CT-colonography in population-based colorectal cancer screening

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Chapter 8

Reasons for participation and non-participation in a colorectal cancer screening program by colonoscopy or CT-colonography: a randomised controlled trial

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Submitted
Abstract

Objective
The effectiveness of colorectal cancer (CRC) screening programs is affected by the initial participation rate. Reasons to accept or to decline a screening invitation could be based on erroneous assumptions. We documented reported reasons of (non-)participation in a randomised controlled trial comparing colonoscopy and CT-colonography.

Materials and methods
A group of 8,844 persons aged 50 to 75 years were randomly invited for CRC screening by colonoscopy (n=5,924) or CT-colonography (n=2,920). All invitees received a validated baseline questionnaire by postal mail with questions about the reasons for (non-)participation. Reasons to participate in screening could be indicated by checking one or more of 16 response options; non-participants could select from 18 (colonoscopy) or 20 (CT-colonography) response options. Invitees could also report other reasons, and were asked to indicate the most decisive reason.

Results
The baseline questionnaire was returned by 2,100 of 5,924 (35%) colonoscopy invitees and 1,189 of 2,920 (41%) CT-colonography invitees.

Reasons of participation: The most frequently cited reasons to accept screening were: ‘it allows early detection of precursor lesions’ (72% in the colonoscopy group and 68% in the CT-colonography group; p=0.04), ‘it allows early detection of CRC’ (60% versus 61%; p=0.77) and ‘I would like to contribute to science’ (63% versus 57%; p<0.05).

Reasons of non-participation: The most frequently cited reasons to decline screening were: ‘the examination strikes me as unpleasant’ (66% versus 30%; p<0.001), ‘the preparation required for the procedure strikes me as too inconvenient’ (34% versus 18%; p<0.001), ‘I do not have symptoms of CRC’ (23% versus 32%; p=0.01) and ‘no time/too much effort’ (14% versus 20%; p<0.05). In colonoscopy non-participants, the inconvenience of the procedure was less often cited
by invitees over 69 years (53% versus 66% overall; \( P=0.02 \)) while absence of symptoms was more often cited by elderly (36% versus 23% overall; \( P=0.01 \)). The most frequently reported decisive reason not to participate in colonoscopy screening was ‘the examination strikes me as unpleasant’ (33%); for CT-colonography screening this was ‘no time/too much effort’ (13%) and ‘I do not have any symptoms of CRC’ (13%).

Discussion
In colonoscopy and CT-colonography screening programs, the procedure itself is mentioned most frequently as a reason not to participate in screening, as well as the absence of symptoms. Future screening programs could tailor the information provided to screening invitees while respecting the principles of informed decision making and patient autonomy.
Introduction
Population screening for colorectal cancer (CRC) has been shown to reduce CRC-related mortality\(^1\)\(^2\). The American College of Gastroenterology (ACG) has recommended colonoscopy every 10 years, beginning at age 50, as the preferred strategy for screening of average risk individuals\(^3\). CT-colonography has been proposed as an alternative to colonoscopy in screening\(^3\). Although colonoscopy and CT-colonography are the most accurate methods to detect colorectal neoplasia, not all eligible individuals are willing to undergo screening by one of these procedures\(^4\)\(^5\). Patient autonomy should be respected in invitees' decision whether or not to participate in screening, but erroneous assumptions about screening may have an undesired effect on initial participation or future program adherence\(^6\). An improved understanding of the reasons to participate or not may be of help in the design of information leaflets and invitation letters, which can remove barriers to participation. Understanding the reasons of non-participation can provide information on such barriers. Previous studies have shown underutilization of CRC screening in certain age-, gender- and socioeconomic status (SES)-groups\(^7\). The main reasons to participate or not may vary between these groups, which would encourage the development of invitation strategies that are tailored to certain subgroups.

Within a randomised controlled trial comparing colonoscopy and CT-colonography in invitational population CRC screening we asked screening invitees to indicate their reasons for (non-)participation. We also asked respondents to cite the most decisive reason. In the analyses we stratified for age, gender and socioeconomic status.

Materials and methods

Study population
Between June 8, 2009 and August 16, 2010, 8,844 screening naïve individuals, aged 50 to 75 years, within the Amsterdam and Rotterdam region were randomly allocated 2:1 to an invitation for either colonoscopy screening (n=5,924) or CT-colonography screening (n=2,920). The protocol of this population-based screening pilot has been described in detail elsewhere\(^8\). The results on participation and diagnostic yield of this trial were published recently\(^9\). Invitees within a single household were allocated and invited to the same modality. Allocation was based on a minimization algorithm taking into account age (50-54; 55-59; 60-64; 65-69 and 70-74 years), gender (male/
female) and socioeconomic status (very low, low, average, high, and very high) according to data of Statistics Netherlands. Invitees could not opt for the alternative screening strategy. At the time of the trial, the Netherlands did not have a population-based CRC screening program. Ethical approval was obtained from the Dutch Health Council (2009/03WBO, The Hague, The Netherlands). The trial was registered in the Dutch trial register: NTR1829 (www.trialregister.nl).

Invitation procedure
All invitations were sent out by postal mail by the Comprehensive Cancer Centers in Amsterdam and Rotterdam. Invitees received a pre-announcement, two weeks before the invitation. With the invitation they also received a reply card and a leaflet with information on the CRC screening program in general, on benefits and risks of colonoscopy or CT-colonography, depending on the invitation, and on follow-up in case of a positive test result. We developed these information leaflets based on previous Dutch CRC screening pilots. In doing so we aimed at providing invitees with information about the CRC screening program and the screening procedures itself, in order to facilitate informed decision making on participation. The information leaflet encouraged invitees with symptoms suggestive for CRC, such as rectal blood loss and/or changed bowel habits to consult their general practitioner. Invitees who had a full colonic exam (complete colonoscopy, CT-colonography and/or double contrast barium enema) in the previous five years were excluded from the screening program, as were those planned for surveillance colonoscopy (personal history of CRC, colonic adenomas or inflammatory bowel disease) and patients with an end-stage disease. Further, in CT-colonography screening, respondents were also excluded when they had been exposed to ionizing radiation for research purposes within the previous 12 months and when they had hyperthyroidism or iodine contrast allergy.

Invitees had three options to respond to their invitation: by returning the reply card by postal mail, by calling the Comprehensive Cancer Center, or by sending an email message. With this, non-participants could also check one out of six options to indicate their reason for non-participation either on the reply card, by phone or by mail, depending on their response mode, ensuing from our encouragement not to participate in some circumstances (Table 1).

Those willing to participate in screening were invited for a prior consultation to receive further information on the screening procedure. At
this consultation, we also evaluated any contraindications. A reminder letter was sent to all non-respondents 4 weeks after the initial invitation.

**Table 1** Response options on reply card

- I have symptoms suggestive for CRC
- I have recently undergone a complete colonoscopy
- I have recently undergone a barium contrast enema
- I am coping with another illness
- Other reason, as follows
- I do not want to indicate a reason for non-participation

**Baseline questionnaire**

All invitees received a validated baseline questionnaire by postal mail, regardless of their response to the invitation, on which they could indicate reasons for participation or non-participation. This baseline questionnaire also contained questions on socio-demographic characteristics, such as educational level and income category. Invitees who indicated they would probably participate in screening received the questionnaire within four weeks before the screening procedure. They were asked to complete the questionnaire prior to the screening procedure and to return it by mail in a prepaid envelope. Invitees who declined or did not respond to the invitation received the same questionnaire four weeks after the initial invitation, together with the reminder letter. Non-participants were also asked to complete the questionnaire and to return it by mail in a pre-paid envelope. Eight weeks after the initial invitation - four weeks after receiving the questionnaire - non-participants were reminded by postal mail to complete and return the questionnaire, if necessary. Completed baseline questionnaires were scanned and responses were automatically transferred to a database.

**Reasons for participation**

Reasons to participate in screening could be indicated by checking one or more of 16 response options. Invitees who intended to be screened could also specify “other reasons.” They were also asked to indicate their most decisive reason to participate.

**Reasons for non-participation**

Colonoscopy and CT-colonography invitees who intended to decline
screening could check one or more of 18 and 20 response options, respectively, to indicate their reasons to not participate in screening. The CT-colonography group was provided with two additional response options than the colonoscopy group, because of the triage character of CT-colonography. Intending non-participants could also specify “other reasons” and they were asked to report their most decisive reason for non-participation.

Statistical analysis
We assessed reasons for participation and non-participation among intending participants and non-participants in the colonoscopy group and in the CT-colonography group. Invitees were classified as intending participants or intending non-participants based on the response to the corresponding questions in the questionnaire. Reasons for participation were counted and proportions were compared between invitees who intended to participate in colonoscopy or CT-colonography screening. Reasons for non-participation were evaluated and compared between both arms among all invitees who intended to decline screening. Relative frequencies for cited reasons were compared between groups using $\chi^2$-statistics. We evaluated differences in the most cited reasons in both programs between subgroups using univariable logistic regression analysis. SPSS version 18.0 for Windows (SPSS, Chicago, Ill) was used to perform all statistical tests.

Results
Figure 1 shows the study flow. The invitation was responded to by reply card, by phone or by email message by 3,983 of 5,924 (67%) colonoscopy invitees and 2,056 of 2,920 (70%) CT-colonography invitees. Of these, 2,707 invitees (68%) in the colonoscopy group and 1,074 invitees (52%) in the CT-colonography group declined the invitation. Almost half of them did not indicate a reason for non-participation in both arms. A full colonic examination in the previous five years was mentioned as a reason for non-participation by 17% in the colonoscopy arm and 19% in the CT-colonography arm.

The baseline questionnaire was returned by 2,100 of 5,924 (35%) colonoscopy invitees and 1,189 of 2,920 (41%) CT-colonography invitees. At the moment of completing the questionnaire, reasons for participation were indicated by 1,328 colonoscopy invitees and 988 CT-colonography invitees ((intending) participants). Reasons for non-participation were selected by 772 colonoscopy invitees and 201 CT-colonography invitees ((intending) non-participants). Background demographics are summarised in Table 2.
CT-colonography in population-based colorectal cancer screening

Figure 1 Study Flow

8,844 invitees

5,924 colonoscopy invitees

1,941 (33%) not returned reply card
3,983 (67%) returned reply card

2,707 (68%) indicated to decline screening:
- 35 (1%) symptoms CRC
- 398 (15%) previous colonoscopy
- 44 (2%) previous barium enema
- 141 (5%) severe disease
- 784 (29%) other reason
- 1,249 (45%) not willing to cite reason
- 56 (2%) died/moved

2,100 (35%) completed baseline questionnaire

772 (13%) intending non-participants indicated reasons to decline screening
1,328 (22%) intending participants indicated reasons to participate

2,920 CT-colonography invitees

2,056 (70%) returned reply card
864 (30%) not returned reply card

1,074 (52%) indicated to decline screening:
- 10 (1%) symptoms CRC
- 185 (17%) previous colonoscopy
- 23 (2%) previous barium enema
- 48 (5%) severe disease
- 279 (21%) other reason
- 510 (48%) not willing to cite reason
- 19 (2%) died/moved

1,189 (41%) completed baseline questionnaire

988 (34%) intending participants indicated reasons to participate
201 (7%) intending non-participants indicated reasons to decline screening
A total number of 1,191 of 1,328 (90%) intending participants in the colonoscopy arm and 930 of 988 (94%) intending participants in the CT-colonography arm actually underwent the screening procedure. Almost all intending non-participants kept to the decision to decline screening; in both arms only one invitee decided to participate afterwards. Two invitees (one in both arms) withdrew consent after participation.

Table 2 Respondents’ baseline characteristics

<table>
<thead>
<tr>
<th>Respondents (n)</th>
<th>Intending participants</th>
<th>Intending non-participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Colonoscopy</td>
<td>CT-colonography</td>
</tr>
<tr>
<td>Age in years (median, IQR)</td>
<td>60 (55-65)</td>
<td>60 (55-65)</td>
</tr>
<tr>
<td>Gender (% male)</td>
<td>673 (51%)</td>
<td>493 (51%)</td>
</tr>
<tr>
<td>Socioeconomic status (n, %)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Very low</td>
<td>196 (15%)</td>
<td>176 (18%)</td>
</tr>
<tr>
<td>- Low</td>
<td>265 (20%)</td>
<td>186 (19%)</td>
</tr>
<tr>
<td>- Average</td>
<td>275 (21%)</td>
<td>187 (19%)</td>
</tr>
<tr>
<td>- High</td>
<td>260 (20%)</td>
<td>228 (24%)</td>
</tr>
<tr>
<td>- Very high</td>
<td>314 (24%)</td>
<td>191 (20%)</td>
</tr>
<tr>
<td>Ethnicity (n, %)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Caucasian</td>
<td>1,226 (94%)</td>
<td>924 (94%)</td>
</tr>
<tr>
<td>Married/lived together (%)</td>
<td>1,140 (86%)</td>
<td>835 (85%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Elementary (%)</td>
<td>63 (5%)</td>
<td>55 (6%)</td>
</tr>
<tr>
<td>- Secondary (%)</td>
<td>889 (67%)</td>
<td>591 (61%)</td>
</tr>
<tr>
<td>- Tertiary and postgraduate (%)</td>
<td>336 (25%)</td>
<td>304 (31%)</td>
</tr>
</tbody>
</table>

As not all respondents completed the questions on their marital status, education and ethnicity, the percentages mentioned for these items are not based on the total number of respondents, but on the total number of participants and non-participants who answered those questions.

Reasons for participation

Figure 2 summarises cited reasons for participation in the baseline questionnaire in both arms. The dominant reason to participate in screening was because of the early detection of colorectal polyps, more often cited by colonoscopy participants than by CT-colonography participants (72% versus 68%). A large proportion of participants in both arms selected the early detection of CRC (60% versus 61%) and obtaining certainty of the presence or absence of CRC (55% versus 50%) as a reason to participate in screening.
Figure 2 Reasons for participation in screening

- It allows early detection of precursor lesions: 68% (p=0.04)
- I would like to contribute to science: 57% (p=0.047)
- It allows early detection of colorectal cancer: 60% (p=0.77)
- I want to obtain certainty of my risk for colorectal cancer: 54% (p=0.08)
- I want to pay attention to my health: 51% (p=0.001)
- I will receive a medical check-up if I participate: 50% (p=0.24)
- I want to be in control of my health: 24% (p=0.83)
- By participating I reduce my risk of colorectal cancer related death: 24% (p=0.09)
- By participating I reduce my risk of having invasive surgery later in life: 23% (p=0.90)
- By participating I reduce my risk of colorectal cancer later in life: 19% (p<0.001)
- Because of colorectal cancer incidence among friends: 16% (p=0.11)
- Partner, relatives and/or friends thought I should participate: 11% (p=0.69)
- I have symptoms suggestive for colorectal cancer: 6% (p=0.35)
- I find participation interesting: 7% (p=0.67)
- I am afraid I may have colorectal cancer: 2% (p=0.29)
- Other reasons: 6% (p=0.15)
The willingness to contribute to science was more often cited among colonoscopy than CT-colonography participants (63% versus 57%). CT-colonography participants cited paying attention to own health more often than colonoscopy participants (58% versus 51%).

The preventive character of the screening test (early detection of colorectal polyps and CRC) was cited as most decisive reason to participate in both screening programs (Table 3). A total of 163 (14%) intending colonoscopy participants and 96 (12%) intending CT-colonography participants were not or only a little certain on their decision to participate in screening.

**Table 3** Most decisive reason to participate in screening

<table>
<thead>
<tr>
<th>Reason</th>
<th>Colonoscopy</th>
<th>CT-colonography</th>
</tr>
</thead>
<tbody>
<tr>
<td>It allows early detection of CRC</td>
<td>272 (21%)</td>
<td>215 (22%)</td>
</tr>
<tr>
<td>It allows early detection of precursor lesions</td>
<td>260 (20%)</td>
<td>171 (18%)</td>
</tr>
<tr>
<td>I want to obtain certainty of my risk for CRC</td>
<td>183 (14%)</td>
<td>118 (12%)</td>
</tr>
<tr>
<td>I will receive a medical check-up if I participate</td>
<td>118 (9%)</td>
<td>122 (13%)</td>
</tr>
<tr>
<td>I want to pay attention to my health</td>
<td>96 (7%)</td>
<td>105 (11%)</td>
</tr>
<tr>
<td>I would like to contribute to science</td>
<td>120 (9%)</td>
<td>93 (10%)</td>
</tr>
</tbody>
</table>

**Reasons for non-participation**

Figure 3 summarises the cited reasons to decline the invitation. The majority of colonoscopy non-participants cited the expected inconvenience of the examination as reason not to participate in screening, more often than CT-colonography non-participants (66% versus 30%). Also the expected inconvenience of the preparation was more often cited among colonoscopy non-participants compared to CT-colonography non-participants (34% versus 18%). Absence of symptoms was cited in both programs as a reason to decline screening but more often in the CT-colonography group than in the colonoscopy group (32% versus 23%). CT-colonography non-participants more often cited lack of time (20% versus 14%).

The most frequently reported decisive reason to decline colonoscopy screening was the inconvenience of the examination (33%); for CT-colonography screening this was lack of time (13%) and absence of symptoms (13%)(Table 4). Two out of three colonoscopy non-participants (68%) were rather or very certain on their decision to decline screening compared to 71% of CT-colonography non-participants.
**Figure 3 Reasons for non-participation in screening**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Coloscopy</th>
<th>CT-colonography</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>The examination strikes me as unpleasant</td>
<td>30%</td>
<td>34%</td>
<td>p&lt;0.001</td>
</tr>
<tr>
<td>The preparation required for the procedure strikes me as too inconvenient</td>
<td>18%</td>
<td>23%</td>
<td>p&lt;0.001</td>
</tr>
<tr>
<td>I have not developed any symptoms and therefore deem an examination unnecessary</td>
<td>23%</td>
<td>32%</td>
<td>p=0.12</td>
</tr>
<tr>
<td>I can unsufficiently assess the consequences of participation</td>
<td>21%</td>
<td>20%</td>
<td>p=0.89</td>
</tr>
<tr>
<td>I believe the risks related to the examination outweigh the benefits</td>
<td>11%</td>
<td>19%</td>
<td>p=0.017</td>
</tr>
<tr>
<td>No time / too much effort</td>
<td>14%</td>
<td>20%</td>
<td>p=0.043</td>
</tr>
<tr>
<td>I am afraid I will feel embarrassed during the examination</td>
<td>11%</td>
<td>5%</td>
<td>p=0.41</td>
</tr>
<tr>
<td>I am coping with another illness / family problems</td>
<td>6%</td>
<td>7%</td>
<td>p=0.42</td>
</tr>
<tr>
<td>I believe the probability of something being detected is small</td>
<td>7%</td>
<td>9%</td>
<td>p=0.06</td>
</tr>
<tr>
<td>I have recently undergone a full colonic examination</td>
<td>5%</td>
<td>5%</td>
<td>p=0.44</td>
</tr>
<tr>
<td>Others have discouraged me to participate</td>
<td>5%</td>
<td>5%</td>
<td>p=0.79</td>
</tr>
<tr>
<td>I would rather not know whether I have CRC, I will find out once symptoms start</td>
<td>9%</td>
<td>9%</td>
<td>p=0.014</td>
</tr>
<tr>
<td>I lack trust in the examination</td>
<td>4%</td>
<td>3%</td>
<td>p=0.38</td>
</tr>
<tr>
<td>I am afraid to be diagnosed with cancer</td>
<td>3%</td>
<td>6%</td>
<td>p=0.06</td>
</tr>
<tr>
<td>Information in the leaflet is not sufficiently clear to me</td>
<td>2%</td>
<td>2%</td>
<td>p=0.67</td>
</tr>
<tr>
<td>I have blood in my stool</td>
<td>1%</td>
<td>1%</td>
<td>p=0.57</td>
</tr>
<tr>
<td>My defecation pattern has changed over the last 3 months</td>
<td>1%</td>
<td>3%</td>
<td>N/A</td>
</tr>
<tr>
<td>I would rather not undergo a follow-up colonoscopy</td>
<td>8%</td>
<td>N/A</td>
<td>p= N/A</td>
</tr>
<tr>
<td>I prefer a primary colonoscopy instead of a primary CT-colonography</td>
<td>23%</td>
<td>29%</td>
<td>p=0.009</td>
</tr>
<tr>
<td>Other reason</td>
<td>N/A</td>
<td>N/A</td>
<td>p= N/A</td>
</tr>
</tbody>
</table>
Subgroup analysis: gender, age and SES

In each age group of colonoscopy non-participants, the expected inconvenience of the examination was often mentioned as a reason to decline the invitation, yet the proportion varied significantly between age groups (p=0.018); it was cited less often in the highest age group (overall: 66%; 70 to 74 years: 53%). The number of non-participants referring to absence of symptoms also varied between age groups (p=0.011); this was cited more often in the highest age group (overall: 23%; 70 to 74 years: 36%). Reasons for non-participation did not vary among SES-groups or between males and females. For CT-colonography, no significant variations were observed among age or SES-groups or between males and females.

Table 4 Most decisive reason to decline screening

<table>
<thead>
<tr>
<th>Reason</th>
<th>Colonoscopy</th>
<th>CT-colonography</th>
</tr>
</thead>
<tbody>
<tr>
<td>The examination strikes me as unpleasant</td>
<td>256 (33%)</td>
<td>14 (7%)</td>
</tr>
<tr>
<td>No time / too much effort</td>
<td>39 (5%)</td>
<td>25 (13%)</td>
</tr>
<tr>
<td>I have not developed any symptoms and therefore deem an examination unnecessary</td>
<td>46 (6%)</td>
<td>25 (13%)</td>
</tr>
<tr>
<td>I can insufficiently assess the consequences of participation</td>
<td>46 (6%)</td>
<td>13 (7%)</td>
</tr>
<tr>
<td>I am coping with another illness / family problems</td>
<td>27 (4%)</td>
<td>13 (7%)</td>
</tr>
<tr>
<td>I believe the risks related to the examination outweigh the benefits</td>
<td>55 (7%)</td>
<td>6 (3%)</td>
</tr>
<tr>
<td>The preparation required for the procedure strikes me as too inconvenient</td>
<td>42 (5%)</td>
<td>8 (4%)</td>
</tr>
</tbody>
</table>

Discussion

Early detection of CRC and finding precursor lesions were the dominant reasons to accept the invitation for colonoscopy and CT-colonography screening. The expected burden of the bowel preparation and the procedure itself were the most frequently reported reasons to decline colonoscopy screening. A large proportion of CT-colonography non-participants reported a low priority to participate in screening or felt that participation is unnecessary in absence of symptoms.

Participants in this study had been randomly invited for population-based screening for CRC using either colonoscopy or CT-colonography. In both programs, a large number of invitees who filled in reasons for participation also underwent the screening test (90% and 94%). Further, almost all invitees
who filled in reasons for non-participation kept to their decision to decline screening. The response rate itself was limited (35% and 41%), though higher than in some other screening program\textsuperscript{14}. We have tried to improve response rates by sending reminders, but partial response is hard to avoid in non-participation studies\textsuperscript{14,15}. A lower proportion of CT-colonography invitees than colonoscopy invitees filled in reasons for non-participation. This may be a result of the higher actual participation rate in CT-colonography screening (34% versus 22%), a difference that should be kept in mind when interpreting the results\textsuperscript{9}.

Our baseline questionnaire had been previously piloted in other screening programs\textsuperscript{11,12}. The reported reasons for participation and non-participation may have been influenced by social desirability considerations. We solicited reasons for participation and non-participation by offering fixed response options, although respondents also could specify other reasons. We here reported reasons for participation and non-participation of intending participants and non-participants, close to the point of decision making, not the actual participants. A total of 138 invitees in the colonoscopy group and 59 invitees in the CT-colonography group reconsidered their decision after completing the questionnaire. It is very well possible that the arguments for considering participation evolve over time, and even change after the decision has been made.

The results of this study are to some extent reassuring for those developing screening programs. A CRC-mortality reduction in screening is mainly achieved by the early detection of CRC or its precursor lesions\textsuperscript{1,2,16}. This is well understood by the participants, as the benefits of the early detection of CRC or precursor lesions was most frequently cited as a reason to participate in screening, in both trial arms. In lung and prostate cancer screening, four out of five screening participants expected to have an advantage of early detection of cancer\textsuperscript{14,15}.

A contribution to science was frequently cited as reason to participate (63% and 57%), although cited as the most decisive reason by only 10% of participants in both arms. The latter suggest this form of altruism may have been reported because of its socially desirable character. This is supported by findings from another study reporting on benefits of participation in a screening colonoscopy research study\textsuperscript{17}. After intensively interviewing a selected group of colonoscopy screening participants in a one year period, participants reported that internal benefit being the greatest benefit they received. Participation because of external benefit - helping others and
sharing information with others - was only reported by 11%. It would be interesting to form focus groups of screening participants and to follow them during a longer period to evaluate changes in reported reasons for (non-) participation. Possibly, external reasons (e.g. contribution to science) may be reported less frequently.

A larger proportion of CT-colonography than colonoscopy non-participants mentioned time-related or priority-related reasons to decline the invitation to screening. In FOBT screening, this argument is more frequently cited among non-participants. Both colonoscopy and CT-colonography screening take more time and effort than FOBT-screening, where the FOBT can be returned by mail. One may have expected that colonoscopy and CT-colonography non-participants would have cited this reason more often. Likely, the aversion to CT-colonography and especially to colonoscopy was caused by the expected burden, more than by time-investment.

For 66% of colonoscopy and 30% of CT-colonography non-participants, the anticipated inconvenience of the examination itself was one of the reasons to decline screening. This shows that the screening technique itself puts up barriers to participate in screening. This differs from CRC screening using FOBT, where only 7% cited test related reasons as reason to decline screening. In lung cancer and prostate cancer screening, one out of five non-participants cited the screening technique as a barrier to participate in screening. This indicates that full colonic exams, like colonoscopy and to a lesser degree CT-colonography, are felt to be too burdensome to be used in screening. Efforts should be made to reduce the anticipated burden of colonoscopy and CT-colonography. This could include reducing the amount of fluid intake, needed for the bowel preparation.

Other findings may be reason for concern in developing CRC screening programs. A larger proportion of CT-colonography than colonoscopy non-participants cited the absence of symptoms as reason to decline screening: 32% versus 23%. With both screening techniques, this proportion is higher than in lung cancer screening (20%), but lower than in prostate cancer screening (57%). We feel these findings deserve further attention in future campaigns and information leaflets. Such initiatives and products should emphasize that screening is designed for individuals who do not have complaints and that most large polyps and CRCs do not cause symptoms. On the other hand, 6% to 7% of participants in both programs cited having complaints as reason to participate in screening which is remarkably low compared to lung cancer (13%) and prostate cancer screening programs.
(25%). Possibly, knowledge about screening is higher among participants than in non-participants, a finding previously reported in other screening studies\textsuperscript{14,20}.

We conclude from this questionnaire study performed within a randomised controlled trial that the expected burden of both colonoscopy and CT-colonography screening put up barriers to participate in these programs. In addition, a large proportion of CT-colonography non-participants felt they should not participate in absence of symptoms. Patient autonomy should be respected in the decision to participate or not in screening, but future education programs should more convincingly point out that not having colorectal complaints does not rule out the presence of CRC or precursor lesions.
References


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