

## RESEARCH ARTICLE

# Predictors of Re-participation in Faecal Occult Blood Test-Based Screening for Colorectal Cancer

Stephen R Cole<sup>1,2\*</sup>, Tess Gregory<sup>3</sup>, Alex Whibley<sup>1,2</sup>, Paul Ward<sup>4</sup>, Deborah Turnbull<sup>5</sup>, Carlene Wilson<sup>1,6</sup>, Ingrid Flight<sup>7</sup>, Adrian Esterman<sup>8</sup>, Graeme P Young<sup>1</sup>

### Abstract

**Background:** There is little information on longitudinal patterns of participation in faecal occult blood test (FOBT) based colorectal cancer (CRC) screening or on demographic or behavioural factors associated with participation in re-screening. The lack of an agreed system for describing participatory behaviour over multiple rounds also hampers our ability to report, understand and make use of observed associations. Our aims were to develop a system for describing patterns of participatory behaviour in FOBT-based CRC screening programs and to identify factors associated with particular behavioural patterns. **Methods:** A descriptive framework was developed and applied to a data extract of screening invitation outcomes over two rounds of the NBCSP. The proportion of invitees in each behaviour category was determined and associations between behaviour patterns and demographic and program factors were identified using multivariate analyses. **Results:** We considered Re-Participants, Dropouts, Late Entrants and Never Participants to be the most appropriate labels for the four possible observed participatory categories after two invitation rounds. The screening participation rate of the South Australian cohort of the NBCSP remained stable over two rounds at 51%, with second round Dropouts (10.3%) being balanced by Late Entrants (10.5%). Non-Participants comprised 38.7% of invitees. Relative to Re-Participants, Dropouts were older, more likely to be female, of lower SES, had changed their place of residence between offers had a positive test result in the first round. Late Entrants tended to be in the youngest age band. **Conclusions:** Specific demographic characteristics are associated with behavioural sub-groups defined by responses to 2 offers of CRC screening. Targeted group-specific strategies could reduce dropout behaviour or encourage those who declined the first invitation to participate in the second round. It will be important to keep first round participants engaged in order to maximise the benefit of a CRC screening program.

**Keywords:** Colorectal cancer - screening program - re-screening - faecal occult blood test - prevention - South Australia

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### Introduction

Public health authorities throughout the world are progressively introducing faecal occult blood test (FOBT)-based population screening programs for early detection of colorectal cancer (CRC) that, in line with the evidence base, offer multiple rounds of screening. While there has been a substantial amount reported in the literature on behavioural outcomes following an initial round of screening offers, there is much less information available on patterns of participation in FOBT-based CRC screening over multiple rounds or on demographic or behavioural factors associated with participatory behaviour over more than one round. The lack of an agreed and useful system for describing participatory behaviour over multiple rounds also hampers our ability to report, understand and make use of observed associations with particular

behavioural patterns.

Repeated participation is crucial to efficacy of FOBT-based screening. The evidence for the benefit of FOBT-based screening comes from clinical trials of screening that involved multiple rounds of offers over a period of at least ten years (Mandel et al., 1993; Hardcastle et al., 1996; Kronborg et al., 1996; Hewitson et al., 2007; Lindholm et al., 2008). Results from the longest trial showed that mortality in those offered annual or biennial FOBT-based screening was reduced by 33% and 21% respectively, compared to a population not offered screening (Mandel et al., 1993). While the difference in mortality reduction between annual and biennial screening was not statistically significant, the trend toward greater mortality reduction with more testing points highlights the importance of re-participation.

Invitees to Australia's National Bowel Cancer

<sup>1</sup>Flinders Centre for Innovation in Cancer, <sup>2</sup>Discipline of Public Health, Flinders University, <sup>3</sup>Bowel Health Service, Repatriation General Hospital, <sup>4</sup>Australian Institute for Social Research, <sup>5</sup>School of Psychology, CCRE Nutritional Physiology, Discipline of Medicine, University of Adelaide, <sup>6</sup>Cancer Council South Australia, <sup>7</sup>CSIRO Preventative Health Flagship, Adelaide, Australia  
\*For correspondence: [Steve.cole@health.sa.gov.au](mailto:Steve.cole@health.sa.gov.au)

Screening Pilot Program (NBCSPP) received a second invitation to screen in Phase 1 of the National Bowel Cancer Screening Program (NBCSP). We reasoned that this population could, within the Australian setting, provide valuable information on likely population screening re-participation rates and might also provide information on demographic or program factors that predict an invitee's behavioural response to a second screening offer.

Our specific aims were: (1) To develop a simple system for describing patterns of participatory behaviour; (2) To apply this terminology to the 2 rounds of screening through the NBCSP and to determine the proportion of people falling into each participatory category and (3) To determine demographic and program factors associated with re-screening behaviour. Our ultimate goal was to develop recommendations for strategies to maximise re-participation in FOBT-screening.

## Materials and Methods

### *Defining patterns of participatory behaviour*

We developed a simple and practical nomenclature using descriptors that covered all possible behavioural patterns after two rounds of offers. We categorised invitees into Re-Participants and Never Participants (no change in participatory behaviour in the second round from the first), Dropouts (participated in the first round but declined the second) and Late Entrants (declined the first offer but participated in the second). We applied this nomenclature to screening participation data over the 2 rounds of the NBCSP.

### *Eligibility for screening invitations*

Round 1 invitations were issued to all South Australians who were recorded by Australia's Health Insurance Commission or the Australian government Department of Veterans Affairs as being aged 55-74 on 1 January 2003 and residing in any one of 9 postcode specific areas in urban Adelaide. The same population was invited again in Round 2 with the exception of those who had opted to be removed from the NBCSP register or were recorded as deceased (Young, 2009).

### *Study population*

Round 1 (Pilot) invitations were issued to 18,431 South Australians. Of this population, 1279 people opted out and 574 people were recorded as deceased before round 2 invitations (NBCSP Phase 1) were issued. The final data set comprised information from 16,578 invitees. This was reduced to 16,433 after exclusion of people whose age or postcode was subsequently found not to match round 1 eligibility criteria.

### *The NBCSP process*

Invitations to screen were posted to all eligible people and included a faecal immunochemical test (FIT). Two different FITs (InForm™, Enterix Australia or Detect™, Bayer Health Care) with similar performance characteristics but different procedures for use were distributed in round 1. The invitation process for the

second round was identical although only Detect™ was distributed. Participants returned specimens to a central laboratory and received written notification of the result. Test positive participants were encouraged to consult their GP for referral for colonoscopy.

### *Data acquisition*

Ethical approval for the project was obtained from the Research and Ethics Committee of the Repatriation General Hospital Daw Park and from the Departmental Ethics Committee of the Australian Government Department of Health and Ageing. Final approval for data release was granted by the NBCSP data custodian Medicare Australia.

### *Data fields*

Available data fields relevant to the study aims were: date of birth, sex, first and second round address postcodes, first round FOBT type offered (Detect was offered to all invitees in round 2), participation status for rounds 1 and 2, and round 1 FOBT result.

Date of birth was converted to age on 1 January 2003 and grouped into 5 year age bands. Postcode was converted to the equivalent Index of Relative Socioeconomic Advantage and Disadvantage (IRSD) value (AIHW, 2006), and grouped by quintiles.

### *Factors associated with participatory behaviours*

We undertook a stepwise analysis of the data firstly using univariate Chi<sup>2</sup> analyses, followed by multivariate analyses by generalised estimating equations (GEE, SPSS Version 17).

In our multivariate analyses we compared the characteristics of Dropouts relative to Re-Participants, Never Participants to Late Entrants and Re-Participants with Never Participants.

## Results

### *Re-screening rates*

Patterns of participatory behaviour after 2 rounds of invitations from the NBCSP are shown in Table 1. Of the 16,433 people who were offered screening in both rounds and who satisfied the data inclusion criteria, 40.5% completed both offers and were categorised as Re-Participants. Never Participants comprised 38.7% and 61.3% participated at least once over the two rounds of

**Table 1. Screening Participation Rates for Round 1 and Round 2 of NBCSP Pilot Invitees in South Australia**

Participation	n	%
Round 1: Participants	8345	50.8
Non-Participants	8088	49.2
Total	16433	
Round 2: Re-participants	6656	40.5
Dropouts	1689	10.3
Late Entrants	1726	10.5
Never Participants	6362	38.7
Total	16433	

**Table 2. Number and Proportion of Round 2 Invitees in Each Participation Category by Invitee Characteristic, and Significant Univariate Associations**

Invitee characteristic	Behaviour category								Comparison between behavioural categories (X <sup>2</sup> )			
	RP		NP		DP		LE		All	RP vs DP	NP vs LE	RP vs NV
	n	%	n	%	n	%	n	%				
Age (years)												
55-59	1957	29.4	2059	32.0	459	27.2	656	38.0				
60-64	1594	23.9	1347	21.3	328	19.4	394	22.8	121.1**	43.7**	35.2**	23.5**
65-69	1614	24.2	1487	23.5	402	23.8	368	21.3				
70-74	1491	22.4	1487	23.5	500	29.6	308	17.8				
Gender												
Female	3687	55.4	3360	52.8	981	58.1	868	50.3	29.6**	3.9*	3.4	8.7*
Male	2969	44.6	3002	47.2	708	41.9	858	49.7				
SES (IRSAD quintile)												
1 (lowest SES)	310	4.7	597	9.6	114	6.7	110	1.4				
2	963	14.5	1183	18.6	288	17.1	293	3.6				
3	351	5.3	552	8.7	100	5.9	98	5.7	292.8**	25.7**	43.7**	275.2**
4	1272	19.1	888	14.0	324	19.2	279	16.2				
5 (highest SES)	3760	56.5	3142	49.4	863	51.1	946	54.8				
Postcode change												
No Change	6027	90.5	3110	48.9	842	49.9	808	46.8	10.0*	9.0**	0.2	3.9*
Change	629	9.5	667	10.5	201	11.9	174	10.1				
FOBT Type at Pilot												
Detect <sup>TM</sup>	3513	52.8	3110	48.9	842	49.9	808	46.8	30.0**	4.6*	2.3	19.8**
InForm <sup>TM</sup>	3143	47.2	3252	51.1	846	50.1	918	53.2				
Pilot Test Result												
Negative FOBT	6129	92.1			1313	77.7						
Positive FOBT	499	7.5			310	18.4				340.3**		
Inconclusive FOBT	28	0.4			66	0.8						

\* p<0.05, \*\*p<0.01, SES was classified using postcode (at round 1) and the ABS Index of Relative Socioeconomic Advantage and Disadvantage (IRSAD) for 2006. Two people had postcodes that did not correspond to the SEIFA codes and could not be classified. Their data are excluded from this table, RP: Re-participation, NP: Never Participation, DP: Dropout, LE: Late Entry

**Table 3. Joint Predictors of Screening Behaviour**

		Dropouts vs Re-Participants			Late Entrants vs Never Participants			Re-Participants vs Never Participants		
		Risk Ratio	p-value	95% CI	Risk Ratio	p-value	95% CI	Risk Ratio	p-value	95% CI
Age band (years)	55-59 <sup>a</sup>	1.00	1.00	1.00	1.00			1.00		
	60-64	0.88	0.05	0.78, 1.00	0.95	0.34	0.85, 1.06	1.12	0.01	1.07, 1.17
	65-69	1.00	0.96	0.89, 1.13	0.85	0.01	0.76, 0.95	1.08	0.01	1.03, 1.13
	70-74	1.22	0.01	1.09, 1.37	0.72	0.00	0.64, 0.82	1.04	0.13	0.99, 1.09
Gender	Female <sup>a</sup>	1.00			1.00			1.00		
	Male	0.92	0.04	0.84, 0.99	1.06	0.19	0.97, 1.15	0.95	0.01	0.92, 0.98
SES quintile	1 (lowest SES) <sup>a</sup>	1.00			1.00			1.00		
	2	0.88	0.17	0.73, 1.06	1.29	0.01	1.05, 1.57	1.31	0.01	1.18, 1.45
	3	0.88	0.25	0.70, 1.10	0.98	0.86	0.76, 1.26	1.14	0.04	1.00, 1.2
	4	0.83	0.05	0.69, 1.00	1.52	0.01	1.25, 1.86	1.73	0.01	1.57, 1.90
	5	0.76	0.01	0.65, 0.90	1.47	0.01	1.23, 1.76	1.6	0.01	1.45, 1.75
Postcode change	No change <sup>a</sup>	1.00	1.00	1.00	1.00			1.00		
	Change	1.22	0.01	1.07, 1.38	0.94	0.38	0.82, 1.08	0.95	0.07	0.90, 1.01
FOBT type at Pilot	Detect <sup>TMa</sup>	1.00	1.00	1.00	1.00			1.00		
	Inform <sup>TM</sup>	1.09	0.05	1.00, 1.18	1.06	0.16	0.98, 1.16	0.93	0.01	0.90, 0.96
Pilot test result	Negative <sup>a</sup>	1.00	1.00	1.00						
	Positive	2.10	0.01	1.90, 2.33						
	Inconclusive	3.81	0.01	3.29, 4.40						

<sup>a</sup>Reference group for categorical predictors

invitations. In the second round Dropouts comprised 10.3% which was balanced by 10.5% of the invited population who were Late Entrants.

*Associations with participatory behaviours*

Results of univariate analyses are shown in Table 2. Comparisons included between all groups, Re-Participants versus Dropouts, Never Participants versus Late Entrants

and Re-Participants versus Never Participants.

When all participatory groups were compared together, significant heterogeneity between groups was observed for all variables (excluding FOBT test result as this was not available for non-participants). In two-group comparisons, Re-Participants differed significantly from Dropouts for all available demographic characteristics, as did Re-Participants from Never Participants. All

variables significant at the univariate level were included in multivariate GEE models to identify joint predictors of rescreening behaviours.

#### *Dropouts compared to Re-participants*

Table 3 shows that Dropouts were more likely to be aged 70-74, and less likely to be aged 60-64. Men were significantly less likely to dropout than women. People in the highest two SES groups were significantly less likely to dropout than people in the lowest SES group. Those who had a different postcode between the first and second round screening offers were also more likely to dropout.

Invitees who had been offered InForm™ in round 1 were more likely to be Dropouts in round 2. The result of the first round FOBT result also influenced second round uptake as people who tested positive in the first round were less likely to participate in the second round. Those who received an inconclusive result in the first round were also more likely to reject a second offer of screening than people with a negative test.

#### *Late entrants compared to never participants*

People aged 65-69 years and 70-74 years were significantly less likely to become Late Entrants (Table 3) and those in the highest two SES groups were more likely to become Late Entrants.

#### *Re-participants compared to never participants*

Re-participants differed from Never Participants in all characteristics, except postcode change. Women and people aged 60-69 years, those from higher SES and those who received InForm™ in round 1 were more likely to be Re-Participants in the second round.

## **Discussion**

In this study we identified socio-demographic and screening program variables associated with different patterns of participatory behaviour following two rounds of an organised, population-based screening program for CRC.

We propose a nomenclature that allows the identification after two rounds of invitations of population sub-groups with stable screening behaviour (Re-Participants and Never Participants), and changeable behaviour (Dropouts and Late Entrants) relative to first round participation status. We did not use the term 'relapse' to describe behaviour of second round non-participation following first round participation as this already has distinct meaning in the medical literature. In programs of more than two rounds the changeable category could be further sub-divided into groups where the change is sustained or unsubstituted.

It is important to examine participation patterns round by round to identify predictors of different behaviour patterns and to determine if particular sub-populations are more or less likely to demonstrate specific screening behaviours. Understanding the behaviour of people in screening programs, especially why they fail to participate or decline further screening after first participating (hence 'Dropout'), should allow the development of strategies

that target these behaviours and thus improve re-screening rates.

As one goal was to identify characteristics of those who declined to participate, it was important to identify characteristics associated with Never-Participants and Dropouts. Conversely, characteristics associated with late entry to a screening program could suggest strategies to apply to first round non-participants to improve second round participation.

Our analysis has shown that in the South Australian cohort offered 2 rounds of screening, participation was 51% in the first round and this rate was maintained in the second round. A program participation rate target of 70% was proposed for the NBCSP (AIHW, 2007) based on the assumption that at least 20-25% of the target population is unsuitable for FOBT-based screening alone because of their previous diagnostic history, recent testing or higher level of risk (BCSPMESC, 2005). Thus there is a considerable gap between actual participation rate and the target rate, indicating the need to identify strategies to improve participation in re-screening.

The re-screening rate in the NBCSP differs from the English Bowel Cancer Screening Program Pilot where second round participation fell significantly from 58.5% in the initial round to 51.9% in the second round. The difference may be partly due to the higher initial participation rate in the English Pilot (UKCCSPG, 2004) combined with the use across the UK programs of the less preferred guaiac FOBT (Cole et al., 2003).

The first and second round participant populations comprised of slightly different but overlapping populations because people who declined screening in round 2 but had previously participated in the Pilot (Dropouts) were replaced by an equivalent number of new participants from the group who had earlier declined screening (Late Entrants). This mirrors findings from the Scottish feasibility trials where Dropouts were also balanced by Late Entrants (Steele et al., 2009).

Reports on rates of re-participation in the literature are scarce and inconsistent, and vary depending on country and whether the data comes from randomised controlled trials, feasibility studies or full programs (Jansen, 1984; Kewenter et al., 1988; Hardcastle et al., 1996; Hart et al., 1997; Faivre et al., 1999; Mandel et al., 1999; Jorgenson et al., 2002; Weller et al., 2007; Lindholm et al., 2008; Steele et al., 2009). Some studies failed to invite first-round non-participants in subsequent rounds (Kronborg et al., 1989) although our results show that this would be unwise in organised programs because such people may become Late Entrants. The NBCSP data presented here are consistent with second round participation rates seen in feasibility trials of occult blood-based screening delivered by mail (von Euler-Chelpin et al., 2010).

Over time and increasing numbers of rounds of screening offers, individuals may move from one behavioural group to another as a result of a complex interaction of psychosocial factors or a consequence of diagnostic procedures and change in medical status. Understanding why people change behaviour, especially why they decline after first participating should aid development of strategies to keep people engaged in

screening.

Although data were available for only a modest set of variables, we identified particular characteristics that were associated with behaviours of interest. Our primary goal was to identify factors associated with dropping out. Multivariate analyses indicated that, relative to re-participation, dropping out was jointly associated with being female, being in the oldest age group, (70-74 years at first invitation), being from lower SES and having had a positive or inconclusive test result in the first round.

The relationship of age with FOBT-based CRC screening behaviour is complex and non-linear. Many groups, including our own (Cole et al., 2003; von Euler-Chelpin et al., 2010), have already reported that after a first screening offer targeted at a population aged 50-74, invitees aged 60-69 are most likely to participate, while those aged 50-59 and 70-74 are less likely to participate.

Results from this study show that, relative to Re-Participants, Dropouts were more likely to be 70-74 years of age, the oldest age band offered screening, consistent with previous findings (Thomas et al., 1995). Examination of Late Entrants revealed that invitees in the oldest age band are least likely to take up a second round invitation if they did not previously participate. These observations might be explained by the fact that the second offer in the NBCSP was made approximately 3 years after the first, and many who were in this age band at first offer would be approaching 80 years of age and may now have other health priorities. However, the association is consistent with literature that suggests that older people may experience difficulty adhering to health practices like medication compliance (Doggrell, 2010). These results highlight the fact that special efforts, perhaps through targeted invitations or reminders, should be used to encourage the older age group who have the highest risk for developing CRC to maintain participation in CRC screening.

The effect of gender on participation across the two rounds of screening was also complex. Although women are more likely to participate at an initial offer (Vernon, 1997; Cole et al., 2003; von-Euler-Chelpin et al., 2010) and comprised the majority of the Re-Participant group, men were more likely than women to re-participate if they had participated at the initial offer of screening. This finding confirms other research showing that men are more adherent than women in ongoing CRC screening (Gili et al., 2006; Sewetch et al., 2007; Fenton et al., 2010; Janda et al., 2010).

The association of re-participation with socioeconomic status was similar to that found after an initial offer (Farrands et al., 1984) and followed a linear trend, with people in the lower SES groups most likely to dropout in the second round of a screening program while those of higher SES were most likely to re-participate, consistent with previous reports (Neilson and Whynes, 1995; Weller et al., 2007; Ward et al., 2011) Also, people in the highest two SES groups were more likely to enter into the program at the second round if they had not participated previously. Higher SES invitees were more likely to have screened at least once in the program compared to those of lower SES. These observations together highlight the role of

socioeconomic status and inequality in CRC screening participation and re-participation.

Dropping out was also associated with being offered a different FOBT test type in the second round compared to the first, as well as with receiving an inconclusive result in the first round. This implies that participants wish for a stable and consistent program, and are discouraged by returning an inconclusive result, which could be seen by the participant as a consequence of an inferior screening program. A lower re-participation rate for people returning a positive test result was possibly due to having undergone follow-up colonoscopy and change in actual or perceived risk level. We analysed the results on a program basis rather than a health status basis as we were not able to ascertain who did proceed to colonoscopy; future studies need to define how much this contributes to non-participation in a program.

The strength of the research is that the population sample comprised all people in the target age range living within defined areas, identified from federal government health insurance enrolment record data (AIHW, 2007) so that there are unlikely to be sampling biases. Similarly, the NBCSP is organised by federal government which is likely to provide some reassurance as to the value of screening and the credibility of the screening program, potentially removing some variables that might impact on participation rates.

The inability to examine additional potential predictors of participation limits the findings of the study. It is possible that variables including language spoken at home, education, chronic ill health, marital status and mobility may all impact on ongoing participation in screening and future research should examine the influence of these variables.

Nonetheless, the identification of population sub-groups with different participatory behaviours allows targeted interventions aimed at improving re-participation in those sub-populations. It would be feasible to develop re-invitation letter formats that appeal specifically to those sub-groups that are more likely dropout, or to encourage those that did not participate in a first offer to enter the program later on. Research is needed to trial different letter formats to determine if targeted approaches are successful.

The descriptive framework is potentially applicable to any number of screening rounds, and was developed to identify sub-populations in ongoing screening programs that potentially could be offered targeted invitations to improve re-participation rates. It addresses change in behaviour as we consider that various factors such as personal circumstances and conflicting guidelines around the frequency of FOBT screening for faecal blood contribute to whether a person participates in consecutive offers. Categorising invitees according to sustained behaviour over multiple rounds of offers should minimise the influence of more temporary factors on participation and sub-group allocation.

In conclusion, we propose a simple descriptive framework CRC screening over multiple rounds based on stable or changing behaviour, and the concept of sustained change. We documented participation over 2 rounds of screening offers from Australia's NBCSP, applied the

descriptive framework to test its practicality and identified invitee characteristics that predict participatory behaviours of particular interest, especially the characteristics of those who failed to re-participate. Our research has demonstrated that age, gender and SES were all significant demographic correlates of participation in second round CRC screening in the NBCSP. To improve re-participation rates, re-invitation formats could incorporate different specific messages for particular sub-populations. This approach needs to be tested, either within the NBCSP or in smaller trials.

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