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What influences the decision to participate in colorectal cancer screening with faecal occult blood testing and sigmoidoscopy?

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Abstract ***Introduction:*** Uptake is an important determinant of the effectiveness of population-based screening. Uptake of colorectal cancer (CRC) screening generally remains suboptimal.
Aim: To determine factors influencing the decision whether to participate or not among individuals invited for faecal occult blood test (FOBT) or flexible sigmoidoscopy (FS) screening.
Methods: A questionnaire was sent to a stratified random sample of individuals aged 50–74, previously invited for a randomised CRC screening trial offering FOBT or FS, and a reference group from the same population not previously invited (screening naïve group). The questionnaire assessed reasons for (non)-participation, individuals' characteristics associated with participation, knowledge, attitudes and level of informed choice.
Results: The response rate was 75% ($n = 341/452$) for CRC screening participants, 21% ($n = 676/3212$) for non-participants and 38% ($n = 192/500$) for screening-naïve individuals. The main reasons for FOBT and FS participation were acquiring certainty about CRC presence and possible early CRC detection. Anticipated regret and positive attitudes towards CRC screening were strong predictors of actual participation and intention to participate in a next round. The main reason for non-participation in FOBT screening was lack of abdominal complaints. Non-participation in FS screening was additionally influenced by worries about burden. Eighty-one percent of participants and 12% of non-participants made an informed choice on participation.

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Conclusion: Only 12% of non-participants made an informed choice not to participate. These results imply that governments and/or organizations offering screening should focus on adequately informing and educating target populations about the harms and benefits of CRC screening. This may impact uptake of CRC screening.

1. Introduction

Colorectal cancer (CRC) is an important health problem in the Western world.[1] CRC screening is effective in reducing CRC-related mortality,[2–6] and therefore widely recommended.[7–10] CRC screening through various types of faecal occult blood tests (FOBTs) primarily aims at the early detection of CRC, whereas endoscopic examinations (flexible sigmoidoscopy (FS), colonoscopy) are effective for both early detection of CRC and removal of premalignant lesions.

Uptake is an important determinant of the effectiveness of population screening programmes on a population level. In many countries, the consistent uptake of CRC screening, both of primary as well as repeat screening, has remained suboptimal.[11] Furthermore, uptake of endoscopic screening is generally inferior to FOBT screening.[12–14] Hence, increasing uptake of CRC screening is vital for reducing CRC related mortality.[15] Uptake is influenced by test-related factors (e.g. burden of the test, type of test (for FOBTs)), organizational factors (e.g. preannouncements/reminders, method of invitation and ability to perform the test at home), and subject-related factors (e.g. demographics, barriers (e.g. time-requirements), psychosocial factors including knowledge and awareness of CRC and CRC screening, attitudes towards it and perceived susceptibility).

While increasing CRC screening uptake is an important target, people make an autonomous decision on participation after weighting the pros and cons of screening.[16] The consistency between an invitees' attitudes and subsequent screening behaviour is an important marker for success of CRC screening programmes.[17] It is therefore imperative to reveal the reasons for participation and non-participation. Especially reasons that may be modifiable (e.g. organizational factors, perceived barriers and lack of knowledge) and require action, while others should be respected (well-informed decision on (non-) participation).

The aim of our study is to determine factors influencing participation and non-participation among individuals invited for CRC screening within a randomised trial comparing FOBT and FS screening. A reference group of screen naïve individuals was included. Furthermore, we evaluated whether the decision (not) to participate was well informed.

2. Materials and methods

2.1. Study population

Between March 2009 and December 2010, a questionnaire was sent to individuals previously invited for a randomised CRC screening trial and to a reference group of individuals not previously invited for CRC screening. Within this CRC screening trial, average risk individuals aged 50–74 years, randomly selected from population registries, had been randomised 1:1:1 and invited to participate in guaiac-based FOBT (gFOBT), faecal immunochemical test (FIT) or FS screening.[13] All FIT invitees were invited for a next (second) screening round.[18] Importantly, individuals who declined FS screening subsequently received an invitation for FIT screening.[19] The study protocols are described in detail elsewhere.[13,18,19] The socio-economic status (SES) was based on the data of Statistics Netherlands (www.cbs.nl), providing average SES per postal code area, each representing small neighbourhoods.

From the participants and non-participants in all screening arms of the trial, a random sample stratified for sex and SES was drawn to ensure sufficient data from both genders and all socio-economic classes. The questionnaire was sent to (1) participants of FOBT screening ('FOBT participants'); (2) non-participants of FOBT screening ('FOBT non-participants'); (3) participants of FS screening ('FS participants'); (4) non-participants of FS screening who did attend subsequent FIT screening ('Declined FS, accepted FOBT') and (5) non-participants of FS screening who also declined the subsequent FIT screening invitation ('Declined both FS and FOBT'); (Fig. 1). The reference group consisted of 500 screening naïve individuals ('Screening naive'), randomly selected from the same target-population, and also stratified for sex and SES.

2.2. Invitation of subjects

Subjects received a preannouncement by mail, including a reply card that could be returned if individuals did not want to receive the questionnaire. Two weeks later, a questionnaire with a postage-paid self-addressed return envelope and an information brochure with general and background information about CRC and CRC screening were sent. All non-respondents received a reminder after 4 weeks, this time interval was chosen