

Low priority main reason not to participate in a colorectal cancer screening program with a faecal occult blood test

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ABSTRACT

Background Compared with screening programs for breast and cervical cancer, reported participation rates for colorectal cancer (CRC) screening are low. The effectiveness of a screening program is strongly influenced by the participation rate. The aim of this study was to investigate the main reasons not to participate in a population-based, invitational CRC screening program.

Methods In the Dutch study program for CRC screening, a random selection of 20 623 persons were invited received a faecal occult blood test. Of the non-participants, 500 were randomly selected and contacted for a standardized telephone interview from November 2006 to May 2007 to document the main reason not to participate.

Results In total, 312 (62%) non-participants could be included for analysis. Most frequently, reported reasons for non-participation were time-related or priority-related (36%), including 'did not notice test in mailbox' (13%) and 'forgot' (8%). Other reasons were health-related issues, such as 'severe illness' (9%), or emotional reasons, such as 'family circumstances' (7%).

Conclusions The majority of the reported reasons not to participate reflect low priority for screening. Adding extra instructions and information, and addressing specific concerns through additional interventions should be considered to improve individual decision-making about participation in future CRC population-based screening programs.

Keywords Screening, cancer

Introduction

Several Western countries have initiated population-based screening programs for colorectal cancer (CRC). A challenge in screening for CRC is the relatively low participation rate compared with screening programs for breast or cervical cancer.^{1,2} Three studies have shown that high levels of knowledge are positively associated with participation and that lack of awareness is a common reason for declining screening.^{3–5}

Psychological research has shown associations between knowledge, the individual's perception of risk and preventive behaviour, such as attending screening.⁶ Previous surveys have shown that not only level of knowledge, but also anxiety and embarrassment can be associated with non-participation in a screening program.^{4,7} In these studies, an important reason for non-participation was that people

'forgot' to get screened or 'did not know they had to get screened'. However, these studies do not take into account whether the test was actually performed or if people had a hypothetical intention to get screened. This is important as literature has shown that screening behaviour cannot be solely predicted from just an intention to get screened.^{3–5,8}

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Since low participation rates limit the effectiveness of screening, it is important to understand the reasons for non-participation. If it results from a lack of awareness or problems in understanding the reasons for screening, population-based programs could consider changing their approach.

The aim of this study was to investigate the reasons not to participate in a population-based screening program for CRC with direct mailing of both information and a faecal occult blood test (FOBT).

Methods

Screening program

The study design of our screening program has been described in detail elsewhere.⁹ This pilot program was conducted to analyse and evaluate the feasibility of a nationwide screening program for CRC with FOBT in the Netherlands. A random representative of 20 623 individuals from the Dutch population were selected between 50 and 75 years was invited between May 2006 and February 2007. All invited subjects were randomized to receive either a 3-day guaiac-based FOBT or a 1-day immunochemical FOBT by direct mail (Figure 1 and Tables 1 and 2 for the baseline characteristics). The kit included an information leaflet and the FOBT. The primary messages highlighted in the leaflet were the screening program itself, the purpose, benefits and limitations of screening, the risk factors associated with CRC and instructions on how to use the FOBT. The leaflet was provided in the Dutch language only.

All invited subjects received a reminder 2 weeks after the initial invite. Invited subjects who did not respond by returning the FOBT within 3 months were defined to not have participated in the screening program (i.e. non-participants). The overall participation rate for the pilot study was 53% ($n = 10993$). From the group of 9630 non-participants, a total of 500 individuals with a listed telephone number were randomly selected.

The non-participants were contacted by one of two interviewers, with a maximum of three attempts. The interviews were conducted between November 2006 and May 2007, within 3–6 months after the initial invitation to the screening program. To optimize and structure the telephone survey, a standardized form was developed. The recipient was asked the main reason not to participate. Answers to the questions were recorded verbatim.

Statistical analysis

Reasons for non-participation were summarized by two independent researchers and independently classified into

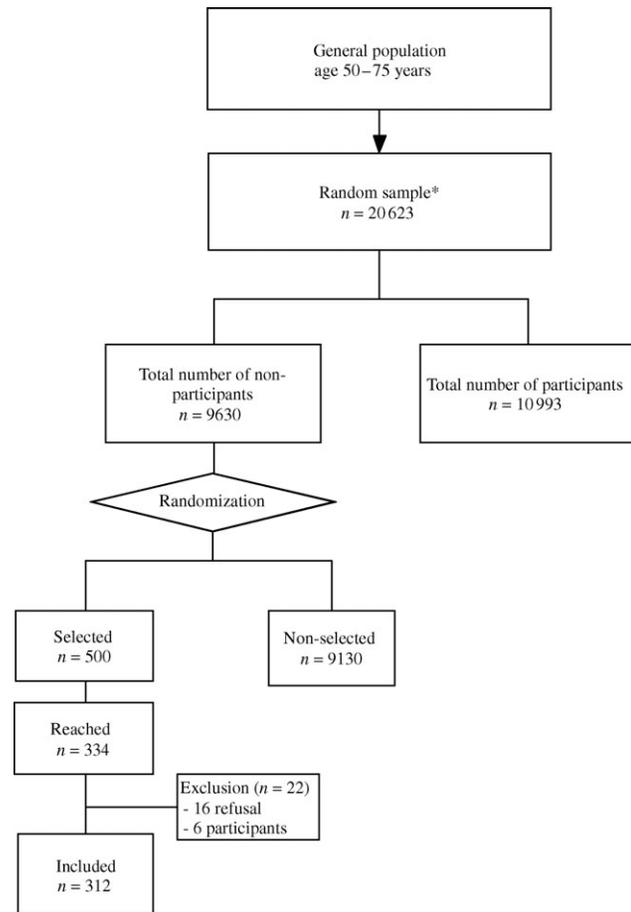


Fig. 1 Study design and sample collection. Asterisk denote that the sample was randomized to either receive a guaiac-based FOBT or an immunochemical FOBT, details reported elsewhere.⁸

Table 1 Characteristics of the reached and non-reached non-participants

	Selected non-participants <i>n</i> = 500		P-value
	Included (<i>n</i> = 312)	Non-included (<i>n</i> = 188)	
Gender			
Male	151 (48%)	89 (47%)	0.89
Female	161 (52%)	99 (53%)	
Age			
50–60 years	125 (40%)	132 (70%)	<0.005
60–75 years	187 (60%)	56 (30%)	
FOBT			
Guaiac-based 3-day FOBT	145 (46%)	109 (58%)	<0.005
Immunochemical 1-day FOBT	167 (54%)	79 (42%)	

Table 2 Characteristics of all participants, divided in to participants and non-participants, compared with the included non-responders

	<i>All invitees (n = 20 623) to the Dutch FOBT screening program</i>	<i>Participants n = 10 972</i>	<i>All non-participants* n = 9651</i>	<i>Included (n = 312) interviewed non-responders</i>
Gender				
Male	10 664 (52%)	4903 (45%)	5056 (52%)	151 (48%)
Female	9959 (48%)	6069 (55%)	4595 (48%)	161 (52%)
Age [†]				
50–60 years	10 285 (50%)	5306 (48%)	4979 (52%)	125 (40%)
60–75 years	10 184 (50%)	5626 (52%)	4558 (48%)	187 (60%)
FOBT				
Guaiac based 3-day FOBT	10 301 (50%)	4813 (44%)	5488 (57%)	145 (46%)
Immunochemical 1-day FOBT	10 322 (50%)	6159 (56%)	4163 (43%)	167 (54%)

*Five hundred individuals were selected from this group of non-responders for this study.

[†]Of 154 invitees no date of birth was available.

categories. Classification conflicts were resolved by consensus. Data were analysed using SPSS (v12.0.2). Differences between included and non-included non-participants were analysed and tested for significance using the Chi-square test. The frequencies of the reported reasons were compared across subgroups defined by age and sex. *P*-values of <0.05 were considered to indicate statistical significance.

Results

Of the, in total, 500 randomly selected non-participants, 334 (67%) were reached by telephone within three attempts (Figure 1). Twenty-two of them were contacted, but could not be analysed: 16 refused to participate in to the telephone interview and six others had already participated in the screening program by the time the individual was interviewed. The baseline characteristics of the 312 non-participants compared with the baseline characteristics of invitees divided into participants and non-participants are shown in Tables 1 and 2. The age of the non-participants included in our analysis was lower compared with the not included non-participants (63 years versus 70 years, *P* < 0.005).

The reported main reasons for non-participation are summarized in Table 3. The largest group of non-participants said they had not found the time to perform the FOBT for various reasons or said that the screening program had low priority (subgroup I, Table 3). The most frequently cited reason was that respondents could not recall having received an FOBT kit in their mailbox (*n* = 41, 13%) or had forgotten the FOBT kit (*n* = 24, 8%). Thirteen of the non-participants who had not returned the FOBT kit (*n* = 13, 4%) said they

intended to send back their FOBT after the telephone interview. No significant differences were observed in priority-related reasons between age groups under or over 60 years (*P* = 0.37) and both sexes (*P* = 0.50).

Other reasons for non-participation were health-related (subgroup II, Table 3). Thirty non-participants (10%) reported having a 'severe illness', including 13 individuals who were recently diagnosed with cancer, four of whom were diagnosed with CRC. Eight non-participants were hospitalized at the time of the invitation, one had severe co-morbidity from longstanding diabetes, and in three cases, the spouse reported a severe illness for their partners [psychiatric problems (*n* = 1) and Alzheimer's disease (*n* = 2)]. Other non-participants stated that they already had 'to go to the hospital too often' (*n* = 17; 5%). These people were monitored in an outpatient clinic for various reasons, including cardiac problems, diabetes and hyperthyroidism. On the other hand, 'feeling healthy' was also reported as reason to decline screening (*n* = 15; 5%). These individuals stated that if they had complaints, they would visit their general practitioner. No significant differences were observed between the age subgroups or the sexes.

Reasons for non-participation that were associated with the test were individuals who found the test was either 'too disgusting' or 'too difficult' to perform (*n* = 22, 7%) (subgroup III, Table 3). This group consisted of more non-participants who had received a Hemocult test (16) than who had received an OC-sensor.⁶ No significant differences were observed between the age subgroups or the sexes.

Poor health or death of family members was also reported as a reason to decline screening at this moment in time in 21 persons (7%).

Table 3 Overview of primary reasons for non-participants

Reached non-participants	312	100%
I. Time or priority related reason	112	35.8%
Did not notice the test in the mailbox	41	13.1%
Forgot	24	7.7%
Too busy	17	5.4%
On vacation	17	5.4%
Did not do it yet	13	4.2%
II. Health-related reason	89	28.5%
Other (severe) illness	30	9.6%
Already too often in the hospital	17	5.4%
Recent colonoscopy was performed	15	4.8%
Feeling healthy	15	4.8%
Complaints of rectal blood loss*	12	3.8%
III. Test-related reason	22	7.1%
Difficulty with performing the test	13	4.2%
Disgusted with test	9	2.9%
IV. Others	89	28.5%
Family circumstances	21	6.7%
Did not feel like it at the time	14	4.5%
Do not want to get screened	12	3.8%
Do not want not know if I have cancer	10	3.2%
Fear of cancer	9	2.9%
Language barrier [†]	6	1.9%
Against scientific research	4	1.3%
No guarantee to privacy	4	1.3%
Feeling too old	4	1.3%
Do not see use of screening	3	1.0%
Fatalism	2	0.6%

*The leaflet encouraged invitees not to participate in the case of 'rectal blood loss' in the last 3 months, but to consult their general practitioner for further investigation of these complaints.

[†]A language barrier was reported when the reached non-participant did not understand Dutch.

Discussion

Main findings of this study

This study revealed that the majority of reasons for non-participation were related to low priority for screening. This was despite the fact that an information leaflet was especially designed to accompany the FOBT. The screening program was designed to mimic the real population-based screening setting for implementation of nation wide screening in the near future. We believe these results are comparable with other FOBT screening situations in which an FOBT is offered by mail.^{10,11}

Second, in spite of our the fact that our information leaflet clearly stated that CRC is often not accompanied with

complaints until a late stage of the disease and that the purpose of screening is to detect early lesions in asymptomatic individuals, lack of knowledge may also be present in those who stated that their main reason for declining screening was having no complaints.

What is already known on this topic

Literature has shown that a common reason to decline screening is that individuals 'forgot' to take part, respectively, as high as 35%.⁷ We believe this effect is probably due to lack of priority or awareness and knowledge. Our concern is that lack of knowledge and low levels of awareness may interfere with being able to make an informed choice in screening.^{3-5,12} Furthermore, it has been argued that screening programs should not be evaluated based on their participation levels only. In respect to the subjects' autonomy, a person invited to a screening program should be able to make an informed decision to participate or decline, although measurement of informed choice is difficult.^{13,14}

What this study adds

This study revealed that the majority of reasons for non-participation were related to low priority, which is associated with lack of knowledge. Our study is the first to evaluate reasons for non-participation in an invitational screening program, rather than in a hypothetical situation. As hypothesized, 'direct mailing of the FOBT' lowers the percentage non-responders who stated they 'forgot' to perform the FOBT when compared with an intention to get screened setting as reported in literature, from 35% to 8%.⁷

Limitations of this study

There was a significant difference in age between the selected and the reached non-participants in our study. Relatively more elderly people were reached by phone. This effect could be explained by the fact that more telephone calls were conducted during office hours when younger individuals were still at work. This might have led to a form of selection bias and could explain the relatively high number of individuals reporting severe illness as reason for non-participation. Another potential limitation of this study is the possible discrepancy between the reported reason and the actual motive not to participate, as we had to rely on telephone questions rather than long in-depth interviews.

In conclusion, for the development of future screening programs, it should be considered to add extra instructions targeting specific concerns raised in the specific population. As a result of better guidance and education, those people invited to screening may be able to make a conscious

informed choice, eventually raising participation levels and the effectiveness of population-based screening for CRC.

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