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a systematic review
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Published in:
Public Health

DOI:
10.1016/j.puhe.2020.10.025

Publication date:
2021

Document version:
Accepted manuscript

Document license:
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Citation for published version (APA):

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Factors affecting patient adherence to publicly funded colorectal cancer screening programs: a systematic review

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Abstract (250 words)

Background: Colorectal cancer (CRC) is the third most common cancer. Many countries in Europe have already implemented systematic screening programmes according to the recommendations by the European Union. The impact of screening is highly dependent on participation rates.

Objectives: To identify barriers, facilitators and modifiers to participation in systematised, stool sample based, publicly financed CRC screening programs.

Methods: A systematic search in PubMed, Embase, MEDLINE, CINAHL, Cochrane. CENTRAL, Google Scholar and PsycINFO was undertaken. We included both qualitative and quantitative studies reporting on barriers and facilitators (excluding sociodemographic variables) to participation in stool sample based CRC screening. Barriers and facilitators to participation were summarised and analysed.

Results: The inclusion criteria were met in 21 studies. Reported barriers and facilitators were categorised into the following seven themes (examples): Psychology (fear of cancer), religion (believing cancer is the will of Good), logistics (not knowing how to conduct the test), health-related factors (mental health), knowledge and awareness (lack of knowledge about the test), role of the general practitioner (being supported in taking the test by the general practitioner), and environmental (knowing someone who has participated in a screening program). Six studies reported that non-participation was not due to a negative attitude towards screening for CRC.

Conclusion: Many barriers to screening were found. It is important to work with peoples’ fear of screening. Moreover, this review suggests that it might be possible to increase participation rates, if the population-wide awareness and knowledge of potential health benefits of CRC screening are increased and proper logistical support is provided.

Keywords: Colorectal cancer; screening; stool sample; barriers; review; mixed methods
Background

Colorectal cancer (CRC) is the third most common cancer.[1] Already in 2003, the European Union issued recommendations to implement national screening programs (SP) for CRC. In 2015, 20 out of the 28 members of the European Union had pilots, ongoing rollouts or completed rollouts of SP for CRC.[2] The preliminary results from SP in the United Kingdom, The Netherlands and Denmark are promising when it comes to early detection of CRC, a more favourable postoperative outcome and reduced mortality.[3, 4]

SP differs with regard to organisation and primary screening tools, which include immunochemical faecal occult blood test (iFOBT), guaiac faecal occult blood test (gFOBT), flexible sigmoidoscopy, colonoscopy and CT colonography. These differences make SP hard to compare across centres and countries.[5] However, the iFOBT has become the most widespread screening tool, because of higher sensitivity, minimal invasiveness and easier applicability for the participants.[6, 7]

The efficiency of the SP depends on a high participation rate. With reported participation rates differing between 26% and 73%, it is not sufficiently understood why a high fraction of the invited population does not participate and if anything can be done to facilitate participation.[4, 8] Studies suggest that short education, low income and non-Western ethnicity are associated with lower participation rates.[9] There is inconsistency regarding the impact of sex on participation.[10–12] A qualitative systematic review and meta-study synthesis found awareness to be an important modifying factor. The barriers were associated with fear, fatalism, aversion and culture.[13] As the review included all kinds of screening tools, the conclusions had to be interpreted within the context of the procedures in each SP. As example, fear of physical discomfort could be a barrier for screening with primary sigmoidoscopy or colonoscopy contrary to screening based on stool sampling, as this does not involve the same physical discomfort.[14]

Both iFOBT and gFOBT are stool based screening tools, which are easy to use by laypersons at home making them ideal for screening. The iFOBT only requires one stool sample and no dietary restrictions, whereas the gFOBT requires three stool samples and some dietary restrictions. Both tests fulfil the criteria for screening recommended by the Council of the EU for men and women aged 50–74 years.[15]

The aim of this review was to investigate facilitators, barriers and modifiers to participation in systematised, stool sample based and publicly funded SP for CRC.

Methods
This systematic review was conducted in accordance with the PRISMA guidelines[16] and the protocol has been published on Prospero (CRD42018092850).

Search Strategy
PubMed, Embase, MEDLINE, CINAHL, Cochrane CENTRAL and PsycINFO were systematically searched for literature investigating why people do not participate in SP for CRC. Moreover, a search of grey literature was performed with Google Scholar. A broad and high sensitivity search was conducted according to the recommendations of the Cochrane Collaborations Handbook.[17] The search included studies published since the commencement of the respective databases until March 5th, 2018. No limitation was set on study design or language. The search strategy had a combination of synonyms of the keywords including “colorectal cancer”, “screening”, “faecal immunochemical test”, “adherence” and “participation”. Search strategy and filters were modified for each database. Reference lists of the included articles were screened for additional relevant articles.

Study Selection
We included both qualitative and quantitative original studies investigating reasons for non-participation in systematised SP for CRC conducted with faecal occult blood test (FOBT). Included studies were examined for eligibility that required a full text in English, French, German or Danish. As the population had to be asymptomatic and in average risk of CRC, articles reporting on screening of high-risk subjects were excluded. To ensure comparability between studies, studies were only included if screening was performed using iFOBT or gFOBT. The screening had to be systematic, implying a specific program within a well-defined screening population consisting of the entire defined age group of the target area. All articles based on opportunistic SPs were thus excluded. Articles reporting on age groups below 40 years or above 80 years were excluded to improve homogeneity of the populations. We excluded articles investigating only the effect of socioeconomic factors on SP participation rates, because these have already been investigated thoroughly. Moreover, we excluded studies implementing and evaluating specific interventions implemented to increase participation rates in SP, because this subject was already well described in the literature.[14, 18–22]

After publication of the protocol, two more inclusion criteria were added to make studies more comparable. We chose to only include studies where systematised, stool sample based,
publicly funded SP were reported. In addition, we chose to exclude studies evaluating interventions aiming at increasing rates of participation.

Data Collection

The full texts of the included studies were independently reviewed by two authors (JD and LJM). An extraction template was made, and data were collected on demography, study type and the mode of screening.

Screening barriers and facilitators were extracted from all studies. We defined barrier as reason for non-participation and facilitator as reasons enhancing the likelihood of participation. For the qualitative studies, all qualitative data describing potential barriers and facilitators reported by the participants were written into a template. For the quantitative studies, factors significantly associated with (non-) participation and factors reported as important for participation were entered into a template. “However, we excluded sociodemographic variables (e.g. age, gender, income, ethnicity, occupation and education) associated with (non)-participation from the analysis. We did this for the following reasons. Firstly, the association between sociodemographic variables and participation in screening has been investigated many times before. We had therefore chosen not to include studies exclusively investigating these variables (see inclusion criteria), and thus, we considered it more correct to exclude these variables all together. Second, we were interested in reasons for non-participation. Therefore, we considered it important with a mixed methods approach to the review that included both quantitative and qualitative results. Sociodemographic variables are rarely factors for non-participation in a qualitative study (e.g. being a male is not a reason for non-participation).”

Study methodological quality was systematically accessed using the Critical Appraisal Skills Program tools for qualitative (10 items) and quantitative (11 items) studies. [23, 24] Quality correlated with the rate of correctly answered questions in the manuscript.

Analysis

The analysis was guided by the framework published by Harden et al. [25] The included studies were first sorted by methodology (qualitative or quantitative). The first stage was to recode and label barriers and facilitators that covered comparable content, although their presentations were different. For example, “anxiety and fear: potential cancer diagnosis”, [26] ”fear of a possible diagnosis“[27] and “These fears were related to the illness, colorectal cancer…”[28] were recoded
into the category “fear of having cancer”. In the second stage, sub-themes were made that integrated the barriers and facilitators from the first stage but at a higher abstraction level, although still in a descriptive manner. Thus, the descriptions “fear of colonoscopy”, “fear of colostomy” and “fear of the test being mixed up in the mail” were integrated into the broader sub-theme “fear”. Finally, more analytical themes were constructed to represent the drivers of the barriers and facilitators. Thus, ‘fear’ and ‘disgust and embarrassment’ were categorised into the theme ‘psychology’. This last process was done by a narrative summary technique.[17]

All coding and analysis were done by two independent reviewers (JD and LJM). Consensus was achieved through discussion in case of disagreement.

Results

Study characteristics and quality
A total of 7,567 studies were identified for screening of title and abstract (Figure 1). A complementary search on Google Scholar resulted in additional 41 potential studies. A total of 7,139 were excluded based on the titles and further 90 were excluded after reading the abstract based on the inclusion/exclusion criteria. This left 383 papers for full text reading. From these we identified 21 studies eligible to the inclusion criteria, of which 11 were qualitative,[8, 26–35] and 10 were quantitative.[36–45] It was not possible to conduct a meta-analysis on the quantitative studies because of heterogeneous designs.

Tables 1 and 2 show the description of the studies. A majority (n=15) were conducted in Europe.[8, 26, 28, 30–35, 39, 40, 42–45] There were four studies from Australia,[27, 36, 38, 41] one from the US[37] and one from Canada.[29] The setting of the publicly funded SP programs varied as four studies reported on pilot projects,[27, 36, 37, 45] seven on regional SP[8, 28, 30–32, 42, 43] and nine on national SP.[26, 33–35, 38–41, 44] Almost all studies reported that screening invitations were distributed by ordinary mail, but only four reported that sending out reminders was part of the program.[28, 30, 31, 37] Participation rates were between 26% and 58%.[8, 34]

The evaluation of the study-quality using the Critical Appraisal Skills Program tools showed high quality of all the included studies. The scores for the qualitative and quantitative studies were ≥8 of 10 and ≥10 of 11, respectively.

Screening barriers and facilitators
We identified seven different themes within barriers and facilitators (Table 3). A detailed description of Barriers and facilitators included in each theme can be seen in Supplemental Table 1.

**Psychology**

Feeling indifferent about taking the test was a barrier to participation as described in both qualitative and quantitative studies.[8, 26–28, 30–33, 35, 45] Another barrier was procrastination that “....refers to torn feelings and indecision”[31] In addition, invited people might not want to participate in SP because of embarrassment or disgust of the test.[26–33, 35–38, 41, 43–45] “I didn’t really like the whole process...I thought, that’s disgusting.”[29] Poor trust in the local clinic, hospital or healthcare system was reported as a barrier to screening in six studies.[8, 26, 28, 32, 35, 38] Preferred ignorance of potential cancer was also a common barrier.[26, 44, 45] A qualitative study reported that some non-participants distinguished between being unwell and knowing about being unwell. If they received a positive test, they would know that they were unwell and therefore needed to redefine themselves, which they did not want to.[35]

Fear was reported as a reason for non-participation in most studies, though the reported subject of fear differed. Fear was associated with the responsibility of taking the test,[26, 30, 32, 33, 35] a subsequent colonoscopy,[8, 26, 29, 31, 32, 34, 35, 39, 42, 44] creation of a colostomy,[32, 39] development of constipation prior to the test,[30, 37] that the test would be lost in the mail and received by a wrong person.[35, 37] “put your name in the post.... I thought oh God, y’know it’s got your name on it and what if they open it.”[35] Fear of having cancer was commonly reported a barrier. Interestingly, however, it acted as a facilitator for others.[26, 28, 31–33, 35, 37, 38, 40, 44, 45] Finally, other mental or emotional problems were frequently reported as barriers to participation.[26, 32, 33, 39, 40, 42]

**Religion**

The belief that “if it is God’s will, it will happen” was predominant in ethnic minority groups according to a qualitative study.[33] “I believe that by the grace of God, I will not go through such illness. So, I believe nothing as such will happen to me because I have God who is taking care of me. So I don’t want the screening and all that, I don’t bother”[33] Fatalism or the thought “if I have cancer, I will die anyways” also precluded participation.[26, 32, 40, 45]

**Logistics**
Logistical factors were many and included not recalling receiving the invitation, and technical problems with the test kit. “I thought, I don’t know how to do this, it’s a lot of mucking around was my first reaction.” In addition, there were barriers related to recent bowel examinations prior to the screening invitation, forgetfulness, lack of time or other priorities or worries about having to pay for a colonoscopy.

In contrast, logistical support could serve as a perceived facilitator. Examples included the submissions of an antibacterial wipe and a disposable glove together with the FOBT kit, clear presentation of the purpose of the invitation or raising awareness through media campaigns.

Health-related issues
Other physical problems, functional limitations, low self-perceived health status and mental health problems were additionally reported as participation barriers.

Knowledge and awareness
Perceived lack of relevance of participation was a barrier in different manners as exemplified by lack of symptoms, the general perception of “it is not relevant for me”, feeling satisfied with a prior negative screening or considering oneself as too young or too old for testing. “I’ve got no symptoms so I’m alright, y’know, I exercise and I’m fit.” A health perception of diseases being caused solely by living unhealthy was also associated with non-participation.

Lack of knowledge concerning what the FOBT implied or misinterpretation of the test were other common barriers. Poor knowledge about screening and low health literacy were also associated with lower participation rates.

General practitioner
Involvement of the general practitioner in recruitment and decision-making was perceived as an important facilitator. The screening offices were perceived less legitimate than the personal general practitioner, when it came to ensuring protection of health.
the invitation letter from the general practitioner could facilitate participation.[27, 29, 34] A participant in a Canadian study said: “My physician... directed me to have the stool test”. [29]

Environmental
A partner or friend participating in screening,[26–29, 31, 32, 37] encouragement by network,[28, 29, 37, 38] or previous screening for CRC[27, 29–31, 33, 37, 38, 43] were associated with increased participation rates. Knowing someone diagnosed with cancer could both act as a facilitator and a barrier.[27] Several studies reported that participation in SP was seen as a civil duty facilitating participation.

Several studies described that non-participation was incidental rather than representative of a negative attitude towards screening or a conscious decision not to participate.[26, 27, 29, 31, 33, 35]

Discussion
This systematic review explored barriers and facilitators concerning participation in stool sample based and publicly funded screening for CRC. Stool sample based SPs are recommended by the EU.[2] We found qualitative and quantitative literature of high quality describing barriers and facilitators that could be divided into seven themes: psychology, religion, logistics, health-related issues, knowledge and awareness, general practitioner, and environmental factors.

It may not be possible to target and change all of the above barriers. However, the results suggest that an increase in public knowledge and awareness could lead to a higher participation rate. Logistical barriers could also be targeted by providing technical guidance and supplies together with logistical support from the screening centres or the general practitioners.

Fear of a subsequent colonoscopy was an important barrier.[8, 26, 29, 31, 32, 34, 35, 39, 42, 44] According to a review on CRC screening predominantly including North American studies,[46] the laxative bowel preparation was the major barrier for screening colonoscopy. In contrast, the studies included in this review were mainly European and reported that fear was specifically associated with the colonoscopy.[8, 26, 29, 32, 34, 35] This could represent cultural and practice differences between North America and Europe. Thus, it may be important to work with specific types of fear of screening to increase participation rates.
Some people preferred colonoscopy, because they believed it to be a more thorough examination.[14, 21, 31] However, the fear that SP with an initial FOBT test would lead to a colonoscopy was more often reported as a barrier in the reported studies.[20, 27–29, 31] A potential avoidance of colonoscopy was also used as an argument for having an initial FOBT test.[30, 37] The participant’s collection of stool samples for the gFOBT was considered a taboo and hence a barrier. This aversion might be possible to overcome, as iFOBT requires only one rather than three samples. Because studies also show that interval cancers are rarer after iFOBT, we expect iFOBT to play a bigger role in future screening.[47] Not enough studies specified what kind of stool sample was used to stratify the results according to the use of iFOBT or gFOBT.

This review was the first to apply a number of very specific inclusion criteria, which ensured higher homogeneity of the various SPs conducted across regions and countries. Hereby, the barriers and facilitators were specifically relevant to the programs using these types of screening. Furthermore, the participants of the included studies represented a broad range of countries and ethnic groups, which enhanced the external validity of the results. Another strength of the study was the integration of both qualitative and quantitative studies, and the fact that interpretations were done independently by two researchers.

This systematic review has some limitations. Non-participation was generally not caused by a negative attitude towards CRC screening. It is likely that this finding might represent selection bias, as people participating in studies of barriers of screening are more prone to screening in general. Moreover, the inclusion of both qualitative and quantitative studies on an equal basis was a discipline lacking international consensus.[48] Thus, a barrier could be reported because it was just mentioned by a few patients in an interview or reported by most participants in a large questionnaire survey. By doing this, the review captured most of all possible barriers and facilitators. However, it cannot be used to ascertain which barriers were the most prevalent or most important. Qualitative data is considered highly contextualized. Pooling of these data with quantitative results may lead to the loss of valuable context specific qualitative information.[49] However, as the aim of this study was to get as broad a perspective of the subject as possible, the inclusion of studies of mixed methodologies was deemed necessary.

In this review we chose to exclude sociodemographic variables (age, gender, ethnicity, income, occupation, education). This means that this review does not fully answer the question “which groups of people are most likely/least likely to participate in screening”. Instead it answers the question “what are the reasons for non-participation/participation?”
Although studies on interventions to increase participation rates in screening have already been conducted,[44–46] there are so far no such studies regarding publicly funded systematic FOBT-based SP as conducted according to the recommendations of the European Union.[2] As participation rates are still low, interventional studies are warranted for these public SPs to confirm if implementation of specific interventions actually influences the participation rates in CRC screening.

**Conclusion**
This systematic review integrating qualitative and quantitative studies found a range of barriers and facilitators of CRC screening, which could be divided into the themes: psychology, religion, logistics, health-related issues, knowledge and awareness, general practitioner, and environmental factors. The review suggests that participation in systematic, publicly funded SP with FOBT might be improved, if there is increased general awareness and knowledge of how screening may diagnose CRC at an earlier stage. Involvement of general practitioners, implementation of media campaigns and the creation of a logistical support unit can result in higher participation rates.

**Acknowledgement**
This research was part of a larger research project funded by the Health Foundation (Helsefonden) (19-B-0032), the Capital Regions Research Foundation for Health Research (A6205), Danish Cancer Research Foundation (FID20823), the Gangsted Foundation (A35137), Inge and Jørgen Memorial Fund (10537-003) and a research grant from Bispebjerg and Frederiksberg Hospital (no grant number provided).

The authors declare no conflict of interest.
The manuscript is a review and according to Danish law, ethical approvals are not necessary for reviews.

**Author contribution**
MR and LNJ conceived of the study. JD and LJM extracted and analysed the data under the supervision of MR and LNJ. JD and ATJ drafted the manuscript, which was critically revised by all authors.

References


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<tr>
<th>Author &amp; Year</th>
<th>Country</th>
<th>Type of study</th>
<th>Population</th>
<th>Study focus</th>
<th>Age (years)</th>
<th>Sex: Female/Male</th>
<th>Test, Frequency</th>
<th>National/Regional</th>
<th>Adherence rate</th>
</tr>
</thead>
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<tr>
<td>Aubin-Auger 2011</td>
<td>France</td>
<td>Semi-structured Interview</td>
<td>Invited screening population</td>
<td>Obstacles to mass SPSP* in France</td>
<td>50-74</td>
<td>11/13</td>
<td>gFOBT, Every two years</td>
<td>Regional (in all regions)</td>
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<td>Benito 2017</td>
<td>Spain</td>
<td>Focus groups</td>
<td>Participants</td>
<td>Factors related to longitudinal adherence of SPSP</td>
<td>50-69</td>
<td>22/23</td>
<td>gFOBT+iFobt, Every two years</td>
<td>Regional</td>
<td>36%</td>
</tr>
<tr>
<td>Broc **2017</td>
<td>France</td>
<td>Phone interviews (mixed methods)</td>
<td>Non-participants</td>
<td>Motivation, ambivalence and self-determination in participation in SPSP</td>
<td>50-74</td>
<td>5894/0</td>
<td>FOBT*, Every two years</td>
<td>Regional</td>
<td>-</td>
</tr>
<tr>
<td>Clarke 2016</td>
<td>Ireland</td>
<td>Semi-structured interviews</td>
<td>Invited screening population</td>
<td>Gender differences in influences on decisions to participate in SP</td>
<td>50-74</td>
<td>22/25</td>
<td>iFOBT, Every two years</td>
<td>Regional</td>
<td>44%</td>
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<tr>
<td>Clavarino 2004</td>
<td>Australia</td>
<td>Semi-structured interviews</td>
<td>Invited screening population (pilot screening)</td>
<td>Understanding of the screening process from the perspectives of consumers, GPs and specialist gastroenterologists</td>
<td>50-74</td>
<td>7/5</td>
<td>gFOBT/iFOBT, -</td>
<td>Pilot</td>
<td>-</td>
</tr>
<tr>
<td>Dharni 2010</td>
<td>UK</td>
<td>Qualitative Interviews</td>
<td>Non-participants</td>
<td>Factors affecting SPSP participation</td>
<td>55-75</td>
<td>21/29</td>
<td>gFOBT, Every two years</td>
<td>National</td>
<td>40%</td>
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<tr>
<td>Garcia **2011</td>
<td>Spain</td>
<td>Phone interviews</td>
<td>Invited screening population</td>
<td>Barriers and facilitators associated with participation in the first round of SP</td>
<td>50-69</td>
<td>955/1006</td>
<td>FOBT, Every two years</td>
<td>Regional</td>
<td>26%</td>
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<td>Country</td>
<td>Methodology</td>
<td>Group</td>
<td>Beliefs and experiences of non-participants</td>
<td>Age Range</td>
<td>Non-respondents</td>
<td>FOBT Type</td>
<td>Frequency</td>
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<td>Hall 2013</td>
<td>UK</td>
<td>In-depth Interviews</td>
<td>Non-participants</td>
<td>Beliefs and experiences of non-participants</td>
<td>60-74</td>
<td>14/13</td>
<td>gFOBT, Every two years</td>
<td>54%</td>
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<td>Kirkegaard 2015</td>
<td>Denmark</td>
<td>Semi-structured interview and guided discussion groups</td>
<td>Invited screening population</td>
<td>Information and preferences for format and content in a decision aid for people invited to SP</td>
<td>50-74</td>
<td>20/18</td>
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<td>58%</td>
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<td>Focus group</td>
<td>Invited screening population</td>
<td>Reasons for non-participation and subsequent participation among participants who had initially not taken part in SP</td>
<td>60-74</td>
<td>61/67</td>
<td>gFOBT, Every two years</td>
<td>35-61%</td>
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<td>Canada</td>
<td>Focus groups</td>
<td>Invited screening population</td>
<td>Perception of the mailed invitation, CRC screening and their screening experience for those invited to SP</td>
<td>50-74</td>
<td>32/26</td>
<td>FOBT*, -</td>
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SP = Colorectal cancer screening program
*Type of FOBT not defined
** Mixed method study
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<td>Australia</td>
<td>Questionnaire</td>
<td>Invited screening population and non-participants</td>
<td>Demographic and psychosocial factors associated with participation in SP</td>
<td>50-74</td>
<td>4/5-78</td>
<td>FOBT, -</td>
<td>Pilot</td>
<td>-</td>
</tr>
<tr>
<td>Gordon 2013</td>
<td>US</td>
<td>Questionnaire</td>
<td>Invited screening population</td>
<td>Beliefs, influences and motivators for participants, converts and non-participants in SP</td>
<td>52-76</td>
<td>1020/1026</td>
<td>iFOBT, -</td>
<td>Pilot</td>
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<td>Australia</td>
<td>Survey</td>
<td>Invited screening population</td>
<td>Comparison of the social cognitive and social ecological predictors of intentions to screen with predictors of participation.</td>
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<td>648/602</td>
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<td>National</td>
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<td>UK</td>
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<td>Invited screening population</td>
<td>Association between health literacy and participation in CRC screening</td>
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<td>1254/1010</td>
<td>FOBT*, Every two years</td>
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<td>Invited screening population</td>
<td>Predictors of participation in CRC and mediators of association</td>
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<td>291/238</td>
<td>FOBT*, Every two years</td>
<td>National</td>
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<td>Methodology</td>
<td>Population</td>
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<td>Stage of Change</td>
<td>Number/Total</td>
<td>Setting</td>
<td>Participation Rate</td>
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</tr>
<tr>
<td>Paddinson 2010</td>
<td>Australia</td>
<td>Questionnaire</td>
<td>Invited screening</td>
<td>Stage of change distribution for SP, and the factors associated with varying position on the continuum of change</td>
<td>50-70</td>
<td>28/31</td>
<td>National</td>
<td>59%</td>
<td></td>
</tr>
<tr>
<td>Ricardo-Rodrigues 2011</td>
<td>Spain</td>
<td>Longitudinal</td>
<td>Invited screening</td>
<td>Adherence to SP and possible associated factors</td>
<td>50-69</td>
<td>3774/2972</td>
<td>Regional (7 out of 17 regions included)</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Rossi 2005</td>
<td>Italy</td>
<td>Questionnaire</td>
<td>Invited screening</td>
<td>Reasons for non-participation and participation in SP</td>
<td>50-74</td>
<td>3927/3368</td>
<td>Regional (pilot)</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Smith 2016</td>
<td>UK</td>
<td>Questionnaire</td>
<td>Invited screening</td>
<td>If there was an educational gradient in perceived benefits and barriers in SP</td>
<td>60-74</td>
<td>1177/999</td>
<td>National</td>
<td>54%</td>
<td></td>
</tr>
<tr>
<td>Van Rijn 2008</td>
<td>The Netherlands</td>
<td>Quantitative phone interview</td>
<td>Non-participants</td>
<td>Main reasons not to participate in SP</td>
<td>50-75</td>
<td>161/151</td>
<td>Pilot</td>
<td>53%</td>
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</tbody>
</table>

SP= Colorectal cancer screening program
*Type of FOBT not defined
<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
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</thead>
<tbody>
<tr>
<td>Psychology</td>
<td>Feeling indifferent/forgetfulness[8, 26–28, 30, 31, 35, 45]</td>
</tr>
<tr>
<td></td>
<td>Disgust and/or embarrassment[26–33, 35–38, 41, 43–45]</td>
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<tr>
<td></td>
<td>Fear[26, 28–35, 37, 38, 43–45]</td>
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<tr>
<td></td>
<td>Trust in health institutions[8, 26, 28, 32, 35, 38]</td>
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<tr>
<td></td>
<td>Doubt about own ability to conduct FOBT[26, 30, 32, 35]</td>
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<tr>
<td></td>
<td>Procrastination[26, 29, 31, 35, 37]</td>
</tr>
<tr>
<td>Religion</td>
<td>Destiny[31, 33, 37, 44]</td>
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<tr>
<td></td>
<td>Fatalism[26, 32, 40, 45]</td>
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<tr>
<td>Logistics</td>
<td>Not recalling reception of an invitation[29, 32, 45]</td>
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<tr>
<td></td>
<td>Technical issues related to FOBT[26, 27, 30, 32, 33, 37, 44, 45]</td>
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<tr>
<td></td>
<td>Prior bowel exams[8, 26, 27, 30, 31, 35, 37, 43, 45]</td>
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<tr>
<td></td>
<td>Lack of prioritization[8, 26–28, 30, 31, 33, 35, 44, 45]</td>
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<tr>
<td></td>
<td>Worries for costs[30, 37]</td>
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<tr>
<td></td>
<td>Timing[8, 27, 30, 31, 34, 35, 38, 43–45]</td>
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<tr>
<td></td>
<td>General logistical support[8, 26, 29, 34]</td>
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<tr>
<td></td>
<td>Practical aids[37]</td>
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<td></td>
<td>Readability of invitation letter[30, 31]</td>
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<td>Media campaigns[28–30, 32, 33]</td>
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<tr>
<td>Health</td>
<td>Health related issues[8, 26, 28, 30, 33, 37, 39, 40, 42, 43, 45]</td>
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<td>Mental problems[26, 32, 33, 39, 40, 42]</td>
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<tr>
<td>Knowledge and awareness</td>
<td>Perceived relevance[8, 26–28, 30, 32–38, 45]</td>
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<td></td>
<td>Health perception[26, 28, 30, 32, 35]</td>
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<tr>
<td></td>
<td>Absence of bowel related symptoms[26, 27, 29, 31, 32, 37, 43, 45]</td>
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<td></td>
<td>Belief that one is too old/young[26–29, 45]</td>
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<tr>
<td></td>
<td>Doubt about the implications of the FOBT[28, 30, 32]</td>
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<tr>
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<td>Disagreement concerning the indication for the test[8, 27, 30, 37]</td>
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<tr>
<td></td>
<td>Health literacy[26, 39]</td>
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<tr>
<td></td>
<td>Amount of information[29, 34, 37, 43]</td>
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<tr>
<td>GP</td>
<td>Level of recommendation and support by GP[8, 26, 28–31, 35, 37, 43]</td>
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<td></td>
<td>Signed invitation letter from GP[27, 29, 34]</td>
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<tr>
<td>Environment</td>
<td>Participation in other screening programs[8, 27, 30, 31, 33, 38, 42]</td>
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<tr>
<td></td>
<td>Social encouragement for participation[26, 28, 30, 32, 33, 35, 37, 38, 44]</td>
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<tr>
<td></td>
<td>Acquaintance with someone diagnosed with CRC[26–33, 37, 38, 43]</td>
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<td></td>
<td>Civic duty[26, 33, 37]</td>
</tr>
</tbody>
</table>

FOBT: Faecal occult blood test  
GP: General practitioner  
CRC: Colorectal cancer