including studies identified from the reference lists of relevant studies, found only 15 CRC screening studies providing information on rates of rescreening using a FOBT, many of which were published as recently as 2010. These studies are presented in Table 1 and Table 2; they include national program reports, randomised controlled trials and research studies. In order to be considered a rescreening study reports had to provide data on participation in at least two consecutive screening rounds. In addition, in order to identify the comparative non-adherent behaviour, relapse/drop out, it was also important that studies provided information to determine the proportion of the population reparticipating in each
round. Nine studies provided rates of rescreening and relapse for two rounds of screening. Table 1 provides overall percentages of people participating in each of the screening rounds and then provides a percentage of those rescreening in the second round. The study by Garcia et al. (2012) did not provide data on rates of screening participation in two rounds, however the single screening opportunity assessed in the study was only offered to those who were adherent with a preceding FOBT and were therefore potential rescreeners.

The proportion of participants rescreening from round 1 to round 2 was between 53.2% and 87.2%. These data indicate that between 12.8% and 46.8% of people participating initially in FOBT screening relapse or drop out in subsequent rounds. It is interesting to compare these data to cross sectional reports of overall participation for each round. These indicate either steady or slight increases in participation from round 1 to round 2. The discrepancy between these two sets of observations highlights the fact that people who did not participate in round 1 may decide to participate in the program for the first time in round 2. Unfortunately, these cross sectional reports of compliance per round are the primary performance indicators for national screening programs (Gellad et al., 2011; Gimeno-García, 2012) obscuring the rates of dropout. Depending on cross sectional data for the analysis of screening program success therefore has the potential to overestimate the success of national programs in achieving high rates of ongoing participation because rates may not distinguish new from repeat participants.
Table 1 Rates of reparticipation in two rounds of screening reported in the literature.

<table>
<thead>
<tr>
<th>Author</th>
<th>Study description</th>
<th>Total participation round 1</th>
<th>Total participation round 2</th>
<th>Rate of reparticipation</th>
<th>Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population screening programs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. (Australian Institute of Health and Welfare and Australian Government Department of Health and Ageing, 2008)</td>
<td>Australian National Bowel Cancer Screening Pilot Program</td>
<td>45.4%</td>
<td>49.1%</td>
<td>79.7%</td>
<td>Biennial</td>
</tr>
<tr>
<td>2. (Weller et al., 2007)</td>
<td>UK Colorectal Cancer Screening Pilot</td>
<td>51.9%</td>
<td>58.5%</td>
<td>81.1%</td>
<td>Biennial</td>
</tr>
<tr>
<td>3. (Steele et al., 2009)</td>
<td>Scottish Demonstration Pilot</td>
<td>55.0%</td>
<td>53.0%</td>
<td>85.4%</td>
<td>Biennial</td>
</tr>
<tr>
<td>4. (Zorzi et al., 2007)</td>
<td>Italian Screening Programs for CRC</td>
<td>47.1%</td>
<td>50.4%</td>
<td>77.2%</td>
<td>Annual</td>
</tr>
<tr>
<td>5. (Faivre et al., 1991)</td>
<td>France, The Burgundy Study</td>
<td>54%</td>
<td>55.5%</td>
<td>83.6%</td>
<td>Annual/biennial</td>
</tr>
<tr>
<td><strong>Research studies</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. (Garcia, et al., 2012)</td>
<td>Spain, predictors of reparticipation</td>
<td>-</td>
<td>-</td>
<td>87.2%</td>
<td>Biennial</td>
</tr>
<tr>
<td>7. (Fenton et al., 2010)</td>
<td>USA, analysis of Medicare claims data</td>
<td>22.8%</td>
<td>44.4%</td>
<td>53.2%</td>
<td>Biennial</td>
</tr>
<tr>
<td>8. (Myers, Balshem, Wolf, Ross, &amp; Millner, 1993)</td>
<td>USA, intervention study</td>
<td>41.3%</td>
<td>58.7%</td>
<td>55.9%</td>
<td>Annual</td>
</tr>
<tr>
<td>9. (Janda, Hughes, Auster, Leggett, &amp; Newman, 2010)</td>
<td>Australia, Rural intervention study</td>
<td>34.1%</td>
<td>34.7%</td>
<td>75.2%</td>
<td>Biennial</td>
</tr>
</tbody>
</table>
To date no CRC studies have provided detailed rescreening data beyond two rounds of screening. Several studies, however, spanning between three and thirteen years, have provided data on levels of complete/adequate compliance during a defined study period; these are described in Table 2. Definitions of complete/adequate compliance varied between studies. For example, Gellad et al. (2011) defined ‘adequate adherence’ as participation in at least four of a possible five FOBTs during a five year observation period, whereas in the Hardcastle et al. (1996) RCT, complete adherence was defined as participation in all screening offers during the trial. Together these studies broadly describe the proportion of the population who adhere to study defined guidelines over multiple screening rounds. It is not possible however, to determine the proportion of the population who drop out/relapse during the study period from these data. Gellad et al. (2011) did report that out of the five screening rounds 42.1%, 26% and 17.8% of the screening population participated in one, two or three FOB tests respectively. These data indicate that a substantial proportion of participants were adherent at certain stages of the program and not for others. It cannot be determined from these data the sequences in which participants dropped in and out of the program, although the findings do point to the presence of both relapse and irregular patterns of participatory behaviour.

Despite problems in clearly identifying the patterns of rescreening adherence, the studies in Table 2 do show a substantial decline in the proportion of the population adherent with screening over multiple screening rounds. Rates of complete adherence with screening are lower than the rates of reparticipation reported in Table 1, suggesting that rescreening adherence continues to decline over time. Rates of complete screening reported in the research studies listed in Table 2 are also substantially lower than those reported in the RCTs that established the evidence base for FOBT screening. Retrospective
analyses of Medicare claims data in the United States for example, revealed rates of complete screening were as low as 13.7% (Gellad, et al., 2011) during a five year observation period. As mentioned previously, screening recommendations in Australia differ from the United States. Specifically, colonoscopy is also a recommended screening option for average risk populations and there is evidence to suggest greater public preference for colonoscopy as a screening method (Meissner, Breen, Klabunde, & Vernon, 2006). Cross sectional adherence to FOBT screening has been shown to be higher in Australia compared to the United States, likely as a result of the difference in screening recommendations (von Euler-Chelpin, Brasso, & Lynge, 2010). It is therefore likely that rates of rescreening adherence will be higher amongst an Australian population, however to date no Australian studies have examined adherence with more than two screening rounds.
Table 2 Rates of complete/adequate compliance with more than two screening rounds using FOBT

<table>
<thead>
<tr>
<th>Study</th>
<th>Proportion complete adherence</th>
<th>Interval duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Randomised controlled trials</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. UK, Hardcastle et al (1996)</td>
<td>38.2%</td>
<td>Biennial</td>
</tr>
<tr>
<td>11. USA, Mandel et al. (1993)</td>
<td>46.2% Annual</td>
<td>Annual/Biennial</td>
</tr>
<tr>
<td>12. Denmark, Jorgensen, Kronborg and Fenger (2002)</td>
<td>59.7% Biennial</td>
<td>Biennial</td>
</tr>
<tr>
<td>Research studies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. USA, retrospective examination of veteran health care data (Gellad, et al., 2011)</td>
<td>14.1% Male</td>
<td>Annual</td>
</tr>
<tr>
<td></td>
<td>13.7% Female</td>
<td></td>
</tr>
<tr>
<td>14. USA, retrospective examination of Medicare claims data (Cooper &amp; Doug Kou, 2008)</td>
<td>22.9%</td>
<td>Annual</td>
</tr>
<tr>
<td>15. USA, self-reported retrospective adherence (O’Malley, Forrest, &amp; Mandelblatt, 2002)</td>
<td>29%</td>
<td>Biennial</td>
</tr>
</tbody>
</table>

Of the 15 studies included in Table 1 and Table 2, only the seven research studies identified *predictors* of rescreening. Of these seven, four (Fenton, et al., 2010; Garcia, et al., 2012; Janda, et al., 2010; Myers, et al., 1993) assessed predictors of rescreening compared to relapse. Three of these studies were published as recently as 2010, after the data reported in this thesis were collected. The remaining comparative studies compared rescreeners with all non-adherent participants (including; non-participants, relapse and other irregular screening patterns). These studies primarily focused on associations between demographic variables (e.g., age, gender) and rescreening and these results will be discussed in later sections. Before these issues can be addressed it is important to consider in more detail the methodological difficulties associated with measuring and defining outcome in rescreening research described previously.
Methodological Difficulties in Rescreening Research

Data on rates of rescreening for CRC with FOBT show low rates of ongoing screening particularly as the number of screening opportunities increase. There is therefore a need to develop strategies to improve rescreening participation. However there are several methodological issues to consider when measuring rescreening adherence. Vernon, Briss, Tiro and Warnecke (2004), in a review of approaches to measurement in screening research, highlighted several important methodological considerations. Central to this review was the need for agreed operational and conceptual definitions of behavioural outcomes and agreed approaches to measurement to ensure consistencies between studies. Primarily this review focused on examples from amongst the breast cancer screening literature. The following sections will outline some of the common approaches and unique challenges associated with measuring compliance with CRC rescreening.

Assessing outcomes in CRC screening research.

Observed versus self-reported participation.

Participation in screening is the primary outcome assessed in most CRC screening research (Beydoun & Beydoun, 2008). Participation can be assessed two ways; by participant self-report or by direct observations of screening participation through structured screening programs or information taken from medical records. Both methods are frequently utilised in the CRC screening literature.

There are several advantages to using self-reported measures of adherence; these measures are more readily obtained particularly in behavioural studies utilising survey or qualitative techniques to collect data (e.g., Duncan et al., 2009; Paddison & Yip, 2010). In the case of rescreening, self-report is advantageous as it can allow for an exploration of
prior screening behaviour over many years (Watson-Johnson et al., 2011), data that may not always be available from medical records or program data. However, there are several difficulties inherent in this approach. Prior research has documented self-report bias for many different health behaviours (Galea & Tracy, 2007), in particular a tendency to exaggerate adherence to comply with personal or societal expectations (Festinger & Carlsmith, 1959). In addition, in CRC screening research, self-report relies on participants’ correct interpretation of the reason for participation (screening versus diagnostic testing) and correct recollection of screening instances (Vernon, Briss, Tiro, & Warnecke, 2004). Recollection of frequency and consistency of screening compliance are particularly important when determining rescreening compliance and this can be difficult where participants are required to depend on their memory to recall multiple screening opportunities over a number of years.

There are several recommended approaches for improving accuracy of self-reported screening including; the use of simplified language when describing the different forms of screening (Baier et al., 2000; Vernon et al., 2004), asking participants to provide a reason as to why they participated in order to distinguish between diagnostic and asymptomatic screening (Vernon, Meissner, et al., 2004), and simplifying recall by asking participants to approximate the time of the last screen (e.g., within the last year) as opposed to requesting exact dates (Vernon, Briss, et al., 2004). These structured approaches to obtaining self-report data have been shown to correlate well with measures of observed screening participation (Baier, et al., 2000) and remain a suitable measurement method for studies that do not have access to observed screening. Notwithstanding the possible valid utilisation of self-report data, researchers have suggested that reliability of self-report decreases as number of lifetime screening
opportunities increases (Rauscher, O’Malley, & Earp, 2002), suggesting that rescreening research utilising self-report should limit requested screening recall to shorter, more recent time frames.

**Intention versus action.**

There are many examples within the CRC screening literature where studies utilise measures of intention to participate in future screening as opposed to actual screening participation (e.g., Duncan, et al., 2009; Kiviniemi, et al., 2011; Tong, Hughes, Oldenburg, & Mar, 2006). A recent study has further confirmed that predictors of intention and action with regard to FOBT use vary (Gregory et al., 2011).

The reasonably moderate size of the intention-behaviour correlation is well documented (.40 to .82; sample-weighted average correlation .53; Sheeran 2002). However, when intention and behaviour were dichotomised by Sheeran (2002) into intention and no intention, and action and no action, results indicated that although only 47% of those intending to act did act, 93% of those who did not intend to act, did not act. This indicates that intentions to not participate are highly predictive of subsequent non-adherence. The importance of this observation cannot be under-estimated. Reliance on looking at variables that predict behavioural compliance may miss out on identifying behaviours that predict withdrawal from screening programs or making the decision not to act, and it is this decision that is most predictive of actual behaviour.

Although actual screening participation is often the preferred measure when determining adherence with screening (Vernon, Briss, et al., 2004), from an intervention perspective there remains some benefit in ensuring participants do not form negative intentions with regard to future screening participation. This indicates the importance of
addressing facilitators and barriers of both intention and behaviour when planning interventions designed to facilitate screening compliance.

The importance of understanding influence on both intention and behaviour is highlighted in both continuum theories of behaviour change (e.g., The Theory of Planned Behaviour, TPB, Ajzen, 1991) and stage theories (e.g., Transtheoretical Model of Behaviour Change, TTM, Prochaska & DiClemente, 1983). These models identify intention as a proximal determinant of behaviour. Discrepancies between the predictors of intention and the predictors of action are to be expected. Although some variables, such as attitudes to rescreening and normative beliefs about the behaviour are likely to increase intention (Ajzen, 1991) additional variables such as control beliefs (Ajzen, 1991), cues to action (Janz & Becker, 1984), decisional balance (Prochaska & DiClemente, 1983), personal ability and access to appropriate resources (Sheeran, 2002) may provide additional incremental validity to the prediction of behaviour.

Recent CRC research has found similarities and differences between the predictors of screening intention and initial screening participation (Gregory, et al., 2011). Primarily, certain social cognitive variables (for example; locus of control, perceived susceptibility) were better predictors of intention than participation; whilst others (for example perceptions of barriers and benefits) were associated with both. No equivalent research exists for CRC rescreening. There are therefore, benefits to exploring both intention and participation as long as intention is not equated to actual participation. From an intervention perspective, factors associated with both intentions and participation may be used to develop broad strategies targeting multiple factors in order to encourage both the decision to participate, and subsequent participation in, CRC screening.
Defining outcomes in CRC rescreening research.

The previous sections outlined some of the issues inherent in obtaining measures of screening participation. How these outcomes, irrespective of their origins, are subsequently defined and analysed also has important implications for the interpretation of results, particularly for complex behaviours such as CRC rescreening.

Vernon et al. (2004) identified several variations in the definitions used to measure screening adherence for mammography. These definitions were found to vary by screening interval and the number of sequential mammograms required to be considered ‘adherent’. Similarly, Clark, Rakowski and Bonacore (2003) reported difficulty attempting to obtain an estimate of mammography rescreening compliance from rates reported in the literature, with differences in definitions leading to substantial differences in rates of adherence between studies. Similar discrepancies are evident in the CRC rescreening literature. For example, rescreening studies have examined both annual (e.g., Gellad, et al., 2011) and biennial (e.g., Garcia, et al., 2012; Janda, et al., 2010) screening intervals and have adapted varying definitions of adherence. For example, as mentioned previously, Gellad et al. (2011) defined adherence as participation in four out of five annual screening offers, Hardcastle et al. (1996) defined adherence as participation in all screening offers whilst an additional study, not previously included because it did not report rates of rescreening (Neilson & Whynes, 1995), defined ‘persistent compliers’ as those participating in five consecutive screening rounds of a potential eight. In these instances different definitions also lead to different behaviours being assessed with some assessing participation in all screening and others assessing participation in some screening offers.

Several of these inconsistencies are unlikely to be resolved. In particular, FOBT screening guidelines vary from country to county and therefore result in inevitable
differences between studies. Vernon et al. (2004) suggest that at the very least studies provide clear descriptions of the methodology and definitions used to measure rescreening to allow for an accurate interpretation of the results. In addition, Vernon et al highlight the importance of identifying the outcome measure that best determines ‘success’ from a public health perspective, i.e., the behaviour that would lead to the greatest reductions in CRC incidence and mortality. The epidemiology of CRC is complex, variations in family history, lifestyle factors and bowel conditions, amongst others, contribute to variations in disease progression (A. B. Benson, 2007). Despite the various definitions of adherence used in CRC rescreening studies to date, randomised controlled trials emphasise the importance of participation in all screening opportunities (Hardcastle, et al., 1996; Jorgensen, et al., 2002; Mandel, et al., 1993), with greater benefit coming from shorter screening intervals (Mandel, et al., 2000). The focus of CRC rescreening research therefore should be on maintaining rescreening but also on preventing relapse or other irregular screening patterns that may lead to missed opportunities for early detection.

Frameworks for describing and analysing CRC rescreening behaviour.

In order to describe rescreening participation, and compare predictors of rescreening adherence and non-adherence, it is important that all possible rescreening behaviours are considered. In a single screening opportunity the outcome is dichotomous; participants can either participate or not participate. However, this is not the case for rescreening as the number of potential outcomes increases with the number of screening opportunities assessed. For example, with two rounds of screening, someone may participate in the first round of screening, but not the second (i.e., relapse, dropout). Alternatively, someone may participate in the second offer but not the first (i.e., delayed participation), or they may decline all the offers (i.e., non-participation). The potential
combinations of participation and non-participation become substantially more complex as more rounds are included. However, despite the many potential combinations of rescreening adherence and non-adherence, many rescreening studies (e.g., Cooper & Doug Kou, 2008; Gellad, et al., 2011; O’Malley, et al., 2002) continue to dichotomise outcomes, into adherent (i.e., rescreeners) or non-adherent. In these cases ‘non-adherence’ may describe someone who has participated in none of the screening offers, or all but one of the screening offers. Grouping non-adherent participants in this way may means that the particular needs of certain non-adherent sub groups are not being recognised. For example, those that screen previously but then decline subsequent screening offers (relapse/drop out) are likely to differ from those who never participate because prior experience with the behaviour may be contributing to subsequent refusal (Garcia, et al., 2012; Rakowski, Dube, et al., 1996).

There is substantial evidence to suggest that tailoring interventions to subgroups of the population (i.e., those with different levels of readiness to participate in screening) is more effective than generic messages delivered to the population as a whole (Champion et al., 2003; Sohl & Moyer, 2007), therefore it is important to expand traditional notions of adherence (traditionally measured as a dichotomous outcome, adherence versus non-adherence) to frameworks that recognise the different non-adherent subgroups.

As described earlier, stage models of behaviour change such as the Transtheoretical model (TTM) (Prochaska & DiClemente, 1983) and the Precaution Adoption Process Model (PAPM) (Weinstein, 1988) provide a framework for categorising screening and rescreening participation based upon prior experience with screening and intentions for future participation. The TTM has been the stage model most frequently used in the CRC screening literature (Spencer, Pagell, & Adams, 2005). The TTM was originally developed
to assess behaviour change amongst those attempting to quit smoking (Prochaska & DiClemente, 1983) or address other addictions. Its widespread uptake saw it being increasingly utilised for the prediction of more spasmodic behaviours including cancer screening participation (Spencer, et al., 2005). The TTM describes participants’ readiness to engage in screening and rescreening according to several sequential ‘stages’. The stages of change, as described by Rakowski et al. (1996) for mammography screening and rescreening, are described in Table 3.

Table 3 Stage of Readiness definitions as they apply to mammography screening defined by Rakowski et al (1996)

<table>
<thead>
<tr>
<th>Stage of Readiness</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Precontemplation</td>
<td>Has never had a mammogram and does not plan to have one within the next 1-2 years</td>
</tr>
<tr>
<td>Contemplation</td>
<td>Has never had a mammogram, but plans to have one in the coming year, or is off schedule after having a prior mammogram but intends to have another in a time frame that will keep the woman on schedule</td>
</tr>
<tr>
<td>Action</td>
<td>Has had one mammogram on schedule and intends to have one another one on a time frame that will keep the woman on schedule</td>
</tr>
<tr>
<td>Maintenance</td>
<td>Has had at least two mammograms on schedule and intends to have another on a time frame that will keep the woman on schedule</td>
</tr>
<tr>
<td>Relapse</td>
<td>Has had one or more mammograms in the past, but is now off schedule and does not plan to have a mammogram within the next 1-2 years</td>
</tr>
<tr>
<td>Relapse risk</td>
<td>Is currently on schedule, but does not plan to have another mammogram in a time period that would keep the woman on schedule</td>
</tr>
</tbody>
</table>

People in each ‘stage’ of readiness for screening are hypothesised to be qualitatively different from one another according to behavioural constructs defined by the model (i.e., self-efficacy, decisional balance). Targeting the behavioural characteristics of each stage is required to encourage behaviour change. The TTM describes several ‘processes of change’ likely to encourage change (for example, consciousness raising and self-liberation) which were designed primarily to encourage smoking cessation (Prochaska & DiClemente, 1983).
The model theorises that different processes of change are important at different stages, for example, consciousness raising (i.e., obtaining information on the target behaviour) is important at the contemplation stage, whilst counter conditioning and stimulus control (i.e., removing temptation for relapse) are important for action and maintenance (Prochaska & DiClemente, 1983). However, amongst the CRC screening literature it has been common to use the TTM staging framework in association with other behavioural models (for example the Health Belief Model, Janz & Becker, 1984) and demographic variables known to be associated with screening participation (Duncan, et al., 2009; Gregory, et al., 2011; Rawl et al., 2005).

Progression through the stages, from precontemplation to maintenance, is hypothesised to be linear (Prochaska & DiClemente, 1983). The aim for health promotion programs, therefore, is to identify factors associated with each stage and tailor information accordingly to encourage forward movement through the stages. In original applications of the model, relapse was the term used to describe backward regression to a previous stage (Prochaska & DiClemente, 1983). However, in applications of the TTM to cancer screening, relapse is the term used to describe those who ‘drop out’ of screening after previously participating (i.e., regression to precontemplation after being previously in the action or maintenance stage) (LaPelle et al., 2008; Rakowski, Dube, et al., 1996). Relapse has therefore been frequently examined as a separate ‘stage’ in the recognition that the characteristics of those in the pre action stages (precontemplation and contemplation) are likely to differ from those who have previously participated in screening and then decided not to participate in the future (LaPelle, et al., 2008; Rakowski, Dube, et al., 1996).

Several components of the TTM make it a useful framework for describing rescreening behaviour. Firstly, the TTM does not dichotomise adherent and non-adherent
behaviour, rather it recognises that people are likely to progress through a series of different stages when making the decision to participate and reparticipate in screening. Secondly, the aim of the TTM is to encourage behaviour maintenance; it does not assume that performing the behaviour once is the same as maintaining this behaviour over time and, finally, it allows for a focus on relapse behaviour as distinct from other forms of non-participation. Previous research applying the TTM to CRC screening has focused primarily on encouraging action. Few studies have extended the model to include a maintenance stage (Hay et al., 2003; Manne et al., 2002; Menon, Belue, Skinner, Rothwell, & Champion, 2007; Paddison & Yip, 2010). The majority of these studies included a collapsed action/maintenance stage that included all prior screeners. Only one of these studies actually included a maintenance stage and an action stage (Manne, et al., 2002), with differences between the two according to behavioural variables (i.e., decisional balance) consistent with the predictions of the TTM. The study by Manne et al. (2002) focused on high risk individuals with siblings affected by early onset CRC; no studies have examined maintenance amongst average risk patients.

Criticisms of the TTM are largely related to the core assumptions of the model; that movement through the stages of change is sequential and that participation in screening involves deliberate cognitive decision making. Also, as discussed previously, there remains some debate on the utility of encouraging behavioural intention as opposed to action (West, 2005). Research applying the TTM to CRC screening has largely supported the use of the TTM staging framework, identifying several differences between the stages according to a variety of demographic and behavioural variables (e.g., perceptions of benefits and barriers, age; Duncan, et al., 2009; Rawl, et al., 2005). Several intervention studies have reported increases in intention and participation for CRC screening utilising messages or
cues to action tailored according to decision stage (e.g., Cole et al., 2007; Myers et al., 2008; Vernon et al., 2011). There has been no research conducted within the CRC screening literature on encouraging screening maintenance based on TTM constructs, however findings amongst the mammography screening literature have highlighted the importance of developing unique interventions, for example reminding participants to rescreen, in order to bridge the gap between action and maintenance (Clark et al., 2002).

An alternative approach to measuring rescreening behaviour is to simply describe the varying patterns of participatory behaviour in order to identify target behaviours for improvement (Sheeran, Conner & Norman, 2001). In a study of rescreening adherence over two rounds Janda et al. (2010) observed four possible rescreening behaviours 1) those participating in both rounds, 2) those participating in round two but not round one 3) those participating in round one but not round two and 4) those not completing an FOBT in any round. Drosseart et al. (2003) described these patterns, for mammography screening, as 1) consistent attendance 2) delayed attendance 3) drop out and 4) refused attendance. These behaviours are similar to those described by the TTM but are based on observations of rescreening behaviour as opposed to intentions (Sheeran, et al., 2001). In addition these measures are an improvement on other methods previously used in the CRC rescreening literature (for example, counting the number of screening instances, Gellad, et al., 2011) as they provide information on the sequence of participation and drop out. For both studies demographic (Janda, et al., 2010) and behavioural characteristics (Drossaert, et al., 2003) differentiated those in the different behavioural categories. However, whilst the Drossaert et al. study included observations from three rounds of screening (i.e., drop out was defined as participation in round 1 followed by refusal of either round two or three), the study did not attempt to describe all of the potential behavioural patterns. Irregular
screening patterns, for example those who participate in rounds one and three, but not two, were not described. These behavioural descriptors may therefore require further refinement when applied across more than two screening rounds. Nonetheless they do provide an initial framework within which to consider the variety of non-adherent behaviours that occur across multiple screening rounds.

Factors associated with Rescreening

Low rates of consistent screening compliance highlight the importance of developing interventions to encourage rescreening. Table 1 and Table 2 described studies that provided rates of rescreening adherence across two or more screening rounds. Many of these studies reported data from national screening programs and randomised controlled trials and the aims of many of these studies were to determine rates of adherence, reductions in incidence, mortality and cancers detected during the screening programs. Subsequently these studies did not provide any data comparing the demographic or behavioural characteristics of participants who rescreened and those who did not. Reviews of the literature found only nine studies that statistically compared rescreeners with non-adherent screeners or relapse/drop out participants. These studies included primarily demographic comparisons with a few comparing participants according to other background factors (e.g., provider interactions, involvement in other preventive health activities). These studies are described in Table 4 along including multivariate associations with rescreening compared to relapse or non-adherence. Results are presented in Table 4 to indicate which demographic categories (e.g., male, those older than 60) were found to be more likely to be adherent with rescreening compared to non-adherence or relapse.
The previous sections highlighted the variety of potential adherent and non-adherent behaviours that occur with two or more opportunities to screen, however only five of the rescreening studies identified predictors of rescreening compared to relapse (Fenton, et al., 2010; Garcia, et al., 2012; Janda, et al., 2010; Myers, et al., 1993; 1990). Janda et al. (2010) included other possible comparative categories (i.e., delayed participation); however no quantitative comparative data were provided. The remainder used dichotomous outcome measures comparing those defined as ‘rescreeners’ (definitions varied see Table 4) with all those not defined as non-rescreeners (non-adherent).
**Table 4 Multivariate demographic associations with rescreening adherence and study descriptions**

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Study design</th>
<th>Rescreening definition</th>
<th>Comparative category</th>
<th>Age</th>
<th>Gender</th>
<th>Socioeconomic factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myers (1990), USA</td>
<td>Prospective, survey</td>
<td>Screening within the year preceding study + participation in study FOBT offer</td>
<td>Relapse</td>
<td>≥60</td>
<td>No relationship</td>
<td>No relationship</td>
</tr>
<tr>
<td>Myers (1993), USA</td>
<td>Prospective, intervention</td>
<td>Participation study FOBT 1 and 2</td>
<td>Relapse</td>
<td>≥65</td>
<td>No relationship</td>
<td>No relationship</td>
</tr>
<tr>
<td>Neilson and Whynes (1995), UK</td>
<td>Retrospective, survey</td>
<td>Participation in 5 consecutive FOBT during 8 year study period</td>
<td>Refusal of 3 consecutive FOBTs during 8 year study period</td>
<td>No relationship</td>
<td>No relationship</td>
<td>Occupation classification (white collar)</td>
</tr>
<tr>
<td>O’Malley (2002), USA</td>
<td>Retrospective, survey</td>
<td>Self-report, 2 FOBTs within the past three years</td>
<td>Non-adherence</td>
<td>-</td>
<td>-</td>
<td>Higher level of education, health insurance (yes) Higher level of education</td>
</tr>
<tr>
<td>Cooper and Doug (2008), USA</td>
<td>Retrospective, claims data</td>
<td>Participation in 5 annual FOBT</td>
<td>Non-adherence</td>
<td>70-74</td>
<td>Male</td>
<td>-</td>
</tr>
<tr>
<td>Fenton (2010), USA</td>
<td>Retrospective, claims data</td>
<td>Participation in 2 biennial FOBT</td>
<td>Relapse</td>
<td>Older age, continuous measure</td>
<td>Male</td>
<td>-</td>
</tr>
<tr>
<td>Janda (2010), USA</td>
<td>Retrospective, screening program</td>
<td>Participation in study FOBT 1+2</td>
<td>Relapse</td>
<td>≥60</td>
<td>No relationship</td>
<td>No relationship</td>
</tr>
<tr>
<td>Garcia (2012), USA</td>
<td>Prospective, screening program</td>
<td>Participation in study FOBT 1+2</td>
<td>Relapse</td>
<td>No relationship</td>
<td>No relationship</td>
<td>Higher level of education No relationship</td>
</tr>
<tr>
<td>Gellad (2011), USA</td>
<td>Retrospective, claims data</td>
<td>≥ 4 of a possible 5, annual FOBT</td>
<td>Non-adherence</td>
<td>No relationship</td>
<td>-</td>
<td>No relationship</td>
</tr>
</tbody>
</table>
Demographic predictors of rescreening

Several studies found older age to be more predictive of rescreening compared to relapse (Janda, et al., 2010; Myers, et al., 1993; 1990). However, results were inconsistent; some studies reported no relationships irrespective of the comparison group (Garcia, et al., 2012; Gellad, et al., 2011). In addition, Cooper and Doug et al. (2008) found that those aged 70-74 years were more likely to have complied with screening in the five years preceding the study compared with older (75-85) participants, even when controlling for participant death in these age groups. This finding suggests that rescreening compliance is in fact less likely in the oldest age groups. The literature on single/initial screening has similarly documented that compliance with screening increases with age, but then peaks and decreases again amongst those in the oldest age groups (≥70) (von Euler-Chelpin, et al., 2010). Further research is required to verify this finding for CRC rescreening.

Studies examining the associations between gender and rescreening have also been inconclusive. Four studies comparing those who rescreen with those who relapse found no differences (Garcia, et al., 2012; Janda, et al., 2010; Myers, et al., 1993; 1990). However, Fenton et al. (2010) found higher reparticipation rates in men. Cooper and Doug Kou (2008) also reported higher participation in men when comparing those who rescreened with all non-adherent participants. This is contrary to early findings that reported higher initial FOBT screening participation in women (Vernon, 1997), suggesting gender may have different associations with initial compared with repeat screening. Reports from the Jorgensen et al. (2002) RCT observed higher initial participation in women but subsequently reported men to be more likely to accept
screening in the last four screening offers. This difference however, was not statistically verified; more rescreening research is required to explore this effect.

Only a few studies examined markers of socioeconomic status including; education (Cooper & Doug Kou, 2008; Garcia, et al., 2012; O’Malley, et al., 2002), health insurance (O’Malley, et al., 2002), and employment (Neilson & Whynes, 1995). Consistent with the literature on single round screening adherence (Beydoun & Beydoun, 2008; Garcia, et al., 2012) those from areas of higher education, with ‘white collar’ jobs, and health insurance, were more likely to rescreen for CRC (Garcia, et al., 2012; Neilson & Whynes, 1995; O’Malley, et al., 2002). In contrast, Gellad et al. (2011) found that amongst a sample of Medicare beneficiaries in the United States, health care eligibility and insurance status, had no effect on rescreening adherence. It has been noted previously that markers of SES are likely to differentially predict screening participation between countries depending on the health systems in place to support screening. For example, the lack of association between SES markers and rescreening amongst those receiving screening as part of Medicare might be due to the availability of services (Gellad, et al., 2011). Access to health care has been frequently identified as a barrier to mammography rescreening (Watson-Johnson, et al., 2011). In several recent Australian studies, where screening was offered free of charge to participants, SES, defined according to area of residence, was not associated with uptake of a single screening offer (Cole, Young, Byrne, Guy, & Morcom, 2002; Cole, et al., 2011). Further research is required to determine how SES is related to rescreening in Australia.

**Background predictors of CRC rescreening**

Several rescreening studies have examined the association between lifestyle and health systems factors and CRC rescreening. Health systems factors associated with
rescreening compliance include; the presence of other bowel disorders (Neilson & Whynes, 1995), comorbidity (Cooper & Doug Kou, 2008; Fenton, et al., 2010; Neilson & Whynes, 1995), more frequent physician visits (Fenton, et al., 2010), and having a ‘regular’ GP (O’Malley, et al., 2002). Lifestyle factors such as regular dental visits (Neilson & Whynes, 1995) have also been associated with rescreening compliance. Participation in other preventive health activities has also been consistently associated with participation in initial screening (Power, Miles, von Wagner, Robb, & Wardle, 2009; von Euler-Chelpin, et al., 2010). These findings together suggest that the predisposing factors that might motivate people to engage in other preventive health behaviours are the same factors that motivate people to participate regularly in screening (Lemon, Zapka, Puleo, Luckmann, & Chasan-Taber, 2001). These results also raise the possibility that it may be regular exposure to those who are likely to promote health behaviour, for example GPs, that increases screening participation (Schenck et al., 2011).

**Prior participation in FOBT screening**

Prior participation in screening has been consistently associated with participation in rescreening (Fenton, et al., 2010; Garcia, et al., 2012; Janda, et al., 2010; Myers, et al., 1993; 1990) and rescreening intention (Menees et al., 2010; Tong, et al., 2006). In several rescreening studies, prior participation was the strongest predictor of reparticipation over and above demographic and background variables (Fenton, et al., 2010; Garcia, et al., 2012; Myers, et al., 1990). These results indicate that, amongst a general population of people eligible for screening, those who have previously participated in screening are more likely to accept a screening offer than those who have not previously participated. In a review of the application of health behaviour theories to initiation and maintenance of behaviour, Conner (2008) highlighted prior experience
as the main factor differentiating initiation and maintenance of behaviours. This is because elements of prior experience (e.g., satisfaction) are likely to influence perceptions of future testing, affecting participants belief in their ability to repeat the behaviour (i.e., self-efficacy, Conner, 2008). However, as rescreening data clearly show, not all people who initially participate will maintain this behaviour over time. This finding further emphasises the importance of using multilevel frameworks for analysing rescreening compliance, categorising participants according to whether or not they have previously participated in screening will control for the strong predictive effects of prior participation and allow for an identification of factors that may lead to relapse.

Whilst several studies have highlighted the association between prior compliance and its positive association with future screening participation, there is also some evidence to suggest that negative experiences with prior screening may in fact contribute to relapse. Satisfaction with prior screening has been consistently associated with repeat participation in the mammography rescreening literature (Marshall, 1994; Orton et al., 1991) and conversely, women reporting less satisfaction in previous screens have been found to be less likely to reparticipate (Gierisch, Earp, Brewer, & Rimer, 2010). There is also some evidence to support the generalisability of these results to CRC rescreening; both Myers et al. (1993) and Garcia et al. (2012) found that participants with an inconclusive result in round 1 (which would have necessitated completion of an additional FOBT or further diagnostic testing) were less likely to participate in round 2. In addition, prior negative experiences with screening have been identified as potential barriers to rescreening in qualitative research (Chapple, Ziebland, Hewitson, & McPherson, 2008). There have been no CRC rescreening studies however to
specifically assess the effect of a satisfactory prior experience on compliance with future offers.

**Behavioural predictors of rescreening.**

To date only one early study (Myers, et al., 1990) has attempted to explore behavioural associations with rescreening. The study by Myers et al. (1990) included a limited number of behavioural variables (e.g., control beliefs, perceived efficacy of FOBT testing, perceived likelihood of having an abnormal result on a future FOBT). Belief in the curability of CRC was associated with rescreening compared to relapse in multivariate analyses (Myers, et al., 1990). This study was however, limited by the use of predominantly single item behavioural measures and included an intervention to encourage screening, which may have mediated the effects of many variables included in the model. In addition, this study was conducted over 20 years ago, since then there have been substantial advances in both FOBT technology and literature on behavioural determinants of participation. There has been no research conducted in the area since and with the recent introduction of FOBT screening programs worldwide, there is a need for more investigation in this area.

**Summary and Suggestions for Future Research**

This chapter highlights the importance of a dedicated focus on encouraging CRC rescreening adherence. A review of the existing research on CRC rescreening identified several gaps in the literature. Firstly, there has been very little research amongst the CRC screening literature that has examined predictors of rescreening. Secondly few studies in the rescreening literature have extended rescreening observations beyond two rounds of screening. Whilst several recent studies have acknowledged the importance of focusing on how rescreening behaviour differs from relapse/drop out
behaviour, the majority of studies continue to dichotomise outcomes in rescreening research. The use of multilevel frameworks that recognise the many different patterns of screening adherence and non-adherence is suggested to allow for an identification of target behaviours for intervention.

Finally, the few studies that have examined predictors of rescreening adherence have focused on demographic and background predictors. There are inconsistencies between studies as to how demographic predictors relate to rescreening highlighting the importance of a continued focus on how these variables may influence rescreening behaviour. In particular, because many studies compared rescreening participation with all non-adherent behaviour further research may help determine if these demographic differences are associated with different subgroups of participants or non-adherence as a whole. In addition, knowledge of how demographic variables are associated with rescreening behaviour tells us very little about how to tailor information to encourage screening. In order to develop interventions to improve compliance with rescreening it is important that future research consider potential behavioural predictors of rescreening compliance. The following chapter discusses the inclusion of behavioural variables in future rescreening research drawing on examples from amongst the initial/single screening literature and mammography rescreening literature.
Chapter Two- Thesis Design

Preamble

The previous chapter outlined some of the gaps in the literature on CRC rescreening adherence. Primarily, very few studies have examined predictors of rescreening compliance with the majority of the screening literature continuing to focus on variables associated with participation in single screening opportunities. Those that have examined predictors of rescreening adherence have focused on demographic and background variables. In addition, many rescreening studies have failed to recognise the variety of different non-adherent behaviours (i.e., relapse/drop out versus non participation versus inconsistent participation) that occur across multiple rounds of screening. Chapter one outlined a potential framework for describing CRC rescreening based upon the behavioural descriptors of the Transtheoretical Model of behaviour change (TTM) (Prochaska & DiClemente, 1983). However, in order to encourage reparticipation amongst people in these specific subgroups it is important that rescreening research identify behavioural factors, as well demographic factors, which may contribute to differences in rescreening adherence.

Research on factors associated with participation in single screening opportunities continues to focus on associations between screening compliance and social cognitive variables (Beydoun & Beydoun, 2008; Gimeno-García, 2012; Kiviniemi, et al., 2011). Social cognitive variables refer to measures of individual attitudes and behaviour that interact with, or are mediated by, a person’s perceptions of their social surroundings (Conner & Norman, 2005). Primarily, the importance of studying these factors is that they are assumed to be amenable to change, therefore interventions aiming to improve participation in screening would benefit from an understanding of
which modifiable individual level factors are likely to facilitate or impede screening participation (Conner & Norman, 2005).

There are a number of social cognitive models, for example; the TTM (Prochaska & DiClemente, 1983), the Health Belief Model (HBM) (Janz & Becker, 1984), the Theory of Planned Behaviour (TPB) (Ajzen, 1991) and Social Cognitive Theory (SCT) (Bandura, 1982), that have been used to explain participation in single screening opportunities (Beydoun & Beydoun, 2008; Kiviniemi, et al., 2011). Many of the social cognition models include similar factors, or variations of similar factors, and therefore it has not been the models themselves but the individual model components that have been the focus of the majority of screening research (Kiviniemi, et al., 2011). Many studies have included combinations of variables from multiple models (i.e., the TTM, TPB, HBM) to explain screening adherence. The following sections outline several of the social cognitive factors commonly examined in CRC screening research. The chapter concludes with an overview of the thesis aims and methodology.

**Social Cognitive Associations with CRC Screening**

**Barriers and benefits.**

Several theories of health behaviour (e.g., HBM, TTM, SCT) postulate that people will participate in preventive health activities based on perceptions of the barriers and benefits associated with participating. Those with fewer perceived barriers (also termed cons or costs) and greater perceived benefits (pros, advantages) are hypothesised to be more likely to participate in preventive health activities.

Traditionally these two factors have been considered in conjunction with other social cognitive factors such as perceived severity and susceptibility or self-efficacy (for example, the HBM, Janz & Becker, 1984). A recent review examining the use of social
cognitive models, and their various components, within the CRC screening literature, reported barriers and benefits to be included in over 33 FOBT studies each, with other model constructs given considerably less attention (Kiviniemi, et al., 2011). Perceived benefits and barriers predicted screening intention and behaviour, in the expected direction, in over 22 of the studies included in this review (Kiviniemi, et al., 2011). In addition, a recent study by Gregory et al. (2011) found that low perceived barriers and greater perceived benefits were significant multivariate predictors of both initial screening intention and participation in the same sample over and above demographic and background variables.

Perceived barriers to initial CRC screening include; faecal aversion (Cole, et al., 2003), fear of cancer (Chapple, et al., 2008), ‘feeling healthy’ (Chapple, et al., 2008) and knowledge deficits that contribute to the belief that screening is ‘not important’ (Berkowitz, Hawkins, Peipins, White, & Nadel, 2008). By contrast, perceived benefits include; ‘peace of mind’ (Hay, et al., 2003; Reeder, 2011), reassurance, early detection (Rawl, et al., 2005) and simplicity (Reeder, 2011). No CRC studies have examined the relevance of these beliefs for rescreening participation.

Findings from amongst the mammography rescreening literature suggest that the barriers associated with initial screening may differ from those associated with rescreening participation (Rauscher, Hawley, & Earp, 2005). For example, barriers to mammography rescreening have been found to be related to practical barriers such as access to screening services and establishing rescreening routines (Watson-Johnson, et al., 2011) as opposed to those associated with the screening test itself. Several qualitative studies have explored potential barriers to FOBT rescreening including; fear of subsequent colonoscopy (Chapple, et al., 2008), having a ‘busy lifestyle’ (Chapple, et
al., 2008; Janda, et al., 2010), confusion over test reliability (Beeker, Kraft, Southwell, & Jorgensen, 2000), inadequate knowledge of screening guidelines and consequently the belief that it is ‘not necessary’ to repeat screening (Beeker, et al., 2000), and prior negative experiences follow up examinations (Chapple, et al., 2008).

**Perceived severity and susceptibility.**

According to the HBM, a person will be more likely to participate in screening if they a) perceive greater benefits of participation, b) perceive fewer barriers associated with participation, and c) believe themselves to be personally susceptible to CRC and d) believe the consequences of getting CRC to be severe (Janz & Becker, 1984). Each factor is believed to individually contribute to participation.

Perceptions of CRC susceptibility has been consistently associated with increased initial screening adherence (Kiviniemi, et al., 2011) and intention (Gregory, et al., 2011; Kiviniemi, et al., 2011). Additionally those with a family history of CRC have also been found to be more receptive to screening programs (Berkowitz, et al., 2008; Beydoun & Beydoun, 2008; Manne, et al., 2002). There is evidence to suggest that perceived susceptibility continues to motivate participation beyond the initial screen. Manne et al. (2002) found that amongst a select sample of siblings of individuals with early onset CRC (a high risk sample) perceptions of susceptibility increased from the precontemplation stage of adoption (no screening) to the maintenance stage (rescreening). Similarly, Watson-Johnston et al. (2011) found individuals no longer compliant with mammography rescreening (relapse/drop out) to report low perceived susceptibility.

The association between perceived severity of CRC and screening is less consistent. Several studies have shown perceptions of increased disease severity to be
associated with higher levels of screening adherence (Kiviniemi, et al., 2011). However, there have been a few studies that have shown the opposite, with those perceiving greater severity to be less likely to screen (Chapple, et al., 2008; Clavarino, et al., 2004; Kiviniemi, et al., 2011). Protection Motivation Theory (PMT) (Rogers, 1975) theorises that people will appraise the threat of an illness based on their perceptions of severity and susceptibility. Specifically, increases in both will lead to fear arousal, whereby threat is perceived to be high, and will subsequently encourage behaviour to reduce the disease threat. However, both Chapple (2008) and Claverino (2004) found that personal experience with CRC (e.g., knew a friend/family member who had died from the disease) resulted in increased perception of severity, increased fear of cancer and subsequently less inclination to participate. In these instances cancer was perceived to be so severe that you were better off ‘not knowing’ (Chapple, et al., 2008). Similarly, the mammography and pap screening literature reports inconsistent relationships between perceptions of severity and screening participation (Tanner-Smith & Brown, 2010) and reparticipation (Watson-Johnson, et al., 2011).

**Perceived behavioural control.**

Perceptions of control or capability to participate in screening are hypothesised by several social cognitive models (e.g., TPB, HBM, TTM) to increase screening intention and participation. Perceptions of control are generally described as either internal (the person believes that they have control over their own actions) or external (the person believes that their actions are controlled by external factors) (Conner & Norman, 2005).

Self-efficacy (Bandura, 1982) is one control belief that has received considerable attention in the CRC screening literature (Kiviniemi, et al., 2011). Self-efficacy is included in several social cognitive theories (e.g., SCT, TPB) and sometimes as an
additional component in the HBM (Conner & Norman, 2005). Self-efficacy is a wholly internal concept that predicts behaviour is a function of an individual’s perception that they possess the competence to complete certain tasks (Schwarzer & Renner, 2000). Self-efficacy is context specific and normally assessed by participants’ perceived ability to perform the task (i.e., FOBT screening) despite potential barriers to participation (e.g., aversion to testing) (Luszczynska & Schwarzer, 2003). Self-efficacy has been found to increase intentions (Kiviniemi, et al., 2011; Menon et al., 2007) and participation in FOBT screening (Beydoun & Beydoun, 2008; Hay, et al., 2003; Kiviniemi, et al., 2011). Mammography research also suggests that self-efficacy may be important for maintaining rescreening participation due to its role in managing relapse, with those with higher perceived self-efficacy having more optimistic beliefs about their capacity to deal with potential barriers during the maintenance period (Luszczynska & Schwarzer, 2003). Similarly, data collected both before and after FOB test completion have shown increased perceptions of self-efficacy for screening following participation (Flight, Wilson, & McGillivray, 2012) suggesting better self-efficacy for subsequent rescreening.

Alternatively, Wallston, Studler Wallston & DeVellis (1978) have proposed a global measure for use in understanding the influences of control on health behaviour in general that incorporates both internal and external components. The Multidimensional Health Locus of Control Scale (MHLC) measures control according to three subscales; 1) Internal Health Locus of Control, which measures the extent to which an individual feels they are in control of their own health, 2) Chance Health Locus of Control, which measures the extent to which a person believes that their health is controlled by chance or fate, and 3) Powerful Others Locus of Control, which measures the extent to which a person believes that other people (doctors, family members) have control over their
health. The assumption of this model is that internal and external components of control are (partially) independent contributors to variance in health behaviours. In other words while someone may score low on Chance as a factor in health outcomes this may be paired with a belief in the important potential influence of the doctor (i.e., Powerful Others). The MHLC has received little attention in the CRC literature; Gregory et al. (2011) found lower scores on chance locus of control to be significantly associated with initial screening intention only, whilst an early study by Myers et al (1990) reported a univariate association between increased internal control and rescreening. Despite its infrequent use, the MHLC provides a potentially useful way of measuring external sources of control that is relevant for health behaviours.

**Social influence.**

Social influences may also play an important role in encouraging screening and rescreening participation. Social cognitive models frequently include measures of social influence (e.g., TPB, SCT) and epidemiological studies have consistently established the predictive validity for screening (Beydoun & Beydoun, 2008; Kiviniemi, et al., 2011).

Social influence can function in a number of ways. The TPB for example, includes a measure of subjective norms which refers to the individuals perception that there is pressure from ‘significant others’ e.g., family, friends, health providers, to perform the desired behaviour. However, extensions of the model suggest that descriptive norms, i.e., social pressure to perform a desired behaviour based on the perception that significant others also perform the behaviour, can also influence intentions to participate in preventive health activities (Conner & Norman, 2005). Perceived social pressure from significant others to perform the behaviour (i.e., subjective or injunctive norms, Conner & Norman, 2005) has received the most attention in CRC screening
(Manne, Kashy, Weinberg, Boccarino, & Bowen, 2012; Tiro, Vernon, Hyslop, & Myers, 2005; Zajac et al., 2010). The TPB hypothesises subjective norms to be associated primarily with forming an intention to participate, however there is evidence to suggest perceived social norms/influences to participate in screening is also associated with uptake of screening (Beydoun & Beydoun, 2008; Cole, et al., 2002; Kiviniemi, et al., 2011; Zajac, et al., 2010).

General practitioner endorsement is a specific form of social influence that has received considerable attention in the screening literature (Beydoun & Beydoun, 2008; Zajac, et al., 2010). Several intervention studies have found that invitations to screen with FOBT, which are endorsed by a general practitioner, achieve higher rates of both initial (Cole, et al., 2002) and ongoing participation (Zajac, et al., 2010). These data suggest that GPs have the potential to encourage initial, and reinforce continued, CRC screening and rescreening. Consequently, as highlighted in the previous chapter, several studies have found that frequent general practitioner visits are also associated with initial (Schenck, et al., 2011; Zarychanski, Chen, Bernstein, & Hebert, 2007) and repeat FOBT compliance (Fenton, et al., 2010). It remains unclear whether this effect is a result of more frequent visits increasing the opportunities for GPs to recommend screening, or if it reflects a predetermined characteristic that motivates participation in preventive health activities generally. Although satisfactory patient-provider communication has been associated with uptake of screening in intervention trials (Maxwell, Bastani, Crespi, Danao, & Cayetano, 2010), several studies have also found that not all GPs recommend, or even support FOBT, screening during routine checkups (Aubin-Aug et al., 2011).
Implementation intentions.

Many of the social cognitive factors described above have been found to be associated with both intention and participation (Kiviniemi, et al., 2011). However, there is evidence to suggest that amongst the same sample, some social cognitive predictors (e.g., susceptibility) may be less important for predicting participation compared with intention (Gregory, et al., 2011).

Gollwitzer (1999) suggested implementation intentions, that is the linking of plans to participate in a behaviour with the ‘when, where and how’ the behaviour will take place, strengthens behavioural intention subsequently increasing the likelihood that the behaviour will be performed. The effect of forward planning on CRC screening uptake has received little attention, despite evidence that the development of implementation intentions has been shown to increase participation rates for breast cancer and ovarian cancer rescreening (Andrykowski, Zhang, Pavlik, & Kryscio, 2007; O’Neill et al., 2008) and promotes transitions between the TTM stages of change for a variety of health behaviours (e.g., dental hygiene and dietary habits, Armitage, 2006; Schüz, Sniehotta, Mallach, Wiedemann, & Schwarzer, 2009). Flight et al. (2012) found that participants mailed a free FOBT kit and encouraged to record their plans for when, where and how they would complete the test, were not significantly more likely to complete the test than those who did not record plans.

There has been no research on the effect of implementation intentions on the enactment of self initiated screening. The mailing of a screening questionnaire and a free FOBT kit has been shown to consistently improve screening uptake compared with the questionnaire alone in a randomised controlled trial (Church et al., 2004). The mailing of free FOBTs removes many of the structural and economic barriers associated with
screening. Therefore it is likely that the formation of implementation intentions will be more relevant for developing plans about when to rescreen than they are for forming plans for completion of a mail delivered FOBT, particularly as hypothesised barriers to rescreening include those associated with establishing a rescreening routine (Watson-Johnson, et al., 2011). For example, for mammography screening, which involves action on the part of the participant to organise, book and attend screening, developing plans for future participation (e.g., organising time off work, arranging travel to the appointment, thinking about when they will next screen) has been shown to increase participation in screening (Steadman, Rutter, & Quine Lyn, 2006) and intentions for rescreening (O’Neill, et al., 2008).

**Thesis Aims**

Chapters one and two highlighted two primary gaps in the CRC rescreening literature. Firstly, very few studies have described patterns and variations in rescreening compliance, particularly beyond two rounds of screening. Secondly, no rescreening research has examined associations between behavioural variables and rescreening behaviour. This thesis has two general research aims;

1. To describe rescreening adherence in a South Australian population-based sample according to multilevel descriptive frameworks.

2. To determine the utility of social cognitive variables in the explanation of variance in rescreening intention and behaviour.
Within the wider aims, each of the three papers presented in this thesis were designed to address specific aims as outlined in the points below. Each paper aimed to explore the broader research aims in different contexts.

1. Explore and identify social cognitive variables that may explain variations in rescreening behaviour.
2. Describe participants according to readiness (intention) to rescreen for CRC according to the TTM staging framework and identify demographic, background and social cognitive variables that differentiate those in the different stages.
3. Describe patterns of participation in three consecutive FOBT screening opportunities and identify demographic, background and social cognitive variables that predict variations in patterns of longitudinal adherence to FOBT screening.

**Methodology**

This thesis used a sequential mixed methods approach to address the study aims. Despite the available literature on social cognitive predictors of initial screening, very little is known about the relevance of these variables to explain rescreening adherence. In order to identify social cognitive variables relevant for inclusion in future rescreening research, a qualitative, exploratory study was conducted with a group of rescreening participants. The purpose of this investigation was to inform the development of a large quantitative questionnaire designed to measure and predict rescreening intention and adherence.

There are generally two types of mixed methods research designs; concurrent designs (data are collected and analysed simultaneously) and sequential designs (studies are sequentially conducted and analysed separately with the results of one leading to the next) (Tashakkori & Teddlie, 2003). The selection of both the model
design and the rationale behind this selection are crucial components for conducting and evaluating mixed methods research (Creswell, Fetters, & Ivankova, 2004; Dures, Rumsey, Morris, & Gleeson, 2011). This thesis employed a qualitative-quantitative sequential design. The qualitative data were analysed separately and used to develop the questionnaire used in the subsequent quantitative analyses. The primary aims of this thesis were to describe and predict rescreening behaviour therefore the theoretical drive was largely deductive, and priority was given to the quantitative (questionnaire) elements (Morse, 2003). Creswell, Fetters and Ivankova (2004) refer to this approach as the ‘instrument design model.’

An advantage of a mixed methods approach is that it has the ability to capitalise on the strengths of both qualitative (i.e., exploratory, inductive) and quantitative (i.e., theory testing, deductive) techniques (Tashakkori & Teddlie, 2003). Qualitative research methods have been frequently utilised to develop questionnaires in the cancer screening literature (Collins et al., 2010; Engelman et al., 2010; Weitzman, Zapka, Estabrook, & Goins, 2001) and have proven to be useful for the exploration of participants’ screening experiences leading to the development of survey tools (Engelman, et al., 2010), intervention studies (Menon et al., 2008) and national screening programs (Bethune & Lewis, 2009; Woolcott, 2004). In Australia, a qualitative evaluation of participants’ experiences of screening for bowel cancer during the Australian NBCSPP (Woolcott, 2004) was conducted in order to inform the ongoing development of the national screening program. This approach was particularly salient for this thesis given the limited research in the area.
Thesis Design

Data for this thesis were collected at three sequential time points in order to address the three specific aims described above. Detailed information on each study is provided in the corresponding chapters. A brief summary is provided below.

To identify social cognitive variables that may explain variations in rescreening behaviour (aim one, paper one) semi structured interviews were conducted with 17 people who had previously participated in FOBT screening (i.e., actual and potential rescreeners). Data were analysed using qualitative methods. The purpose of this study was not only to explore variables potentially predictive of rescreening adherence but also to inform the development of a quantitative survey instrument to address aims two and three. Interviews were conducted in May of 2008.

A behavioural questionnaire, from here on referred to as the Rescreening Questionnaire, was developed based on the results of the qualitative analyses. The rescreening questionnaire included social cognitive, demographic and other background measures to assess participants’ attitudes and behaviours concerning FOBT screening. Detailed information on the rescreening questionnaire is provided in chapter four. The rescreening questionnaire was mailed to a random sample of 4000 men and women aged 50-74 living in South Australia in November of 2008. The response rate was 49% (1941/4000). The data collected in the rescreening questionnaire were used to address aim two, paper two. In order to identify social cognitive, demographic and background variables associated with intention to rescreen for CRC with an FOBT only those who indicated in the questionnaire that they had used an FOBT in the past (i.e., before they
were invited to participate in the rescreening questionnaire, self-report data) were included in the analyses (n= 849).

Following questionnaire completion, all questionnaire respondents (irrespective of any previous screening experience reported in the questionnaire) were mailed three consecutive opportunities to participate in a free Faecal Immunochemical Test (FIT). Screening was offered at annual intervals beginning in November of 2008 and finishing in November of 2010. The data collected in the rescreening questionnaire, and the adherence data collected following the three year screening observation period, were used to address aim three, paper three. Screening offers were managed by the Bowel Health Service (BHS), Repatriation General Hospital (RGH) Daw Park in South Australia. Screening offers were administered through the mail at no cost to the participant. Screening tests were processed at the BHS and participants were informed of their test result through the mail. The BHS provided informational support and assistance for arranging follow up examinations (e.g., colonoscopy) where required. Consistent with the NBCSP participants were responsible for covering any additional costs associated with follow up testing. During the three year observation period data were collected on both adherence to the FIT screening offers and any other self-reported screening participation (either FOBT or endoscopic screening) that may have occurred independent of the study screening offers. Chapter five describes how these self-report data were obtained and incorporated into the study outcomes. Those who reported participating in endoscopic screening during the three year screening observation period were excluded from analyses as the primary focus was on adherence to FOBT.

This research was funded by a National Health and Medical Research Grant (NHMRC). As described above, thesis aims were addressed based on analyses utilising a
small sample of interview participants and a large study population invited to participate in a quantitative screening questionnaire and subsequent screening offers. Thesis aims two and three analyse two overlapping subpopulations of those invited to participate in the questionnaire and the screening offers. These subpopulations were selected to address the thesis aims, specifically the groups were selected in order to restrict the thesis analyses to an examination of FOBT rescreening. Figure 1 describes the flow of survey respondents into the two different quantitative papers whilst Table 5 summarises all thesis aims, papers in which these aims are addressed, study outcomes and inclusion criteria for analyses.

Figure 1 NHMRC project overview and thesis subpopulations

<table>
<thead>
<tr>
<th>NHMRC study</th>
<th>Exclusions</th>
<th>Thesis analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rescreening questionnaire mailed to N= 4000</td>
<td>n= 148 missing data&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Aim 2, paper 2 n= 859</td>
</tr>
<tr>
<td>Non respondents n= 2,059</td>
<td>n= 944 no previous experience with FOBT (determined via questionnaire response)</td>
<td></td>
</tr>
<tr>
<td>n= 13, request no further contact following questionnaire</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rescreening questionnaire respondents, n= 1941</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIT screening offered to n= 1928 (three year observation period)</td>
<td>n=148 missing data&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Aim 3, paper 3 n= 1540</td>
</tr>
<tr>
<td></td>
<td>n= 240 self-report participation in endoscopic screening</td>
<td></td>
</tr>
</tbody>
</table>

Note: <sup>a</sup>for the thesis analyses utilising questionnaire data those who completed less than 80% of the total questionnaire were excluded from analyses. Details are provided in chapter four.
Table 5 Aims, sampling frame, sample size and outcome measures for the three thesis paper

<table>
<thead>
<tr>
<th>Qualitative</th>
<th>Quantitative, questionnaire response rate 49% (1941/4000)</th>
<th>Quantitative, questionnaire response rate 49% (1941/4000)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Paper one (2008)</strong></td>
<td>Qualitative exploration of participants experiences screening and rescreening with faecal occult blood tests for colorectal cancer.</td>
<td>Using the Transtheoretical Model to describe readiness to rescreen for colorectal cancer with faecal occult blood testing.</td>
</tr>
<tr>
<td><strong>Aim</strong></td>
<td>Explore and identify social cognitive variables that may explain variations in rescreening behaviour (aim 1).</td>
<td>Describe participants according to readiness (intention) to rescreen for CRC according to the TTM staging framework and identify demographic, background and social cognitive variables that differentiate those in the different stages (aim 2).</td>
</tr>
<tr>
<td><strong>Sample</strong></td>
<td>Convenience sample of prior FOBT participants</td>
<td>Random selection of participants obtained from AEC electoral data (N=4000)</td>
</tr>
<tr>
<td><strong>Inclusion criteria for analysis</strong></td>
<td>Prior rescreening participants (N=17)</td>
<td>Rescreening questionnaire respondents who reported in the questionnaire that they had previously participated in FOBT screening (N= 849)</td>
</tr>
<tr>
<td><strong>Method</strong></td>
<td>Individual interviews</td>
<td>Self-report questionnaire</td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
<td>Description of influences on behaviour</td>
<td>Stage of readiness to rescreen (TTM)</td>
</tr>
</tbody>
</table>

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Summary

Social cognitive variables have been extensively examined in association with initial screening uptake however they are yet to be explored in the context of CRC rescreening. This chapter outlined several social cognitive variables potentially relevant for predicting rescreening intention and behaviour. Qualitative techniques were proposed to determine variables relevant for inclusion in a questionnaire to assess attitudes toward rescreening. Quantitative techniques were proposed to determine the relevance of social cognitive variables for explaining variations in rescreening intention and adherence.
Chapter Three, Paper One- Qualitative Exploration of Participants Experiences
Screening and Rescreening with Faecal Occult Blood Tests for Colorectal Cancer

Preface

Paper one reports on qualitative data obtained in interviews with participants who had previously screened for CRC with FOBT. The broad purpose of this study was to use qualitative exploratory techniques to identify variables relevant for inclusion in the rescreening questionnaire. Chapter two highlighted social cognitive variables associated with initial screening and their potential for inclusion in rescreening research. The majority of FOBT rescreening research however, has to date only identified demographic and background factors associated with rescreening. This exploratory study was conducted in order to explore any additional factors that may also be associated with rescreening behaviour.

Extensive research already exists on barriers to initial participation amongst those who have not yet participated in screening. This study therefore aimed to recruit only participants with prior screening experience (i.e., potential or actual rescreeners). Participants were recruited from a list of men and women who were previous participants in an average risk FOBT-based screening program coordinated by the Bowel Health Service (BHS) Repatriation General Hospital Daw Park that concluded in 2007. The aim was to recruit participants who had been adherent with rescreening during the program (i.e., participated in all screening offers, rescreeners) and those who had participated in earlier but not later offers (i.e., dropped out following earlier participation, relapse). The purpose of this distinction was because relapsed screeners and rescreeners were hypothesised to have different attitudes toward rescreening.
Invitations to participate in the interviews were mailed to 20 rescreeners and 40 relapse/drop out screeners. More invites were mailed to relapse/drop out participants in anticipation that recruitment would be more difficult amongst this subgroup (Galea & Tracy, 2007). The aim was to recruit the required number of participants to achieve data saturation, previous research has suggested that this can be achieved with as little as 12 participants (Guest, Bunce, & Johnson, 2006), therefore an initial mail out of 60 invitations, with an expected response rate of one in five (20%), was considered appropriate to address the study aims. Fifteen of those invited for interview contacted the university to volunteer participation, all of whom were previously adherent with the BHS program (i.e., rescreeners). A further two participants (also rescreeners) were recruited via snowball sampling techniques (Grbich, 1999). No relapse participants responded to the interview invitations. No further invitations were mailed as this method did not appear to be appropriate for recruiting relapse participants.

In an additional effort to recruit relapse participants, an advertisement was placed in two local “Messenger” newspapers within the council areas that were involved in the Australian National Bowel Cancer Screening Pilot Program (NBCSPP). Messenger newspapers are free weekly community newspapers that focus on local news and events. The two newspapers selected for the current study were the Portside Messenger, which covers Adelaide’s northern metropolitan beach suburbs and has a readership of 53,000 people, and the Weekly times, which covers Adelaide’s western beach suburbs along with the inner west city fringe suburbs and has a readership of 65,000 (NewsSpace The Site for Media Professionals, 2012). Together these two papers cover the majority of postcodes that were selected for inclusion in the NBCSPP. These communities were targeted in order to reach an audience with the greatest potential for
having completed at least one FOBT. The advertisement asked for those who had participated in at least one FOBT, and had decided not to screen again in the future, to contact the University. This approach was unsuccessful, no relapse participants contacting the university to participate following the advertising effort.

Difficulty recruiting those who are more averse to screening has been documented previously (Cole, et al., 2011). A similar study that interviewed relapsed mammography screeners recruited 128 women using cash incentives (75 dollars per interview) and utilised experienced recruitment officers targeting women in five American States (Watson-Johnson, et al., 2011). Such recruitment strategies were beyond the scope of this thesis. Interviews were therefore conducted with the 17 rescreeners who were recruited solely through the mailed recruitment effort (prior BHS screening participants).

The interview schedule and aims were adjusted to focus predominantly on the screening experiences of rescreeners only, for which a satisfactory sample size had been obtained, and included several questions designed to encourage discussions about potential barriers to reparticipation. Despite the limitations inherent with this approach, the attitudes of rescreeners toward screening and rescreening as well as their perceptions of potential barriers to rescreening were considered worthwhile contributions to future research focusing on rescreening behaviour. In particular the study aimed to focus on differentiating factors associated with initial and rescreening experiences in order to identify potentially unique facilitating/impeding factors for rescreening. Whilst chapter two outlined several potential social cognitive variables for explaining rescreening behaviour the approach to analysis in paper one was exploratory. The aim of this approach was to allow for the exploration of new themes
and ideas without being restrained by pre-existing theoretical frameworks. The results of these analyses were then included in the rescreening questionnaire to determine the influence of identified themes on a broader more representative sample.

Note- this study has been formatted for submission to the Journal of Nursing Research and is included here as a manuscript in its entirety including abstract.
Abstract

Background: Repeated participation in faecal occult blood test (FOBT) screening for colorectal cancer (CRC) is required for reductions in incidence and mortality; However, to date there have been no studies to explore behavioural factors associated with repeated participation.

Objectives: This study reports on an exploration of participants’ experiences of, and attitudes toward, initial and repeated screening with FOBT with the primary aim being to inform the development of future research and survey instruments.

Method: Semi structured telephone interviews were conducted with a purposive sample of 17 people who had used an FOBT at least once in the past. Interviews were designed to elicit descriptions of both initial and subsequent participation in FOBT screening along with motivating or impeding factors associated with each. Analysis was conducted within the framework of inductive thematic analysis.

Results: Results indicated few differences between the motivations behind initial and repeated screening participation; many behavioural factors associated with initial participation appeared relevant for future rescreening research. These included barriers and benefits of participation, health value, locus of control, knowledge and perceptions of disease severity and susceptibility. Previous participation in screening did however appear to influence perceived and actual benefits and barriers to participation, with rescreening participation largely impeded by structural barriers (e.g., establishing a screening routine) as opposed to those associated with aversion to testing.

Discussion: Results highlight the importance of considering prior screening experience when evaluating rescreening participation. In addition, the use of variables previously
associated with initial screening appeared relevant for inclusion in studies of rescreening. Future studies should consider longitudinal approaches to best explore how these influences operate and change throughout the screening cycle (i.e., from initial to repeated participation).

Key Words: early detection of cancer, qualitative research, health behaviour.
Background

Colorectal Cancer (CRC) is the third most commonly diagnosed cancer in males, and the second in females, worldwide (Jemal, et al., 2011). National screening programs using annual or biennial Faecal Occult Blood Tests (FOBT) are run in many European countries (France, Denmark, Italy), the United Kingdom and Australia among others (V. S. Benson, et al., 2008). The success of these programs is dependent on continued participation in FOBT screening every one to two years (Hardcastle, et al., 1996; Jorgensen, et al., 2002; Mandel, et al., 2000). Longitudinal adherence to screening recommendations however have been reported to be as low as 13.7% (Gellad, et al., 2011). Research programs therefore need to focus not only on encouraging initial screening uptake but on identifying factors that may encourage maintenance of this behaviour over time.

Although substantial research has been conducted on ways of improving initial CRC screening uptake (Gregory, et al., 2011; Holden, Jonas, Porterfield, Reuland, & Harris, 2010; Kiviniemi, et al., 2011), there have been very few studies to consider factors that influence maintenance of this behaviour. Research, primarily from amongst the mammography literature (Gierisch, et al., 2010; Rauscher, et al., 2005; Watson-Johnson, et al., 2011), suggests that factors associated with initial or one off screening differ from those associated with continued compliance. The experience of having previously participated in screening in particular has been suggested to contribute to differences in attitudes toward initial and repeat compliance (Gierisch, et al., 2010; Tang, Patterson, Roubidoux, & Linping, 2009). Despite substantial evidence to support the use of behavioural measures for predicting initial CRC screening uptake (Beydoun & Beydoun, 2008; Kiviniemi, et al., 2011) CRC rescreening studies to date have focused
primarily on determining demographic and/or health systems factors associated with rescreening adherence (Cooper & Doug Kou, 2008; Fenton, et al., 2010; Garcia, et al., 2012; Gellad, et al., 2011; Janda, et al., 2010). Studies focusing on the variety of additional behavioural factors that could potentially influence rescreening behaviour are required to broaden the existing literature on rescreening.

The purpose of the current study was to explore previous screening participants’ experiences with initial and subsequent participation in order to compare and contrast the factors associated with each. Due to the limited amount of research conducted in this area we used qualitative techniques with the aim of identifying behavioural variables that have not previously been explored in the context of rescreening. Semi-structured interviews with a small sample of rescreeners were used with the primary aim to identify factors relevant for inclusion in a questionnaire about attitudes to rescreening.

Method

Selection criteria.

Interview participants were English speaking, aged 50 and over, and had screened at least once for CRC with a FOBT. Only people who had previous experience screening with FOBT and were within the target age group for CRC screening in Australia (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005) were approached to participate. All participants were at average risk for CRC, which means that they had no significant personal or family history of CRC or irritable bowel conditions (Rozen, et al., 2006).
Recruitment.

Participants were recruited from a list of previous research participants involved in an average risk screening program run by the Bowel Health Service (BHS) Repatriation General Hospital, Daw Park. As part of this program participants were provided with yearly FOBTs and five-yearly Flexible Sigmoidoscopy (FS). The program was developed in order to evaluate the effectiveness of interval screening for detecting CRC amongst an average risk population and finished in 2007. The program represents a purposive sample (Grbich, 1999) of people who had either been referred to the program by their general practitioner or had contacted the hospital themselves to enquire about available screening programs. Sixty participants, all of whom had completed at least one of the FOBT offers, were invited for interview. These people were approached in order to investigate the perceptions of, and attitudes to, screening among a sample of actual or potential rescreeners. Maximum variation sampling (Grbich, 1999) was used to ensure participants represented both genders and covered a broad range of ages. Ethics approval was obtained to contact prior screening participants.

Invitations to participate in the interviews were mailed from the hospital outlining the aims of the study. Included with the invitation letter were a reply-paid envelope and a reply slip, on which interested participants could provide their telephone number or email address. In addition all interviewed participants were asked if they knew of anyone else who would be interested in participating in the study (snowball sampling, Grbich, 1999). Interviews were conducted until data saturation was reached (Guest, Bunce, & Johnson, 2006).
Interviews.

Interviews were conducted over the telephone and lasted approximately half an hour. Consent was obtained over the phone and participants were also asked if they would consent to having the interview recorded.

The main focus of the interviews was to gather information on participants’ knowledge of colorectal cancer and screening, their experiences screening with FOBT as well as motivating or impeding factors associated with participation with particular emphasis on separating influences on initial screening participation from influences on rescreening behaviour. Interviews were minimally directive to allow for the emergence of new themes and ideas. Interviews were recorded and transcribed by the interviewer.

Analysis.

The data were analysed according to the principles of inductive thematic analysis (Pope & Mays, 1995). This method has advantages for the present study as the primary aim of this approach is to provide a rich overall description of the data set without being constrained by pre-existing codes (Braun & Clarke, 2006).

The data were analysed in accordance with the five phases of thematic analysis as outlined by Braun and Clarke (2006). Firstly, the entire data set was read in order to allow familiarisation with the data. Codes were developed during phase two and then further developed into potential themes, which explain the codes in more detail in relation to the research question, during phase three. The fourth phase involved reviewing the themes and establishing how these could be meaningfully organised to describe the data set. Finally the themes were defined and named providing detailed information about each theme. The themes were organised according to how they relate
separately to initial screening participation and repeated screening participation, or both, to allow for comparisons between the two.

Results

Participants.

Fifteen members of the hospital screening program returned reply slips to participate in the study (25% response rate). An additional two participants also volunteered to participate following a recommendation from a previous interviewee (i.e., identified via snowballing).

A total of 8 women and 9 men participated in the interviews (N=17). Ages ranged from 51 to 77 with a mean age of 65.71 (SD=7.5). The majority of participants were married (n=12) whilst those remaining were widowed (n = 3) or divorced (n=2). Participants had either screened previously with the hospital program (n=15) or as part of the Australian National Bowel Cancer Screening Program (NBCSP) (n=2). The majority of participants were rescreeners (n=14) with many being unable to recall exact numbers of screening tests completed. Three participants were potential rescreeners (having screened once previously for CRC) all of whom indicated intentions for future participation. Disparities in years of screening experience were not considered problematic as all participants had prior screening experience and the potential for rescreening participation.

Factors associated with participation in initial and repeated screening.

Themes related to participation in either initial, repeat screening or both are outlined in Table 6. In many cases it was unclear whether factors were associated with either initial or rescreening, often participants would simply refer to ‘screening’ as a
whole when discussing their motivation. In these cases the data are presented as being associated with both initial and repeat compliance. However, interview questions that related to screening experiences, initial reactions to testing and knowledge of CRC and screening facilitated discussions that did elicit specific responses to initial and rescreening compliance and associated factors. It was also apparent throughout the conversations that some factors associated with overall screening compliance appeared to be associated differently for initial and repeat compliance. For example, becoming a certain age was associated with initial uptake, whilst increasing age was associated with rescreening compliance. These distinctions are made clear throughout the text.

Table 6 Factors associated with participation in initial and repeat screening

<table>
<thead>
<tr>
<th>Factor</th>
<th>Initial</th>
<th>Repeat</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• CRC (e.g., awareness of risk factors)</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>• Rescreening awareness</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Benefits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Ease of completion</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Convenience</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>• Reassurance</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>• Early detection</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Barriers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Aversion to testing</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Fear</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Stigma</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Remembering when to screen</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Obtaining future screening tests</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• GP influence and recommendations</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>• Social influence: knowing someone with CRC</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Social influence: discussions of CRC and screening</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Health value and health maintenance</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Control</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
Knowledge.

Risk factors.

Participants demonstrated good knowledge of CRC and the associated risk factors; those most commonly mentioned were age, family history and lifestyle. Whilst age and family history often increased participants’ perceived susceptibility to the disease and thus motivated participation in initial and repeated screening, lifestyle factors (e.g., diet) were viewed more as a form of primary prevention and did not appear to directly motivate participation. Age was the only risk factor that functioned differently to motivate initial compared with repeat screening. Whilst becoming “a certain age” tended to motivate initial participation, increasing age was associated with the need to continue screening.

Interviewer: “can you tell me why you think you decided to keep doing the screening [following initial participation]?”

Participant: “oh, because I am getting older I guess and therefore more prone possibly to have cancer.”

Interestingly, increasing age was also mentioned by two of the participants as a reason to increase the frequency of repeated screening.

“I think that maybe they [screening programs] could make it a bit more often the older that you get there might be this, um, maybe 55 maybe once every two years and 60 maybe once a year or something.”

Importance of rescreening.

Despite some confusion concerning the recommended frequency of screening, the need to rescreen was well understood. Participants were aware that CRC could “pop up at any time” and this motivated rescreening compliance. A lack of awareness of the need for rescreening was also often suggested as a possible barrier to rescreening amongst ‘other’ non-compliant people.
“I would think people could become complacent having had the test and having a negative result then they might think, “oh well, I’m ok for a few years”, and I can only think they’d be lulled into a false sense of ah... what can I say, wellbeing?”

**Benefits.**

**Ease.**

Screening was predominantly described by participants as easy, simple and convenient. Despite reported ease and simplicity of the testing, participants descriptions of their initial reactions to the test were generally quite adverse, indicating that positive attitudes toward ease and use came after initial compliance.

*Interviewer:* “and what was your initial reaction to this offer [first FOBT] when it arrived?

*Participant:* “oh well I er, I was a bit confused to start (laughs) but no it’s quite simple, yes.”

Participants also frequently reported that FOBT became even easier and more ‘routine’ with repeated use.

**Convenience.**

Convenience was predominantly related to involvement in the hospital program where FOBT’s were delivered yearly through the mail at no cost to the participant. Many participants were very satisfied with this screening program and disappointed at its closure. This convenience also appeared to result in opportunistic forms of screening with many becoming involved in screening and staying in the program simply because the offer was there and the test was free. This was also the case for three participants who had screened outside of the program. Two participants whose prior experience had been with the NBCSP admitted their initial involvement was entirely because the FOBT was sent to them. Another participant who screened prior to involvement in the hospital
program screened initially because his wife had arranged for it to be mailed to him. NBCSP participants had only screened the one time but intended to screen in the future, only “if they keep sending them [the FOBT tests], yes”.

Reassurance.

A ‘sense of knowing’ about possible colorectal cancer was both a major motivator and a benefit of initial and continued screening compliance. For most participants the perceived reassurance that could be achieved following initial participation motivated involvement. This was then confirmed with actual reassurance following completion, motivating continued compliance as highlighted by one participant, “I just think it’s an excellent way of marking one thing off that your body could be free of.”

Early detection.

The majority of participants were aware that screening leads to early detection and that early detection improves treatment options. Early detection was therefore a perceived benefit of participation and a motivating factor for both initial and repeat compliance. Early detection also directly motivated rescreening participation for 5 participants for whom the detection and removal of polyps had occurred in prior screenings.

Barriers.

Participants were overwhelmingly positive about screening and therefore found it difficult to suggest any barriers to participation when asked directly. Discussions of barriers therefore were largely related to why ‘others’ (i.e., non-compliant screeners) may not want to participate in initial or repeated screening.
Aversion, fear and stigma.

Faecal aversion, fear of finding cancer and stigma concerning the “bowel area”, were all suggested as potential barriers to initial participation. However, amongst study participants these barriers were outweighed by the benefits of screening.

“Rubbing a toothbrush, er rubbing a paintbrush, around in, in your stool, in the toilet is far easier than waking up with the realisation that you’ve got well progressed bowel cancer.”

Faecal aversion or unpleasant experiences with screening tests were suggested by a small few as a potential barrier to rescreening; however these barriers did not impede participation for study participants. Even those who reported unpleasant experiences with follow up examinations, such as colonoscopy, said that they would screen again with either method. Aversion to the testing therefore was described as a perceived barrier to screening, one that ceased to be relevant having actually completed a screening test.

Whilst participants had difficulty understanding why someone might not want to rescreen, they often mentioned structural barriers to rescreening that they themselves faced, or imagine they will face, since the completion of the hospital program.

Remembering when to rescreen.

Difficulty remembering when to screen was a major rescreening barrier for many study participants. Because the majority were members of a regular screening program, FOBT kits were sent yearly, which was a major benefit of the screening program and also identified as something that would be difficult to maintain now that the program had finished.
Participant 1: “I’d prefer a [screening] program because if there wasn’t a program I would have to write it down on a calendar and go to the trouble of remembering it myself wouldn’t I?”

Participant 2: “If you have people like you [the interviewer] ringing people, you know, sending letters out, you know, you’ve got a chance [to increase screening], you know?”

Reminders were often suggested as an important way to improve screening compliance outside of a structured program.

**Obtaining future screening tests.**

Although not specifically stated by study participants as a barrier to rescreening, conversations concerning the cessation of the screening program indicated that study participants were previously quite reliant on the program to facilitate screening. The majority of participants were aware that they could go to their doctor for information on how to screen, however many were yet to follow through on this notion and were close to becoming overdue for screening.

Participant 1: “I’m about due for another one [FOBT] now, now I’m not quite sure what I’m going to do about it I don’t even know, but ill speak to my doctor about how I go about it.”

Participant 2: “well they’ve stopped the ah the thing [hospital program] now, so I’m not quite sure what to do frankly”

It was observed that one participant was overdue for screening (having previously screened on an annual schedule); she had not participated again because she had not been sent a test.

**Interviewer: “over a year ago [last screening test completion], so last year in January?”**

**Participant:** “yes yep, because they sent me a letter to say that they weren’t continuing with the program.”
Social factors.

General practitioner recommendations and interactions with health care providers.

The majority of respondents originally participated in screening as a result of a doctor’s referral into the hospital program therefore doctors were repeatedly identified as an important source of both influence and information about CRC and screening. As health care providers, doctors were viewed as the most informed on the topic of CRC screening and their advice appeared to be more influential than other sources of information. One participant highlighted this by comparing doctor recommendations with those of the media,

*I suppose the doctor’s awareness, um, if doctors encourage people, and that’s what, you know, my doctor encouraged me to do it and that’s why I did it. If I’d seen it, you know, on television or something that said “ring this number” I probably wouldn’t have done it.*

Doctors were also seen as important agents for facilitating rescreening. Two participants, suffering from other health issues, highlighted that they would screen again when their doctor recommended it to them as opposed to independently following screening guidelines and it was also suggested that screening for CRC be included in regular “health checkups” in order to avoid relapse.

Interactions with friends and family.

Social support and endorsement were identified as important influences, predominantly for initial screening compliance. For a substantial portion of respondents knowing someone who had had CRC increased their perceptions of severity of the illness and raised awareness of CRC, motivating participation in the screening program.

*well when I chose to do it my main reasons were um when I could er, id seen so many people come down with bowel cancer and ah I thought well I’m not going to be one of those so if I’ve got it I’ll do something about it.*
Discussions with friends and family members about CRC and FOBT screening were also common amongst study participants, however it is not clear whether this directly influenced decisions to screen or rescreen. It was acknowledged by some respondents that this willingness to discuss CRC and screening was an uncommon characteristic and that their perception of CRC is that it is a “private” disease. Increasing public awareness of CRC was therefore suggested as an important overall screening facilitator.

**Health Value.**

Throughout the interviews many participants stressed the importance of looking after ones health and this was often a motivating reason to participate in initial and repeat screening. Study participants viewed the need to stay healthy as ‘common sense’ and this led to an increased desire to participate in programs, such as screening, that provided an avenue for health maintenance.

“Yeah I was perfectly happy [to participate] because I think, aren’t most people? Because, you know, we are pretty interested in keeping healthy.”

**Control.**

Interest in general health maintenance was a prominent characteristic of the sample with many participants keeping regular doctor appointments and others even keeping ‘health diaries’ documenting their health status and adherence to testing recommendations (not CRC screening specifically). Also evident in discussions about the importance of health was participants’ interest in having control over their health status; “you can’t rely on other people to look after your health”. Again, the extent to which this is a unique characteristic affecting rescreening compliance is unclear.
Discussion

Discussions with rescreening participants highlighted several areas of consideration for further rescreening research. The primary aim of the study was to identify factors associated with repeat compliance. However, participants demonstrated difficulty separating repeat from initial compliance often referring to ‘screening’ as a whole when discussing their reasons for involvement. This tendency to discuss ‘screening’ as opposed to initial and repeat screening suggests that amongst study participants initial and repeated screenings were not thought about as separate events, but an ongoing process. However, discussions concerning experiences with screening or initial reactions to the testing were able to provide some clarity around possible predictors of repeat participation. Discussion of barriers to screening also assisted in distinguishing correlates of initial and repeat screening.

The themes identified as being associated with screening and rescreening are largely consistent with the published literature. Important influences included weighing-up of barriers and benefits (Janz & Becker, 1984; Rawl, et al., 2005), health value (Lau & Hartman, 1986) and health maintenance behaviours (Berkowitz, et al., 2008; Janda, et al., 2010; Menees, et al., 2010), control (Bandura, 1982; Gregory, et al., 2011; Wallston, et al., 1978), doctor recommendations (Zajac, et al., 2010), knowledge (Berkowitz, et al., 2008; Janda et al., 2003) and perceptions of severity and susceptibility (Janz & Becker, 1984; Lipkus, Green, & Marcus, 2003). Nevertheless there appeared to be variations in the way factors operated to influence initial and repeat compliance. For example, the way in which age functioned to influence screening participation differed from initial to repeat compliance and there also appeared to be some variation in the impact of social influence from initial to repeat participation, amongst others. However,
due to the retrospective nature of the study, it was difficult to distinguish predisposing factors from those that resulted from regular involvement in a screening program. Rescreening research to date has not focused on the effects of behavioural variables on reparticipation (Fenton, et al., 2010; Janda, et al., 2010) and future research should consider including the above mentioned variables in studies designed to understand screening and rescreening compliance.

Existing screening literature provides many examples of how the themes identified in this study can be operationalised as quantitative measures. Tiro et al. (2005), for example, have developed validated scales to measure perceived social influence to participate in CRC screening from friends, family and health professionals. Similarly, Wallston et al. (1978) have developed scales designed to measure several dimensions of perceived control for health behaviours whilst Luszczynska & Schwarzer (2003) provide useful suggestions for the measurement of self-efficacy for specific health behaviours. Few validated scales are available for measuring perceived barriers and benefits toward FOBT screening (Rawl et al., 2001). However, there are several examples within the literature where studies have developed their own barriers and benefits scales designed to address specific research questions (for example, Gregory, et al., 2011; Hay, et al., 2003). Based on the results of the current study, future research aiming to develop barriers and benefits scales for rescreening should consider including items to address; ease of screening participation, perceived convenience of FOBT screening; psychological benefits and barriers (i.e., reassurance and aversion) and practical benefits and barriers (i.e., early detection outcomes and obtaining screening tests). Furthermore, in order to properly understand how these variables operate and change throughout the screening cycle the application of staging theories, such as the
Transtheoretical Model of Behaviour Change (Prochaska, et al., 1988) that allow for cross sectional comparisons of participants at different stages of screening, or longitudinal studies that regularly assess attitudes to screening would be beneficial.

Discussions of prior screening experiences provided some suggestion of possible differences in correlates of initial and repeat compliance. Past research has often focused on how perceptions of barriers and benefits associated with screening can facilitate or impede initial screening uptake (Gregory, et al., 2011; Kiviniemi, et al., 2011; Rawl, et al., 2005). However, discussions with rescreeners revealed how perceived and actual benefits and barriers may change following screening completion. For example many participants recalled being initially averse to screening. However, upon completion of the screening many reported is as easy and convenient, an attitude that was reinforced with repeated use of the test. Past participation in screening also appeared to reinforce the importance of early detection and reassurance.

Although perceived and actual benefits of participation continued to motivate adherence for repeated participation, there were some differences identified between barriers associated with initial and repeat participation. Following initial completion, participants were less concerned with the finer details of test completion and more concerned with establishing a screening routine and obtaining future screening tests. The reliance on screening programs to facilitate involvement is particularly problematic as structured repeated offer screening programs are yet to be established in Australia (Australian Government Department of Health and Ageing, n.d-b). Again, it was difficult to establish whether participation was associated with positive attitudes or vice versa, however it would appear that barriers associated with screening have the potential to change as a result of participation and that prior participation is an important part of
understanding future compliance. Future rescreening research would therefore benefit from the inclusion of measures designed to assess past participation in FOBT screening. Vernon et al. (2004) provide several suggestions for ascertaining previous use of CRC screening tests utilising self-report measures.

There were several limits to the generalisability and utility of the current study. Firstly, as already mentioned, the retrospective design not only relied on participants to recall motivations to participate from many years ago, but it was also difficult to distinguish whether factors were predisposing or arose in response to screening participation. Secondly, convenience sampling techniques resulted in a small, heterogeneous sample of rescreeners with largely positive attitudes to screening. Attempts to recruit non-rescreeners were made (targeted advertising in local newspapers, over sampling of program participants who were recorded as not regularly accepting the hospital screening offers) however time and study limitations prevented further recruitment efforts. It has been well documented that those who refuse participation in voluntary studies are characteristically and behaviourally different from those who do participate (Galea & Tracy, 2007) and in the current study such respondents may have provided some interesting contrasts to the attitudes observed here. However, the aim of the present study was not to establish cause and effect relationships between variables but rather to explore factors that might be relevant for an examination of rescreening behaviour. Characteristics observed amongst the study population, including good knowledge of CRC and screening, positive attitudes toward health and health maintenance and a willingness to discuss screening, differed from those identified in prior research as characteristic of screening non-adherence (Berkowitz, et al., 2008; Fenton, et al., 2010; 2010; Janda, et al., 2003). These findings
therefore provide a useful foundation to suggest variables for inclusion in a larger study that compares predictors of adherent and non-adherent rescreening behaviours.

Several suggestions for future rescreening research arose from the present study. Firstly, behavioural variables already identified as being associated with initial screening compliance appear relevant for inclusion in future rescreening research. Cross sectional or longitudinal studies are recommended as the most effective way of determining how these variables operate. Secondly, prior participation in screening should be considered when examining screening adherence as the experience has the potential to moderate attitudes toward screening.
Chapter Four, Paper Two- Using the Transtheoretical Model of Behaviour Change to Describe Readiness to Rescreen for Colorectal Cancer with Faecal Occult Blood Testing

This study has been published in the Health Promotion Journal of Australia and is presented here as a manuscript formatted according to the APA 6th edition consistent with the rest of the thesis. The pre publication version, formatted as it appears in the journal can be found in Appendix B.


Statement of Authorship:

Amy Duncan (Candidate)
Collected data, performed analyses on the data, interpreted the data, drafted and prepared the manuscript for review and responded to reviewer comments.
I hereby certify that the statement of contribution is accurate
Signed

Deborah Turnbull, Tess Gregory, Stephen Cole, Graeme Young, Ingrid Flight and Carlene Wilson (Co-authors)

Deborah Turnbull and Carlene Wilson provided ongoing supervision throughout the research program that led to this publication. The remaining co-authors were all Chief Investigators and/or employees on the grant that funded the data collection. Amy Duncan was responsible for writing this paper and for analyses and interpretation of data; the role of the co-authors was to comment on drafts, make suggestions on the presentation of the material and provide assistance with responding to reviewer and editorial comments. We give our permission for this paper to be incorporated in Amy Duncan’s submission for the degree of Doctor of Philosophy from the University of Adelaide.

Deborah Turnbull
Tess Gregory
Stephen Cole

Graeme Young
Ingrid Flight
Carlene Wilson
Preface

Paper two was the second empirical study conducted in this thesis. The rescreening questionnaire, developed based on the results of paper one, was used to collect data on intentions and attitudes toward rescreening in paper two. The outcome measure in paper two was intention to rescreen for CRC, which was defined according to the staging framework specified by the TTM (Prochaska & DiClemente, 1983; Rakowski, Dube, et al., 1996). Measures of prior self-reported adherence to FOBT screening recommendations were also obtained according to the guidelines outlined by Vernon et al. (2004) and Baier et al. (2000) for ascertaining self-report. Only those who had ever participated in an FOBT screening test in the past (i.e., before they completed the rescreening questionnaire) were included in the analyses in paper two. This was because the aim was to determine predictors of intention to rescreen for CRC, which necessitated prior experience with the behaviour.

Paper one indicated that variables previously identified as being associated with initial screening participation (those described in chapter two) would be relevant for inclusion in the rescreening questionnaire. Consistent with the literature on initial screening participation, the themes identified in paper one related to a variety of social cognitive constructs as opposed to complete models. Consequently the rescreening questionnaire included constructs central to a number of prominent models including: the HBM (Janz & Becker, 1984), the TPB (Ajzen, 1991), Implementation Intentions theory (Gollwitzer, 1999) and the TTM (Prochaska & DiClemente, 1983). The specific constructs and measures included in the rescreening questionnaire are described in more detail in the manuscript.
In addition to the social cognitive variables described in chapter two, the rescreening questionnaire included a measure of Health Value (Lau & Hartman, 1986) designed to measure the extent to which participants value good health. This measure is not CRC specific and was included to explore a potential underlying characteristic that motivates participation in preventive health activities as demonstrated by participants in paper one. In addition to a general measure of perceived benefits of screening participation, the rescreening questionnaire included a measure of response efficacy designed to measure the extent to which participants believe that participating in FOBT will result in detection of CRC if present (Boer & Seydel, 1996). Also included were several items designed to measure participants’ perceptions of the availability of social support for health decision-making (social support, Conner & Norman, 2005). This variable was included because participants in paper one reported frequent conversations with friends or family members about CRC and screening. Moreover, prior research has found that greater social inclusion (e.g., being married, having friends of family to discuss health problems with, involvement in community organisations) is related to increased screening compliance (Honda & Kagawa-Singer, 2006; Manne, et al., 2002; Ye, Williams, & Xu, 2009). Additionally, it has been documented that it is not the size of these networks, but the quality, that is associated with compliance (Honda & Kagawa-Singer, 2006; Manne, et al., 2002). Finally, the questionnaire included a single item to measure prior satisfaction with FOBT screening.

In summary, the rescreening questionnaire included several behavioural variables; social cognitive measures informed by the results of paper one and developed based on research from amongst the initial screening literature, and a measure of satisfaction with prior screening. Demographic and background variables previously
The complete rescreening questionnaire is included in Appendix A. The rescreening questionnaire included several scales and items that were not analysed in this thesis (e.g., section 3, home stool test screening decisions); results from these additional data will be reported elsewhere. The questionnaire was piloted with a small convenience sample (n=11) prior to use, however substantial missing data were observed for a small subset of questionnaire respondents (n=148, 7.62%). Questionnaire respondents with substantial missing data (greater than 20%) were excluded from all analyses in this thesis that utilised data obtained in the rescreening questionnaire (Hair, Anderson, Tatham, & Black, 1998). The adjusted response rate was therefore 1793/4000 (44.83%). Details of the excluded respondents are provided in paper two; results suggest missing data may have arisen as a result of language and/or age barriers. The complex questionnaire design may also have contributed to the missing data and is discussed in the overall limitations of this thesis.

This paper has been published in the Health Promotion Journal of Australia. The manuscript is included here in its entirety including abstract and has been formatted according to APA 6th edition. The manuscript as it appears in the journal is included in Appendix B.
Abstract

Issue addressed: This study used the Transtheoretical model of behaviour change (TTM) to describe reparticipation in colorectal cancer (CRC) screening according to social cognitive and background variables.

Methods: A random sample of men and women aged 50-74 years living in South Australia completed a questionnaire measuring TTM stage and attitudes toward screening using a faecal occult blood test (FOBT). Participants were categorised according to four stages of readiness to rescreen; action, maintenance, relapse and inconsistent. Multivariate techniques were used to determine predictors of lower readiness stages compared with maintenance.

Results: Of the 849 study participants, 29.9% were non-adherent or had no intentions to maintain adherence (inconsistent and relapse). Compared with maintenance rescreeners, relapse participants reported less; social influences to screen (RR=0.86, p<.001), satisfaction with prior screening (RR=0.87, p=.03), self-efficacy (RR=0.96, p=.01) and screening benefits (RR=0.84, p<.001). Relapse participants were also more likely to be unaware of the need to repeat screening (RR=1.41, p=.02) and to not have private health insurance (RR=1.33, p=.04). Inconsistent screeners were less likely to have planned when they will next rescreen (RR= 0.84, p=.04) and reported greater barriers to rescreening (RR=1.05, p=.05). Action participants were younger (RR= 0.98, p<.001), reported less social influences to screen (RR=0.94, p<.001) and were less likely to have known someone who has had CRC (RR=0.82, p=.01).
Conclusions: Social cognitive, demographic and background variables significantly differentiated screening maintenance from lower readiness stages.

So what? This is one of very few studies within the CRC screening literature to address behavioural factors associated with reparticipation and to extend the use of the TTM to explain CRC rescreening. An understanding of the variables associated with differing levels of non-adherence provides a useful foundation for the development of interventions to improve reparticipation.
**Background**

Ongoing commitment to screening for Colorectal Cancer (CRC) with faecal occult blood testing (FOBT) is crucial for reductions in morbidity and mortality (Mandel, et al., 1993). Screening programs utilising FOBT are run worldwide with national programs in many parts of Europe, Australia and the United Kingdom (V. S. Benson, et al., 2008). The success of such screening programs is dependent on continued participation according to recommended guidelines, which in Australia recommend FOBT screening at least once every one to two years from the age of 50 onwards (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005). However, reports from the Australian National Bowel Cancer Screening Pilot Program showed a substantial (approximately 20%) decrease in reparticipation rates amongst those who initially participated in FOBT screening (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005). Similar findings have been reported overseas (Faivre, et al., 1991; Weller, et al., 2007). Whilst patient reminders have been shown to moderately improve reparticipation (5-15% increase) (Holden, et al., 2010), few studies have examined the benefit of behavioural or education based interventions on reparticipation (Myers, et al., 1993). Early findings from the CRC (Myers, et al., 1993) and more recently the mammography screening literature (Clark, et al., 2002) indicate that behavioural interventions designed to improve initial screening uptake have no lasting effect on reparticipation. These findings highlight the need for a dedicated effort to understanding the factors associated with reparticipation for the development and trail of interventions aimed specifically at encouraging reparticipation.

CRC screening research has begun to acknowledge the need for a dedicated approach to understanding rescreening behaviour (Fenton, et al., 2010; Janda, et al.,
2010; Myers, et al., 1993). However, the majority of studies primarily view screening in terms of current adherence, grouping currently adherent screeners and comparing them with those who are currently non-adherent (Beydoun & Beydoun, 2008; Hay, et al., 2003; Menees, et al., 2010; Neilson & Whynes, 1995; Sewitch, Fournier, Ciampi, & Dyachenko, 2007). Stage theories of behaviour change, such as the Transtheoretical Model of Behaviour Change (TTM) (Prochaska, et al., 1988), provide an alternative way of categorising participants that incorporates measures of intention to participate, and past experience with the behaviour. Models incorporating prior experience and intention have been shown to better discriminate mammography rescreening compliance according to behavioural variables, than those that utilise simple adherence status (Rakowski et al., 1996). Similarly, prior screening experience has been shown to influence rescreening participation for mammography (Tang, et al., 2009) and CRC screening (Janda, et al., 2010; Menees, et al., 2010; Myers, et al., 1993). The use of stage theories as a foundation for intervention development has been well documented for a variety of health behaviours (Noar, Benac, & Harris, 2007) including cancer screening (Spencer, et al., 2005). The advantage of utilising stage theories to explain screening behaviour is that they describe behaviour change as the end point of a process, as opposed to a discrete event, taking into account the complex attitudinal and behavioural factors associated with different levels of readiness to participate.

The TTM, the stage theory most frequently applied to cancer screening behaviour (Spencer, et al., 2005), describes people as belonging to one of five different stages; pre-action (precontemplation, contemplation and preparation), action and maintenance. The model proposes that each readiness stage is characterised by differing behavioural and attitudinal variables (Prochaska, et al., 1988). The aim for health promotion programs is
to facilitate forward movement from the pre-action stages to action (initial participation) and finally maintenance (continued reparticipation). The TTM also includes a relapse stage where those who have previously participated in the behaviour discontinue participation in screening; these participants are also traditionally categorised by a lack of intention to reparticipate (Prochaska, et al., 1988). Recent research also suggests the potential for an additional ‘inconsistent’ category which includes those who screen intermittently but maintain intentions for future screening (Janda, et al., 2010; LaPelle, et al., 2008; Rakowski, Ehrich, et al., 1996). These inconsistent screeners have been found to be behaviourally different to traditional relapse participants in studies of mammography adherence (LaPelle, et al., 2008; Rakowski, Ehrich, et al., 1996). To date, the majority of CRC screening studies utilising the TTM have focused on the action stage (initial participation) (Brenes & Paskett, 2000; Duncan, et al., 2009; Menon, Belue, et al., 2007; Rawl, et al., 2005; Trauth, Ling, Weissfeld, Schoen, & Hayran, 2003) with few extending the model to describe screening maintenance and relapse.

The aim of the present study was to enhance understanding of the factors associated with intentions to maintain adherence to FOBT rescreening utilising an expanded TTM to compare those in the relapse, inconsistent and action stages with those in the maintenance stage according to demographic, background and social cognitive variables.

Methods

Participants were recruited as part of an ongoing longitudinal study designed to measure screening adherence in South Australia that began in 2008. The names and addresses of 12,000 men and women between the ages of 50 and 74 were obtained from
the Australian Electoral Roll. The names were randomly drawn from four large electoral
districts in South Australia (total population of 546,765, Australian Bureau of Statistics,
n.d) chosen for their broad socioeconomic range. Names were then checked against a
CRC high risk data base at a participating hospital responsible for managing a variety of
high risk programs and screening services in South Australia. Those identified as above
average risk (defined as having; a personal history of CRC, a family history of CRC, a
personal history of polyps or long term inflammatory bowel conditions, Rozen, et al.,
2006) were excluded. Following exclusions, the remaining names and addresses were
further randomised to select 4000 potential study participants. Human Research Ethics
Committee approval was obtained prior to beginning the study.

**Rescreening questionnaire.**

The questionnaire used in the present study was adapted from a previous
questionnaire, from here on referred to as the *initial screening questionnaire*, that
measured social cognitive and demographic predictors of initial screening uptake
Additional items and modifications to the initial screening questionnaire were then
made based upon the results of a pilot study that interviewed *rescreening* participants
(unpublished).

**Stage of readiness (Transtheoretical Model) for rescreening.**

TTM outcome measures were based on the research of Rakowski et al. (1996),
whose work has been widely used in the study of cancer screening behaviour (Spencer,
et al., 2005). Australian screening guidelines were used to identify stage of readiness as
they apply to FOBT screening (i.e., screening at least once every one to two years)
(Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005).
Stages were consistent with those described by Rakowski et al. Maintenance was defined as having participated in FOBT screening twice previously on schedule (no more than 24 months apart within the past four years) with intention to participate again on schedule (within the next two years). Action was defined as having participated in FOBT screening only once previously on schedule (within the past two years) with intention to participate again on schedule (within the next two years). Relapse was defined as having previously participated in FOBT screening (schedule not defined) with no intention to participate again within the next two years. Inconsistent screening was defined as having previously participated in screening, but not on schedule (screened more than two years ago) with intentions to screen again within the next two years. Participants were asked to select which one option they believed best described their experience with FOBT screening. Options for questionnaire respondents who had not previously participated in CRC screening with FOBT were provided however these were not included in the present analysis of rescreening intention.

**Planning the process of screening.**

Participants who indicated that they intend to screen in the future using a FOBT (action, maintenance and inconsistent), were asked to indicate the extent to which they knew *when* they would next screen, *where* they would obtain their next FOBT and *what steps* were required in order to complete their next FOBT (implementation intentions, Gollwitzer, 1999). Responses were measured on 5-point Likert Scales ranging from strongly disagree to strongly agree.
Social cognitive variables.

Health beliefs and attitudes toward screening.

A variety of variables consistent with the Health Belief Model (HBM) (Janz & Becker, 1984) and other social cognitive variables, previously associated with screening adherence (Cole, et al., 2011; Gregory, et al., 2011), were measured in the questionnaire. Variables were measured on 5-point Likert Scales with responses ranging from strongly disagree to strongly agree and measures were obtained by summing the individual items. Measures of perceived susceptibility, severity, chance health and internal locus of control were obtained from the initial screening questionnaire (Gregory, et al., 2011). Measures of perceived barriers and benefits of screening included a combination of items from the initial screening questionnaire and new items designed to assess barriers to rescreening identified during the pilot phase. The resulting measures of barriers and benefits incorporated both the practical aspects of screening (“I think obtaining a home stool test would be difficult”) and attitudinal factors (“receiving information about bowel cancer screening in the mail can be embarrassing”). Also included in the rescreening questionnaire were existing measures of response efficacy (Cronbach’s α = 0.67, 3-point response scale, Boer & Seydel, 1996) and health value (Cronbach’s α = 0.67, Lau & Hartman, 1986), along with a 6-item measure of self-efficacy based on the measurement recommendations of Luszczynska and Schwarzer (2003). Examples of the questionnaire items and measures of internal consistency (Cronbach’s α) for the scales used in the rescreening questionnaire are shown in Table 7.
Table 7 Social cognitive measures used in the rescreening questionnaire

<table>
<thead>
<tr>
<th>Variable</th>
<th>Example</th>
<th>Cronbach’s α</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chance Health Locus of Control</strong></td>
<td>“Most things that affect my health happen to me by chance”</td>
<td>.70 (4 items)</td>
</tr>
<tr>
<td><strong>Internal Health Locus of Control</strong></td>
<td>“I am in control of my health”</td>
<td>.66 (2 items)</td>
</tr>
<tr>
<td><strong>Health Value</strong></td>
<td>“There is nothing more important than good health”</td>
<td>.70 (4 items)</td>
</tr>
<tr>
<td><strong>Response Efficacy</strong></td>
<td>“Participation in home stool test screening leads to the detection of small abnormalities.”</td>
<td>.59 (4 items)</td>
</tr>
<tr>
<td><strong>Self-Efficacy</strong></td>
<td>“I am confident that I will be able to screen regularly for bowel cancer with a home stool test even if I find the test to be embarrassing”</td>
<td>.96 (6 items)</td>
</tr>
<tr>
<td><strong>Barriers</strong></td>
<td>“Giving a sample of faeces to another person to test for bowel cancer screening is embarrassing”</td>
<td>.77 (7 items)</td>
</tr>
<tr>
<td><strong>Facilitators/Benefits</strong></td>
<td>“Having regular home stool tests would give me peace of mind about my health”</td>
<td>.62 (4 items)</td>
</tr>
<tr>
<td><strong>Perceived Severity</strong></td>
<td>“A diagnosis of bowel cancer would severely affect my lifestyle”</td>
<td>.57 (2 items)</td>
</tr>
<tr>
<td><strong>Perceived Susceptibility</strong></td>
<td>“There is a good chance that I will get bowel cancer”</td>
<td>.65 (2 items)</td>
</tr>
</tbody>
</table>

*Perceived social endorsement (social influence and social support).*

Availability of social support was measured using a 6-item scale (Cronbach’s α =0.86) from the initial screening questionnaire (Gregory, et al., 2011). Perceived beliefs about, and desire to comply with family members and general practitioner attitudes to screening were assessed using a 4-item social influence measure (Cronbach’s α= 0.70). Items were developed by Tiro et al. (2005) who designed the scale for use in CRC screening research (Cronbach’s α= 0.61). Responses were measured on 5-point Likert Scales ranging from strongly disagree to strongly agree and overall scores were obtained by summing the individual items.
Satisfaction with prior screening

Participants’ evaluations of their most recent experience screening with FOBT were measured with a single item (please rate the extent to which you were satisfied with the overall experience of screening for your most recent home stool test) using a 5-point Likert scale ranging from very unsatisfied to very satisfied.

Background variables.

CRC and screening knowledge.

Six items were developed to measure participants’ knowledge of CRC risk factors (age, diet and lifestyle, family history) and screening (treatment benefits of early detection, detection of precancerous growths and importance of repeat adherence). Response options were agree, disagree and unsure/don’t know; correct responses were scored as one, incorrect and unsure/don’t know were scored as zero.

Social interactions concerning CRC and other health maintenance activities.

Three dichotomous items assessed participants’ levels of social exposure to CRC and screening (Have you discussed home stool testing with anyone? Have you ever known anyone who has screened for bowel cancer with a home stool test? Have you ever known anyone who has had bowel cancer?). Participation in other preventive health activities was assessed by determining frequency of GP visits within the past 12 months, participation in screening for other cancers in the past, and whether or not the participant had a regular GP. Previous experiences with cancer were also assessed (family history of CRC, prior cancer diagnosis).
Demographic.

Demographic details (age, gender, marital status, education, health insurance) were collected and respondents’ postal codes were used to assign a measure of socioeconomic disadvantage, based on place of residence, according to the Australian Bureau of Statistics’ Socio Economic Index for Areas (SEIFA) (Pink, 2004).

Analyses.

Data were first analysed for their univariate (ANOVA) associations with stage of readiness to rescreen. Categorical data and data that did not meet the assumptions of parametric testing (i.e., were not normally distributed) were analysed using non-parametric alternatives (Chi Square and the Kruskal-Wallis Test) (Neideen & Brasel, 2007). Significant differences between maintenance and remaining stages identified post hoc (Hochberg GT2, Chi Square, Mann-Whitney U test with the Bonferroni correction) were then incorporated into three separate multivariate models to determine the factors associated with each stage of readiness, compared with maintenance. Data were assessed prior to analyses to ensure suitability for modelling (Hair, et al., 1998). Generalised Estimating Equations (log link, Poisson distribution) were selected for multivariate analyses (Ballinger, 2004).

Exclusions.

The overall response rate for the questionnaire was 48.5% (1941/4000). The primary outcome was stage of TTM for rescreening, therefore participants who had not screened previously with FOBT (n=944, 48.6%) and those who did not answer the TTM staging question (n=36, 1.85%) were not included in the current analyses. Missing values analysis identified 112 (5.77%) participants for whom data were missing for
more than 20% of the total questionnaire items. These cases were considered to be too extreme to warrant imputation and were removed from analysis (Hair, et al., 1998)².

Results

Questionnaire respondents.

Present analyses were restricted to the 849 (43.7%) participants who indicated in the questionnaire that they had participated in FOBT screening in the past (i.e., potential and actual rescreeners). These respondents were 391 (46.1%) men and 458 (53.9%) women aged between 50 and 74 (\(\bar{x} = 61.47, SD = 6.42\)). The majority of respondents were either married or in a de facto relationship (80.4%) and only 45.2% were currently in the workforce, with the remainder being predominantly retired or home carers. Although 28.7% of the respondents were born outside of Australia, only 8.7% spoke a language other than English at home. Almost half of the sample (49.8%) reported their highest level of educational achievement to be secondary school or lower. Respondents’ measures of relative socio economic disadvantage ranged from 756 to 1107 (\(\bar{x} = 1007.62, SD = 64.96\)) indicating relatively low levels of disadvantage amongst the study population, however this is comparable with 2006 Census data for South Australia which showed approximately 88 percent of the population resided within this range (Australian Bureau of Statistics, 2008).

²A demographic comparison of participants excluded on the basis of missing data found that excluded participants were significantly more likely to speak a language other than English at home \(\chi^2(1) = 34.45, p<0.001\), were older \(t(1910) = 6.02, p<0.001\) and less likely to be in the workforce \(\chi^2(1) = 11.16, p<0.001\), they also reported slighter higher levels of socio economic disadvantage \((M=982.72, SD=66.93)\) than included respondents \((M=999.09, SD=68.11, t(1931)=2.81, p=0.005)\).
Distribution across the stages of the TTM.

The majority of participants were previously adherent with screening recommendations (previous screening was on schedule) and had intentions to continue screening in the future with 39.1% (n=332) in the action stage and 31.0% (n=263) in the maintenance stage. Inconsistent participants comprised 15.5% (n=132) of the sample whilst 14.4% (n=122) indicated no intentions for future screening despite prior participation (relapse).

Univariate analyses.

Table 8 and Table 9 present the significant results of the univariate analyses for demographic/background and social cognitive variables. Results show that a variety of social cognitive, background and demographic variables differentiated maintenance from remaining stages. Post hoc tests revealed that unique characteristics were associated with each stage; for example, compared with maintenance satisfaction with prior screening was significantly lower amongst inconsistent and relapse participants, but not action. Variables that differentiated each stage from maintenance as identified post hoc were then incorporated into multivariate models.
**Table 8 Significant univariate differences between maintenance and remaining categories for social cognitive variables**

<table>
<thead>
<tr>
<th></th>
<th>Maintenance</th>
<th>Action</th>
<th>Inconsistent</th>
<th>Relapse</th>
<th>F (df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean(SD)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Planning processes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What steps</td>
<td>4.38(0.72)</td>
<td>4.07(0.88)**</td>
<td>3.94(0.88)**</td>
<td>-</td>
<td>15.76(2, 357.03)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Where</td>
<td>4.13(0.98)</td>
<td>3.61(1.21)**</td>
<td>3.72(1.09)**</td>
<td>-</td>
<td>16.75(2,371.49)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>When</td>
<td>3.29(1.14)</td>
<td>2.78(1.06)**</td>
<td>2.75(0.93)**</td>
<td>-</td>
<td>19.95(2, 724)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>Health beliefs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barriers</td>
<td>14.16(3.81)</td>
<td>15.11(3.73)*</td>
<td>16.04(3.78)**</td>
<td>17.35(4.16)**</td>
<td>21.36(3, 845)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Benefits</td>
<td>17.09(1.78)</td>
<td>16.53(1.84)**</td>
<td>16.52(1.64)*</td>
<td>15.19(1.71)**</td>
<td>32.06(3,845)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Social support</td>
<td>23.96(3.41)</td>
<td>23.07(3.52)*</td>
<td>22.65(3.87)**</td>
<td>21.89(3.83)**</td>
<td>10.30(3,845)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Social Influence</td>
<td>15.19(2.66)</td>
<td>13.82(2.58)**</td>
<td>14.14(2.38)**</td>
<td>12.76(2.22)**</td>
<td>28.93(3,845)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Chance health</td>
<td>8.92(2.52)</td>
<td>9.35(2.43)</td>
<td>9.48(2.50)</td>
<td>9.78(2.68)*</td>
<td>3.79 (3, 845)</td>
<td>.010</td>
</tr>
<tr>
<td>Response efficacy</td>
<td>11.19(1.43)</td>
<td>11.09 (1.45)</td>
<td>11.30(2.83)</td>
<td>10.83(1.46)**</td>
<td>10.40(3)a</td>
<td>.015</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>4.43(0.81)</td>
<td>4.34(0.75)</td>
<td>4.10(0.86)**</td>
<td>3.84(1.01)**</td>
<td>48.30(3)a</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

*Note. SD= standard deviation. F= F ratio, df= degrees of freedom, p=probability.

*a Data were not normally distributed therefore the Kruskal-Wallis test was reported.

*p<.05. **p<.01
<table>
<thead>
<tr>
<th></th>
<th>Maintenance</th>
<th>Action</th>
<th>Inconsistent</th>
<th>Relapse</th>
<th>$\chi^2$ (df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Count (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Background</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Known someone who has had CRC</td>
<td>214(81.4)</td>
<td>233(70.6)**</td>
<td>101(77.1)</td>
<td>89(73.6)</td>
<td>9.56(3)</td>
<td>.02</td>
</tr>
<tr>
<td>Discussed FOBT screening</td>
<td>277(86.3)</td>
<td>271(81.6)</td>
<td>100(76.3)*</td>
<td>73(59.8)**</td>
<td>37.58(3)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Known someone who has screened with FOBT</td>
<td>177(67.3)</td>
<td>192(58.0)*</td>
<td>88(67.2)</td>
<td>62(50.8)**</td>
<td>13.06(3)</td>
<td>.02</td>
</tr>
<tr>
<td>Regular GP</td>
<td>254(97.3)</td>
<td>300(90.9)**</td>
<td>121(92.4)*</td>
<td>112(92.6)*</td>
<td>10.12(3)</td>
<td>.02</td>
</tr>
<tr>
<td>Rescreen knowledge (incorrect)</td>
<td>10(3.8%)</td>
<td>15(4.5)</td>
<td>12(9.1)*</td>
<td>37(30.3)**</td>
<td>86.81(3)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>Demographic</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private health insurance (none)</td>
<td>28(10.8)</td>
<td>52(15.8)</td>
<td>23(17.4)</td>
<td>35(28.7)**</td>
<td>19.66(3)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Born in Australia</td>
<td>201(77.0)</td>
<td>237(71.8)</td>
<td>85(64.4)**</td>
<td>78(63.9)**</td>
<td>10.46(3)</td>
<td>0.02</td>
</tr>
<tr>
<td><strong>Mean (SD)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age$^a$</td>
<td>62.69(6.17)</td>
<td>60.25(6.15)**</td>
<td>62.47(6.44)</td>
<td>61.09(7.04)</td>
<td>8.52(3,845)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

*Note. SD= standard deviation. F= F ratio, df= degrees of freedom, $\chi^2$= chi square, p=probability

$^a$Age was measured on a continuous scale

**p<.01, *p<.05,
Multivariate analyses.

Table 10 presents the results of three separate multivariate models with maintenance as the referent category for each.

Action.

Compared to people in the maintenance stage, those in the action stage were 18% less likely to have known someone who has had CRC. There were also small but significant differences found for age and social influence with action participants reporting lower levels of social influences to screen and younger age.

Inconsistent.

Only two significant differences were identified between inconsistent participants and those in the maintenance stage. Inconsistent participants reported only slightly increased (5%) barriers toward CRC screening in addition to being 16% less likely to have planned when they will next screen.

Relapse.

A variety of different variables differentiated relapse from maintenance. Relapse participants reported less social influence to screen, fewer benefits of screening participation, less self-efficacy and less satisfaction with previous screening. Relapse participants were more likely (33%) to have no private health insurance and were 41% more likely to be unaware of the need for future screening participation if previous screening tests were normal.
Table 10 Multivariate analyses of factors associated with the action, inconsistent and relapse stages relative to maintenance

<table>
<thead>
<tr>
<th></th>
<th>Action RR</th>
<th>95% CI</th>
<th>Inconsistent RR</th>
<th>95% CI</th>
<th>Relapse RR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>p</td>
<td></td>
<td>p</td>
<td></td>
<td>p</td>
<td></td>
</tr>
<tr>
<td>Social cognitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barriers</td>
<td>1.02</td>
<td>.13</td>
<td>1.00-1.04</td>
<td>1.05</td>
<td>.04</td>
<td>1.00-1.09</td>
</tr>
<tr>
<td>Benefits</td>
<td>0.99</td>
<td>.47</td>
<td>0.95-1.03</td>
<td>0.99</td>
<td>.86</td>
<td>0.90-1.09</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>0.99</td>
<td>.35</td>
<td>0.98-1.01</td>
<td>1.01</td>
<td>.58</td>
<td>0.97-1.06</td>
</tr>
<tr>
<td>Response efficacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social influence</td>
<td>0.94</td>
<td>&lt;.001</td>
<td>0.91-0.97</td>
<td>0.94</td>
<td>.06</td>
<td>0.87-1.00</td>
</tr>
<tr>
<td>Social support</td>
<td>1.01</td>
<td>.35</td>
<td>0.99-1.04</td>
<td>1.01</td>
<td>.64</td>
<td>0.96-1.06</td>
</tr>
<tr>
<td>Chance health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction with prior screening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0.87</td>
<td>.11</td>
<td>0.74-1.03</td>
<td>0.87</td>
<td>.03</td>
<td>0.76-0.98</td>
</tr>
<tr>
<td>Background</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Known someone who has had CRC</td>
<td>0.82</td>
<td>.01</td>
<td>0.71-0.95</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Known someone who has screened</td>
<td>0.99</td>
<td>.84</td>
<td>0.86-1.14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussed FOBT screening</td>
<td>0.96</td>
<td>.81</td>
<td>0.68-1.36</td>
<td>0.77</td>
<td>.07</td>
<td>0.58-1.03</td>
</tr>
<tr>
<td>Regular GP</td>
<td>0.84</td>
<td>.09</td>
<td>0.68-1.03</td>
<td>0.78</td>
<td>.37</td>
<td>0.46-1.33</td>
</tr>
<tr>
<td>Rescreen knowledge (incorrect)</td>
<td>1.37</td>
<td>.21</td>
<td>0.84-2.25</td>
<td>1.41</td>
<td>.02</td>
<td>1.06-1.88</td>
</tr>
<tr>
<td>Plans for future FOBT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Where</td>
<td>0.96</td>
<td>.28</td>
<td>0.89-1.03</td>
<td>1.08</td>
<td>.47</td>
<td>0.88-1.32</td>
</tr>
<tr>
<td>When</td>
<td>0.94</td>
<td>.15</td>
<td>0.86-1.02</td>
<td>0.84</td>
<td>.04</td>
<td>0.71-1.00</td>
</tr>
<tr>
<td>What steps</td>
<td>0.97</td>
<td>.53</td>
<td>0.89-1.06</td>
<td>0.80</td>
<td>.06</td>
<td>0.64-1.01</td>
</tr>
<tr>
<td>Demographic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.98</td>
<td>&lt;.001</td>
<td>0.97-0.99</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health insurance (none)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Born in Australia</td>
<td>0.80</td>
<td>.14</td>
<td>0.59-1.08</td>
<td>0.91</td>
<td>.49</td>
<td>0.70-1.18</td>
</tr>
</tbody>
</table>

Note. RR = risk ratio, p = probability, 95% CI = confidence interval.
Discussion

The need to implement health promotion programs that encourage CRC rescreening compliance is an important public health goal. In Australia, since the implementation of a nationwide FOBT screening program, understanding and supporting decisions to participate in CRC screening has become increasingly important (Cole, et al., 2011; Gregory, et al., 2011; Janda, et al., 2010). A substantial proportion (29.9%) of prior screeners in the present study identified themselves as either non-adherent, or expressed no intention to maintain adherence, despite prior participation. These figures highlight the importance of encouraging rescreening as well as initial uptake if morbidity and mortality are to be reduced (Mandel, et al., 1993). In order to achieve screening maintenance following initial participation it is important that the variables differentiating the various levels of commitment to screen are understood.

The present study separated relapsed screeners into two categories, inconsistent screeners and traditional relapse. Whilst both represent target categories for intervention, differences between inconsistent and maintenance rescreeners were few, whilst there were many between relapse and maintenance participants. Relapse participants reported more negative attitudes toward screening compared to maintenance (fewer perceived benefits, less self-efficacy) and reported fewer social influences to screen. These attitudes are similar to those reported by people yet to participate in FOBT screening (Brenes & Paskett, 2000; Rawl, et al., 2005; Trauth, et al., 2003). This suggests comparable invitational strategies to encourage participation in both. However, unlike those who have never screened, relapse participants have the potential to be affected by prior screening experience (Janda, et al., 2010; Myers, et al., 1993; Tang, et al., 2009). Relapse participants were the only people to report
significantly lower levels of satisfaction with prior screening. In addition, those in the relapse category were significantly more likely to agree that rescreening was unnecessary following a ‘normal’ result on a prior screening. These findings suggest that a ‘one size fits all’ approach to encouraging screening amongst all non-adherent screeners (i.e., relapse participants and those who are yet to participate) may not benefit those who have screened previously. Instead, future research should focus on identifying aspects of the screening experience that may lead to dissatisfaction and on ensuring that screening practices include information on the importance of repeat participation. In addition, no studies have been identified that have documented the relationship between prior negative experiences and attitudes to screening. If fewer perceived benefits and poorer self-efficacy in the current study were a result of negative experiences with prior screening, this is also likely to have implications for rescreening research.

Few differences were identified between maintenance and inconsistent screeners. Whilst greater perceived barriers were reported amongst inconsistent screeners these differences were only small and may be a reflection of the large sample size. These findings, however, do support those observed amongst inconsistent mammography screeners who also reported greater practical barriers to rescreening (LaPelle, et al., 2008). Future research using additional populations may be required to verify this difference for CRC screening. Inconsistent participants were however, substantially (16%) less likely to have planned when they will next participate in screening. ‘Planning processes’ that speculate when, where or how an intended behaviour can be completed has been well documented as a facilitator bridging the gap between intention and behaviour (Gollwitzer, 1999) and may explain the moderate
increases in reparticipation observed in reminder intervention trials (Holden, et al., 2010). Despite being non-adherent with screening guidelines, inconsistent screeners did not greatly differ from maintenance screeners according to social cognitive variables. These findings considered in combination with the comparisons between relapse and maintenance suggest each stage is characterised by unique attitudes toward screening and future research should continue to emphasise this distinction by considering both relapse categories separately.

In past research, adherent screeners (action and maintenance) have been collapsed into a single adherent stage (Brenes & Paskett, 2000; Hay, et al., 2003; Spencer, et al., 2005). However, in the present study small but significant differences between action and maintenance participants were observed. Action participants were younger and less likely to have known someone with CRC and also reported lower levels of social influence to screen. Whilst this age difference may account for disparities in knowing someone with CRC, the age differences were only small and could be a result of the one to two year intervals required to rescreen for CRC. The social differences, however, which were also observed for relapsed screeners, do present some interesting areas for further investigation. Social influence has been previously shown to be important for encouraging initial uptake (Tiro, et al., 2005); however, results of the present study indicate social factors may continue to motivate screening beyond initial uptake. Action participants have not yet had an opportunity to reparticipate in screening; therefore it is unclear whether these differences in social factors between action and maintenance lead to relapse. Results however do suggest that continued GP endorsement and family support are an important characteristic of screening.
maintenance and therefore should be highlighted in messages to those who have only just begun to screen as well as those who are no longer adherent.

This study highlights the importance of prior screening experience and future intentions when categorising rescreening participants for study. However, there are several limitations. Firstly, past research utilising surveys in CRC screening research has documented greater questionnaire participation amongst those more receptive to CRC screening participation (Cole, et al., 2011). The present study achieved a modest unadjusted response rate of just below 50%. Whilst this is comparable with similar Australian research (Gregory, et al., 2011), response bias may have contributed to the primarily positive attitudes toward screening observed here and limited generalisability to the wider population (Galea & Tracy, 2007). However, the proportion of those identifying themselves as relapse and inconsistent participants (29%) were similar to rates of screening relapse reported in the Australian National Bowel Cancer Screening Program (approximately 20%) which suggests adequate sampling of those from different stages of readiness to rescreen. There were also a small portion of respondents for whom substantial missing data rendered them unsuitable for comparative analyses. Whilst this may also have potentially limited the generalisability of the sample, demographic analyses found age, socio-economic and language barriers to be associated with exclusion, factors which have been previously identified as characteristic of survey non respondents (Galea & Tracy, 2007).

It is also important to note that results are based on retrospective reporting and may be influenced by current attitudes toward screening and cognitive dissonance, possibly resulting in participants exaggerating the negativity of their prior screening experience (Festinger & Carlsmith, 1959). Although it is not uncommon for studies to
utilise retrospective reporting (Neilson & Whynes, 1995), in order to further examine the effects of prior experiences on subsequent screening, future research may benefit from obtaining measures of satisfaction immediately following FOBT completion. Finally, all stage categories were based on measures of future intentions to rescreen, which were prudent for a study utilising the TTM (Prochaska, et al., 1988; Rakowski, Ehrich, et al., 1996), however, it would also be useful to conduct similar comparative studies that follow up on these screening intentions with observed screening behaviour.

Self-reported rates of rescreening in the present study show a substantial portion of prior screeners were either non-adherent with screening guidelines or had no intention to continue screening. The use of an expanded TTM proved relevant for an exploration of the characteristics associated with FOBT rescreening behaviour. Unique differences were observed between maintenance participants and comparative stages providing a useful foundation for further research into the development and trail of interventions to encourage reparticipation in colorectal cancer screening.
Chapter Five, Paper Three- Adherence to Faecal Occult Blood Testing Over Multiple Screening Rounds: Behavioural Predictors of Participation in Three Consecutive Screening Opportunities.

Preface

Paper three was the final empirical study conducted in this thesis. The paper reports on data obtained in the rescreening questionnaire along with participatory data obtained from three annual FOBT screening offers. FOBT screening was managed by the Bowel Health Service (BHS), Repatriation General Hospital Daw Park. All questionnaire respondents were offered screening at yearly intervals. The protocol for screening offers was designed to replicate as closely as possible the invitation strategies utilised by the NBCSP (Australian Government Department of Health and Ageing, n.d-b) and is described in the manuscript. Appendices C through E include copies of the information mailed to screening invitees per round, all screening information originated from the BHS on company letter head. Screening offers were provided free of charge however participants were responsible for any additional costs associated with follow up examinations if required.

Paper two used questionnaire data to differentiate participants in different stages of readiness to rescreen according to the framework proposed by the Transtheoretical Model of Behaviour Change (TTM) (Prochaska & DiClemente, 1983). Demographic, background and social cognitive differences observed between those in the maintenance stage (rescreening, target behaviour) and those in the lower stages of readiness supported the use of a multilevel framework for exploring rescreening adherence. The purpose of this paper, however, was to determine if these same data were predictive of
variations in rescreening adherence monitored over three consecutive annual screening rounds.

In this paper participants were categorised according to patterns of participation observed over three screening rounds. As with paper two, a multilevel framework that described the different adherent and non-adherent behaviours was utilised. However, in contrast to paper two, this study focused on observed screening behaviour and did not include measures of intended participation (Sheeran, et al., 2001). Consequently, the TTM was not the framework used to categorise behaviour. For three screening rounds there were eight possible patterns of participation that were then collapsed into five categories of adherence that described these patterns. In the absence of existing theoretical frameworks to describe longitudinal behaviour, the definitions of adherence and non-adherence that were used to collapse the categories were consistent with those described throughout the thesis (i.e., relapse/drop out, rescreening)\(^3\). The adherence behaviours explained in this paper describe adherence to the three year screening offers provided in this study only. The categories were labelled according to the behavioural pattern they described, consistent with previous mammography research (Drossaert, et al., 2003). For example, rescreening, which is consistently described throughout this thesis as participation in consecutive screening opportunities without lapses in participation, was described in paper three as a pattern of ‘consistent reparticipation’. This approach served two purposes; firstly to differentiate the stages of readiness to screen described in paper two from the patterns of adherence behaviour reported in paper three, and secondly to emphasise that the categories described in this paper

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\(^3\) Rescreening is defined in chapter one as participation in more than one screening opportunity without lapses in participation. Relapse/drop out is the term used to describe the comparative non-adherent behaviour to rescreening described as participation in screening followed by subsequent refusal of screening. Non-participation is defined as refusal of all screening opportunities.
represent screening behaviours, they are not labels to define individuals. The resulting adherence categories allowed the paper to address several of the important behaviours identified in paper two, such as maintenance and relapse, but also additional categories of irregular participatory behaviour, such as delayed entry and intermittent reparticipation that occurred over the three year observation period (Sheeran et al., 2001).

In contrast to paper two, the sample analysed in paper three included all those who completed the rescreening questionnaire irrespective of whether they had previously participated in FOBT screening. However, consistent with paper two, those with incomplete questionnaire data were excluded from analyses. Both observed study FOBT participation and self-reported alternate/additional CRC screening participation (i.e., other FOBT screening or endoscopic screening) were recorded during the study period. As a result of the substantial portion of participants who volunteered additional self-report data, two study outcomes (adherence categories) were initially assigned to each participant, 1) adherence with the BHS offered screening and 2) adherence with both the BHS screening offers and other CRC self-report screening outside of the program. The proportion of participants in each adherence category was substantially different for the study FOBT only outcome compared to the outcome that also included self-report data; primarily there was a substantial increase in the proportion of those in the consistent reparticipation category when self-report data were included. In order to avoid misclassifying participants, the decision was made to include self-report FOBT data in the outcome measure as well as observed program participation. Those reporting endoscopic screening during the program were excluded from analyses; the details and rationale for this decision are discussed in the manuscript.
Paper three utilised the same approach to analyses as reported in paper two. However, in paper three it was necessary to conduct two multivariate analyses, one that included the total sample (n=1540) and one that included only those who reported prior FOBT screening experience in the rescreening questionnaire (n=720). The reason for the subsample analyses was to determine whether satisfaction with prior FOBT (i.e., screening that occurred before the participant was recruited into the thesis project which was established in the rescreening questionnaire) was predictive of adherence to the screening offered by the BHS. Whilst these additional analyses were able to provide some insight into the influence of satisfaction on program adherence, it is important to note that the samples used in each analysis were different and therefore not directly comparable. In addition, planning processes were not assessed in paper three as this would have required further subgroup analyses (including only those who reported intention to screen at baseline). To avoid excessive additional analyses on reduced sample sizes, planning processes were excluded from paper three on the basis that the items were designed to measure participants’ plans for future screening independent of an organised screening opportunities.

In summary this paper sought to determine predictors of adherence to three annual screening opportunities. This paper has been prepared for submission to BMC Public Health and is therefore presented here as a manuscript in its entirety including abstract and detailed introduction.
Abstract

Background: Social cognitive variables have frequently been examined for their association with initiation of colorectal cancer (CRC) screening. To date, no studies have examined the association of these variables with adherence over multiple rounds i.e., rescreening. The aim of this study was to describe multiple patterns of participatory behaviour in three faecal occult blood test (FOBT) screening rounds and to determine social cognitive, demographic and background variables predictive of variations in adherence.

Methods: A random sample of 4000 men and women between the ages of 50 and 74 living in South Australia were invited to participate in a baseline behavioural questionnaire and three consecutive FOBT screening offers. Questionnaire response rate was 48% (1941/4000). Patterns of participation across the three screening rounds were recorded and then described as one of five screening behaviours; consistent reparticipation (adherent with all screening rounds), consistent refusal (adherent with no screening rounds), drop out (adherent with earlier but not later rounds), intermittent reparticipation (adherent with alternate rounds) and delayed entry (adherent with later but not the initial round(s)). Univariate and multivariate analyses were conducted to determine questionnaire variables predictive of non-adherence (those that did not participate in every screening offer) relative to consistent reparticipation. Subgroup analyses were also conducted to determine the additional influence of satisfaction with screening amongst those who reported prior FOBT screening participation at baseline.
Results: Demographic and background variables were better predictors of rescreening behaviour in multivariate analyses compared with social cognitive variables. The non-adherent categories were characterised by unique demographic predictors compared with consistent reparticipation including, male gender (delayed entry), younger age (all non-adherent behaviours), less frequent GP visits (intermittent reparticipation) and being unmarried (drop out). Less satisfaction with screening at baseline was significantly associated with drop out, consistent refusal and delayed entry behaviour over and above other social cognitive predictors.

Conclusions: Comparisons between the varying levels of non-adherence and consistent reparticipation identified unique characteristics associated with each non-adherence category. Social cognitive predictors did not substantially predict non-adherence, however less satisfaction with prior screening at baseline was predictive of several non-adherent behaviours.
Background

Continued adherence to screening recommendations for colorectal cancer (CRC) with a faecal occult blood test (FOBT) has been shown to reduce incidence of and mortality from CRC (Hardcastle, et al., 1996; Jorgensen, et al., 2002; Mandel, et al., 2000). In Australia FOBT screening is recommended every one to two years for those aged 50 and over (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005). FOBT screening programs are run in many countries including The Netherlands, Italy, the United Kingdom, Australia and parts of the United States and Canada (V. S. Benson, et al., 2008). Initial uptake and continued adherence are crucial to the success of population screening programs (Jorgensen, et al., 2002). Recent research has highlighted the importance of using longitudinal observations of screening participation to measure adherence adequately (Cooper & Doug Kou, 2008; Gellad, et al., 2011). Studies of this nature have documented remarkably low rates of ongoing adherence ranging from 13.7% (Gellad, et al., 2011) to 22.9% (Cooper & Doug Kou, 2008) for recommended levels of screening participation (i.e., participation in all screening offers) over multiple screening rounds. These findings highlight the importance of a dedicated focus on identifying the factors associated with screening relapse (i.e., program dropout) or irregular patterns of participation, as well as initial uptake, if adequate adherence over time is to be achieved.

The majority of past CRC screening research has focused on predictors of participation in single screening opportunities (i.e., initial uptake) (Beydoun & Beydoun, 2008; Kiviniemi, et al., 2011). The focus of the current study was to determine predictors of participation in more than one screening opportunity (i.e., repeat or
continued adherence) which, from here on, will be referred to as rescreening. Existing research on rescreening has, to date, been primarily limited to an examination of demographic and background (i.e., health systems) factors (e.g., Fenton, et al., 2010; Garcia, et al., 2012; Janda, et al., 2010). Significant positive predictors include, greater frequency of general practitioner (GP) visits (Fenton, et al., 2010), older age (Fenton, et al., 2010; Janda, et al., 2010; Myers, et al., 1993) and male gender (Fenton, et al., 2010).

Social cognitive variables, for example variables from the Health Belief Model (Janz & Becker, 1984) (perceived barriers, benefits, susceptibility, severity and self-efficacy) (Beydoun & Beydoun, 2008; Kiviniemi, et al., 2011), measures of social influence (Tiro, et al., 2005), support (Honda & Kagawa-Singer, 2006) and control beliefs (Kiviniemi, et al., 2011), have all been shown to predict initial CRC screening participation and form the basis of many behavioural and educational interventions to improve screening uptake (Holden, et al., 2010). Our previous work has shown social cognitive variables to be associated with rescreening intention (Duncan et al., 2012). However, no studies have examined the utility of these variables for predicting longitudinal adherence.

The impact of prior participation is an important factor to consider when predicting maintenance of health behaviours (Conner & Norman, 2005). Prior participation in FOBT screening has been repeatedly identified as one of the primary predictors of adherence with subsequent screening (Cooper & Doug Kou, 2008; Garcia, et al., 2012; Janda, et al., 2010; Myers, et al., 1993). These studies highlight that compliance with subsequent screening is more likely amongst those who have participated previously. However, despite the predictive power of prior participation, screening rates clearly highlight a decrease in rates of subsequent participation amongst
previously adherent screeners (e.g., Fenton, et al., 2010; Garcia, et al., 2012; Gellad, et al., 2011).

Those who refuse screening following prior participation, referred to in the screening literature as displaying relapse (Rakowski, Dube, et al., 1996) or drop out behaviour (Drossaert, et al., 2003), represent a unique group of people who have presumably overcome initial barriers to screening, yet refuse subsequent participation (Garcia, et al., 2012). It is possible that the experience of screening may influence attitudes toward future adherence (Rakowski, Dube, et al., 1996). Studies of mammography screening have highlighted the importance of satisfaction with prior screening as a predictor of rescreening participation (Peipins, Shapiro, Bobo, & Berkowitz, 2006; Tang, et al., 2009) and recent research has also reported an association between increased satisfaction and FOBT rescreening intention (Duncan, et al., 2012). These findings highlight the importance of attending to the quality of the initial experience of screening when determining predictors of rescreening.

Crucial to an examination of rescreening is a clear framework to measure adherence (Vernon, Briss, et al., 2004). Despite the recent emergence of several studies examining demographic predictors of FOBT rescreening (Fenton, et al., 2010; Garcia, et al., 2012; Gellad, et al., 2011; Janda, et al., 2010), there has been little research dedicated to understanding screening relapse/drop out and other irregular screening patterns.

Studies on longitudinal adherence have generally utilised research designs that make accurate identification of predictors of rescreening difficult. For example, many compare rescreening (defined as adherence with all offers) with all non-adherent behaviours (did not adhere to all offers) (Cooper & Doug Kou, 2008; Gellad, et al., 2011). This approach to categorisation does not differentiate between those who relapse/drop
out from other non-adherent behaviours. There is however, an intervention orientated reason to consider different patterns of non-adherent behaviour, such as relapse/drop out, as distinct from other non-adherent behaviours such as consistent refusal of all offer (Rakowski et al., 1996). As highlighted above, those who refuse screening offers after having completed initial FOBTs are likely to have different reasons for doing so than someone who has no previous experience using the test. Similarly, there is evidence from amongst the mammography screening literature to suggest that other non-adherent behaviours, such as delayed participation (i.e., refusal of initial but not subsequent offers; Drossaert et al., 2002), or intermittent participation (LaPelle et al., 2008) are also associated with unique behavioural predictors. There is substantial evidence to suggest that interventions targeted to population subgroups are more successful in encouraging participation than a standard population approach (Champion et al., 2003; Sohl & Moyer, 2007). Identifying the needs of different non-adherent subgroups could therefore inform the development of interventions to target demographic or behavioural factors likely to contribute to various patterns of non-adherent behaviour.

The current study aimed to identify factors significantly associated with different behavioural categories of adherence defined according to patterns of participation observed in three annual FOBT screening offers. Potential social cognitive, demographic and background factors measured at baseline, prior to the first screening offer, and derived from behavioural models that have successfully predicted initial screening uptake (Kiviniemi, et al., 2011) and rescreening intention (Duncan, et al., 2012) were tested for their ability to predict variations in rescreening adherence.
Methods

Study population.

The study population was drawn from a list of 12,000 people aged 50 to 74 residing in the surrounding suburbs of Adelaide, South Australia provided by the Australian Electoral Commission. The population was randomly selected from four South Australian electoral districts including suburbs with a broad socioeconomic range (in Australia, electoral roll registration is mandatory for people aged over 18 years). Potential study participants were cross checked against a CRC high risk database held by the Bowel Health Service (BHS), Repatriation General Hospital, Daw Park, South Australia. High risk for CRC is defined as having either; a personal history of CRC, a family history of CRC or long standing irritable bowel conditions (Rozen, et al., 2006). Those present on the database were excluded from possible selection. A randomly selected subsample of 4,000 was then invited to participate in the study.

Study design.

All participants selected for study involvement were first mailed an advance notification letter, followed by a baseline behavioural questionnaire (the rescreening questionnaire) and associated study information one week later, in November of 2008. Those who completed the questionnaire were then offered an opportunity to participate in three consecutive FOBT-based screening offers coordinated by the BHS. Questionnaire respondents were mailed a screening test kit two weeks following return
of the questionnaire. Subsequently, screening offers were mailed from October 2009 and September 2010, approximately one and two years after the initial offer.

Offers were not mailed if; invitees contacted the BHS to opt out of the study, the BHS received information about alternative screening test participation (an ongoing program of FOBT-based screening or recent colonoscopy/flexible sigmoidoscopy based screening) or recent diagnostic evaluation of the bowel precluded the need for further screening with FOBT within the time frame of the study. Questionnaire non-respondents were followed-up with a reminder postcard at one week and reminder letters at three and six weeks (Dillman, 2000); those who did not complete the questionnaire during this time-frame were not invited to participate in subsequent screening offers. Study invitees were informed at the outset of the study that screening invitations would follow questionnaire completion. This study was approved by human research ethics committees at the Repatriation General Hospital and the University of Adelaide.

**Materials.**

**Rescreening questionnaire.**

The rescreening questionnaire administered at baseline was designed to measure participants’ prior experience with FOBT screening and to collect information on a variety of social cognitive, demographic and other background variables likely to predict rescreening. Social cognitive measures in the current study were; items relevant to the Health Belief Model (barriers, benefits, severity, susceptibility) (Gregory, et al., 2011; Hay, et al., 2003; Janz & Becker, 1984), self-efficacy (Bandura, 1982) chance health and

---

4 Australian screening guidelines recommend screening at least once every one to two years (an annual or biennial screening interval). In this study we adopted an annual screening interval; this was necessary for timely completion of the project and is consistent with evidence showing greater reductions in incidence for annual screening (Mandel, et al., 2000). Whilst the authors acknowledge the possibility that screening invitees may have previously adhered to biennial intervals, the aim of this study was to measure factors associated with compliance to an annual schedule of FOBT screening.
internal locus of control (Wallston, et al., 1978), response efficacy, (3 item response scale, Boer & Seydel, 1996), social support (Gregory, et al., 2011), social influence (Tiro, et al., 2005) and health value (Lau & Hartman, 1986). Social cognitive items were measured on 5-point Likert scales where higher scores indicate greater agreement with each item. Individual items were then summed to create summary measures on each of the main variables.

Demographic (marital status, age, gender, health insurance, education, employment, birth country) and background data (CRC and screening knowledge, other preventive health activities, interactions regarding CRC and screening) were also obtained. A measure of relative socioeconomic disadvantage, obtained from the Australian Bureau of Statistics’ Socio Economic Index for Areas (SEFIA), was also assigned based on respondents’ postal codes (Pink, 2004).

Participants who reported having used an FOBT in the past (i.e., before their involvement in the current study) were asked to rate their overall satisfaction with their previous FOBT screening experience on a 5-point scale ranging from very unsatisfied to very satisfied. Details of the questionnaire design, reliability statistics and example questionnaire items are provided elsewhere (Duncan, et al., 2012)

**FOBT screening offer.**

Annual offers to participate in screening were mailed to participants from the BHS and included; 1) an invitation letter, 2) a two sample immunochemical FOBT kit (OC-Sensor, Eiken Chemical Co., Japan), 3) a bowel cancer information brochure, 4) a Participant Details Form requesting personal details, doctor details, and consent to obtain follow-up information, 5) a reply-paid envelope to the BHS and 6) a Screening Status Information Form where participants could provide details of any
current CRC screening. The Screening Status Information Form was used to determine self-reported screening status at time of each offer. Advance notification letters (Cole, et al., 2007) were mailed two weeks prior to each offer. Reminder letters were mailed to non-participants after six weeks. Tests were developed at the BHS and a nurse practitioner facilitated follow-up of positive results.

**Study outcome.**

Screening adherence determined after three annual FOBT screening rounds was the primary outcome of the study. Adherence per round was measured based on either return of the completed FOBT or self-reported adherence with any other CRC screening test. Self-report was obtained either via the Screening Status Information Form or by participants contacting the BHS directly. Those reporting FOBT participation outside the program were only classified as adherent for the year that the FOBT was reported. All self-report data were recorded by the BHS and participants were categorised as ‘adherent’ or ‘non-adherent’ for each round according to predetermined adherence criteria (FOBT within the past nine months, endoscopy-based screening within the past five years) (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005; Levin, et al., 2008). Those reporting use of endoscopic screening, (colonoscopy or Flexible Sigmoidoscopy (FS) with or without FOBT utilisation) were excluded from analyses. This exclusion was because the focus of this study was to determine the relevance of questionnaire variables to the prediction of rescreening adherence using FOBT. Several studies have reported demographic and behavioural differences between those who utilise endoscopy over FOBT (Fenton, et al., 2010; Hawley et al., 2012).
The present study explored social cognitive predictors of FOBT rescreening and a variety of non-adherent behaviours. Exclusion of colonoscopy patients ensured that participants were not misclassified as having ‘dropped out’ of the program when they had in fact chosen a different screening method, or declined as a result of diagnostic evaluation or regular colonoscopic surveillance.

Participants were coded as adherent (Y) or non-adherent (N) for each round resulting in eight possible patterns of participation. Participants were first coded according to participation in the BHS FOBT screening offers. Additional self-report data for other FOBT and endoscopy were then included. This process ensured that observed FOBT participation was the main source of data, which was then supplemented with self-report data. Patterns of participation were then collapsed into five categories of adherence behaviour based on those described by Drossaert et al., (2003) for mammography rescreening. The categories were; consistent reparticipation (adherent with all screening rounds; target behaviour), consistent refusal (adherent with no screening rounds) drop out (participation in any round followed by subsequent refusal) and delayed entry (initial refusal followed by participation in later rounds). An additional behavioural category, intermittent reparticipation, was also included in order to describe the behaviour of those who dropped out in round two but then reparticipated in the final screening round. These adherence categories describe behaviour observed during the three year study period only. The eight participation patterns and associated adherence categories are described in Table 11.
Table 11 FOBT screening patterns and behaviours defined for three screening rounds.

<table>
<thead>
<tr>
<th>Participation patterns across three screening rounds</th>
<th>Adherence category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Round 1</td>
<td>Round 2</td>
</tr>
<tr>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
</tbody>
</table>

Analyses.

Univariate (ANOVA and Chi squared) comparisons with post hoc tests (Hochberg GT2 and 2x2 Chi Square) were conducted comparing consistent reparticipation and the remaining ‘non-adherent’ (drop out, intermittent reparticipation, delayed entry, consistent refusal) categories. Skewed variables were analysed using non-parametric alternatives (Neideen & Brasel, 2007). Significant differences determined at the univariate level were then incorporated into four separate multivariate models, utilising log poisson generalised estimating equations, with consistent reparticipation (i.e., full adherence with guidelines) as the referent category.

To determine the impact of satisfaction with screening before study involvement on adherence, a second multivariate analysis was conducted on the subpopulation of
participants who reported prior FOBT use in the rescreening questionnaire. These models incorporated all the variables included in the initial multivariate analyses with the addition of a single item measure of satisfaction with past screening.

**Exclusions.**

The questionnaire response rate was 48.5% (1941/4000). Those who requested no further contact following questionnaire completion (n=13, 0.6%), those who participated in other screening (colonoscopy/FS) (n=240, 12.4%) and those with incomplete questionnaire data (n=148, 7.6%) were excluded from analyses. The remaining 1540 questionnaire respondents (79.3%) were included in the analyses for this study. Figure 2 shows the process for determining eligibility for study analyses.

*Figure 2 Process of determining eligibility for analyses*

1. **4000 Mailed rescreening questionnaire**
2. **1941 rescreening questionnaire respondents**
   - 13 request no further contact
   - 1928 invited to screen
   - 240 participated in endoscopic screening
   - 148 incomplete questionnaire data
3. **1540 eligible for analyses**
   - 820 no prior FOBT screening
   - 720 eligible for subgroup analyses
Results

Participants.

The final sample (N=1540) comprised 710 (46.1%) men and 830 (53.9%) women aged 50 to 74 (M=59.93, SD=6.48). Of the study sample 1,413 (91.75%) participated only in the screening offered by the BHS whilst the remaining 127 (8.25%) reported other FOBT participation either in addition to, or instead of, the screening offered by the BHS. The majority were married (n=1189, 77.2%), and just over half were still in the workforce (n=803, 52.1%). The majority had completed at least secondary school education (n=1041, 67.6%), spoke English at home (n=1329, 86.3%), and were born in Australia (n=1091, 70.8%). SEIFA scores were divided into quintiles with the lowest quintile (1) indicating greater levels of disadvantage and the highest (5) indicating lower levels of disadvantage. A substantial portion of participants were in the highest (n =453, 29.4%) and lowest quintiles (n=326, 21.2%) with the remainder spread evenly between. These scores indicate that participants were from a broad range of socioeconomic backgrounds with slightly larger clusters at each extreme. Compared to survey non respondents, survey respondents more likely to be from areas of less disadvantage [$\chi^2 (4)= 68.36, p<.001$] and were slightly less likely to be from the youngest (50-54, 55-59) and oldest (70-74) age groups [$\chi^2 (5)= 24.92, p<.001$]

Rescreening adherence.

Table 12 shows the proportion of participants for each category of adherence. Just over 50% of invitees were adherent with screening for all three years.
Table 12 Proportion of study participants in each adherence category upon study completion (i.e., at year 3)

<table>
<thead>
<tr>
<th>Adherence category</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consistent reparticipation</td>
<td>859 (55.8%)</td>
</tr>
<tr>
<td>Drop out</td>
<td>136 (8.8%)</td>
</tr>
<tr>
<td>Intermittent reparticipation</td>
<td>67 (4.4%)</td>
</tr>
<tr>
<td>Delayed entry</td>
<td>167 (10.8%)</td>
</tr>
<tr>
<td>Consistent refusal</td>
<td>311 (20.2%)</td>
</tr>
<tr>
<td>Total</td>
<td>1540 (100%)</td>
</tr>
</tbody>
</table>

Univariate differences between consistent reparticipation and non-adherence.

Table 13 shows the significant univariate predictors of patterns of non-adherence compared to consistent reparticipation. Significant post hoc comparisons, indicated with asterisks, highlight specific differences between consistent reparticipation and each of the non-adherent categories. Social cognitive variables only differentiated consistent reparticipation from drop out and consistent refusal.

Table 14 shows the significant demographic and background predictors of non-adherence compared to consistent reparticipation. Unlike social cognitive variables, demographic and background predictors were identified for all non-adherent categories.
Table 13 Significant social cognitive differences between consistent reparticipation and each non-adherent category

<table>
<thead>
<tr>
<th>Variable</th>
<th>Consistent reparticipation n=859</th>
<th>Drop out n= 136</th>
<th>Intermittent reparticipation n=67</th>
<th>Delayed entry n=167</th>
<th>Consistent refusal n=311</th>
<th>F(df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barriers</td>
<td>16.29(4.22)</td>
<td>17.90(4.35)**</td>
<td>16.51(3.68)</td>
<td>16.60(4.35)</td>
<td>18.03(4.81)**</td>
<td>11.82(4,705.95)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Benefits</td>
<td>16.15(1.96)</td>
<td>15.72(1.98)</td>
<td>15.97(1.76)</td>
<td>15.90(1.93)</td>
<td>15.06(2.24)**</td>
<td>16.73(4,1535)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>23.73(4.69)</td>
<td>22.36(4.27)*</td>
<td>23.69(4.23)</td>
<td>23.35(4.59)</td>
<td>21.56(5.02)**</td>
<td>14.38(4,676.40)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Response efficacy</td>
<td>11.06(1.46)</td>
<td>11.26(1.13)</td>
<td>10.78(1.89)</td>
<td>10.97(1.61)</td>
<td>10.46(1.73)**</td>
<td>37.68(4)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Social support</td>
<td>22.96(3.81)</td>
<td>22.98(3.60)</td>
<td>22.91(3.27)</td>
<td>22.47(3.51)</td>
<td>21.79(4.38)**</td>
<td>6.05(4,722.45)</td>
<td>.001</td>
</tr>
<tr>
<td>Social influence</td>
<td>13.75(2.59)</td>
<td>13.54(2.62)</td>
<td>13.13(2.67)</td>
<td>13.36(2.43)</td>
<td>12.76(2.79)**</td>
<td>8.65 (4,1535)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

Note. F= F ratio; df= degrees of freedom, SD= standard deviation, p= probability

*Data were not normally distributed therefore the Kruskal-Wallis test was reported.

*p<.05. **p<.01
<table>
<thead>
<tr>
<th>Variable</th>
<th>Consistent reparticipation</th>
<th>Drop out</th>
<th>Intermittent reparticipation</th>
<th>Delayed entry</th>
<th>Consistent Refusal</th>
<th>F (df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age a</td>
<td>61.17 (6.34)</td>
<td>58.85 (6.55)**</td>
<td>57.70 (6.24)**</td>
<td>57.85 (5.56)**</td>
<td>58.57 (6.63)**</td>
<td>19.76 (4, 593.58)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>GP visits a</td>
<td>3.98 (1.161)</td>
<td>4.01 (1.14)</td>
<td>3.48 (1.32)**</td>
<td>3.95 (1.23)</td>
<td>3.85 (1.29)</td>
<td>3.141 (4, 528.88)</td>
<td>.010</td>
</tr>
<tr>
<td>Number (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Health insurance none</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>extras</td>
<td>145 (17.0)</td>
<td>34 (25.4)**</td>
<td>16 (23.9)</td>
<td>31 (18.6)</td>
<td>75 (24.2)*</td>
<td>19.76 (4, 593.58)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>extras</td>
<td>74 (8.7)</td>
<td>21 (15.7)</td>
<td>6 (9.0)</td>
<td>9 (5.4)</td>
<td>21 (6.8)</td>
<td>26.25 (4)</td>
<td>.010</td>
</tr>
<tr>
<td>hospital</td>
<td>55 (6.5)</td>
<td>6 (4.5)</td>
<td>4 (6.0)</td>
<td>9 (5.4)</td>
<td>14 (4.5)</td>
<td>20.90 (4)</td>
<td>.004</td>
</tr>
<tr>
<td>both</td>
<td>578 (67.8)</td>
<td>73 (54.5)</td>
<td>41 (61.2)</td>
<td>118 (70.7)</td>
<td>200 (64.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender (male)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married (yes) b</td>
<td>368 (43.0)</td>
<td>57 (42.5)</td>
<td>23 (34.3)</td>
<td>100 (59.9)**</td>
<td>159 (51.1)*</td>
<td>23.68 (4)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Workforce (yes) b</td>
<td>688 (80.7)</td>
<td>95 (70.9)**</td>
<td>53 (79.1)</td>
<td>131 (78.9)</td>
<td>222 (71.4)**</td>
<td>26.92 (4)</td>
<td>.004</td>
</tr>
<tr>
<td>Disadvantage 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>167 (19.5)</td>
<td>29 (21.3)*</td>
<td>15 (22.7)</td>
<td>34 (20.5)</td>
<td>81 (26.1)**</td>
<td>18.49 (4)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Disadvantage 2</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>140 (16.3)</td>
<td>35 (25.7)</td>
<td>11 (16.7)</td>
<td>26 (15.7)</td>
<td>56 (18.1)</td>
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<td>Disadvantage 3</td>
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</tr>
<tr>
<td></td>
<td>142 (17.7)</td>
<td>20 (14.7)</td>
<td>16 (24.2)</td>
<td>21 (12.7)</td>
<td>38 (12.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disadvantage 4</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>149 (17.4)</td>
<td>24 (17.6)</td>
<td>4 (6.1)</td>
<td>31 (18.7)</td>
<td>34 (11.0)</td>
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<td>Disadvantage 5 (least)</td>
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<td></td>
<td>250 (29.1)</td>
<td>28 (20.6)</td>
<td>20 (30.3)</td>
<td>54 (32.5)</td>
<td>101 (32.6)</td>
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<td>Knowledge (incorrect)</td>
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<tr>
<td></td>
<td>124 (14.5)</td>
<td>23 (16.9)</td>
<td>13 (19.7)</td>
<td>24 (14.5)</td>
<td>71 (22.8)**</td>
<td>12.49 (4)</td>
<td>.014</td>
</tr>
<tr>
<td>Known CRC yes b</td>
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<tr>
<td></td>
<td>621 (72.6)</td>
<td>85 (63.4)*</td>
<td>42 (62.7)</td>
<td>105 (63.3)*</td>
<td>191 (62.2)**</td>
<td>55.73 (4)</td>
<td>&lt;.001</td>
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<tr>
<td>Discussed FOBT (yes) b</td>
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<tr>
<td></td>
<td>541 (63.0)</td>
<td>68 (50.4)**</td>
<td>38 (56.7)</td>
<td>91 (54.8)*</td>
<td>120 (38.8)**</td>
<td>17.05 (4)</td>
<td>.002</td>
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<td>Known a screener (yes) b</td>
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<tr>
<td></td>
<td>467 (54.5)</td>
<td>56 (41.5)**</td>
<td>32 (47.8)</td>
<td>63 (38.0)**</td>
<td>93 (30.2)**</td>
<td>61.22 (4)</td>
<td>&lt;.001</td>
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<tr>
<td></td>
<td>562 (65.7)</td>
<td>82 (60.7)</td>
<td>38 (56.7)</td>
<td>117 (70.5)</td>
<td>173 (66.0)**</td>
<td>14.62 (4)</td>
<td>.006</td>
</tr>
</tbody>
</table>

Note. SD = standard deviation; F = F ratio; χ² = chi square; p = probability; SES = socioeconomic status determined by SEIFA index of disadvantage; knowledge = response to knowledge item regarding the importance of repeated screening, comparative category is ‘correct’; Known CRC = known a person who has had CRC; Discussed FOBT = ever discussed FOBT screening; Known a screener = known a person who has screened for CRC; Other screening = ever participated in other (not CRC) screening tests.

*variables were measured on increasing, continuous scales; **comparative category is ‘no’.*p<.05, **p<.01
**Multivariate predictors of non-adherence.**

Table 15 presents the results of four separate multivariate models with consistent reparticipation as the referent category for each. Risk ratios (RR) above 1 indicate an increase in the likelihood of being in the comparative non-adherent category compared with consistent reparticipation, and a value below 1 indicates a decrease in likelihood. Only variables that were identified post hoc as being associated with each pattern were entered into the multivariate models, therefore each model varies in terms of potential predictors. Those that were found to be significant predictors are highlighted in bold.

Few social cognitive variables contributed to the multivariate modelling of drop out and consistent refusal behaviours. Drop out was associated with greater perceived barriers to screening at baseline; however this increased the likelihood of being in the drop out category by only 5%. Similarly, lower self-efficacy, at baseline, significantly increased the likelihood of being in either the drop out or consistent refusal category by 3% and lower response efficacy increased the likelihood of consistent refusal. In addition, drop out was characterised by younger age, not being married and being less likely to have any form of private health insurance, or more likely to only have extras cover. These demographic variables were better predictors of drop out than social cognitive variables, with predictors such as lack of health insurance increasing the likelihood of drop out by between 44% and 61%. Demographic and background variables were also better predictors of consistent refusal with those in the consistent refusal category being 26% less likely to have known someone else who has screened for CRC, to be younger, and less likely to be in the third quintile of disadvantage than the 5th, which indicates low levels of disadvantage.
Those who were in the intermittent reparticipation or delayed entry behavioural categories were also significantly younger than consistent reparticipants, as were those who dropped out or who consistently refused; however this only increased the likelihood of being in either category by approximately 6%. Few variables predicted intermittent reparticipation and delayed entry at the multivariate level. Intermittent reparticipants reported significantly fewer GP visits in the year preceding the study and delayed participants were substantially (71%) more likely to be male.
### Table 15 Multivariate predictors of non-adherence relative to consistent reparticipation

<table>
<thead>
<tr>
<th>Variable</th>
<th>Drop out</th>
<th></th>
<th></th>
<th>Intermittent reparticipation</th>
<th></th>
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<th>Consistent refusal</th>
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<td></td>
<td>RR</td>
<td>p</td>
<td>95%CI</td>
<td>RR</td>
<td>p</td>
<td>95%CI</td>
<td>RR</td>
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<td>RR</td>
<td>p</td>
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</tr>
<tr>
<td>Barriers</td>
<td>1.05</td>
<td>.015</td>
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<td>.313</td>
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<td><strong>Cognitive</strong></td>
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</tr>
<tr>
<td>Benefits</td>
<td>0.97</td>
<td>.002</td>
<td>(0.95-0.99)</td>
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<td></td>
<td></td>
<td></td>
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<td>.105</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>0.97</td>
<td>.003</td>
<td>(0.95-0.99)</td>
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<td>0.97</td>
<td>.007</td>
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<tr>
<td>Response efficacy</td>
<td>0.93</td>
<td>.007</td>
<td>(0.83-0.97)</td>
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<td></td>
<td></td>
<td>0.93</td>
<td>.007</td>
</tr>
<tr>
<td>Social support</td>
<td>1.02</td>
<td>.173</td>
<td>(0.92-1.01)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.02</td>
<td>.173</td>
</tr>
<tr>
<td>Social influence</td>
<td>0.96</td>
<td>.137</td>
<td>(0.92-1.01)</td>
<td></td>
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<td></td>
<td></td>
<td>0.96</td>
<td>.137</td>
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<tr>
<td>Known CRC</td>
<td>0.86</td>
<td>.147</td>
<td>(0.71-1.05)</td>
<td></td>
<td>0.82</td>
<td>.184</td>
<td>(0.62-1.10)</td>
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<td>0.87</td>
<td>.144</td>
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<tr>
<td>Discussed screening</td>
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<td>.814</td>
<td>(0.68-1.38)</td>
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<td>0.98</td>
<td>.899</td>
<td>(0.74-1.31)</td>
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<td>.113</td>
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<tr>
<td>Known screener</td>
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<td>.390</td>
<td>(0.58-1.24)</td>
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<td>0.74</td>
<td>.056</td>
<td>(0.54-1.01)</td>
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<td>0.74</td>
<td>.011</td>
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<td><strong>Demographic</strong></td>
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<tr>
<td>Age</td>
<td>0.97</td>
<td>.037</td>
<td>(0.94-0.10)</td>
<td></td>
<td>0.93</td>
<td>.006</td>
<td>(0.88-0.98)</td>
<td>0.94</td>
<td>&lt;.001</td>
<td>(0.91-0.97)</td>
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<tr>
<td>Workforce (yes)</td>
<td>1.34</td>
<td>.108</td>
<td>(0.94-1.91)</td>
<td></td>
<td>1.01</td>
<td>.980</td>
<td>(0.58-1.75)</td>
<td>1.218</td>
<td>.289</td>
<td>(0.85-1.76)</td>
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<td>Married (yes)</td>
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<td>.036</td>
<td>(0.60-0.98)</td>
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<td>1.44</td>
<td>.020</td>
<td>(1.06-1.96)</td>
<td>1.03</td>
<td>.832</td>
<td>(0.81-1.30)</td>
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<td>.050</td>
<td>(1.15-2.25)</td>
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<tr>
<td>Insurance (extras only)</td>
<td>1.61</td>
<td>.005</td>
<td>(1.15-2.25)</td>
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<tr>
<td>Gender(male)</td>
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<td>&lt;.001</td>
<td>(1.28-2.29)</td>
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<td>1.08</td>
<td>.463</td>
<td>(0.88-1.32)</td>
<td>1.05</td>
<td>.687</td>
<td>(0.83-1.34)</td>
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<tr>
<td>Disadvantage (1)</td>
<td>1.09</td>
<td>.559</td>
<td>(0.82-1.45)</td>
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<td>Disadvantage (2)</td>
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<td>.141</td>
<td>(0.86-2.97)</td>
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<td>Disadvantage (3)</td>
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<td>.865</td>
<td>(0.51-2.25)</td>
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<tr>
<td>Disadvantage (4)</td>
<td>1.56</td>
<td>.123</td>
<td>(0.89-2.72)</td>
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</tbody>
</table>

**Note.** RR = risk ratio; p = probability; 95% CI = confidence interval.

* Reference category is hospital and extras combined cover; b Reference category is female; c Reference category is the fifth quintile of disadvantage (least disadvantage).
Satisfaction with prior FOBT participation.

A measure of satisfaction was only available for participants who reported in the rescreening questionnaire (baseline measure) that they had previously participated in FOBT-based screening (n=720). Details of prior testing were limited to a single item measure of overall satisfaction with screening. Specific information including previous FOBT test results and type of FOB test utilised were not obtained. To determine the potential impact of satisfaction with previous screening on non-adherence to the screening offered in this study the multivariate models described above were repeated for the reduced sample with the addition of the single item satisfaction measure. As highlighted previously, the outcome categories in this study describe adherence behaviours observed during the specified study period in relation to three sequential screening offers. The same adherence categories were therefore used to describe the behaviour of participants in the subsample despite the fact that all subsample participants had indicated adherence to screening before their involvement in the study. The outcomes from these models are summarised in Table 16.

To put this additional analysis into context, the demographic characteristics of the reduced sample (n=720) were compared with the full sample (N=1540). Several small but significant differences were identified between the two. Compared to those in the full sample those in the reduced sample were; older ($\bar{x} = 61.44, SD=6.41$ compared with $\bar{x} = 59.93, SD=6.48$), less likely to speak a language other than English (13.1% compared with 13.7% [$\chi^2(1) = 10.77, p<.001$]), less likely to be still in the workforce (47.1% compared with 52.1% [$\chi^2(1) = 7.08, p=.008$]) more likely to be married (81.0% compared with 77.2% [$\chi^2(1) = 5.80, p=.016$]), had fewer people living in the lowest quintile of disadvantage (16.46% compared with 29.4%) and more living in the highest
(32.4% compared with 21.2%, \( \chi^2(4) = 20.65, p<.001 \)). No significant differences were found for gender, birth country or education.

The reduction in the sample size also had a significant effect on the proportion of participants in each of the non-adherent categories \( \chi^2(4) = 51.49, p<.001 \). Amongst the subsample there were substantially more in the consistent reparticipation category (n=480, 66.80% compared with n=859, 55.8%), and substantially less in the consistent refusal category (n =78, 10.83% compared n=311, 20.2%). Proportions of those in the delayed entry (n=83, 11.53% compared with n=167, 10.8%), intermittent reparticipation (n=31, 4.3% compared with n= 67, 4.4%), and drop out (n=47, 6.53% compared with n= 136, 8.8%) categories remained relatively similar in the subpopulation. Social cognitive variables did not differentiate categories of non-adherence amongst a sample of participants who had previously participated in FOBT screening. Less satisfaction however, was significantly predictive of all non-adherent behaviours with the exception of intermittent reparticipation. Specifically, less satisfactory experiences with prior FOB testing substantially (42%) increased the likelihood of drop out behaviour in the study period, increased the likelihood of refusing all study screening offers by 26% and increased the likelihood of refusing initial screening offers (delayed entry) by 23%. Demographic variables (gender, age and disadvantage) also continued to predict non-adherence. In addition, several previously predictive variables (marital status, health insurance) were not associated with outcomes in the subgroup analyses whilst new variables (i.e., workforce, discussed CRC with others) were predictive.
<table>
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<tr>
<th>Variable</th>
<th>Drop out RR</th>
<th>p</th>
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<th>Intermittent reparticipation RR</th>
<th>p</th>
<th>95% CI</th>
<th>Delayed entry RR</th>
<th>p</th>
<th>95% CI</th>
<th>Consistent refusal RR</th>
<th>p</th>
<th>95% CI</th>
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<td>(social cognitive and satisfaction)</td>
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<td>Other screening (yes)</td>
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<td>Age</td>
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<td>(0.92-0.10)</td>
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<td>.215</td>
<td>(0.89-1.03)</td>
<td>0.93</td>
<td>.001</td>
<td>(0.89-0.97)</td>
<td>0.97</td>
<td>.229</td>
<td>(0.93-1.02)</td>
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<td>Workforce (yes)</td>
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<td>.030</td>
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<td>(0.62-2.85)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.99</td>
<td>.983</td>
<td>(0.51-1.92)</td>
</tr>
<tr>
<td>Insurance(extras only)</td>
<td>1.22</td>
<td>.452</td>
<td>(0.72-2.07)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.64</td>
<td>.359</td>
<td>(0.25-1.67)</td>
</tr>
<tr>
<td>Gender(male)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.95</td>
<td>.003</td>
<td>(1.26-3.02)</td>
</tr>
<tr>
<td>Disadvantage (1)</td>
<td>1.15</td>
<td>.760</td>
<td>(0.47-2.78)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.55</td>
<td>.079</td>
<td>(0.28-1.07)</td>
</tr>
<tr>
<td>Disadvantage (2)</td>
<td>0.54</td>
<td>.163</td>
<td>(0.23-1.29)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.69</td>
<td>.220</td>
<td>(0.39-1.25)</td>
</tr>
<tr>
<td>Disadvantage (3)</td>
<td>0.36</td>
<td>.646</td>
<td>(0.25-1.66)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.42</td>
<td>.027</td>
<td>(0.19-0.91)</td>
</tr>
<tr>
<td>Disadvantage (4)</td>
<td>2.03</td>
<td>.10</td>
<td>(0.88-4.68)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.47</td>
<td>.028</td>
<td>(0.24-0.92)</td>
</tr>
</tbody>
</table>

Note: RR= risk ratio; p= probability, 95% CI= confidence interval.

*a reference category is hospital and extras combined cover;  
b reference category is female;  
c reference category is the fifth quintile of disadvantage (least disadvantage).
Discussion

Recent studies have highlighted the importance of monitoring longitudinal screening adherence in order to measure adequately rescreening (Cooper & Doug Kou, 2008; Gellad, et al., 2011). In this study, longitudinal adherence was measured according to a predefined framework that described a variety of non-adherent screening patterns over a period of three years (Drossaert, et al., 2003). Results show just over 50% of participants provided with annual invitations to screen with FOBT were adherent with all three rounds. A substantial portion of participants were non-responsive to all invitations (20.2%), and irregular patterns of adherence were observed for the remaining 24% of participants. Colorectal cancer epidemiology is complex (Rozen, Liphshitz, & Barchana, 2011) and there is evidence to support the benefit of both annual and biennial screening (Hardcastle, et al., 1996; Jorgensen, et al., 2002; Mandel, et al., 2000) with the greatest benefit reported for annual screening (Mandel, et al., 2000). These complications however, simply further emphasise the importance of ensuring that screening programs are able to achieve adequate levels of initial and continued adherence, without drop out or other irregular patterns, in order to maximise population benefit. Although, some demographic and background characteristics of those who drop out of screening programs have previously been identified (Garcia, et al., 2012; Myers, et al., 1993), there has been no research conducted on behavioural factors that may influence drop out; there has also been no research conducted on those who intermittently drop in and out of screening programs, or why some participants take longer to respond to screening invitations than others.

Social cognitive predictors contributed little to models of non-adherence with FOBT use offered repeatedly over three years. Drop out and consistent refusal were
characterised by slightly more negative attitudes toward FOBT screening (for example, poorer self-efficacy), however these associations were not substantial. Despite little influence from social cognitive variables, different demographic and background variables predicted several patterns of non-adherence. These findings suggest that programs trying to achieve higher rates of ongoing participation (rescreening) might benefit from targeting specific demographic subpopulations.

Demographic findings were largely consistent with existing literature (Gimeno-García, 2012; von Euler-Chelpin, et al., 2010). However, the use of a multilevel framework to categorise the different non-adherent behaviours also led to some new findings. For example, being male was significantly associated with delayed entry into the program. Prior research has consistently reported lower levels of initial FOBT participation amongst men (Le Retraite et al., 2010; Pornet, Dejardin, Morlais, Bouvier, & Launoy, 2010; Ward et al., 2011). However these findings suggest that men may simply take longer to respond to invitations to screen, and may benefit from different recruitment strategies than women to encourage first time compliance.

Similarly, the finding that those who consistently refused participation were less likely to be from areas of moderate disadvantage, compared to the area of least disadvantage, is also an interesting contribution. Non-participation in single screening opportunities has been consistently associated with markers of socioeconomic deprivation (von Wagner et al., 2011; Ward, et al., 2011). The results of the present study may indicate that the behaviour of refusing a single screening offer is different from the behaviour of refusing multiple screening offers. Prior research has shown lower levels of CRC screening knowledge, lack of private health insurance, and several social cognitive variables (i.e., greater perceived barriers, fewer benefits) to be
predictive of non-participation in single screening opportunities. However, many of these variables were not substantially predictive of consistent refusal of screening offers. Consistent refusal therefore may reflect an informed decision (i.e., the decision to refuse screening is based on adequate knowledge of screening test, its purpose and limitations, Smith et al., 2010) to not participate in FOBT-based CRC screening. Further research would be required to explore this notion.

The present study is the first amongst the CRC rescreening literature to describe multiple non-adherent behavioural patterns (i.e., delayed entry, intermittent reparticipation, drop out). Study results found different demographic variables, for example gender, health insurance and marital status, to be predictive of different types of non-adherent behaviours over the three year observation period. These findings support the use of a multilevel framework that takes into account different types of adherent and non-adherent behaviours for describing rescreening behaviour. It is however important to note that the demographic results reported here do not enable us to determine why these subgroups respond differently; it is likely that other social, psychological and practical barriers to adherence are also important to identify in order to appropriately target intervention material to demographic subpopulations.

Less satisfaction with previous FOBT screening experiences was the only behavioural variable to explain multiple non-adherent behaviours. The most substantial impact was observed amongst those in the drop out category, with less satisfaction increasing the likelihood of program drop out by 42%. Prior research in the mammography screening literature has consistently shown less satisfaction with initial screening to be predictive of non-compliance with subsequent offers (Peipins, et al., 2006; Tang, et al., 2009). These findings indicate that satisfaction can also have a
longitudinal effect on adherence behaviour leading to consistent refusal of screening as well as irregular participatory patterns. The importance of ensuring initial and continued satisfaction with screening cannot be underestimated. Future rescreening research should consider exploring which aspects of prior screening, for example, the type of FOB test utilised (Cole et al., 2003), the service provided as part of the screening experience or the receipt of abnormal test results (Myers et al., 1993) may contribute to perceived satisfaction and how these factors may be improved to encourage rescreening. Measures of satisfaction with screening obtained during the study observation period (i.e., those relating specifically to the FOB test used in this study), and how these may have changed from baseline measures, may also aid interpretation of results.

There are several limitations associated with the data described in the present study. Firstly, it is important to note that the populations used for the two multivariate analyses (initial analyses and the satisfaction subgroup analyses) did differ in terms of sample size and baseline demographics. In addition, satisfaction measures were determined based upon prior FOBT satisfaction determined at baseline, not satisfaction with the FOBT used in the study. The satisfaction analyses used a substantially reduced sample of participants, all of whom had prior experience with screening and therefore, consistent with prior research (Cole, et al., 2011; Duncan, et al., 2012), were characterised by different demographic variables than the full sample that included those with and without prior screening experience. It is therefore unsurprising that the variables that predicted non-adherence amongst this group were different to the variables that predicted non-adherence amongst the wider sample.
This subgroup was not the focus of the initial social cognitive analyses because the inclusion criteria would have led to a substantially reduced sample size and a reduced number of invitees in each behavioural category. In addition, the primary interest was in examining prospective attitudinal determinants of longitudinal behaviour in three consecutive screening offers irrespective of prior behaviour. Conducting similar analyses on directly comparable populations of a larger size may be required to understand the interaction between satisfaction, past experience and social cognitive variables. What these additional analyses do indicate however is that amongst a population of people with previous screening experience the social cognitive variables included in this study did not predict non-adherence.

Secondly, outcome measures were based upon both observed screening participation and self-report data. There are several issues associated with utilising self-report data in CRC screening. These include the potential for participants to exaggerate compliance to conform with study or personal expectations (Festinger & Carlsmith, 1959) or for participants to have difficulty recalling frequency and compliance with screening guidelines across multiple screening rounds (Vernon, Briss, et al., 2004). Nevertheless, in the present study observed participation was only supplemented with self-report data when it was volunteered by participants. Participants were not required to provide reasons for non-adherence, therefore it is unlikely that invitees felt compelled to exaggerate adherence. In addition, participants were not asked to recall multiple screening instances but simply whether they were adherent at time of offer. This simplified approach has been associated with more reliable self-report (Rauscher, et al., 2002; Vernon, Meissner, et al., 2004). In addition, this study was conducted within an organised screening context amongst a general population of people eligible for FOBT.
screening and it would be unrealistic to assume that participants had not been exposed to other screening opportunities, particularly with the recent introduction of a free nationwide screening program in Australia (Australian Government Department of Health and Ageing, n.d-b). Adherence with other types of screening tests (either endoscopic or FOBT) during the three year screening observation period were reported by 19% of screening invitees. The exclusion of self-report data therefore would have led to serious misclassification of many participants and distorted the results.

Finally, this study is the first to measure the proportion of invitees in different categories of non-adherence with screening across multiple screening rounds longitudinally, and to identify differences in behavioural and demographic characteristics between categories of FOBT screening non-adherence. Whilst observed differences between the categories for demographic and background variables support the use of a detailed framework for understanding rescreening adherence behaviours there are limitations to this approach. Screening participation is an ongoing behaviour; the analyses presented here describe participants based on observed behaviour only over three consecutive screening rounds, and labels assigned to participants’ behaviours will change from one round to the next; category membership is not fixed.

The findings presented here suggest characteristics that may be targeted at a broad population level to improve rates of participation; but they may not be useful for determining how an individual may behave in the future. In addition, predefined behavioural definitions were used to guide the categorisation of invitees and some definitions collapsed multiple patterns of behaviour. This approach was beneficial as it allowed for a detailed comparison of several different types of adherence behaviour without focusing on all eight of the observed patterns. This is particularly relevant for
studies focusing on greater numbers of screening rounds, where possible patterns of behaviour will continue to increase. This approach does however overlook the potential for differences within the categories, for example, potential differences between sustained and sporadic non-adherent behaviour. Future research may want to consider exploring alternate rules for categorisation in order to determine the most effective approach for describing, and improving, rescreening adherence.

Conclusions

This study identified several demographic, background and behavioural variables associated with differing levels of non-adherence after three annual offers of FOBT screening for CRC. It is the first study to differentiate between types of non-adherence and the first to apply social cognition variables to understanding rescreening. Social cognitive models were less likely to predict non-adherence than background and demographic variables. However, less satisfactory prior screening experiences were a major determinant of non-adherence.
Chapter Six - Discussion

Preface

This chapter provides an overview of the main results of the thesis and discusses the contribution of these findings to CRC screening research. Suggestions for future research and implications for interventions and screening practice are discussed over and above suggestions made in individual chapters. As discussed in chapter two, there were two general thesis aims; firstly to describe rescreening adherence in a South Australian population according to multilevel frameworks and secondly to determine the utility of social cognitive variables in the explanation of variance in rescreening intention and behaviour. Each paper addressed a specific aim within these general research questions. The final discussion focuses predominantly on behavioural associates of rescreening observed in the three papers. Demographic and background variables are discussed briefly where they inform discussions of future research and screening practice.

Rescreening Adherence in Australia

Research in Australia and overseas has shown that a substantial portion of those who participate in screening drop out following initial uptake (for e.g., Gellad, et al., 2011; Janda, et al., 2010; Weller, et al., 2007). Drop out and other inconsistent patterns of adherence pose a threat to screening programs aiming to maximise participation in order to reduce population CRC incidence and mortality. Rescreening adherence data were collected in two different ways. In paper two, self-reported past rescreening adherence and future intentions were reported from a random, cross-sectional sample of South Australian men and women between the ages of 50 and 74. Amongst this
sample, prior screening may have occurred either as part of a screening program or may have been self-initiated (i.e., predominantly opportunistic screening). In paper three, rescreening adherence was assessed in this same sample longitudinally over three rounds of screening (i.e., organised screening).

In the thesis study, complete adherence (participation in all three rounds) with the screening offers was 55.8%; past rescreening adherence (at least two FOBTs no more than 24 months apart) was 31%. These rates are consistent with past research that has found greater adherence with organised as opposed to opportunistic screening (Power, et al., 2009). Intention to rescreen amongst those reporting prior screening experience was 85.6% (paper two).

Study duration, screening interval and country of study have been shown to contribute to differences in screening uptake and rescreening adherence (Clark, et al., 2003; Vernon, 1997; von Euler-Chelpin, et al., 2010). Intentions to rescreen for CRC in paper two were consistent with rescreening adherence reported in the NBCSP (Australian Institute of Health and Welfare and Australian Government Department of Health and Ageing, 2008). Paper three was the first study to record rescreening in an Australian population over more than two rounds. No comparable rescreening data are available in Australia. Complete adherence in the original randomised controlled trials that established the efficacy of FOBT screening were between 38.2% and 59.7% (Hardcastle, et al., 1996; Jorgensen, et al., 2002; Mandel, et al., 2000). Whilst adherence to the screening provided to participants in this thesis was within this acceptable range, data were collected over a much shorter time period (three years as opposed to 10-13 years) and are likely to decline further over time (Clark, et al., 2003). Results therefore
indicate that rescreening rates in Australia are below optimal; there is an important need to focus on ensuring adequate initial and continued screening adherence.

Chapter one emphasised the importance of differentiating various typologies of non-adherent rescreening behaviours. Consequently, papers two and three utilised different frameworks to describe rescreening intention and adherence. The different rescreening behaviours (from here on referred to collectively as rescreening outcomes) identified in these two studies are summarised in Table 17. The inclusion of “intention to screen” to the determination of stage membership in paper two resulted in two unique drop out behaviours (relapse and inconsistent), whilst the availability of three rounds of screening data in paper three resulted in the capacity to describe two additional inconsistent screening patterns (intermittent reparticipation and delayed entry). The proportions of participants in each of the stages (paper two) and behavioural categories (paper three) are included in Table 17. Together these studies show that there are several non-adherent behaviours each comprising a substantial proportion of the non-adherent population. Subsequent analyses confirmed that these outcomes were characterised by unique demographic, behavioural and background predictors.
Table 17 Rescreening outcomes and population distribution

<table>
<thead>
<tr>
<th>Category/stage</th>
<th>Definition</th>
<th>Percentage</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper two&lt;sup&gt;a&lt;/sup&gt;</td>
<td><strong>Maintenance</strong> Two prior FOBT no more than 24 months apart within the past four years with an intention to rescreen.</td>
<td>31%</td>
<td>263</td>
</tr>
<tr>
<td></td>
<td><strong>Action</strong> One prior FOBT within the past two years with an intention to rescreen</td>
<td>39.1 %</td>
<td>332</td>
</tr>
<tr>
<td></td>
<td><strong>Relapse</strong> Prior FOBT participation with no intention to rescreen</td>
<td>14.4 %</td>
<td>122</td>
</tr>
<tr>
<td></td>
<td><strong>Inconsistent</strong> Prior FOBT participation, not adherent at baseline, with an intention to rescreen</td>
<td>15.5 %</td>
<td>132</td>
</tr>
<tr>
<td>Paper three&lt;sup&gt;b&lt;/sup&gt;</td>
<td><strong>Consistent reparticipation</strong> Participation in three FOBT rounds</td>
<td>55.8%</td>
<td>859</td>
</tr>
<tr>
<td></td>
<td><strong>Drop out</strong> Participation in either FOBT round one or two followed by non-participation in subsequent rounds</td>
<td>8.83%</td>
<td>136</td>
</tr>
<tr>
<td></td>
<td><strong>Intermittent reparticipation</strong> Participation FOBT round one and three but not two.</td>
<td>4.35%</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td><strong>Delayed entry</strong> Non-participation in either round one or two followed by participation in subsequent rounds</td>
<td>10.8%</td>
<td>167</td>
</tr>
<tr>
<td></td>
<td><strong>Consistent refusal</strong> No participation in any FOBT round</td>
<td>20.19%</td>
<td>311</td>
</tr>
</tbody>
</table>

*Note.*<sup>a</sup> Total study population = 849, <sup>b</sup>Total study population = 1540.

**Behavioural Associations with Rescreening**

An original contribution of this thesis was the inclusion of behavioural variables (social cognitive and satisfaction with past screening) to describe rescreening. The three papers in this thesis examined the utility of social cognitive and behavioural variables for rescreening research in different contexts. In paper one the utility of including behavioural measures was explored in qualitative interviews with prior screeners. In paper two the themes identified in paper one were examined for their ability to differentiate levels of rescreening intention in a cross-sectional sample. In paper three
the same variables were examined for their ability to predict differences in adherence longitudinally.

**Social cognitive variables.**

Paper one identified several social cognitive themes relevant for inclusion in rescreening research. The themes identified in paper one were largely consistent with those examined in the initial screening literature (Beydoun & Beydoun, 2008; Gregory, et al., 2011; Kiviniemi, et al., 2011). Also consistent with the existing literature, these themes included constructs from a variety of different social cognitive models (i.e., the HBM, TTM, TPB, Ajzen, 1991; Janz & Becker, 1984; Prochaska & DiClemente, 1983). This thesis therefore did not aim to determine the utility of a particular model for explaining rescreening, rather to determine the associations between rescreening and individual model constructs (e.g., self-efficacy, barriers and benefits).

At the univariate level, the majority of social cognitive variables included in the rescreening questionnaire were associated with variations in rescreening intention and adherence. Consistent with paper one and prior research in initial screening (Beydoun & Beydoun, 2008; Kiviniemi, et al., 2011), rescreening intention was characterised by self-reported perceptions of; greater benefits associated with screening, self-efficacy about the required behaviour, availability of social support, social influence for CRC screening, higher chance health locus of control, higher response efficacy, more implementation intentions (planning processes) and fewer barriers to screening, by comparison to lower stages of readiness (Prochaska & DiClemente, 1983). Similarly, these same variables, with the exception of chance health locus of control and implementation intentions\(^5\),

\(^5\) Implementation intentions (i.e., planning processes for future screening) were not included in analyses in paper three because screening was provided free on an annual schedule.
were predictive of rescreening adherence. Post hoc analyses of these data in paper three revealed that differences were predominantly between the consistent reparticipation, consistent refusal and drop out behaviours. Social cognitive variables did not predict either delayed entry or intermittent rescreening behaviours.

There were several social cognitive variables that were not associated with rescreening outcomes in either quantitative study. These included; health value, internal health locus of control, perceived severity and perceived susceptibility. These variables were included in the rescreening questionnaire based on the findings of paper one and past research in initial screening (Kiviniemi, et al., 2011). Non-significant outcomes in the quantitative papers may reflect either incorrect operationalisation of the themes identified in the qualitative analyses or suggest that these variables are relevant only for initial screening behaviour.

The remainder of this discussion will focus on the results of the multivariate analyses. To summarise; perceived barriers, benefits, self-efficacy, implementation intentions and social influence were significantly associated with stage of readiness in paper two, whilst perceived barriers, self-efficacy and response efficacy were predictive of adherence categories in paper three. In both studies these variables were predominantly negatively associated with behaviours that demonstrated the least commitment to rescreening recommendations, i.e., relapse, drop out and consistent refusal behaviours were associated with more negative attitudes toward screening. Social cognitive variables were not predictive of adherence in paper three when analyses were restricted to those with prior FOBT screening experience.
In both quantitative studies the contribution of the social cognitive variables to multivariate models, inclusive of significant demographic and background variables, was small. Relative risk values indicated that individual social cognitive variables in paper two each increased the likelihood of being in a lower stage of readiness (comparative to maintenance) by between 4% and 16%. In paper three, social cognitive variables increased the likelihood of non-adherence by between 3% and 7%. In general the contribution of additional variables (i.e., satisfaction with screening, demographic and background variables), was greater than the social cognitive variables; these are discussed in subsequent sections.

The utility of multilevel frameworks to describe rescreening behaviour was supported in papers two and three. In both studies there was very little overlap between the variables associated with the different stages of readiness or categories of adherence. These findings support the hypothesis that different types of non-adherent behaviours are likely to respond to different types of interventions. Consistent with the predictions of the Transtheoretical Model of Behaviour Change (TTM) (Prochaska & DiClemente, 1983), negative attitudes toward screening (i.e., fewer perceived benefits) were associated with relapse (no intention) whilst implementation intentions were associated with inconsistent participation (intention) in paper two. Similarly, in paper three, greater perceived barriers predicted program drop out, whilst lower response efficacy predicted consistent refusal.

Consistent with prior research (Gregory, et al., 2011) few social cognitive variables were predictive of both intention and adherence. Perceived barriers to screening and self-efficacy were the only two variables to predict outcomes in papers two and three. In both studies perceived barriers were associated with increased
likelihood of program drop out (paper three) and past drop out (inconsistent screening, paper two). Past research has consistently found greater perceived barriers to be associated with non-participation in initial screening (Kiviniemi, et al., 2011). Thesis results suggest that barriers to screening continue to influence rescreening behaviour beyond the initial screening experience; those who drop out of screening following initial participation are more likely to perceive attitudinal and structural barriers to rescreening. Similarly, despite evidence to suggest that screening participation improves self-efficacy for subsequent screening (Flight, et al., 2012), lower levels of self-efficacy were associated with relapse behaviour in paper two and were predictive of screening drop out and consistent refusal behaviours in the screening offers.

**Satisfaction with prior screening experiences.**

Satisfaction with FOBT screening completed before involvement in this thesis study consistently predicted rescreening adherence across all three studies. In paper one, participants recalled largely positive experiences relating to test completion and were complimentary of the BHS screening program that they had previously been involved in. Contrary to the social cognitive findings reported above, satisfaction was strongly associated with outcomes in both quantitative studies and also strongly associated with several outcomes within the studies. Risk ratios showed less satisfaction to increase the likelihood of relapse in paper two by 13%, and increased the likelihood of non-adherence in paper three by between 23% and 42%. The finding that satisfaction was associated with both screening intention and longitudinal adherence is particularly salient. To date, no FOBT studies have examined the association between satisfaction and rescreening. In addition, whilst mammography research has extensively examined the impact of prior satisfaction on participation in a subsequent offer (Edwards et al,
this is perhaps the first study to show a detrimental effect over more than one subsequent round.

Behavioural variables were associated with rescreening outcomes however, with the exception of satisfaction, the contribution of the social cognitive variables to multivariate models inclusive of external behavioural influences (demographic and background variables) was small. In addition, different social cognitive variables were associated with intention and adherence.

**Demographic and Background Variables**

Demographic and background variables previously associated with rescreening (Cooper & Doug Kou, 2008; Fenton, et al., 2010; Gellad, et al., 2011; Janda, et al., 2010) were also included in quantitative analyses. In the multivariate models, demographic and background variables substantially increased the likelihood of non-adherence, particularly in paper three. Consistent with the above findings, different stages and categories of behaviour were characterised by different demographic and behavioural predictors. Similarly, few were found to be associated with both intention and action. Specific findings are discussed in the individual chapters. New findings from these studies include the association between relapse and poor rescreening knowledge (paper two), the association between male gender and delayed entry (paper three) and the finding that consistent refusal was associated with less disadvantage (paper three).

**Suggestions for Future Research**

First and foremost, levels of rescreening adherence and intention reported in this study indicate that rescreening in Australia is below optimal. The studies in this thesis however are amongst a small few to dedicate a specific focus to understanding
rescreening behaviour. Whilst it can be argued that encouraging initial uptake is an important public health initiative, CRC screening research should also consider ways of encourage maintenance of screening to ensure the longitudinal effectiveness of screening initiatives.

Satisfaction with screening was an important determinant of rescreening behaviour across the studies. In this thesis satisfaction was operationalised with a single item designed to measure satisfaction with the overall screening experience. In order to translate these findings into screening intervention and practice it is important for future research to explore which aspects of screening contribute to an overall satisfactory experience. Amongst the mammography literature studies have identified several elements of screening participation that contribute to satisfactory experiences; these include satisfaction with clinic services (i.e., treatment from staff), the physical experience (e.g., pain, discomfort; Marshall, 1994; Tang, et al., 2009), the psychological experience (e.g., embarrassment; Marshall, 1994; Tang, et al., 2009) and the nature of the communication with clinic staff (e.g., was the procedure properly explained) (Edwards, et al., 2011; Tang, et al., 2009). Many of these elements however may not be relevant to the explanation of satisfaction with a self-directed non-invasive screening procedure such as use of the FOBT. Qualitative research examining FOBT participation has identified psychological experiences with screening (e.g., embarrassment and aversion) as a potential predictor of subsequent non-adherence (Chapple, et al., 2008). Future research may want to examine other areas including communication with those facilitating testing (e.g., program organisers, nurse practitioners), receipt of abnormal test results (Garcia, et al., 2012; Myers, et al., 2003) and experiences organising and participating in follow up testing as a starting point for evaluating screening experience.
Few social cognition models include constructs that measure prior experience with health behaviours. Future research examining social cognitive variables in rescreening research should consider the inclusion of satisfaction with prior screening in addition to other social cognitive constructs. It may also be important to explore the relationship between satisfaction and other social cognitive variables to determine if attitudes toward rescreening (i.e., perceived barriers/benefits) are influenced by beliefs and expectations resulting from prior experience. In addition, ratings of satisfaction with prior experiences may be also affected by cognitive dissonance (Festinger & Carlsmith, 1959) with participants who perceive fewer benefits and greater barriers to participation reporting less satisfaction with screening in order to justify their beliefs about the behaviour.

Finally, results indicate that levels of satisfaction based on previous experience of CRC screening were predictive of adherence to consecutive screening offers. The prospective design ensured that measures of satisfaction were not influenced by factors associated with service delivery during the screening offers; previous unsatisfactory experiences may have long term effects on compliance. This suggests the importance of assessing satisfaction during exposure to screening offers in order to further explain inconsistent screening behaviour and the potential additional influence of factors relating to service delivery on satisfaction with screening.

The studies in this thesis were the first within the rescreening literature to challenge the notion that non-adherence is a unitary behaviour. Multilevel frameworks allowed for the identification of several non-adherent behaviours, all of which were found to differ from the target behaviour (rescreening) according to their relationship with a number of social cognitive, demographic and background variables. In order to
identify and target the needs of non-adherent subgroups it is important that future research continue to distinguish between the different behavioural groups.

Additionally, as suggested in paper three, future research may want to explore alternate rules for categorisation of behaviour especially for longitudinal research. In the absence of prior research, paper three choose to address behavioural patterns based on studies that had applied this notion to screening over two rounds (Drossaert, et al., 2003; Janda, et al., 2010). With the addition of more screening rounds the combinations of potential screening patterns will increase. Assessing more general behaviours, i.e., consistent versus irregular patterns, may provide a framework that minimises the number of categories and is applicable across multiple rounds. Future research is required to determine the extent to which this approach would result in differences between categories and translate to useful intervention design.

Thesis findings suggest a variety of areas for future research on social cognitive variables and rescreening. The univariate results indicated that social cognitive variables were associated with rescreening outcomes. Multivariate analyses however, revealed that these associations were small, and in many cases absorbed by the inclusion of satisfaction, background and demographic variables.

The finding that demographic and background variables contributed more to multivariate models of both intention and adherence does not negate the need for further investigation of social cognitive variables in rescreening research. Many of the demographic and background variables predictive of screening outcomes are associated with behavioural variables. Marital status for example has been associated with increased social influence and support (Manne et al., 2012), whilst male gender has been associated with a lack of concern regarding health issues (i.e., lower health value)
Demographic data can only provide information on which subgroups are less likely to rescreen; findings cannot provide information on why these subgroups are more resistant. Examining how social cognitive and demographic/background variables interact in a rescreening context is therefore required to inform the development of interventions.

The variables included in this thesis appeared more relevant for predicting rescreening intention than adherence. Findings from paper two that show those who do not intend to rescreen (relapse) were more likely to perceive fewer benefits, fewer social influences and less self-efficacy are important, particularly in light of the strong relationship between negative intention and subsequent non-adherence (Orbell & Sheeran, 1998). The results of paper three however indicate that only few of these variables were marginally predictive of screening adherence in the three consecutive screening offers indicating that further research is required to determine additional influences on adherence.

Social cognitive theories (e.g., TPB, TTM) include intention as an important precursor of action but highlight that additional variables are often required to ‘bridge the gap’ between intention and behaviour. These variables include self-efficacy (TPB, TTM, Ajzen, 1991; Prochaska & DiClemente, 1983) cues to action (HBM, Janz & Becker, 1984), implementation intentions (Gollwitzer, 1999), and removal of systems barriers (Sheeran, 2002). Consistent with these theories lower self-efficacy and greater perceived barriers (both structural and attitudinal) were predictive of non-adherence. These variables however only predicted non-adherence by between 3% and 5%; there is a need to examine additional influences on behaviour. Several elements of the study design are worth considering.
In order to conduct a prospective behavioural analysis of longitudinal adherence it was necessary to offer organised screening. The screening offered in paper three was designed to replicate, as closely as possible, the protocol adapted by the NBCSP (Australian Government Department of Health and Ageing, n.d-b). The study was not designed to be a screening intervention, however many elements of the program have been previously found to improve screening adherence including; advance notification letters (Cole, et al., 2007), screening information leaflets and invitation letters (Senore, Malila, Minozzi, & Armaroli, 2010), free mail-delivered FOBT (Church, et al., 2004) and reminder letters (Holden, et al., 2010). It is possible that involvement in screening offers improved screening intentions (Cole, et al., 2007), educated participants on the benefits of screening (Power, et al., 2009) and removed structural barriers (Senore, et al., 2010). Together these elements could plausibly overcome initially adverse attitudes to screening and act as cues to encourage adherence. Results suggest that in the context of organised screening, many of the social cognitive variables included in the rescreening questionnaire did not substantially influence behaviour. In Australia however, where organised screening is not routinely offered, future research would benefit from examining the social cognitive predictors of adherence to opportunistic screening.

The organised screening context may be one explanation for the discrepancy in measures of intention and adherence. Nevertheless, past research on initial screening uptake has reported social cognitive associations, even in organised screening contexts (Cole, et al., 2011) therefore it is also important to consider alternate explanations such as the study design and duration (longitudinal versus single screening). In paper two, intention to rescreen was measured concurrently with social cognitive variables. Research has shown that social cognitive variables are most strongly associated with
behavioural outcomes when measured temporally close together, therefore minimising the likelihood that participants will change their attitudes between the time the measures are taken and behaviour occurs (Cooke & French, 2008). In paper three, social cognitive predictors were measured three years before the behavioural categories were defined. It is therefore very likely that participants changed their attitudes toward FOBT screening during this time, particularly as a result of regular exposure to screening recommendations through regular screening offers. This may explain why social cognitive variables had little influence on adherence whilst more stable demographic characteristics remained predictive. Future longitudinal research would benefit from obtaining additional attitudinal measures either during the screening observation period, or upon completion of the offers in order to assess change in social cognitive variables and their influence on adherence.

Finally, results indicate the need for examination of other potential social cognitive predictors not included in the rescreening questionnaire. The results of paper one suggested that rescreeners place great emphasis on maintaining good health and actively initiate participation in preventive health behaviours. Past research has consistently reported strong associations between participation in other preventive health activities and screening behaviour (Beydoun & Beydoun, 2008; Gimeno-García, 2012; Senore, et al., 2010). It is hypothesised that an underlying characteristic that motivates participation in preventive health behaviours is responsible for this association (Lemon, et al., 2001). Nonetheless, to date, screening research has continued to measure participation in other health behaviours (Senore, et al., 2010), rather than determining whether this is a proxy for an underlying social-cognitive construct. In this thesis, a previously validated Health Value scale (Lau & Hartman, 1986) along with a
measure of Internal Health Locus of Control (Wallston, et al., 1978) were included in an attempt to measure health specific behavioural characteristics. These variables were not found to be associated with intention or adherence although this may be a reflection of problems in the way these variables were operationalised rather than a true indication of their influence. Future research may want to consider exploring alternate measures and/or theories that may further explore the findings of paper one. Health motivation, for example, measures the extent to which individuals are intrinsically motivated to participate in behaviours that are consistent with their personal values and beliefs (Ryan & Deci, 2000). Health motivation is included in several social cognition theories including Self Determination Theory (Ryan & Deci, 2000) and the Health Belief Model (Janz & Becker, 1984). Past research has found health motivation to be associated with participation in preventive health activities however to date there has been no extensive examination in the context of CRC screening.

**Implications for Screening Practice and Intervention**

Satisfaction with prior screening was strongly associated with rescreening behaviour in this thesis. As highlighted above, further research is required to determine which elements of screening may require modification to improve satisfaction. The results of these future studies will undoubtedly have implications for the design of screening programs and screening practice. The results of the current study however also have some important implications for screening practice. As already highlighted, complete population screening is not yet available in Australia. There are therefore, multiple independent screening programs and paid services that provide screening. Research from amongst the mammography screening literature indicates that the physical act of completing the screening test is only one of many factors that are
associated with screening satisfaction (Tang, et al., 2009). Conducting large population studies of satisfaction with FOBT use may overlook some specific issues associated with the variety of different screening options available in Australia (e.g., service delivery, communication). Regular evaluation of screening services at a local level, perhaps via the inclusion of small participant satisfaction surveys included in screening packages, could provide screening programs with the information required to continually improve on services to encourage repeat attendance.

The use of multilevel frameworks in this thesis was specifically to inform the design of targeted interventions. Results indicate that certain subgroups (i.e., relapse, drop out, consistent refusal) require behavioural interventions designed to modify attitudes to screening. These could include; individual or group education, tailored print materials and provider recommendations (Holden, et al., 2010; Power, et al., 2009; von Euler-Chelpin, et al., 2010; Zajac, et al., 2010). Results suggest that these interventions should aim to improve self-efficacy for screening, reduce perceptions of barriers to screening, improve perceived benefits to screening (including response efficacy), encourage interactions with GPs regarding screening and most importantly, educate participants on the importance of rescreening even when prior test results were negative.

Whilst many of the attitudinal variables may be better manipulated through targeted interventions (e.g., enhancing perceptions of benefits and redressing perceptions of barriers) (Power, et al., 2009) other factors, such as knowledge, may be able to be broadly influenced through modification of information accompanying screening offers. The NBCSP for example does not educate invitees about why rescreening is necessary, rather simply includes the NHMRC cancer screening
recommendations with letters informing participants of a negative result (Australian Government Department of Health and Ageing, n.d-b). Elaborating the importance of rescreening is likely to facilitate biennial participation. It would also appear, based on the results of paper one, that informing participants that rescreening will not be offered through the NBCSP will ensure participants do not rely on the program to facilitate rescreening.

Other non-adherent subgroups, for example, those who intend to screen but have not acted on this intention (inconsistent), may benefit from interventions designed to encourage forward planning (Steadman, et al., 2006) or from reminder letters when rescreening is due. Reminder letters have been previously shown to be effective for increasing repeat attendance at mammography screening (Vernon, McQueen, Tiro, & del Junco, 2010). Again this finding may have important implications for the NBCSP. Whilst the NBCSP is not able to provide biennial rescreening kits free of charge, it may be possible and cost effective to send mailed reminders to past participants reminding them that rescreening is due and providing information on how screening tests can be obtained. This would not only remind people that screening is due but also discourage program reliance.

Finally, results also indicate that increases in rescreening adherence could be achieved by targeting demographic subgroups. Some demographic information can be obtained for medical research purposes (i.e., electoral roll data) and is therefore easier to obtain than the information required to tailor information provided to potential participants according to significant psychological predictors (e.g., risk perception, response efficacy, intention to screen etc, Wilson et al., 2010). Non-adherence with the screening offers was greater amongst men, those who were unmarried, those with no
private health insurance, those who were still in the workforce and those who were younger. As mentioned above, more research is required to determine why these subgroups were more resistant. However there are several potential explanations; those currently in the workforce, for example, may not adhere to screening recommendations as a result of perceived time constraints (Chapple, et al., 2008). Encouraging screening through workplace interventions that emphasise the ease and convenience of testing and/or provide worksite education and information may improve adherence (Myers, Vernon, Tilley, Lu, & Watts, 1998). Similarly, lack of health insurance was associated with non-adherence even though screening in the program was free. This may reflect concerns about ongoing costs resulting from follow up testing (Beeker, et al., 2000). Screening programs may want to consider finding means of providing free follow up examinations or provide information on what these potential costs may be to encourage screening.

**Strengths and Limitations**

The strengths of this thesis were, firstly, that the studies included in this thesis were amongst a small few to dedicate a specific focus to describing and exploring variations in rescreening behaviour. Specifically, these studies were the first to explore associations between behavioural variables and rescreening behaviour and to use multilevel descriptive frameworks to define rescreening adherence. Secondly, the use of a sequential mixed methods design allowed for a detailed exploration of participants attitudes toward rescreening followed by a large scale questionnaire study that explored the relevance of these findings for predicting variations in rescreening behaviour. The prospective design was beneficial because it allowed for an investigation of the predictive ability of pre-existing attitudes and characteristics to determine rescreening
adherence, irrespective of factors associated with program service delivery. Finally, the use of a broad population-based sampling frame in papers two and three increased the generalisability of the findings to the general population of those eligible for FOBT screening in South Australia. No comparable research has been conducted in an Australian context and results therefore have important implications for encouraging rescreening at a population level.

The results of this thesis should also be considered in light of its limitations as described below.

**Sampling**

Sampling bias may have affected results in this thesis. As already discussed in paper one, recruiting those who relapsed from screening was difficult despite the variety of methods utilised in an attempt to recruit this subgroup. Epidemiological research has highlighted the potential for sampling bias in survey based research. Specifically participation is more likely amongst those who find the research topic to be personally relevant, are better educated and of a higher socioeconomic status (Galea & Tracy, 2007). As discussed in paper two, rates of self-reported intention to rescreen were similar to those reported in the NBCSP indicating appropriate sampling of the rescreening subgroups. However, slight skew on some of the social cognitive variables indicated attitudes toward FOBT were largely positive. It is possible that the views and opinions of those strongly opposed to screening were not captured in either study. In addition, in order to identify variables predictive of longitudinal adherence, it was necessary to precede offers of screening with a behavioural questionnaire. Consequently, it is possible that screening adherence was also higher amongst this group than would be observed amongst the general population as a consequence of
exposure to the information included in the questionnaire or the perceived “sunk-costs”
attracted to questionnaire completion.

**Thesis Design**

Elements of the research design may have led to limitations within the studies. Many of these have been previously discussed and are summarised here. Firstly, this thesis utilised a sequential mixed methods approach to data collection. This method was advantageous considering the limited existing research on behavioural associations with rescreening. However, there are some limitations associated with using two different research methods to measure the same phenomenon (Tashakkori & Teddlie, 2003). In paper one for example, interview participants expressed difficulty differentiating between initial and repeat screenings. Consequently, some of the themes (e.g., severity, susceptibility) that were included in the rescreening questionnaire may in fact have been associated with initial screening explaining their lack of association with rescreening outcomes. Similarly, as discussed above, the themes identified in the qualitative study may not necessarily measure the same underlying construct as the scales subsequently included in the rescreening questionnaire (e.g., health value).

Secondly, the social cognitive data for the quantitative component of the research was collected in a single ‘baseline phase’. Previous sections highlighted how this may have had implications for the results of paper three given the time lapse between obtaining questionnaire measures and defining adherence. Collecting data on attitudes toward screening whilst simultaneously measuring intentions to rescreen may also have resulted in cognitive dissonance (Festinger & Carlsmith, 1959), as discussed in paper two. Finally, because data were collected at baseline there were no opportunities to
collect additional data to build on findings, or improve on measurement issues, discussed below.

**Questionnaire Design**

As already discussed the mixed methods approach may have some limitations for the development of the questionnaire. In addition to the issues already discussed, the use of a relatively homogenous sample of rescreeners in paper one may have missed some potentially important barriers to rescreening that could not be identified by those with predominantly positive attitudes toward screening. Other elements of the questionnaire design are discussed below.

Some social cognitive variables in this thesis were measured using only two items (e.g., severity, susceptibility) and in some cases (e.g., satisfaction) single items were used. This approach was necessary to restrict the length of the questionnaire and maximise response rates. Whilst it is not uncommon amongst the screening literature to include fewer than three items for one variable, particularly where multiple social cognitive variables are investigated (e.g., Hay, et al., 2003; McQueen et al., 2010; Sieverding, Matterne, & Ciccarello, 2010), this approach made the data unsuitable for factor analyses (Tabachnick & Fidell, 1996). Existing questionnaire items were used in the rescreening questionnaire where possible, and reliability analyses confirmed the internal reliability of the social cognitive variables. However, in hindsight, the inclusion of additional items for some constructs and reduction of others may have improved the psychometric properties of the data and provided a more reliable survey instrument.

The rescreening questionnaire was designed to measure rescreening adherence, attitudes and intentions amongst a general population eligible for FOBT screening. The
TTM outcome variable was used to distinguish rescreening questionnaire participants according to prior screening experience (yes or no) and intention to rescreen (yes or no). Several questions (i.e., satisfaction with prior screening, implementation intentions) could only be answered by certain subgroups. Respondents were therefore guided through the rescreening questionnaire based upon their response to the TTM staging question. This resulted in a rather complex questionnaire design that may have contributed to the missing data reported earlier and limited the generalisability of the results to the wider population as discussed in paper two.

Concluding Comments

This thesis explored determinants of participation in CRC rescreening with FOBT. Limited research exists on this topic and the behavioural findings represent a valuable contribution to the field. Satisfaction with prior screening was an important determinant of rescreening behaviour. Social cognitive variables explained some additional variance and warrant further investigation. Those who do not adhere to screening recommendations are not characterised by the same attitudes toward screening. Future research would benefit from the inclusion of multilevel frameworks to describe accurately the different attitudes, and demographic and background characteristics, of the non-adherent population.
Appendices

Appendix A: Rescreening Questionnaire

The rescreening questionnaire was presented as an A5 stapled booklet.

Bowel (Colorectal) Cancer Screening Survey
A Collaboration Between
The School of Psychology
The University of Adelaide
The Bowel Health Service
Repatriation General Hospital, Daw Park
The Department of Medicine
Flinders University

The Preventative Health National Research Flagship
CSIRO
&
The Cancer Council SA
Over the next few pages you will be asked some questions about your thoughts and attitudes towards bowel cancer screening and the experience of screening itself. It is important to remember that there are no right or wrong answers; we simply want your impressions. Don’t spend too long on any one question; your initial opinion is all we need. Please note, questions are included on both sides of the pages. Please check that you have answered all the questions on a page before proceeding to the next.

**How to complete this form**

In order to complete this form you will need a black or blue pen only. For each question, simply colour in the circle or circles that correspond with your answer. It is very important that you do not use ticks or crosses to indicate a response.

Like this: ☑ Not like this: ✗ ✕

Please pay careful attention to the instructions for each question. Sometimes you will be asked to skip a question if it does not apply to you and sometimes questions will have more than one part for you to answer.

This is an example of how to correctly respond throughout this questionnaire:

**Example Question:**

*Please rate the extent to which you agree with the following statement*

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Unsure</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Bowel cancer screening is important to me</td>
<td>☺</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

If you strongly agree that bowel cancer screening IS important to you then you would colour in circle number 1 (Strongly Agree), as demonstrated above. If you make a mistake put a cross through the incorrect answer and then colour in the correct one. For Example:

Correct response: ☺ Incorrect response: ✗ ✕
**Bowel Cancer Screening Experience**

In Australia there are 2 main ways that people can screen for bowel cancer. One is with a Home Stool Test (also known as a FOBT, FIT or FHH). With this test you collect some small samples of your stool (bowel motion) at home and send the samples to a laboratory to be tested for signs of possible bowel cancer.

1) Please fill in the ONE option that BEST describes your experience with home stool testing.

<table>
<thead>
<tr>
<th>Option</th>
<th>Screening Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prior to receiving this survey, I had never heard about testing for bowel cancer with a home stool test</td>
<td>1</td>
</tr>
<tr>
<td>I have never used a home stool test and I do not intend to use one in the next year or two</td>
<td>2</td>
</tr>
<tr>
<td>I have never used a home stool test <strong>but</strong> I intend to use one in the next year or two</td>
<td>3</td>
</tr>
<tr>
<td>I have used a home stool test <strong>once within the past 1-2 years</strong> and I intend to have another within the next year or two</td>
<td>4</td>
</tr>
<tr>
<td>I have used a home stool test <strong>twice within the past 2 to 4 years</strong> (no more than 24 months apart) and I intend to have another within the next year or two</td>
<td>5</td>
</tr>
<tr>
<td>I have used a home stool test in the past, but I <strong>do not intend to have another</strong> within the next year or two</td>
<td>6</td>
</tr>
<tr>
<td>I have used a home stool test <strong>more than two years ago</strong>, but I intend to have another in the next year or two</td>
<td>7</td>
</tr>
</tbody>
</table>

The questions that follow are to be answered **based on your response to Question 1**. To help you to answer these questions correctly, look at your response to question 1. You will notice that the responses were numbered from 1 to 7 on the right hand side. Write down the number that you chose in this box:

This number will be referred to as your ‘screening number’. If you forget it you can return here to check it.

Each screening number has a different set of questions to answer. These are organised according to page numbers. Find your screening number below to determine which page number to skip ahead to.
Screening number 1 → skip ahead to page 8
Screening number 2 → skip ahead to page 8
Screening number 3 → continue below on page 4
Screening number 4 → skip ahead to page 5
Screening number 5 → skip ahead to page 5
Screening number 6 → skip ahead to page 5
Screening number 7 → skip ahead to page 5

SECTION 1  Experience with Bowel Cancer Screening

Screening number 3

1) Please indicate the extent to which you agree with the following statements.
Note: ‘Neutral’ means that you neither agree nor disagree with the statement

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) I know where I need to go in order to obtain a home stool test</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>b) I have planned when I will use a home stool test</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>c) I know what steps I need to take in order to complete the home stool test</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
</tbody>
</table>

Now please skip ahead to Section 2 on page 8 to complete the rest of the survey
Screening numbers 4, 5, 6 and 7

1) Why did you do your most recent home stool test? Fill in as many options as you like

○ My doctor recommended the test
○ I was offered the test as part of the Australian National Bowel Cancer Screening Program
○ I was offered the test as part of a screening program (not the Australian National Bowel Cancer Screening Program)
○ It was part of a routine examination or check-up
○ Because of a symptom or earlier health problem
○ It was a follow-up of an earlier abnormal test
○ Other (please specify) .................................................................

2) How did you obtain your most recent home stool test?

○ From my doctor
○ From the chemist
○ It was sent to me as part of the Australian National Bowel Cancer Screening Program
○ It was sent to me as part of a screening program (Not the Australian National Bowel Cancer Screening Program)
○ Other (please specify) .................................................................

3) Please rate the extent to which you were satisfied with the overall experience of screening for your most recent home stool test.

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neutral</th>
<th>Unsatisfied</th>
<th>Very unsatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

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4) Please indicate the extent to which you found your **most recent** home stool test to be...

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Embarrassing</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>b) Unpleasant</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>c) Worthwhile</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>d) Convenient</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>e) Expensive</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>f) Reassuring</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>g) Easy to complete</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
</tbody>
</table>

5) Please indicate the extent to which you agree with the following statements

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) I am disappointed in myself if I forget to use a home stool test</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>b) If the doctor said I didn’t need a home stool test, I would ask again at another visit</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>c) I try to make using a home stool test a regular part of my life</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>d) I know I feel better about myself if I use a home stool test</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
</tbody>
</table>
6) If your screening number is 4, 5 or 7, you have indicated that YOU DO intend to screen again using a home stool test. Please indicate the extent to which you agree with each of the following statements. (If your screening number is 6 proceed to question 7 below)

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) I know where I need to go in order to obtain a home stool test</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b) I have planned when I will next use a home stool test</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c) I know what steps I need to take in order to complete the home stool test</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

7) If your screening number is 6 then you have indicated that YOU DO NOT intend to screen for bowel cancer with a home stool test in the next 1-2 years. Please indicate your reasons for this. You may fill in as many options as you like

- I find it difficult to remember to screen regularly
- My last test was normal therefore I don’t need to screen again
- I have too many other health concerns to worry about bowel cancer screening
- I do not know how to obtain another home stool test
- I do not have enough time in my day to worry about screening with a home stool test
- I am no longer at the age where bowel cancer is of great concern to me
- I found the home stool test too unpleasant to do it again
- I am in good health at the moment, I may consider screening at a later time
- Other (please specify) .................................................................

.................................................................
Section 2 Screening with External Examinations

THIS SECTION TO BE COMPLETED BY ALL SCREENING NUMBERS

In addition to the home stool test, another way that people can test for bowel cancer is by an Internal Examination (Colonoscopy or Flexible Sigmoidoscopy). This involves a specialist using a long flexible instrument with a small camera attached to view the bowel. This procedure is performed in a hospital or specialist clinic.

1) Have you ever had an internal examination for bowel cancer?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>①</td>
<td>②</td>
</tr>
</tbody>
</table>

① please continue to Question 2 below
② please skip ahead to Section 3 page 10

2) Approximately when did you last have this internal examination?

<table>
<thead>
<tr>
<th>Within the last year</th>
<th>Within the last 5 years</th>
<th>Within the last 10 years</th>
<th>More than 10 years ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
</tr>
</tbody>
</table>

3) Why did you do your most recent internal examination? You can fill in as many options as you like

- O My doctor recommended the test
- O I was offered the test as part of a screening program
- O It was part of a routine examination or check-up
- O Because of a symptom or earlier health problem
- O It was a follow-up of an earlier abnormal test
- O Other (please specify) ..........................................................
4) Please indicate the extent to which you found your most recent internal exam to be

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Embarrassing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b) Unpleasant</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>c) Worthwhile</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d) Convenient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>e) Painful</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>f) Expensive</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>g) Reassuring</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>h) Easy to prepare for</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

5) Please rate the extent to which you were satisfied with the overall experience of your last internal examination.

<table>
<thead>
<tr>
<th>Very Satisfied</th>
<th>Satisfied</th>
<th>Neutral</th>
<th>Unsatisfied</th>
<th>Very Unsatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Continue to next page →
Section 3 Home Stool Test Screening Decisions

The remainder of the survey is to be answered by all screening numbers. From this point forward the questions will address your opinions and attitudes toward using a **home stool test** to check for bowel cancer. It is not necessary for you to have experience with using a home stool test. Please remember that there are no right or wrong answers.

1) If you were to be offered an opportunity to check for bowel cancer using a home stool test, do you think you would use the test?

<table>
<thead>
<tr>
<th>Definitely Yes</th>
<th>Probably Yes</th>
<th>Probably Not</th>
<th>Definitely Not</th>
<th>Unsure/Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

**IMPORTANT:** If you answered “unsure/don’t know” to question 1 please skip ahead to question 3 on page 11; otherwise please continue with question 2

2) Please respond to each of the following statements concerning the decision that you made in question 1 about bowel cancer screening using a home stool test

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

a) I feel I have made an informed decision

b) My decision shows what is important to me

c) I expect to stick with my decision

d) I am satisfied with my decision
3) Considering the answer you gave to question 1 on page 10, please indicate the extent to which you agree with each of the following statements about your decision

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree or Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a)</td>
<td>I know the benefits of screening with a home stool test</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b)</td>
<td>I know the negative aspects of screening with a home stool test</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>c)</td>
<td>I am clear about how important the benefits are to me in this decision</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d)</td>
<td>I am clear about how important the negative aspects are to me in this decision</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>e)</td>
<td>I am clear about which is more important to me (the benefits or the negative aspects)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>f)</td>
<td>I have enough support from others to make a decision</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>g)</td>
<td>I am deciding without any pressure from others</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>h)</td>
<td>I have enough advice to make a decision</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>i)</td>
<td>I am clear about which is the best decision for me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>j)</td>
<td>I feel sure about what to decide</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>k)</td>
<td>This decision is easy for me to make</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>l)</td>
<td>I know what options are available to me to protect myself from bowel cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
### Section 4 Bowel Cancer Risk

1) Please indicate the extent to which you agree with the following statements about bowel cancer screening

<table>
<thead>
<tr>
<th></th>
<th>Agree</th>
<th>Disagree</th>
<th>Unsure / Don't Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a)</td>
<td>The risk for getting bowel cancer is unrelated to age</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>b)</td>
<td>Sometimes bowel cancer runs in families</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>c)</td>
<td>Bowel cancer can be treated more effectively when it is detected early</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>d)</td>
<td>The risk for getting bowel cancer is unrelated to diet and exercise</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>e)</td>
<td>It is not necessary to screen again for bowel cancer if your previous screening test was normal</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>f)</td>
<td>Screening for bowel cancer can sometimes detect precancerous growths</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

### Section 5 Attitudes Toward Health and Home Stool Testing for Bowel Cancer.

1) The following two pages contain statements about your attitude towards home stool testing. Please indicate the extent to which you agree with each of them. A ‘neutral’ response means you neither agree nor disagree with that statement

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>a diagnosis of bowel cancer would severely affect my lifestyle</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>giving samples of faeces to another person for bowel cancer testing is unpleasant</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>Screening can pick up bowel cancer early when it can be easily treated</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>----------------</td>
<td>-------</td>
<td>---------</td>
<td>----------</td>
</tr>
<tr>
<td>4.</td>
<td>I think obtaining a home stool test would be difficult</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.</td>
<td>The health consequences of developing bowel cancer are severe</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6.</td>
<td>Home stool tests for bowel cancer are now used routinely</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7.</td>
<td>It would be difficult for me to test consecutive faecal samples because my bowels are not regular</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8.</td>
<td>Compared to other people my age my chance of getting bowel cancer is high</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9.</td>
<td>Giving a sample of faeces to another person to test for bowel cancer screening is embarrassing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10.</td>
<td>It is convenient that I can collect samples for bowel cancer screening at home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11.</td>
<td>You do not need to keep screening for bowel cancer once you have had a couple of normal results</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12.</td>
<td>Having regular home stool tests would give me peace of mind about my health</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13.</td>
<td>There is a good chance that I will get bowel cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14.</td>
<td>Home stool tests are inconvenient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15.</td>
<td>Receiving information in the mail about bowel cancer screening can be embarrassing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16.</td>
<td>If you don’t have your health you don’t have anything</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17.</td>
<td>No matter what I do if I am going to get sick I will get sick</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18.</td>
<td>My good health is largely a matter of good fortune</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>19.</td>
<td>There is nothing more important than good health</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20.</td>
<td>Most things that affect my health happen to me by chance</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21.</td>
<td>When I am sick I just have to let nature run its course</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22.</td>
<td>I am in control of my health</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23.</td>
<td>If I take the right actions I can stay healthy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24.</td>
<td>There are things I care about more than my health</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25.</td>
<td>Good health is only of minor importance in a happy life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26.</td>
<td>If I have questions about home stool testing, I try to get information to answer them</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27.</td>
<td>Having home stool testing every year or two shows that you are keeping up with the latest advances in health care</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28.</td>
<td>If I hear something unfavourable about home stool testing, I try to get information and decide for myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>29.</td>
<td>I am disappointed if my doctor does not remind me to use a home stool test</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>30.</td>
<td>I sometimes think of ways that could get doctors to recommend home stool testing more regularly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Please answer Yes, No or Don't know to the following statements

2) Participation in home stool test screening for bowel cancer leads to......

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) ...certainty about my health status</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>b) ...reassurance</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>c) ...early detection if something is wrong</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>d) ...the detection of small abnormalities</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Please indicate the extent to which you agree with all of the following statements about bowel cancer screening

3) I am confident that I will be able to screen regularly for bowel cancer with a home stool test .....  

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) ...even if it is difficult to find time to complete the test</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b) ...even if I find the test to be difficult to complete</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>c) ...even if I find the test to be embarrassing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d) ...even if I find the test to be distasteful</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>e) ...even if I am nervous about the results of the screening</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>f) ...even if I find it difficult to remember when to screen</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Section 6 Friends and Family

1) Please indicate the extent to which you agree with the following statements

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I want to do what my family thinks I should do about bowel cancer screening</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>I can talk about my problems with my family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>My doctor thinks I should have bowel cancer screening</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4.</td>
<td>I can count on my friends when things go wrong</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.</td>
<td>I get the emotional help and support I need from my family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6.</td>
<td>I want to do what my doctor thinks I should do about bowel cancer screening</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7.</td>
<td>My family thinks I should have bowel cancer screening</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8.</td>
<td>My family is willing to help me make decisions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9.</td>
<td>My family will support me if I decide to screen for bowel cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10.</td>
<td>I can talk about my problems with my friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11.</td>
<td>I can talk with at least one other person about home stool testing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12.</td>
<td>I give my friends encouragement when they say they are planning to use a home stool test</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
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<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>13. I talk about home stool testing with friends</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. People will be pleased if I use a home stool test</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. The more I know about home stool testing, the more I can help other people who want to know about it</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. I sometimes think of ways that could get more people to use home stool tests</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
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<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</table>

2) **What would help you to make the decision to take part in regular bowel cancer screening using a home stool test?** You can fill in as many options as you like

- A recommendation from my doctor
- A letter from the government
- Detailed instructions about how to use the home stool test
- Information that a family member or friend has been diagnosed with bowel cancer
- An automated reminder to screen system that would keep me up to date with screening
- A frank and open media campaign that addressed bowel cancer screening and its benefits
- If the home stool tests were free
- If the home stool test was given a name that was catchy and easy to remember
- If the home stool tests were able to be delivered and returned in the mail
- Other (please specify)

..................................................................................................................

..................................................................................................................

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Section 7 Background information

Please either write in a response or colour the appropriate circle that best describes you
Please be assured that your answers here, and throughout the survey, are confidential.

1) What is your age in years? ............... years

   Male                      OR                      Female
   ①                        ②

2) Are you

   ① Male OR ② Female

3) What is your marital status?

   Married/De facto ①
   Widowed ②
   Single (never married) ③
   Divorced/Separated ④

4) What is your current employment status?

   Full-time employed ①
   Part-time employed ②
   Unemployed ③
   Retired ④
   Home duties/home carer ⑤

→ 4 (a) If you are currently employed, what is your occupation?
(Please be as specific as possible, i.e. bank manager not just manager)

........................................................................................................................................
5) What is the highest level of education you have completed? (For example if you finished high school in year 10 then your highest level of education is junior secondary education)

- Primary school (finished year 7) ① Diploma/Advanced Diploma ⑤
- Junior secondary education (finished year 10) ② Bachelor degree ⑥
- Senior secondary education (finished year 12) ③ Graduate Diploma/Certificate ⑦
- Technical Certificate ④ Postgraduate Degree ⑧

6) Were you born in Australia?

Yes ①

No ②

→ 6(a) if you were born outside of Australia, for how many years have you lived in Australia? ................................. years.

7) Do you speak a language other than (or in addition to) English at home?

Yes ①

No ②

→ 7(a) if yes, which language is it? ..........................

8) There are many different ways in which people think of themselves. Which of the following describes the culture(s) you view yourself as being a part of? (please fill in every option that applies)

- Aboriginal/Torres Straight Islander ⑤
- Australian ⑤
- British/English/Scottish/Welsh ⑤
- Chinese ⑤
- Dutch ⑤
- Vietnamese ⑤
- German ⑤
- Greek ⑤
- Indian ⑤
- Irish ⑤
- Italian ⑤
- Other (please specify) ⑤

..........................
9) Do you have private health insurance?

<table>
<thead>
<tr>
<th>Yes, both extras and hospital cover</th>
<th>Yes, hospital cover only</th>
<th>Yes, extras cover only</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
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<td>2</td>
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<td>4</td>
</tr>
</tbody>
</table>

*We recognise that the following questions are somewhat personal, as they concern any past experiences with bowel cancer diagnosis and associated health behaviour. Please remember that your information is kept strictly confidential.*

10) Have you ever had any screening tests for cancers other than bowel cancer?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
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<td></td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

→ 10(a). If yes, which cancer screening tests have you had?

- Breast Cancer
- Prostate Cancer
- Cervical cancer
- Lung Cancer
- Skin cancer
- Other

11) Do you have a regular doctor?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

→ 11(a) If NO, do you have access to a doctor or healthcare provider who can answer any questions you may have about bowel cancer?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

12) Approximately how many times do you think you have visited a doctor within the last 12 months?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>once</th>
<th>twice</th>
<th>Three times</th>
<th>More than three times</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

13) Have you ever known anyone who has had bowel cancer?

Yes  ①  
No  ②  

→13 (a) if yes, how close was this person to you?

Very close to me  ❌  ❌  ❌  ❌  ❌  ❌  Not very close to me

①  ②  ③  ④  ⑤

14) Have you ever discussed home stool test screening with anyone?

Yes  ①  
No  ②  

→ 14 (a) if yes, who was this person? Fill in as many options as you like

O Partner
O Immediate family member (other than partner)
O Other family member (not partner or immediate family)
O Friend
O Doctor
O Other (please specify)

..........................................................
15) Have you ever known anyone who has screened for bowel cancer with a home stool test?

Yes  ①
No   ②

→ 15(a) If yes, who? Fill in as many options as you like

○ Partner
○ Immediate family member (other than partner)
○ Other family member (not partner or immediate family)
○ Friend
○ Other (please specify) ...........................................

16) Have you ever had a cancer diagnosis of any kind?

Yes  ①
No   ②

→ 16(a). If yes, what type of cancer was it?

○ Bowel cancer
○ Breast Cancer
○ Cervical cancer
○ Skin cancer
○ Prostate cancer
○ Other (please specify) ...........................................
17) To your knowledge has anyone in your immediate family ever had bowel (colorectal) cancer?

   Yes  ①
   No  ②

→ 17(a) If yes, who? (colour all appropriate, if you have had more than one grandparent or sibling who has had bowel cancer please use the extra circles allocated to these people)

   Mother  ①
   Father  ②
   Grandmother  ③  ③
   Grandfather  ④  ④
   Sibling  ⑤  ⑤

18) Have you experienced any of the following in the last 3 months?

   ① Bleeding from the rectum/blood in the stool
   ② An unusual and persistent change in bowel habit (diarrhoea or constipation)
   ③ Symptoms (such as extreme tiredness) diagnosed by your doctor to be due to anaemia
   ④ No I have not experienced any of the above symptoms

→ 18 (a). If yes have you consulted a doctor about any of the above symptoms?

   Yes  ①
   No  ②

Please note that symptoms such as these might warrant medical attention. If you have not discussed them with your doctor we encourage you to do so.
19) In the last 10 years, or since you turned 50 years of age, whichever goes back the furthest, have you ever been referred by a doctor or health professional for an investigation of a bowel problem?

Yes  No
①  ②

→ 19 (a). If yes, what was that investigation? Fill in as many options as appropriate

- O A test on the stools (bowel actions) of some sort
- O Sigmoidoscopy, an internal examination of the bowel done without sedation
- O Colonoscopy, internal examination of the bowel following bowel washout in a special facility
- O X-ray, either Barium enema or CT scan
- O Type uncertain
- O Other
- O (please specify) .................................................................................................................................

→ 19 (b). If yes to 19, do you recall if any of the following were found?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowel polyps that were not considered by your doctor to be important</td>
<td>①</td>
<td>②</td>
<td>③</td>
</tr>
<tr>
<td>Bowel polyps (adenomas, pre-cancers) that your doctor was concerned about or thought might otherwise develop into cancer</td>
<td>①</td>
<td>②</td>
<td>③</td>
</tr>
<tr>
<td>Bowel cancer</td>
<td>①</td>
<td>②</td>
<td>③</td>
</tr>
</tbody>
</table>
Thank you for taking the time to complete this survey.

Please place the completed survey in the reply-paid envelope provided and post to the University of Adelaide (no stamp required)

Please do not fold the survey when putting it in the envelope.

Alternatively, if the reply paid envelope is misplaced, please post the completed survey to the following address. No stamp is required.

Ms Amy Duncan
School of Psychology
Reply Paid 17
UNIVERSITY OF ADELAIDE SA 5005

For any queries, please phone Amy Duncan on (08) 8303 3136.
Appendix B: Prepublication Version of Paper Two

Paper was accepted to the Health Promotion Journal of Australia in April 2012

Title "Using the Transtheoretical Model of Behaviour Change to Describe Readiness to Rescreen for Colorectal Cancer with Faecal Occult Blood Testing.

Authors: Duncan, A 1, Turnbull, D 1, Gregory, T 1, Cole, SR 2, Young, GP 2,3, Flight, I 4, Wilson, C 3,5

Affiliations: 1 School of Psychology, University of Adelaide, Adelaide, South Australia, 2 Bowel Health Service, Repatriation General Hospital Daw. Park, South Australia. 3 Flinders Centre for Cancer Prevention and Control, Flinders University, Bedford Park, South Australia. 4 CSIRO Preventative Health Flagship, Adelaide, South Australia. 5 Cancer Council, South Australia

Acknowledgements:

The authors would like to acknowledge the work of Julie Syrette, CSIRO Food and Nutritional Sciences, for her assistance with the design of the survey instrument and resultant data base.

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5001

Key words: behaviour change, health beliefs, health behaviours, health promotion theory
Abstract

**Issue addressed:** This study used the Transtheoretical model of behaviour change (TTM) to describe reparticipation in colorectal cancer (CRC) screening according to social cognitive and background variables.

**Methods:** A random sample of men and women aged 50-74 years living in South Australia completed a questionnaire measuring TTM stage and attitudes toward screening using a faecal occult blood test (FOBT). Participants were categorised according to four stages of readiness to rescreen; action, maintenance, relapse and inconsistent. Multivariate techniques were used to determine predictors of lower readiness stages compared with maintenance.

**Results:** Of the 849 study participants, 29.9% were non-adherent or had no intentions to maintain adherence (inconsistent and relapse). Compared with maintenance rescreeners, relapse participants reported less; social influences to screen (RR=0.86, p<.001), satisfaction with prior screening (RR=0.87, p=.03), self-efficacy (RR=0.96, p=.01) and screening benefits (RR=0.84, p<.001). Relapse participants were also more likely to be unaware of the need to repeat screening (RR=1.41, p=.02) and to not have private health insurance (RR=1.33, p=.04). Inconsistent screeners were less likely to have planned when they will next rescreen (RR=0.84, p=.04) and reported greater barriers to rescreening (RR=1.05, p=.05). Action participants were younger (RR= 0.98, p=.001), reported less social influences to screen (RR=0.94, p<.001) and were less likely to have known someone who has had CRC (RR=0.82, p=.01).

**Conclusions:** Social cognitive, demographic and background variables significantly differentiated screening maintenance from lower readiness stages.
So what? This is one of very few studies within the CRC screening literature to address behavioural factors associated with reparticipation and to extend the use of the TTM to explain CRC rescreening. An understanding of the variables associated with differing levels of non-adherence provides a useful foundation for the development of interventions to improve reparticipation.
Ongoing commitment to screening for Colorectal Cancer (CRC) with faecal occult blood testing (FOBT) is crucial for reductions in morbidity and mortality [1]. Screening programs utilising FOBT are run worldwide with national programs in many parts of Europe, Australia and the United Kingdom [2]. The success of such screening programs is dependent on continued participation according to recommended guidelines, which in Australia recommend FOBT screening at least once every one to two years from the age of 50 onwards [3]. However, reports from the Australian National Bowel Cancer Screening Pilot Program showed a substantial (approximately 20%) decrease in reparticipation rates amongst those who initially participated in FOBT screening [4]. Similar findings have been reported overseas [5, 6]. Whilst patient reminders have been shown to moderately improve reparticipation (5-15% increase) [7], few studies have examined the benefit of behavioural or education based interventions on reparticipation [8]. Early findings from the CRC [8] and more recently the mammography screening literature [9] indicate that behavioural interventions designed to improve initial screening uptake have no lasting effect on reparticipation. These findings highlight the need for a dedicated effort to understanding the factors associated with reparticipation for the development and trail of interventions aimed specifically at encouraging reparticipation.

CRC screening research has begun to acknowledge the need for a dedicated approach to understanding rescreening behaviour [8, 10, 11]. However, the majority of studies primarily view screening in terms of current adherence, grouping currently adherent screeners and comparing them with those who are currently non-adherent [12, 13, 14, 15, 16]. Stage theories of behaviour change, such as the Transtheoretical Model of Behaviour Change (TTM) [17], provide an alternative way of categorising participants that incorporates measures of intention to participate, and past experience with the behaviour. Models
incorporating prior experience and intention have been shown to better discriminate mammography rescreening compliance according to behavioural variables, than those that utilise simple adherence status [18]. Similarly, prior screening experience has been shown to influence rescreening participation for mammography [19] and CRC screening [8, 10, 16]. The use of stage theories as a foundation for intervention development has been well documented for a variety of health behaviours [20] including cancer screening [21]. The advantage of utilising stage theories to explain screening behaviour is that they describe behaviour change as the end point of a process, as opposed to a discrete event, taking into account the complex attitudinal and behavioural factors associated with different levels of readiness to participate.

The TTM, the stage theory most frequently applied to cancer screening behaviour [21], describes people as belonging to one of five different stages; pre-action (precontemplation, contemplation and preparation), action and maintenance. The model proposes that each readiness stage is characterised by differing behavioural and attitudinal variables [17]. The aim for health promotion programs is to facilitate forward movement from the pre-action stages to action (initial participation) and finally maintenance (continued reparticipation). The TTM also includes a relapse stage where those who have previously participated in the behaviour discontinue participation in screening; these participants are also traditionally categorised by a lack of intention to reparticipate [17]. Recent research also suggests the potential for an additional ‘inconsistent’ category which includes those who screen intermittently but maintain intentions for future screening [10, 18, 22]. These inconsistent screeners have been found to be behaviourally different to traditional relapse participants in studies of mammography adherence [18, 22]. To date, the majority of CRC screening studies utilising the TTM have focused on the action stage (initial participation)
The aim of the present study was to enhance understanding of the factors associated with intentions to maintain adherence to FOBT rescreening utilising an expanded TTM to compare those in the relapse, inconsistent and action stages with those in the maintenance stage according to demographic, background and social cognitive variables.

**Methods**

Participants were recruited as part of an ongoing longitudinal study designed to measure screening adherence in South Australia that began in 2008. The names and addresses of 12,000 men and women between the ages of 50 and 74 were obtained from the Australian Electoral Roll. The names were randomly drawn from four large electoral districts in South Australia (total population of 546,765 [28]) chosen for their broad socioeconomic range. Names were then checked against a CRC high risk data base at a participating hospital responsible for managing a variety of high risk programs and screening services in South Australia. Those identified as above average risk (defined as having; a personal history of CRC, a family history of CRC, a personal history of polyps or long term inflammatory bowel conditions [29]) were excluded. Following exclusions, the remaining names and addresses were further randomised to select 4000 potential study participants. Human Research Ethics Committee approval was obtained prior to beginning the study.

**Rescreening questionnaire**

The questionnaire used in the present study was adapted from a previous questionnaire, from here on referred to as the initial screening questionnaire, that measured social cognitive and demographic predictors of initial screening uptake [30]. Additional items
and modifications to the initial screening questionnaire were then made based upon the results of a pilot study that interviewed rescreening participants (unpublished).

**Stage of readiness (Transtheoretical Model) for rescreening**

TTM outcome measures were based on the research of Rakowski et al., [18], whose work has been widely used in the study of cancer screening behaviour [21]. Australian screening guidelines were used to identify stage of readiness as they apply to FOBT screening (i.e., screening at least once every one to two years) [3]. Stages were consistent with those described by Rakowski et al., [18]. Maintenance was defined as having participated in FOBT screening twice previously on schedule (no more than 24 months apart within the past four years) with intention to participate again on schedule (within the next two years). Action was defined as having participated in FOBT screening only once previously on schedule (within the past two years) with intention to participate again on schedule (within the next two years). Relapse was defined as having previously participated in FOBT screening (schedule not defined) with no intention to participate again within the next two years. Inconsistent screening was defined as having previously participated in screening, but not on schedule (screened more than two years ago), with intentions to screen again within the next two years. Participants were asked to select which one option they believed best described their experience with FOBT screening. Options for survey respondents who had not previously participated in CRC screening with FOBT were provided however these were not included in the present analysis of rescreening intention.
Planning the process of screening

Participants who indicated that they intend to screen in the future using a FOBT (action, maintenance and inconsistent), were asked to indicate the extent to which they knew when they would next screen, where they would obtain their next FOBT and what steps were required in order to complete their next FOBT [31]. Responses were measured on 5-point Likert Scales ranging from strongly disagree to strongly agree.

Social cognitive variables and behavioural variables

Health beliefs and attitudes toward screening

A variety of variables consistent with the Health Belief Model (HBM) [32] and other social cognitive variables, previously associated with screening adherence [30, 33], were measured in the questionnaire. Variables were measured on 5-point Likert Scales with responses ranging from strongly disagree to strongly agree and measures were obtained by summing the individual items. Measures of perceived susceptibility, severity, chance health and internal locus of control were obtained from the initial screening questionnaire [30]. Measures of perceived barriers and benefits of screening included a combination of items from the initial screening questionnaire and new items designed to assess barriers to rescreening identified during the pilot phase. The resulting measures of barriers and benefits incorporated both the practical aspects of screening (“I think obtaining a home stool test would be difficult”) and attitudinal factors (“receiving information about bowel cancer screening in the mail can be embarrassing”). Also included in the rescreening questionnaire were existing measures of response efficacy (Cronbach’s $\alpha = 0.67$, 3-point response scale [34]) and health value (Cronbach’s $\alpha = 0.67$ [35]), along with a 6-item measure of self-efficacy based on the measurement recommendations of Luszczynska and Schwarzer [36].
Examples of the questionnaire items and measures of internal consistency (Cronbach’s α) for the scales used in the rescreening questionnaire are shown in Table 1.

Insert Table 1 about here

**Perceived social endorsement (social influence and social support)**

Availability of social support was measured using a 6-item scale (Cronbach’s α =0.86) from the initial screening questionnaire [30]. Perceived beliefs about, and desire to comply with family members and general practitioner attitudes to screening were assessed using a 4-item social influence measure (Cronbach’s α= 0.70). Items were developed by Tiro et al. [37] who designed the scale for use in CRC screening research (Cronbach’s α= 0.61). Responses were measured on 5-point Likert Scales ranging from strongly disagree to strongly agree and overall scores were obtained by summing the individual items.

**Satisfaction with prior screening**

Participants’ evaluations of their most recent experience screening with FOBT were measured with a single item (please rate the extent to which you were satisfied with the overall experience of screening for your most recent home stool test ) using a 5-point Likert scale ranging from very unsatisfied to very satisfied.

**Background Variables**

**CRC and screening knowledge**

Six items were developed to measure participants’ knowledge of CRC risk factors (age, diet and lifestyle, family history) and screening (treatment benefits of early detection, detection of precancerous growths and importance of repeat adherence). Response options
were agree, disagree and unsure/don’t know; correct responses were scored as one, incorrect and unsure/ don’t know were scored as zero.

Social interactions concerning CRC and other health maintenance activities

Three dichotomous items assessed participants’ levels of social exposure to CRC and screening (Have you discussed home stool testing with anyone? Have you ever known anyone who has screened for bowel cancer with a home stool test? Have you ever known anyone who has had bowel cancer?). Participation in other preventive health activities was assessed by determining frequency of GP visits within the past 12 months, participation in screening for other cancers in the past, and whether or not the participant had a regular GP. Previous experiences with cancer were also assessed (family history of CRC, prior cancer diagnosis).

Demographic

Demographic details (age, gender, marital status, education, health insurance) were collected and respondents’ postal codes were used to assign a measure of socioeconomic disadvantage, based on place of residence, according to the Australian Bureau of Statistics’ Socio Economic Index for Areas (SEIFA) [38].

Analyses

Data were first analysed for their univariate (ANOVA) associations with stage of readiness to rescreen. Categorical data and data that did not meet the assumptions of parametric testing (i.e. were not normally distributed) were analysed using non parametric alternatives (Chi Square and the Kruskal-Wallis Test) [39]. Significant differences between maintenance and remaining stages identified post hoc (Hochberg GT2, Chi Square, Mann-Whitney U test with the Bonferroni correction) were then incorporated into three separate multivariate models to determine the factors associated with each stage of readiness,
compared with maintenance. Data were assessed prior to analyses to ensure suitability for modelling [40]. Generalised Estimating Equations (log link, poisson distribution) were selected for multivariate analyses [41]

**Exclusions**

The overall response rate for the questionnaire was 48.5% (1941/4000). The primary outcome was stage of TTM for rescreening, therefore participants who had not screened previously with FOBT (n=944, 48.6%) and those who did not answer the TTM staging question (n=36, 1.85%) were not included in the current analyses. Missing values analysis identified 112 (5.77%) participants for whom data were missing for more than 20% of the total survey items. These cases were considered to be too extreme to warrant imputation and were removed from analysis [40].

**Results**

**Survey respondents**

Present analyses were restricted to the 849 (43.7%) participants who indicated in the questionnaire that they had participated in FOBT screening in the past (i.e., potential and actual rescreeners). These respondents were 391 (46.1%) men and 458 (53.9%) women aged between 50 and 74 (\(\bar{x}=61.47, SD=6.42\)). The majority of respondents were either married or

---

1 A demographic comparison of participants excluded on the basis of missing data found that excluded participants were significantly more likely to speak a language other than English at home \(\chi^2(1)=34.45, p<0.001\), were older \(t(1910)=6.02, p<0.001\) and less likely to be in the workforce \(\chi^2(1)=11.157, p<0.001\), they also reported slightly higher levels of socio economic disadvantage \(M=982.72, SD=66.93\) than included respondents \(M=999.09, SD=68.11, t(1931)=2.81, p=0.005\).
in a de facto relationship (80.4%) and only 45.2% were currently in the workforce, with the remainder being predominantly retired or home carers. Although 28.7% of the respondents were born outside of Australia, only 8.7% spoke a language other than English at home. Almost half of the sample (49.8%) reported their highest level of educational achievement to be secondary school or lower. Respondents’ measures of relative socio economic disadvantage ranged from 756 to 1107 (\( \bar{x} = 1007.62, \text{SD} = 64.96 \)) indicating relatively low levels of disadvantage amongst the study population, however this is comparable with 2006 Census data for South Australia which showed approximately 88 percent of the population resided within this range [42].

**Distribution across the stages of the TTM**

The majority of participants were previously adherent with screening (previous screening was on schedule) and had intentions to continue screening in the future with 39.1% (n=332) in the action stage and 31.0% (n=263) in the maintenance stage. Inconsistent participants comprised 15.5% (n=132) of the sample whilst 14.4% (n=122) indicated no intentions for future screening despite prior participation (relapse).

**Univariate analyses**

Tables 2 and 3 present the significant results of the univariate analyses for demographic/background and social cognitive variables. Results show that a variety of social cognitive, background and demographic variables differentiated maintenance from remaining stages. Post hoc tests revealed that unique characteristics were associated with each stage; for example, compared with maintenance (\( \bar{x} = 4.43, \text{SD} = 0.81 \)) satisfaction with prior screening was significantly lower amongst inconsistent (\( \bar{x} = 4.10, \text{SD} = 0.86 \)) and relapse participants (\( \bar{x} = 3.84, \text{SD} = 1.01 \)), but not action (\( \bar{x} = 4.34 \text{ SD}=0.75, H(3) = 48.30, p<.001 \)). Variables that
differentiated each stage from maintenance as identified post hoc were then incorporated into multivariate models.

Multivariate analyses

Table 4 presents the results of three separate multivariate models with maintenance as the referent category for each.

Action

Compared to people in the maintenance stage, those in the action stage were 18% less likely to have known someone who has had CRC (RR=0.82, p=.01). There were also small but significant differences found for age and social influence with action participants reporting lower levels of social influences to screen (RR=0.94, p<.001) and younger age (RR= 0.98, p<.001).

Inconsistent

Only two significant differences were identified between inconsistent participants and those in the maintenance stage. Inconsistent participants reported only slightly increased (5%)
barriers toward CRC screening (RR= 1.05, p=.05) in addition to being 16% less likely to have planned when they will next screen (RR=0.84, p=.04).

**Relapse**

A variety of different variables differentiated relapse from maintenance. Relapse participants reported less social influence to screen (RR=0.86, p<.001), fewer benefits of screening participation (RR=0.84, p<.001), less self-efficacy (RR=0.96, p=.01) and less satisfaction with previous screening (RR=0.87, p=.03). Relapse participants were more likely (33%) to have no private health insurance (RR=1.33, p=.04) and were 41% more likely to be unaware of the need for future screening participation if previous screening tests were normal (RR=1.41, p=.02).

**Discussion**

The need to implement health promotion programs that encourage CRC rescreening compliance is an important public health goal. In Australia, since the implementation of a nationwide FOBT screening program, understanding and supporting decisions to participate in CRC screening has become increasingly important [10, 30, 33]. A substantial proportion (29.9%) of prior screeners in the present study identified themselves as either non-adherent, or expressed no intention to maintain adherence, despite prior participation. These figures highlight the importance of encouraging rescreening as well as initial uptake if morbidity and mortality are to be reduced [1]. In order to achieve screening maintenance following initial participation it is important that the variables differentiating the various levels of commitment to screen are understood.

The present study separated relapsed screeners into two categories, inconsistent screeners and traditional relapse. Whilst both represent target categories for intervention,
Few differences were identified between maintenance and inconsistent rescreeners. Whilst greater perceived barriers were reported amongst inconsistent screeners these differences were only small and may be a reflection of the large sample size. These findings, however, do support those observed amongst inconsistent mammography screeners who also
reported greater practical barriers to rescreening [22]. Future research using additional populations may be required to verify this difference for CRC screening. Inconsistent participants were however, substantially (16%) less likely to have planned when they will next participate in screening. ‘Planning processes’ that speculate when, where or how an intended behaviour can be completed has been well documented as a facilitator bridging the gap between intention and behaviour [31] and may explain the moderate increases in reparticipation observed in reminder intervention trials [7]. Despite being non-adherent with screening guidelines, inconsistent screeners did not greatly differ from maintenance screeners according to social cognitive variables. These findings considered in combination with the comparisons between relapse and maintenance suggest each stage is characterised by unique attitudes toward screening and future research should continue to emphasise this distinction by considering both relapse categories separately.

In past research, adherent screeners (action and maintenance) have been collapsed into a single adherent stage [13, 21, 26]. However, in the present study small but significant differences between action and maintenance participants were observed. Action participants were younger and less likely to have known someone with CRC and also reported lower levels of social influence to screen. Whilst this age difference may account for disparities in knowing someone with CRC, the age differences were only small and could be a result of the one to two year intervals required to rescreen for CRC. The social differences, however, which were also observed for relapsed screeners, do present some interesting areas for further investigation. Social influence has been previously shown to be important for encouraging initial uptake [37]; however, results of the present study indicate social factors may continue to motivate screening beyond initial uptake. Action participants have not yet had an opportunity to reparticipate in screening; therefore it is unclear whether these differences in
social factors between action and maintenance lead to relapse. Results however do suggest that continued GP endorsement and family support are an important characteristic of screening maintenance and therefore should be highlighted in messages to those who have only just begun to screen as well as those who are no longer adherent.

This study highlights the importance of prior screening experience and future intentions when categorising rescreening participants for study. However, there are several limitations. Firstly, past research utilising surveys in CRC screening research has documented greater survey participation amongst those more receptive to CRC screening participation [33]. The present study achieved a modest unadjusted response rate of just below 50%. Whilst this is comparable with similar Australian research [30], response bias may have contributed to the primarily positive attitudes toward screening observed here and limited generalisability to the wider population [43]. However, the proportion of those identifying themselves as relapse and inconsistent participants (29%) were similar to rates of screening relapse reported in the Australian National Bowel Cancer Screening Program (approximately 20%) which suggests adequate sampling of those from different stages of readiness to rescreen. There were also a small portion of respondents for whom substantial missing data rendered them unsuitable for comparative analyses. Whilst this may also have potentially limited the generalisability of the sample, demographic analyses found age, socio-economic and language barriers to be associated with exclusion, factors which have been previously identified as characteristic of survey non-respondents [43].

It is also important to note that results are based on retrospective reporting and may be influenced by current attitudes toward screening and cognitive dissonance, possibly resulting in participants exaggerating the negativity of their prior screening experience [44]. Although it is not uncommon for studies to utilise retrospective reporting [14], in order to further
examine the effects of prior experiences on subsequent screening, future research may benefit from obtaining measures of satisfaction immediately following FOBT completion. Finally, all stage categories were based on measures of future intentions to rescreen, which were prudent for a study utilising the TTM [17, 18], however, it would also be useful to conduct similar comparative studies that follow up on these screening intentions with observed screening behaviour.

Self-reported rates of rescreening in the present study show a substantial portion of prior screeners were either non-adherent with screening guidelines or had no intention to continue screening. The use of an expanded TTM proved relevant for an exploration of the characteristics associated with FOBT rescreening behaviour. Unique differences were observed between maintenance participants and comparative stages providing a useful foundation for further research into the development and trail of interventions to encourage reparticipation in colorectal cancer screening.
Reference List (manuscript)


Table 1 Social cognitive measures used in the rescreening questionnaire

<table>
<thead>
<tr>
<th>Variable</th>
<th>Example</th>
<th>Cronbach’s α</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chance Health Locus of Control</strong></td>
<td>“Most things that affect my health happen to me by chance”</td>
<td>.70 (4 items)</td>
</tr>
<tr>
<td><strong>Internal Health Locus of Control</strong></td>
<td>“I am in control of my health”</td>
<td>.66 (2 items)</td>
</tr>
<tr>
<td><strong>Health Value</strong></td>
<td>“There is nothing more important than good health”</td>
<td>.70 (4 items)</td>
</tr>
<tr>
<td><strong>Response Efficacy</strong></td>
<td>“Participation in home stool test screening leads to the detection of small abnormalities.”</td>
<td>.59 (4 items)</td>
</tr>
<tr>
<td><strong>Self-Efficacy</strong></td>
<td>“I am confident that I will be able to screen regularly for bowel cancer with a home stool test even if I find the test to be embarrassing”</td>
<td>.96 (6 items)</td>
</tr>
<tr>
<td><strong>Barriers</strong></td>
<td>“Giving a sample of faeces to another person to test for bowel cancer screening is embarrassing”</td>
<td>.77 (7 items)</td>
</tr>
<tr>
<td><strong>Facilitators/Benefits</strong></td>
<td>“Having regular home stool tests would give me peace of mind about my health”</td>
<td>.62 (4 items)</td>
</tr>
<tr>
<td><strong>Perceived Severity</strong></td>
<td>“A diagnosis of bowel cancer would severely affect my lifestyle”</td>
<td>.57 (2 items)</td>
</tr>
<tr>
<td><strong>Perceived Susceptibility</strong></td>
<td>“There is a good chance that I will get bowel cancer”</td>
<td>.65 (2 items)</td>
</tr>
</tbody>
</table>
Table 2 Significant univariate differences between maintenance and remaining categories for social cognitive variables

<table>
<thead>
<tr>
<th></th>
<th>Maintenance</th>
<th>Action</th>
<th>Inconsistent</th>
<th>Relapse</th>
<th>F (df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( \bar{x} ) (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Planning processes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What steps</td>
<td>4.38(0.72)</td>
<td>4.07(0.88)**</td>
<td>3.94(0.88)**</td>
<td>n/a</td>
<td>15.76(2, 357.03)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Where</td>
<td>4.13(0.98)</td>
<td>3.61(1.21)**</td>
<td>3.72(1.09)**</td>
<td>n/a</td>
<td>16.75(2,371.49)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>When</td>
<td>3.29(1.14)</td>
<td>2.78(1.06)**</td>
<td>2.75(0.93)**</td>
<td>n/a</td>
<td>19.95(2, 724)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>Health Beliefs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barriers</td>
<td>14.16(3.81)</td>
<td>15.11(3.73)*</td>
<td>16.04(3.78)**</td>
<td>17.35(4.16)**</td>
<td>21.36(3, 845)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Benefits</td>
<td>17.09(1.78)</td>
<td>16.53(1.84)**</td>
<td>16.52(1.64)*</td>
<td>15.19(1.71)**</td>
<td>32.06(3, 845)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Social support</td>
<td>23.96(3.41)</td>
<td>23.07(3.52)*</td>
<td>22.65(3.87)**</td>
<td>21.89(3.83)**</td>
<td>10.30(3, 845)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Social influence</td>
<td>15.19(2.66)</td>
<td>13.82(2.58)**</td>
<td>14.14(2.38)**</td>
<td>12.76(2.22)**</td>
<td>28.93(3, 845)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Chance health</td>
<td>8.92(2.52)</td>
<td>9.35(2.43)</td>
<td>9.48(2.50)</td>
<td>9.78(2.68)*</td>
<td>3.79 (3, 845)</td>
<td>.010</td>
</tr>
<tr>
<td>Response efficacy</td>
<td>11.19(1.43)</td>
<td>11.09 (1.45)</td>
<td>11.30(2.83)</td>
<td>10.83(1.46)**</td>
<td>10.40(3)(^a)</td>
<td>.015</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>4.43(0.81)</td>
<td>4.34(0.75)</td>
<td>4.10(0.86)**</td>
<td>3.84(1.01)**</td>
<td>48.30(3)(^a)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

\(^a\)Kruskal-Wallis test statistic **\(p<.01\), \(^*p<.05\)
Table 3 Significant univariate differences between maintenance and remaining categories for demographic and background variables

<table>
<thead>
<tr>
<th></th>
<th>Maintenance</th>
<th>Action</th>
<th>Inconsistent</th>
<th>Relapse</th>
<th>$\chi^2$ (df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Background</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Known someone who has had CRC</strong></td>
<td>214(81.4)</td>
<td>233(70.6)**</td>
<td>101(77.1)</td>
<td>89(73.6)</td>
<td>9.56(3)</td>
<td>.02</td>
</tr>
<tr>
<td><strong>Discussed FOBT screening</strong></td>
<td>277(86.3)</td>
<td>271(81.6)</td>
<td>100(76.3)*</td>
<td>73(59.8)**</td>
<td>37.58(3)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>Known someone who has screened with FOBT</strong></td>
<td>177(67.3)</td>
<td>192(58.0)*</td>
<td>88(67.2)</td>
<td>62(50.8)**</td>
<td>13.06(3)</td>
<td>.01</td>
</tr>
<tr>
<td><strong>Regular GP</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Rescreen knowledge (incorrect)</strong></td>
<td>254(97.3)</td>
<td>300(90.9)**</td>
<td>121(92.4)*</td>
<td>112(92.6)*</td>
<td>10.12(3)</td>
<td>.02</td>
</tr>
<tr>
<td><strong>Demographic</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Private health insurance (none)</strong></td>
<td>28(10.8)</td>
<td>52(15.8)</td>
<td>23(17.4)</td>
<td>35(28.7)**</td>
<td>19.66(3)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>Born in Australia</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong> $^a$</td>
<td>201(77.0)</td>
<td>237(71.8)</td>
<td>85(64.4)**</td>
<td>78(63.9)**</td>
<td>10.46(3)</td>
<td>0.02</td>
</tr>
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</table>

$^a$Age was measured on a continuous scale. **p<.01, *p<.05,
Table 4 Multivariate analyses of factors associated with the action, inconsistent and relapse stages relative to maintenance

<table>
<thead>
<tr>
<th></th>
<th>Action</th>
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<th>Relapse</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>RR</td>
<td>p</td>
<td>95% CI</td>
<td>RR</td>
<td>p</td>
<td>95% CI</td>
</tr>
<tr>
<td><strong>Social cognitive</strong></td>
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<td></td>
</tr>
<tr>
<td><strong>Barriers</strong></td>
<td>1.02</td>
<td>.13</td>
<td>1.00-1.04</td>
<td>1.05</td>
<td>.04</td>
<td>1.00-1.09</td>
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<tr>
<td><strong>Benefits</strong></td>
<td>0.99</td>
<td>.47</td>
<td>0.95-1.03</td>
<td>0.99</td>
<td>.86</td>
<td>0.90-1.09</td>
</tr>
<tr>
<td><strong>Self-efficacy</strong></td>
<td>0.99</td>
<td>.35</td>
<td>0.98-1.01</td>
<td>1.01</td>
<td>.58</td>
<td>0.97-1.06</td>
</tr>
<tr>
<td><strong>Response efficacy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social influence</strong></td>
<td>0.94</td>
<td>&lt;.001</td>
<td>0.91-0.97</td>
<td>0.94</td>
<td>.06</td>
<td>0.87-1.00</td>
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<tr>
<td><strong>Social support</strong></td>
<td>1.01</td>
<td>.35</td>
<td>0.99-1.04</td>
<td>1.01</td>
<td>.64</td>
<td>0.96-1.06</td>
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<tr>
<td><strong>Chance health</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Satisfaction with prior screening</strong></td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>Background</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Known someone who has had CRC</strong></td>
<td>0.82</td>
<td>.01</td>
<td>0.71-0.95</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Known someone who has screened</strong></td>
<td>0.99</td>
<td>.84</td>
<td>0.86-1.14</td>
<td></td>
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<tr>
<td><strong>Discussed FOBT screening</strong></td>
<td>0.96</td>
<td>.81</td>
<td>0.68-1.36</td>
<td>0.77</td>
<td>.07</td>
<td>0.58-1.03</td>
</tr>
<tr>
<td><strong>Regular GP</strong></td>
<td>0.84</td>
<td>.09</td>
<td>0.68-1.03</td>
<td>0.78</td>
<td>.37</td>
<td>0.46-1.33</td>
</tr>
<tr>
<td><strong>Rescreen knowledge</strong></td>
<td>1.37</td>
<td>.21</td>
<td>0.84-2.25</td>
<td>1.41</td>
<td>.02</td>
<td>1.06-1.88</td>
</tr>
<tr>
<td>(incorrect)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Plans for future FOBT</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Where</strong></td>
<td>0.96</td>
<td>.28</td>
<td>0.89-1.03</td>
<td>1.08</td>
<td>.47</td>
<td>0.88-1.32</td>
</tr>
<tr>
<td><strong>When</strong></td>
<td>0.94</td>
<td>.15</td>
<td>0.86-1.02</td>
<td>0.84</td>
<td>.04</td>
<td>0.71-1.00</td>
</tr>
<tr>
<td><strong>What steps</strong></td>
<td>0.97</td>
<td>.53</td>
<td>0.89-1.06</td>
<td>0.80</td>
<td>.06</td>
<td>0.64-1.01</td>
</tr>
<tr>
<td><strong>Demographic</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>0.98</td>
<td>&lt;.001</td>
<td>0.97-0.99</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Health insurance (none)</strong></td>
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<td></td>
<td>1.33</td>
<td>.04</td>
<td>1.01-1.75</td>
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<tr>
<td><strong>Born in Australia</strong></td>
<td>0.80</td>
<td>.14</td>
<td>0.59-1.08</td>
<td>0.91</td>
<td>.49</td>
<td>0.70-1.18</td>
</tr>
</tbody>
</table>
Appendix C: Advance Notification Letter

Bowel Health Service
Ph: 8275 1075

<DATE>
<first name> <last name>
<address 1>
<address 2>

Dear <first name> <last name>,

This letter is to inform you that we will soon be sending you an invitation to participate in the third and final round of our bowel cancer screening research program.

You may not be aware that bowel cancer is one of the most common forms of cancer in Australia affecting both men and women. The risk of developing the disease is increased in those aged 50 years and over. However, bowel cancer is preventable provided that people act to do something about it. Simple and effective screening tests can be used as an aid to detect the condition before it takes hold, that is, while it is still curable. These tests are not unpleasant and can be done in your own home.

The Bowel Health Service, Repatriation General Hospital, undertakes research into bowel cancer prevention. As part of this program you were randomly selected from the Commonwealth Electoral Roll to receive an offer of a free screening test. This will be sent to you by mail in about 2 weeks. General practitioners and other healthcare professionals including specialists recommend that people should do tests of this type on a regular basis. If you are unsure about screening we encourage you to discuss this with your doctor, family or friends.

You do not need to respond to this letter; we will send you more information soon. If you have any queries before that time, please contact the Bowel Health Service on 8275 1075, the Cancer Council South Australia on 131120 or visit their web site at http://www.cancersa.org.au/aspx/detection_bowel_cancer.aspx.

Yours sincerely

Steve Cole
Coordinator
Bowel Health Service

The Australian Electoral Commission (AEC) has supplied name, address, gender and age-range information for this medical research study in conformity with Item 2 of subsection 90B(4) of the Commonwealth Electoral Act 1918 and subregulation 9(a) of the Electoral and Referendum Regulations 1940. The information has been provided by the AEC on a confidential basis and will not be used for any other purpose than to contact participants for this medical research project.

The Research and Ethics Committee of the Repatriation General Hospital has reviewed this study. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make a confidential complaint, you may contact Ms Janet Bennett, the Executive Officer, Research and Ethics RGH, on 82751876. Rd3 EN NHMRC Rescreen 2010
Appendix D: BHS Annual Screening Invitation Letter

Bowel Health Service
Tel 8275 1075

DATE
«complete_name»
«Enrol_st_1»
«Enrol_st_2»
«enrol_suburb» «enrol_state» «Enrol_PC»

Study ID: «Study_ID»

Dear «complete_name»,

It is now approaching 12 months since we last invited you to participate in our bowel cancer prevention program as part of our ‘Re-participation in screening for colorectal cancer: Behavioural outcomes and predictors’ research study.

After reviewing our records and any information you may have already provided, we believe it is now appropriate to invite you to participate in the next round of screening for early detection of curable bowel cancer. Please find enclosed a bowel cancer screening kit as part of this program.

The Bowel Health Service believes that this is an important initiative and that participation in the program will be of benefit to you. The enclosed test is an effective aid to the detection of early bowel cancer, before symptoms become apparent, and it does save lives.

Your participation in this program is of course voluntary. However, if you would like to take part the test will take just a few minutes on two occasions. Please:

- Read the enclosed Bowel Cancer Information Sheet.
- Complete the screening test following the instructions exactly as printed on the kit brochure.
- Complete and sign the Participant Details Form, including the name and address of your preferred doctor.
- Post the completed form and sample tubes to the Bowel Health Service using the pre-paid envelope provided.

The Bowel Health Service will develop the test and inform you of the result within 2 weeks. There will be no cost to you in completing this test. If we do not hear from you, you may receive a reminder letter in a few weeks.

Please do not hesitate to contact your doctor or the Bowel Health Service on 8275 1075 if you have any queries.

Yours sincerely,

Steve Cole
Screening Coordinator
Bowel Health Service

Graeme Young
Professor of Global GI Health

The Australian Electoral Commission (AEC) has supplied name, address, gender and age-range information for this medical research study in conformity with Item 2 of subsection 90B(4) of the Commonwealth Electoral Act 1918 and subregulation 9(a) of the Electoral and Referendum Regulations 1940. The information has been provided by the AEC on a confidential basis and will not be used for any other purpose than to contact participants for this medical research project. The Research and Ethics Committee of the Repatriation General Hospital has reviewed this study. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make a confidential complaint, you may contact Ms Janet Bennett, the Executive Officer, Research and Ethics RGH, on 82751876.
Appendix E: Bowel Cancer Screening Information Sheet

Bowel Health Service
Bowel Cancer Screening Information Sheet

Bowel or colorectal cancer is one of the most common forms of cancer, affecting about one in twenty South Australians over their lifetime. The risk of being diagnosed with bowel cancer rises significantly after the age of 50. The disease is often curable if it is detected in its earlier stages, especially before symptoms develop.

International research has shown that deaths from bowel cancer can be reduced by early detection through participation in screening. As part of our ongoing research into prevention of bowel cancer, we are offering a screening program to randomly selected South Australians aged 50 to 74 years. This program is similar in concept to the successful breast cancer screening program that has been available to women for some time.

YOUR PARTICIPATION
Bowel cancer screening involves completing a simple screening test at home, and if positive, following this up with further tests. Your participation in screening will reduce your chance of being seriously affected by bowel cancer because early bowel cancers and bowel polyps (pre-cancers) may be detected and promptly removed. It will also influence how bowel cancer screening is introduced more widely in Australia as knowledge gained through this research will inform the further development of the National Bowel Cancer Screening Program.

THE TEST
It is important to understand that the screening test (a ‘faecal immunochemical test’ or FIT but often also referred to as an FOBT or faecal occult blood test) is an aid to the early diagnosis of curable bowel cancer. The screening test uses advanced chemical means to reliably detect tiny amounts of blood often released from early bowel cancers and polyps. Small samples of stool (bowel motion) are required for these tests.

If you participate, (and your participation is entirely voluntary), please read and follow the instructions provided with the test kit. After you have collected your samples and completed the Participant Details Form mail them to the Bowel Health Service, Repatriation General Hospital using the reply-paid envelope provided.

IMPORTANT
You should NOT complete the screening test if you have:
- Noticed rectal bleeding anytime in the last month (consult with your GP)
- Inflammatory Bowel Disease (Crohn’s Disease or Ulcerative Colitis)
- Had radiotherapy to your lower abdomen or pelvis (consult with your GP)
- A colostomy
- Significant problems with your heart or lungs which could impact on your ability to have a colonoscopy should you return a positive screening test result.

If you have questions about any of the above, please call the Bowel Health Service Hot Line on 8275 1075.
YOUR TEST RESULTS

We will mail the test result to you within two weeks of us receiving your samples and if positive we will also send a copy to the doctor you nominated on your Participant Details Form.

A positive test result indicates the presence of small amounts of blood in your stool. This may commonly arise from conditions other than bowel cancer. Therefore a positive test result does not confirm the presence of cancer, but it does indicate the need for a more specific examination to establish the source of blood. This would ideally involve a colonoscopy or X-ray examination of the bowel. If your test is positive (about an 8% chance) you will need to organise further tests through your own doctor. They are likely to refer you on to a specialist for further investigations.

A negative test indicates that blood is not present in your stool samples and no further action is required at this time. However you will appreciate that medical tests of this type are not perfect and current practice is to recommend regular re-testing. In the meantime, if there is any reason for concern, you should seek prompt advice from your doctor.

THE PARTICIPANT DETAILS FORM

To facilitate the screening and reporting process, we would be grateful if you could provide some personal details and other information using the enclosed Participant Details Form.

Your doctor’s name and contact details are necessary so that we can also inform them that you have participated in this screening program and that you have returned a positive test result.

RESEARCH

The Bowel Health Service conducts research approved by the Repatriation General Hospital Research and Ethics Committee. In addition to providing a screening program, this study involves research to identify factors that influence people’s participation in screening.

PRIVACY

The personal information provided in your Participant Details Form will be kept entirely confidential and can only be accessed by staff of the Bowel Health Service for the purpose of managing your screening program. Any information that may be provided to other researchers will be in a form such that you will not be able to be identified. Your study records may be viewed by authorised persons within (members of the Research and Ethics Committee) or outside the hospital for the purpose of source data audit. This will be done in a way that respects and protects your privacy.

CONTACT DETAILS

For questions or concerns related to the test procedure or results:

Bowel Health Service Hot Line: 8275 1075. Please mention the NHMRC Screening Study and have your Study ID number available.

For further information about the research study:

Ms Jo Lane, Study Coordinator: 8275 1075
Mr Stephen Cole, Chief Investigator: 8275 1838

This study has been approved by the Research and Ethics Committee at the Repatriation General Hospital, Daw Park. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study, or your rights as a participant, you may contact Mrs Janet Bennett, Executive Officer of the Research and Ethics Committee at the Repatriation General Hospital, Daw Park, telephone 8275 187
References


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delivered intervention to promote colorectal cancer screening: Sometimes more is just the same. Annals of Behavioral Medicine, 41, 284-299.


