



Exploring non-participation in colorectal cancer screening: A systematic review of qualitative studies

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ABSTRACT

Introduction: Worldwide, colorectal cancer is a major public health issue. Despite the existence of screening programmes in many countries, global uptake remains low. This meta-ethnography aimed to analyse qualitative literature to explore attitudes towards colorectal cancer screening and reasons for non-participation in eligible people that do not participate when invited.

Methods: Systematic searches were conducted in five databases in May 2021. Critical appraisal of included studies was performed using the CASP checklist for qualitative studies.

Findings: Thirteen studies were included. Three main themes and eight sub-themes were developed across studies: (1) Differences in motivation, with non-participants expressing a lack of knowledge and varying levels of intention to participate but not feeling screening was personally necessary; (2) Active aversion to screening expressed by fear, discomfort, disgust or not wanting to know; and (3) Contextual barriers of the healthcare system such as practical constraints or poor relationships with healthcare professionals.

Conclusion: Findings suggest multiple pathways to non-participation including ambivalence, aversion to the process and consequences of screening or lack of support. Persuasive messages and prompts to action to target ambivalence, reassurance regarding the screening procedures to target negative reactions, and increased support from healthcare professionals may be beneficial in increasing screening uptake.

1. Introduction

Colorectal cancer is the third most common and the second most deadly cancer worldwide (Xi and Xu, 2021). Globally, colorectal cancer is a burden in terms of health, quality of life, and healthcare costs (Yabroff et al., 2013). To reduce the burden of colorectal cancer and increase early detection, organized screening programmes have been developed in many countries (WHO, 2020).

The objective of screening is to reduce the incidence and/or mortality of a health condition within a population by offering an early treatment or intervention (WHO, 2020). Depending on the country, screening for colorectal cancer can be offered through an organized programme (e.g. managed by the government), or in an opportunistic manner (e.g. offered by physicians on an individual basis). A higher participation in screening is observed in countries where a fully rolled

out organized programme is implemented (Cardoso et al., 2020). Several screening tests are currently in use to detect colorectal cancer at an early stage: the FOBt (Faecal Occult Blood test), the FIT (Faecal Immunochemical Test), colonoscopy, and sigmoidoscopy. Currently, the FIT is the most commonly used internationally (Cardoso et al., 2020). This test consists of taking a single sample of stool with a test kit and sending it to a laboratory by post to check the stool sample for hidden (occult) blood. The FOBt is an older test with a similar process but requires three samples from three bowel movements.

Evidence demonstrates that colorectal cancer screening as part of an organized programme is effective to reduce mortality and is cost-effective (Altobelli et al., 2014). To be effective and efficient, organized screening programmes need a high level of participation (Camiloni et al., 2013). However, colorectal cancer screening uptake rates are below 50% in many countries (Tran et al., 2021), with a target rate of

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65% recommended by the European guidelines (European Commission, 2010).

Many studies have explored the barriers and facilitators to colorectal cancer screening participation using qualitative methods (Aubin-Auger et al., 2011; Chapple et al., 2008; Reeder, 2011), and have been brought together in systematic reviews (Honein-AbouHaidar et al., 2016; Lim et al., 2021). However, existing reviews have focused on various populations without separating people who have already participated in screening from people who did not attend. There has been less of a focus on synthesising the views of eligible people who did not participate in screening. While recruiting non-participants in screening to take part in research studies is challenging, assessing their views, perceptions and attitudes towards screening programmes is essential to understand how to develop interventions to encourage participation. A number of primary qualitative studies have explored the views of people who did not participate in colorectal cancer screening (e.g. Bradley et al., 2015; Cooper and Gelb, 2016; Palmer et al., 2014), but to date these have not been brought together in a systematic review to identify patterns, similarities and differences across studies.

This systematic review aimed to fill this gap by gathering and analysing qualitative literature reporting the views of non-participants regarding colorectal cancer screening programmes. This review has two main questions:

- What are the views, perceptions and expectations of eligible people that do not participate in colorectal cancer screening towards colorectal cancer screening programmes?
- What are the reasons that eligible people do not participate in colorectal cancer screening when invited to participate in a programme?

2. Methods

The synthesis method of this review is meta-ethnography, a method to synthesise qualitative studies (Britten et al., 2002). Meta-ethnography is not a simple aggregation of findings of individual studies, rather it produces a novel interpretation transcending individual study findings (Noblit and Hare, 1999). This method was considered the most appropriate, as meta-ethnography is suitable for the development of analytical rather than descriptive findings to describe complex phenomena (Daker-White et al., 2015), such as non-participation in colorectal cancer screening.

Meta-ethnography consists of re-interpreting the conceptual data provided by authors of included studies (themes or concepts) while considering the primary data (quotes from participants) and using a translation synthesis method (comparing the concepts found in studies to each other). Therefore, based on first order constructs (quotes from participants) and second order constructs (themes described by authors of included studies), the authors of the meta-ethnography aim to develop higher order interpretations (third order constructs).

This systematic review was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology guidelines (Page et al., 2021), and results are reported in line with the ENTREQ (Enhancing transparency in reporting the synthesis of qualitative research) guidelines (Tong et al., 2012). The study protocol was registered in advance on PROSPERO, the international prospective register of systematic reviews (PROSPERO, 2021 CRD42021258273).

2.1. Inclusion criteria

The SPICE (Setting, Perspective, Intervention, Comparison and Evaluation) framework (Booth, 2006) was used to develop the inclusion criteria:

Setting: The review included studies that were conducted in the context of an offer to participate in colorectal cancer screening. Articles

focusing on non-participation in any recommended mass or opportunistic screening for colorectal cancer (e.g. colonoscopy, FIT, FOBt, sigmoidoscopy) in any country were included. This broad approach was chosen in an attempt to get a complete overview of non-participation in colorectal cancer screening and to capture the broad range of potential barriers to screening participation.

Perspective: This review considered all studies that included people who have been invited to, and did not participate, in colorectal cancer screening.

Phenomenon of interest: The review included studies that focused on reasons for non-participation, views, perceptions and expectations of non-participants in colorectal cancer screening.

Comparison: If a paper reported different categories of people who had not participated (e.g. people who intended to participate but did not act on their intention vs people who did not have any intention to participate), then this information was included in our analysis.

Evaluation: The review considered studies related to the reasons for non-participation, views, perceptions and expectations towards colorectal cancer screening of eligible people that did not participate. Studies using qualitative methods of data collection (i.e. focus groups, interviews) and analysis were included, if participant quotes were presented in the results as access to primary data is necessary to perform a meta-ethnography analysis (Sattar et al., 2021). Mixed-methods studies were included where qualitative data was reported separately. Only peer-reviewed publications in English were included.

2.2. Exclusion criteria

The review excluded studies based on the following criteria:

- Articles including adults who had not been invited to colorectal cancer screening or adults who had participated in colorectal cancer screening;
- Articles with mixed samples of people, where some had participated in colorectal cancer screening and some had not (even where results were reported separately). The reason for this exclusion criteria was first, to keep a narrow focus on non-participation by including only primary studies with this specific approach, and second, to reduce the number of records in order to get a manageable number of included studies to perform an in-depth meta-ethnography analysis.
- Articles focused on screening across conditions where findings for colorectal cancer were not presented separately;
- Articles focused on genetic testing. This type of test targets individuals with a high-risk of developing colorectal cancer.

2.3. Search strategy

A search was performed in databases used in previous relevant reviews (Byrnes et al., 2020; Honein-AbouHaidar et al., 2016). Systematic searches were conducted in five databases in May 2021: Elsevier EMBASE; Elsevier SCOPUS; EBSCO CINAHL; NCBI PubMed; PROQUEST PsycINFO. Forward and backward citation searches were performed on all included studies. The search strategy was prepared with the help of a Research Support Librarian based at the University of Galway. Four main concepts including several keywords were searched: "colorectal cancer screening programme"; "non-participants"; "views, perceptions, barriers", and "qualitative or mixed-methods studies". The same search approach was conducted in all databases but keywords were coupled with relevant MESH/thesaurus terms where appropriate. The PubMed search strategy is available in Appendix I.

2.4. Screening process

The search was conducted by ALB in May 2021. All citations retrieved were imported into Covidence and duplicate references were removed. Two independent reviewers (ALB and MF) performed title and

abstract screening and three independent reviewers performed the full text screening (ALB as first reviewer, MF and EM as second reviewer). Disagreements were reconciled through discussion with a third reviewer (JMS).

2.5. Quality assessment

The critical appraisal of included studies was performed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies. Assessment was done by two independent reviewers (ALB and OM) and any discrepancies were solved by discussions with a third reviewer (JMS). None of the studies were excluded on the basis of this assessment but critical appraisal findings were used to inform the synthesis.

2.6. Data extraction and data synthesis

The process of data extraction and analysis was based on available guidance for conducting meta-ethnography (France et al., 2019; Sattar et al., 2021). The research team undertook the following steps: reading and data extraction approach; process for determining how studies are related; process of translating studies; synthesis process. More details are provided in Table 1. The data, analysis scripts and output are available as supplemental files including the newly formed categories (Appendix III) and the data extraction form (Appendix IV).

3. Results

The database search identified 15,553 records, of which 11,014 non-

Table 1
Process of data extraction and analysis.

| Steps of analysis (France et al., 2019) | Description of analysis process (based on Sattar et al., 2021) |
|---|---|
| Reading and data extraction approach | All papers were read by ALB and OM repeatedly to familiarise themselves with the key concepts presented in the studies. First order constructs (i.e. quotations described in each papers) and second orders constructs (i.e. authors interpretation) were extracted from each of the studies in a data extraction form by ALB and then checked by OM. Characteristics of each study (information on study sample, data collection and analysis, study outcomes and conclusions) were extracted by ALB in a separate table. |
| Process for determining how studies are related | ALB looked across the studies to identify common and recurring concepts and compiled a list of the themes. Themes were juxtaposed against each other. Then, new relevant categories were formed in order to group the common concepts from studies. These newly formed categories were labelled to represent all the concepts they contain. The process was then discussed and revised with OM and JMS. |
| Process of translating studies | The studies were arranged chronologically. ALB summarized the themes and concepts from paper 1, then repeated the process with paper 2, comparing what is similar and what paper 2 may add to paper 1. The process was repeated again with all the other articles. The process was discussed and revised with OM and JMS. |
| Synthesis process | By relating the first order data and second order themes extracted, new third author constructs were developed to provide “a fuller account of the given phenomenon and resolve any contradictions”, aiming to provide “a new understanding of the phenomena” (Sattar et al., 2021, p.10). A line of argument synthesis was then developed by exploring the links between the new constructs and how it can apply to the process of screening decision-making and non-participation. The process was discussed and revised with OM and JMS. |

duplicated records were screened based on titles and abstracts. Of these, 290 records were screened for full text screening, and 13 studies were finally included (Fig. 1). No studies were included from forward/backward citation searches performed on included studies.

3.1. Overview of included studies

Thirteen studies were included. Articles were published between 2001 and 2020 and described studies conducted in the following countries: Iran; Northern Ireland; USA (4 studies); Australia; England (3 studies); Belgium; Singapore (2 studies). The number of participants in these studies varied from 20 to 139, and all had not taken part in the screening programme in their country. The articles focused on the following screening tests: FOBt (4 studies); colonoscopy (2 studies); FIT (1 study); Flexible sigmoidoscopy (1 study); multiple tests (5 studies). Data were collected using focus groups (7 studies) or interviews (6 studies). Data were analysed using several methods as described by the authors: thematic analysis (4 studies), open coding (1 study), content analysis (1 study), constant comparative method (1 study), mixed-methods analysis (1 study), inductive phenomenological approach (1 study), and grounded theory analysis (3 studies). No information was provided about data analysis in one study (Cooper and Gelb, 2016). More details on study characteristics are provided in Table 2.

3.2. Methodological quality

The quality assessment performed with the CASP checklist showed that the studies generally met the criteria in terms of clarity of the aims of the research, appropriateness of the qualitative methodology, recruitment strategy, ethical issues, and clarity of research findings. However, a lack of information was often observed regarding the appropriateness of the research design to address the aims of the research, data collection, consideration of the relationship between researcher and participants, and data analysis. The CASP guidance does not suggest a scoring system. Details of the CASP evaluation of each study are available in Appendix II.

3.3. Definitions of non-participation across studies

Non-participation was defined in different ways across studies. For example, in some studies, non-participation was simply defined as when participants had “not undergone screening tests”, “not returned kit”, or “never obtained screening”. (Besharati et al., 2018; Hall et al., 2013; Rogers et al., 2018). Other studies used a more precise definition such as specification that non-participation was for a medical reason (Goodwin et al., 2019), or specification of a duration (e.g. not been screened within the last ten years in Ruffin et al., 2009). More details are presented in Table 2.

Three studies made a distinction between different kinds of participants. The authors of those three studies used this distinction in the data analysis.

Firstly, in McCaffery et al. (2001), three groups with different patterns of decision-making related to screening were identified: (1) Non Responders: “forgetting or avoiding making a decision about the test”; (2) Definitely Not Interested: “a confident rejection of the test based on a few salient factors”; and (3) Probably Not Interested: “a more careful consideration of the test focusing on issues of susceptibility” (p.679).

Secondly, in Goodwin et al. (2019), two groups were identified: (1) Intenders: “those who planned to complete and return the FOBt kit”; and (2) Refusers: “those who did not intend to complete the kit at the time of receiving the kit in the mail” (p.5). Intenders usually related “subsequently forgetting about or losing the kit or delaying the use of it” (p.5). Refusers were “those who did not intend to use the kit, refusing participation before or upon receipt of the kit in the mail—often throwing into the bin immediately, although some read through accompanying paperwork before doing so” (p.5).

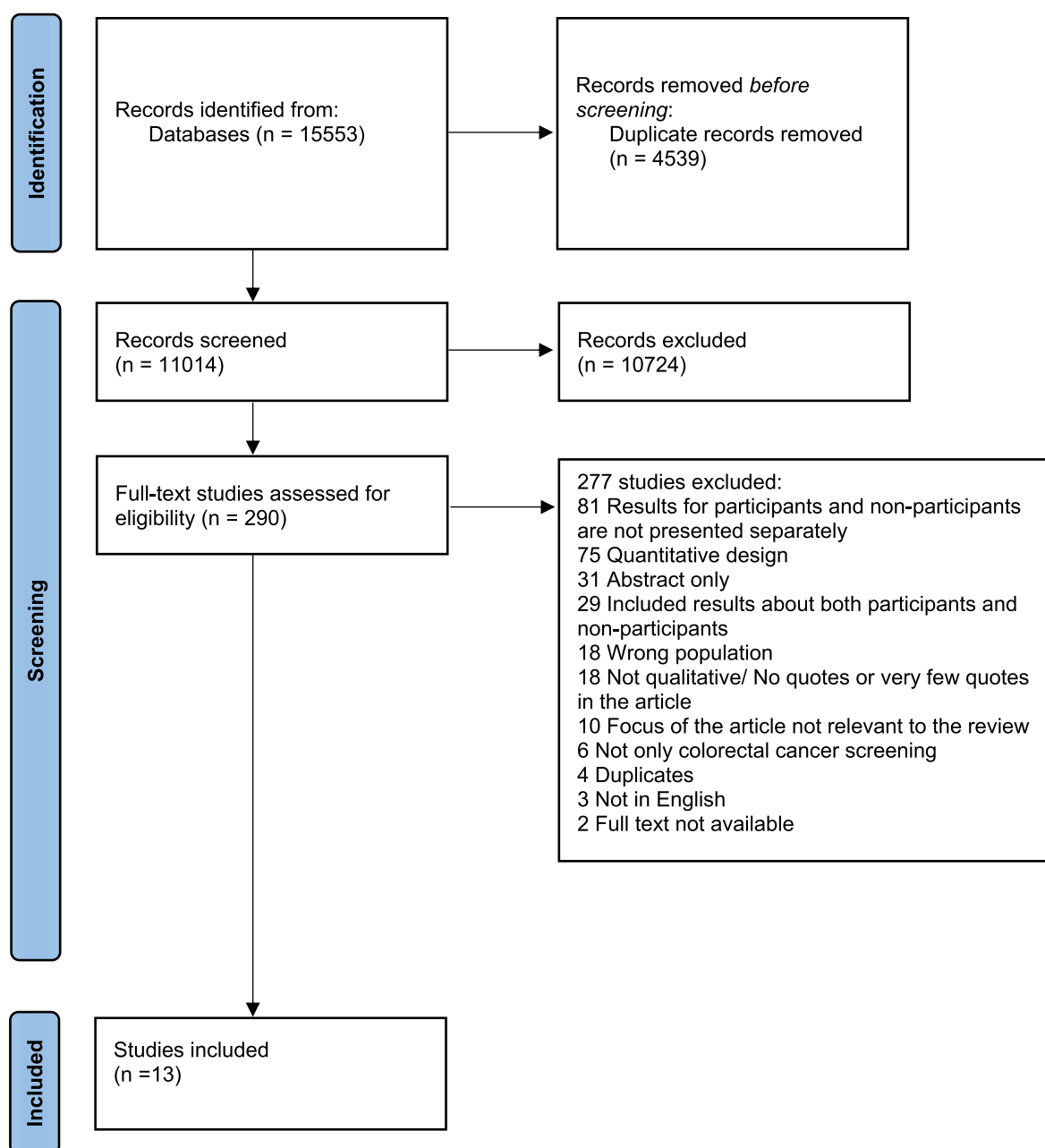


Fig. 1. PRISMA flow diagram.

Thirdly, in Hall et al. (2013), three levels of decision-making were identified: (1) “No decision made”: the kit is generally “put to one side”; (2) “No intention to take part”: screening is perceived as “not necessary” or individuals are “not able to do it now”, and (3) “Intention to take part” but no subsequent participation due to “circumstances beyond control” or “forgot” (p.1648).

3.4. Meta-ethnography

Three main themes associated with eight sub-themes were developed across studies: (1) Differences in motivation: Action and passive non-participation: Lack of knowledge, varying intentions and limited personal relevance, (2) Active aversion to screening: Negative reactions to the process and consequences of screening; and (3) Contextual barriers: Practical constraints and healthcare professionals influence. To report the interpretations of authors of included studies accurately, their wording was kept as expressed in their articles. Wording taken directly

from study authors are marked in italics.

Although different colorectal cancer screening tests were considered in included studies, views across tests were similar and so are reported together. However, distinctions between tests were made when relevant. Similarly, all participants were considered together in the results section, but distinctions by type of participants (e.g. intenders vs. refusers) are highlighted when relevant.

THEME 1. DIFFERENCES IN MOTIVATION: ACTION AND PASSIVE NON-PARTICIPATION: LACK OF KNOWLEDGE, VARYING INTENTIONS AND LIMITED PERSONAL RELEVANCE

The first theme describes the differences in motivation related to colorectal cancer screening. It includes three subthemes exploring lack of awareness and knowledge, varying intentions to get screened and postponement, and limited perceived personal relevance of screening.

Table 2
Characteristics of included studies.

| Authors and year | Country | Test(s) in use | Framework/Theory | Study sample | Inclusion criteria | Definition of non-participants | Data collection methods | Data analysis methods | Study outcomes | Study conclusions |
|-------------------------|------------------|--------------------------------------|------------------|---|--|---|-------------------------|-----------------------|--|---|
| Besharati et al. (2018) | Iran | FOBT Colonoscopy | – | 61 participants (31 men and 30 women) Mean age of participants was 54.92 | Speaking Persian, being older than 40 years, and living in Hamadan | People who had not undergone screening tests | 10 Focus groups | Content analysis | 6 themes were identified: 1, awareness and knowledge; 2, financial problems; 3, low priority of health concerns; 4, fear of detection of cancer; 5, problems related to the nature of CRC screening tests; and 6, mistrust in the health care system. | The findings provide insight into the factors influencing CRC screening among Iranian adults and can help policy makers and health planners in designing effective interventions for increasing CRC screening rates. |
| Bradley et al., (2015) | Northern Ireland | FOBT | – | 28 participants (10 women and 18 men) | <ul style="list-style-type: none"> ► Age 60–71 ► Had not had bowel disease or surgery that would make them ineligible for the NIBCS. ► Had not had colonoscopy in previous year and not on an alternative surveillance programme. ► Had not participated in the NIBCS. ► Had not attended a focus group in the past 2 years. ► Had not been recently bereaved due to cancer. | All had received but not completed a bowel cancer screening kit except for one focus group participant who had recently entered the eligible age range and had not yet received a test kit. | 3 Focus groups | Thematic analysis | 6 key themes were identified: fear of cancer; the test procedure; social norms; past experience of cancer and screening; lack of knowledge or understanding about bowel cancer screening; and resulting behaviour towards the test. | We identified barriers to participation in bowel cancer screening and used these insights to develop new materials to support delivery of the programme. |
| Cooper and Gelb (2016) | USA | FOBT Colonoscopy Sigmoidoscopy | – | 139 participants (68 males and 71 females) | Adults aged 50–75 years who had never been diagnosed with colorectal cancer or polyps and had not been screened as recommended (no colonoscopy within the last 10 years; no FOBT within the last year; and no sigmoidoscopy within the last 5 years in combination with FOBT within the last 3 years). | People who had not received colorectal cancer screening as recommended | 16 focus groups | No information | The most common reason for screening nonparticipation was aversion to some aspect of colonoscopy. Other reasons for screening nonparticipation were absence of symptoms, lack of screening awareness/provider recommendation, and lack of family history. Screening promotion messages that resonated with participants were identified. | Efforts to increase colorectal cancer screening participation may be supported by disseminating messages that counter common concerns about screening. Raising awareness of the range of colorectal cancer screening options may be especially critical given that many unscreened individuals were unwilling to undergo a colonoscopy. |

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Table 2 (continued)

| Authors and year | Country | Test(s) in use | Framework/Theory | Study sample | Inclusion criteria | Definition of non-participants | Data collection methods | Data analysis methods | Study outcomes | Study conclusions |
|-------------------------|-----------|-----------------|--|---|---|--|---------------------------------------|--|---|---|
| Coronado et al., (2015) | USA | FIT Colonoscopy | Grounded theory approach (data analysis) | 20 participants (5 males and 15 females) | Patients who had a clinic visit in the past year, were age-eligible for CRC screening (aged 50 – 74 years), were not up-to-date with screening, and met other study eligibility criteria (e.g., no history of CRC or inflammatory bowel disease) | People who did not return the FIT kit for processing, had not opted out of the program, and were assumed to have a valid address. | 20 one-on-one interviews by telephone | Qualitative content analysis approach with grounded theory coding techniques | Reasons for not completing tests were fear of results or cost of follow-up colonoscopy (n = 9); not having received the test in the mail (n = 7); concerns about mailing fecal matter or that test results could be mixed up (n = 6); and being busy or forgetful (n = 4). | Efforts to improve uptake of colorectal cancer screening in a direct-mailed program ought to address concerns identified in our study. |
| Goodwin et al., (2019) | Australia | FOBT | – | 20 participants (7 males and 13 females). Mean age of participants was 60.7 | Participants were identified through a previous survey study, in which participants were asked to indicate their participation in the screening program. Adults, 50 years or older, living in Australia, were invited to take part in the initial survey. | People were invited to participate if they indicated that they had received a kit through the NBCSP but not completed and returned the kit, and that their reason for nonparticipation was not a medical reason. | 20 interviews | Thematic analysis using an inductive phenomenological approach | Four key themes emerged from interview data. The first reflected intention; whereby participants were either intenders (i.e., they planned to participate) or refusers. Subsequent themes reflected practicalities, emotional reactions, and necessity. Differences between intenders and refusers within these themes as well as opinions regarding interventions were identified. | Interventions involving interactions with health professionals, autonomous decision making, and those which emphasize the positive outcomes of screening may encourage refusers to participate in mail-out bowel cancer screening programs. Messages that reinforce the importance of screening or provide a practical reminder may be more useful for intenders. |
| Hall et al., (2013) | England | FOBT | Grounded theory approach (data collection and data analysis) | 27 participants (14 women and 13 men). Ages ranged from 60 to 72 years. | Participants who volunteered to be interviewed were selected to ensure variation in terms of age, gender, GP practice and how many screening rounds individuals had been invited to take part in. | Patients who had not returned their FOBT screening kits, as sent from the North East Hub of the screening programme. | 27 interviews | Transcripts were coded following the principles of grounded theory | Reasons for non-participation in screening included not feeling that participation is personally necessary, avoiding or delaying decision making, and having some degree of intention to take part but failing to do so because of practicalities, conflicting priorities or external circumstances. | Some non-participants may already have a degree of intention to take part in screening in the future, and this group may be more responsive to interventions based on professional endorsement, repeat invitations, reminders and aids to making the test more practical. |

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Table 2 (continued)

| Authors and year | Country | Test(s) in use | Framework/Theory | Study sample | Inclusion criteria | Definition of non-participants | Data collection methods | Data analysis methods | Study outcomes | Study conclusions |
|--------------------------|---------|------------------------|---|---|---|--|---|---|---|--|
| Hoeck et al., (2020) | Belgium | FIT | – | 41 participants (16 non-migrants and 23 Turkish migrants) | Inclusion criteria were: 56–74 years and being invited (at least once) but not having participated in the CRC screening programme. | Being invited (at least once) but not having participated in the CRC screening programme. | 8 focus groups (4 with participants from the general population and 4 with Turkish migrants). Men and women were separated. | Open coding method. An inductive approach – instead of a theoretical framework – was taken. | Feeling healthy, fear of cancer and embarrassment to talk about CRC screening emerged as common barriers in all FGDs. Having other priorities (non-migrant group) and a lack of understanding mainly due to a language barrier (Turkish migrants) differed between the two groups. Providing face-to-face information, information in group and GP recommendation were perceived as important facilitators to CRC screening in both groups. | Several common and some group-specific barriers and facilitators appeared to play a role in the decision to participate in the CRC screening programme. In order to improve informed decision making and participation in the CRC screening programme in Flanders, the options of more GP involvement, targeted information events, and adapted reminder letters are currently being explored. |
| McCaffery et al., (2001) | England | Flexible sigmoidoscopy | Health Belief Model and Precaution Adoption Process Model (for interpretation of results) | 60 participants (30 men and 30 women) | Asymptomatic general population aged 55–64 years in the UK | People who did not respond to the screening survey (non-responders), and those who responded they were not interested in FS screening. | 60 telephone interviews (3 groups: Non-responders, Definitely not interested, Probably not interested) | A coding scheme was derived from analysis of a set of pilot interviews | The findings suggest that low perceived susceptibility to bowel cancer, in terms of current health status, family history or absence of bowel symptoms, was an important factor in the decision to decline screening. Procedural barriers such as embarrassment, pain/discomfort and perceived unpleasantness of the test were reported as relatively minor, although the test was considered more physically intrusive than other screening tests. | The research has helped to identify the relative importance of different factors already identified by quantitative research and indicates how they might be weighted in the decision process by different groups. This suggests some interesting avenues for both qualitative and quantitative research in the field of cancer screening decision making in the future. |
| Palmer et al., (2014) | England | FOBT | Grounded theory approach (data analysis) | 128 participants (67 men and 61 women) | Individuals residing in areas including the most and least deprived as defined by Index of Material Deprivation who were recorded as having not accepted the invitation to screen on at least one occasion. | Having not accepted the invitation to screen on at least one occasion. | 18 focus groups (repartition: men vs. women; professional occupations vs. non-professional; African-Caribbean ethnicity vs. others) | Inductive approach based on the grounded theory | Participants described sampling faeces and storing faecal samples as breaching a cultural taboo, and causing shame. Completion of the test kit within the home rather than a formal health setting was considered unsettling and reduced perceived | Initiatives to normalise discussion about bowel cancer screening, to link the BCSP to general practice, and to simplify the test itself may lead to increased uptake across all social groups. |

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Table 2 (continued)

| Authors and year | Country | Test(s) in use | Framework/Theory | Study sample | Inclusion criteria | Definition of non-participants | Data collection methods | Data analysis methods | Study outcomes | Study conclusions |
|-----------------------|-----------|---|------------------|--|---|--|--|-----------------------------|---|---|
| | | | | | | | | | importance. Not knowing screening results was reported to be preferable to the implications of a positive screening result. Feeling well was associated with low perceived relevance of screening. Talking about bowel cancer screening with family and peers emerged as the key to subsequent participation in screening. | |
| Rogers et al., (2018) | USA | FOBT FIT Sigmoidoscopy Colonoscopy | – | 27 participants (all men). Mean age: 62.48 | Men who (a) self-described as Somali, (b) were between the ages of 50 and 74, (c) had never obtained CRC screening (FOBT, FIT, sigmoidoscopy, or colonoscopy), and (d) resided in Minnesota | Had never obtained CRC screening (FOBT, FIT, sigmoidoscopy, or colonoscopy) | 3 focus groups | Constant comparative method | Five barriers to CRC screening emerged from the analyses: (1) lack of knowledge, (2) emotional barriers, (3) acculturation, (4) accountability, and (5) fatalistic beliefs. In addition, two factors enabling CRC screening and prevention emerged: the need for tailored interventions and preventive lifestyle behaviors. | The insights gained from this research will assist in developing health promotion and education-focused interventions that encourage Somali immigrants in Minnesota and beyond to seek early detection screening for CRC. |
| Ruffin et al., (2009) | USA | FOBT Flexible sigmoidoscopy Colonoscopy Double contrast barium enema | – | 93 participants (51 African Americans and 42 Caucasian Americans). Mean age: 60 | Eligibility criteria: individuals with self-reported age between 50 and 70 years, and people who had not been screened for colon cancer within the last ten years. | People who had not been screened for colon cancer within the last ten years. | 10 focus group (repartition: men vs women and African Americans vs Caucasian Americans except for one group) | Mixed methods analysis | Participants recognized value of early detection, and identified health symptoms and their doctor's recommendation as influential for obtaining CRC screening. They chose colonoscopy and FOBT as the most preferred tests, while barium enema was least preferred. | New approaches to promoting colorectal cancer screening need to explore methods to facilitate patients establishing and expressing preferences among the screening options. |
| Tan et al., (2017) | Singapore | Colonoscopy | – | 50 colorectal cancer patients and 31 first degree relatives (FDR). Mean age for patients: 63; for FDR: 48. | Inclusion criteria (FDR): eligible to undergo screening colonoscopy as stipulated by the Ministry of Health, Singapore, i.e. only those who are aged at least 50 years or older or are 10 years younger than when | None of the FDR underwent screening colonoscopy. | 50 semi-structured interviews with patients and 31 interviews with FDR | Thematic analysis | For the FDRs, three main themes emerged. These include (i) poor understanding of the exact CRC screening guidelines amongst the FDRs, (ii) the lack of health promotion efforts amongst medical professionals and (iii) barriers to the uptake of | Patients and FDRs are not aware of the increased risks of developing CRC amongst the family members. Guidelines regarding screening are also not clearly understood. The numerous barriers |

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Table 2 (continued)

| Authors and year | Country | Test(s) in use | Framework/Theory | Study sample | Inclusion criteria | Definition of non-participants | Data collection methods | Data analysis methods | Study outcomes | Study conclusions |
|--------------------|-----------|----------------|---|---|--|---|-------------------------|-----------------------|---|--|
| | | | | | the index patient (aged below 60 years) was diagnosed with CRC. | | | | screening colonoscopy such as fear of colonoscopy, high cost of the procedure, its associated inconvenience and perceived invulnerability of the individual. | that are present amongst the CRC patients and their FDRs can be addressed. |
| Tan et al., (2020) | Singapore | Colonoscopy | The study was designed based on the Social Cognitive Theory | 36 siblings of colorectal cancer patients (19 females and 17 males). Median age: 59 | Inclusion criteria: siblings who are eligible to undergo screening colonoscopy as stipulated by the Ministry of Health, Singapore. | None of the participants has undergone screening colonoscopy. | 36 in person interviews | Thematic analysis | Five themes were identified. These include: (i) Misunderstanding their own risk of developing colorectal cancer; (ii) Misperceptions of the role of “screening” for colorectal cancer.; (iii) Misconception of the CRC screening modality for FDRs; (iv) Barriers and facilitators of undergoing screening; (v) Misperceptions of national healthcare policies. | Identifying and addressing the identified barriers for these siblings to undergo screening colonoscopy is easily attainable. A multi-pronged approach should also be adopted to address the various concerns so as to reduce the incidence of CRC amongst these higher risk individuals. |

3.5. Lack of awareness and knowledge about colorectal cancer and screening (reported in 9 studies)

A general lack of awareness and knowledge was reported in most studies as a barrier to screening participation. As people ignore some information that could act as a motivator and have a positive impact on their decision (e.g. colorectal cancer is a common cancer), this lack of awareness and knowledge can result in a non-participation.

Most interviewees in Hall et al. (2013) reported a *perceived lack of knowledge* about the disease, even for those who knew people with colorectal cancer, and that *specific awareness of the programme was low*. Interviewees mentioned that they had been *surprised* both when they received the invitation letter and when they discovered the screening procedures. They often felt that it had arrived “*out of the blue*” and they described the process as “*unfamiliar*” or “*alien*”. The surprising aspect was also mentioned in Bradley et al. (2015). The test kit was often described as *difficult to distinguish from junk mail and private advertising*, and the test procedure was not well understood. In addition, a lot of participants were *surprised at how common bowel cancer is*. Almost all participants reported that they did not know who had sent the invitation and only a minority of participants knew people who had been screened already.

“When I got that I didn’t have a clue where it even came from.” (Bradley et al., 2015)

In contrast, findings from Coronado et al. (2015) showed that most of the participants were aware of the stool card method of screening and the colonoscopy method. Various beliefs about colorectal cancer were expressed, this disease was seen as *dangerous* and beliefs were *shaped by personal or relatives’ history*.

“I have actually taken care of people who have had colon cancer. It is serious ... So, I think we should take care of ourselves.” (Coronado et al., 2015)

In Cooper and Gelb (2016), most participants had already received a colonoscopy recommendation. Half of the participants knew about the FOBT. Some knowledge was expressed by participants regarding risk factors and polyps. However, *lack of awareness in general* was mentioned as a barrier to screening participation.

“I was really surprised about it [colorectal cancer] being the second leading killer.” (Cooper and Gelb, 2016)

In the case of first-degree relatives of colorectal cancer patients, *misperceptions* and a *poor understanding of the colorectal cancer screening guidelines* were highlighted in Tan et al. (2017) and Tan et al. (2020). They were also not aware of their increased genetic risk for colorectal cancer and the need to undergo screening colonoscopy.

“I think it is better to get yourself screened at the age of 50 years old. Regular health screening should be able to cover everything. But I am not aware of the guidelines.” (Tan et al., 2017)

Lack of knowledge and acculturation (cultural issues) were mentioned as barriers in Rogers et al. (2018). Participants suggested using *stories of colorectal cancer survivors* to increase colorectal cancer screening uptake.

“Most Somalis don’t know about colorectal cancer, stomach cancer, or any specific cancer at all. However, I believe if the resources were out there to educate us, everyone would seek them out.” (Rogers et al., 2018)

Similarly, a lack of awareness and knowledge was mentioned in Besharati et al. (2018). The majority of the participants were unaware of the symptoms of colorectal cancer and believed that *as far as they do not have any symptoms, they are not threatened*. Some participants outlined the *role of mass media in promoting self-care and early detection practices*.

“They (public health officials) should have a plan during health week by the name of “FOBT” to raise awareness, put up banners, and have teasers that people over certain age can go to some stations for this test and say what the advantages of this test are.” [Male] (Besharati et al., 2018)

In line with previous studies, a *lack of knowledge and understanding* was found in Hoeck et al. (2020), specifically for Turkish migrants. Consequently, Turkish participants indicated *translated information (even only partly)* as a facilitator for the colorectal cancer screening.

“Nobody understood that letter. It would surprise me if someone did. We received it and threw it away” [male, Turkish] (Hoeck et al., 2020)

In summary, a general lack of knowledge and awareness regarding colorectal cancer is expressed, showed by a common reaction of surprise at the receipt of an invitation to participate in screening. This lack of knowledge can be worsen by cultural barriers or misunderstanding of the recommendations for screening. However, experiences of relatives can help people being aware of colorectal cancer.

3.6. Varying degrees of intention and the role of postponement (reported in 7 studies)

Results from included studies showed a complex interaction between intention and action. Although no one in the included studies actually took part in screening, there were differences in how much people intended to take part, and non-participation was not always intentional.

Findings from McCaffery et al. (2001) showed various reactions to the screening invitation. While some people had clearly made a decision not to participate (Definitely Not Interested respondents), others had *little memory* of the invitation letter (Non-responders), and a third category of people was *unsure about their decision* (Probably Not Interested).

“I thoughtoh I’ll look at that later, and it never even occurred to me to read through it again.” [Non-responder] (McCaffery et al., 2001)

“I just said no and that was it.” [Definitely Not Interested] (McCaffery et al., 2001)

Similarly, accounts from Hall et al., (2013) showed that participants reported various levels of intention to participate in screening, but none of them returned a kit. More precisely, some interviewees had an intention to perform the screening test but failed to do it, some did not have any such intention, and others *put off making a decision*.

“It was a quicker decision the second time. The first time I did think about it.. the second time I didn’t” [female, 66 years] (Hall et al., 2013)

Delaying uptake, leading to non-uptake, was also found in Palmer et al.’s (2014) study, *implying some degree of intention to participate*. This delay seems to be due to a perception of the test as being complicated to perform.

“You’ve got to really sit down and read it, y’can’t, it’s not just something you can pick up and say ‘oh I’ll go and do that now’, you’ve got to study it.” (Palmer et al., 2014)

Similar results were found in the study of Bradley et al., (2015); participants described that the test kits were *set aside for a period of time*, perhaps *with an intention to complete it at a later stage*, but finally *kept indefinitely or eventually put in the bin*.

“Opened it up had a look at it and just put it in the corner and thought I’ll do it in a while.” (Bradley et al., 2015)

Procrastination was also described in the results of Cooper and Gelb (2016).

"I keep putting it off. I guess I am just lazy." (Cooper and Gelb, 2016)

Goodwin et al. (2019) categorized non-participants as either intenders or refusers. *Forgetting about or losing the kit or delaying the use of it* was often reported by intenders.

"I kept going back thinking I really should do this, but I never—you know, I never did it." [52-year-old female intender] (Goodwin et al., 2019)

Postponement was also mentioned in Hoeck et al. (2020), in which participants admitted that barriers such as lack of time or postponement are *mainly fallacies or superficial drivers instead of real motives*.

"Postponing... I always have an explanation, I say I have diarrhea, so it won't be possible. Yes, [these are] all excuses" (Hoeck et al., 2020)

In summary, non-participants were not all non-intenders and some of them showed motivation to undertake screening. However, postponement and procrastination can act as strong obstacles for people who had some degrees of intention, resulting in non-participation.

3.7. Screening as important but not personally necessary (reported in 10 studies)

In the majority of studies, positive attitudes towards screening were reported, however, this did not necessarily mean that individuals felt a personal need to take part in screening. This can be interpreted as a phenomenon of ambivalence.

Positive attitudes towards cancer screening in general were expressed by the majority of participants in McCaffery et al. (2001). A contrast was acknowledged between *positive attitudes in general* and *failure* by the individual to *respond positively* to the invitation. Participants often referred to the test as *unnecessary* in order to explain their decision not to participate in screening. *Issues relating to their family history of cancer and bowel cancer and a lack of bowel symptoms and feelings of good health* were expressed by participants to justify their views.

"I think that it's a good idea, especially in high risk places. I classify myself as a medium risk." (McCaffery et al., 2001)

Participants in Ruffin et al. (2009) often cited *early detection* as a *primary reason* to participate in screening. *Health symptoms or problems; family genetics or family history; age and physical symptoms* were also mentioned. Similarly, the importance of cancer screening and early detection was recognized by almost all interviewees in Hall et al. (2013).

"I'm totally convinced of its necessity in the sense that if you're offered something that can save your life, you're stupid to turn it down". (Hall et al., 2013)

Positive attitudes towards screening were expressed even by participants who thought that *screening was unnecessary for them personally*.

This judgment of good health (having healthy behaviours or feeling healthy) and low relevance of screening was also found in Rogers et al. (2018), Hoeck et al. (2020), and in Palmer et al. (2014). Many participants in Palmer et al. (2014) believed that screening was *irrelevant* because they were convinced *they did not have, and were unlikely to get, colorectal cancer*. This was justified by a *lack of symptoms, being physically active and having no family history of bowel cancer*. Similar results were found in Coronado et al. (2015), Cooper and Gelb (2016), and Tan et al. (2017).

"I've got no symptoms so I'm alright, y'know, I go to the toilet regular and y'know, I exercise and I'm fit." (Palmer et al., 2014)

"It's not a necessary thing for me to do ... I personally don't have bleeding or anything unusual [with bowels]." (Coronado et al., 2015)

On the contrary, screening was considered necessary by participants in Goodwin et al. (2019). This was especially mentioned by intenders,

who also expressed *feelings of regret or guilt* for non-completing the screening test.

"I should really do it, shouldn't I? It makes sense to have it done because early detection is obviously the key to fixing the problem and I know someone who had bowel cancer and it was left a little bit late and she had incredible problems ... you realize you're becoming a greater risk for some of these things because you're getting older". [71-year-old female intender] (Goodwin et al., 2019)

In summary, while screening is often perceived as important, many participants yet remain ambivalent as they don't see a personal interest in getting screened and so they fail to have a sufficient motivation to undertake screening. This low motivation seem to be due in particular to a perceived lack of symptoms, a lack of risk factors, or a general feeling of good health.

THEME 2. ACTIVE AVERSION TO SCREENING: NEGATIVE REACTIONS TO THE PROCESS AND CONSEQUENCES OF SCREENING

The second theme illustrates the aversion expressed by non-participants when invited to screening or while making a decision to participate or not. Negative reactions were separated into three sub-themes: negative emotions acting as deterrents (low acceptability, discomfort, disgust and embarrassment); fear and worry about the consequences of screening; and preference for not thinking about screening and cancer.

3.8. Negative emotions acting as deterrents (reported in 12 studies)

In 12 of 13 studies, the screening procedure was perceived by participants in a negative way. Low acceptability, disgust, embarrassment and discomfort associated with tests for colorectal cancer screening were commonly discussed across studies.

In Hall et al. (2013), commonly mentioned issues related to FOBt included *suitable equipment to catch the stools with, avoidance of contamination with toilet water, hygienic disposal of any equipment used, storage of the kit and having required equipment when and where it was needed*. Most participants who had the intention to participate in screening described "*mentally rehearsing*" the process, however many of them had a low perceived self-efficacy and lacked confidence in their *ability to complete their kit correctly*. According to women, other screening programmes required less "*consideration*" and *preparation* than colorectal cancer screening programmes.

"It's not like your smears or mammograms or anything like that. You get an appointment you do it and that's a lot easier.. you go, you get it done, that's it.. This is actually having to organise yourself and I think that's more difficult You can almost join in the rest of the screening programmes quite mindlessly if you know what I mean." (Hall et al., 2013)

Similarly, participants in Palmer et al. (2014) reported *discomfort* with the *detachment of FOBt testing from 'usual' health-care settings*. For them, it was *unusual* to have an *active role in a health procedure*, while they have the habit of being *passive "receiver" of care*. The *impersonal nature* of the screening programme was also perceived in a negative way in Coronado et al. (2015).

"I thought 'oh my god now we are asked to be doctors'" (Palmer et al., 2014)

"I remember exactly how it made me feel, I was really taken aback by something so personal being sent in the mail. I was like, 'Good god, what is this?' I was really amazed ... I know it's an outreach program, but it's like, you are dealing with poop — I mean, where is the personal touch here?" (Coronado et al., 2015)

Another related barrier found in Bradley et al. (2015), Besharati et al. (2018), and Goodwin et al. (2019) was *disgust* at the idea of having to

handle own faeces, and concern for mess or germs.

"I didn't like the idea of it, collecting my bits of poo." (Bradley et al., 2015)

There were mixed views about the difficulty of completing the kit. One issue particularly highlighted by participants was the necessity to take samples three times (for the FOBt).

"If it was just one time, I would that's alright, but over three consecutive days, particularly when you're working and whatever else, and I guess, yes, I am making excuses, but it's just too hard, it's just too hard." [59-year-old male intender] (Goodwin et al., 2019)

Participants in the study of Coronado et al. (2015) mentioned similar concerns about the FOBt: *handling fecal matter* was described as *unpleasant, embarrassing, unsavory, and socially unacceptable*. Additionally, some participants also expressed concerns regarding the process of sending fecal matter through the mail. This process was described as "odd", and participants feared the results could become *mixed up* with others' results.

"I just thought it was kind of weird. They want me to play in my poop ... and you want me to send this to you through the mail?" (Coronado et al., 2015)

Findings from Palmer et al. (2014) also highlighted an *aversion* to complete FOBt kit as *handling faeces* was considered by participants as *abnormal* and *taboo*. This activity could cause embarrassment and shame: *being found to have stored or posted faecal samples* was considered to be *socially and personally damaging*.

"People's hands have to handle this yes? You don't know how strong germs get ... so I don't fancy it going through the post." (Palmer et al., 2014)

However, in McCaffery et al. (2001), although some participants thought that *the procedure might be embarrassing*, the majority did not perceive embarrassment as having a major impact on their decision-making.

In Hoeck et al. (2020), shame was mentioned in relation to handling stools, but also to the eventuality of undergoing a colonoscopy, or to a *reluctance to talk with family and friends* about screening.

"Is it also because of the shame. For many people, I guess. Some poop and stuff, no..." (Hoeck et al., 2020)

However, in the same study, although a *general embarrassment to talk to others about colorectal cancer and stool samples* was cited as a barrier, the discussions during the focus groups were not described as *shameful*. *The power of discussing the topic in group* had also an *unintended effect* on the focus groups' participants: many of them were convinced to participate in screening as a result of these discussions. *Information in group* and *more publicity* (need for more information) were cited as potential facilitators to screening participation.

Participants in Coronado et al. (2015), Cooper and Gelb (2016), Ruffin et al. (2009), Tan et al. (2017) and Tan et al. (2020) expressed concerns regarding invasive tests such as colonoscopy.

"I wouldn't want to have that probe stuck up ... it would be quite uncomfortable" (Ruffin et al., 2009)

"They have to drink the liquid and they have to keep going to the toilet. The process is actually very fearful and uncomfortable." (Tan et al., 2017)

Although a range of negative perceptions of screening were described, fear of pain did not seem to be a reason why people did not take part. For example, *very few people referred to pain* as the reason not to have a flexible sigmoidoscopy (endoscopic procedure) in one study (McCaffery et al., 2001). Some participants described having *already made a decision without considering pain*; some others thought the test

would not be painful; and others thought they could cope with the pain.

"I've never been bothered about pain If you've got to suffer the pain you suffer it, and that's that." (McCaffery et al., 2001)

In summary, negative emotions were widely expressed by the participants, and in particular a low acceptability, a feeling of embarrassment and disgust, and a general discomfort associated with screening tests. Negative emotions can induce a strong aversion towards the screening process.

3.9. Fear and worry associated with the consequences of screening (reported in 7 studies)

Results from included studies highlighted the negative emotions associated with the consequences of screening.

Fear, worry and anxiety were expressed by participants in McCaffery et al. (2001). Participants conveyed a *fear of unknown*, involving a *fear of unknown procedures* as well as a *fear of not knowing what the test might find*.

"I don't want to have the worry it's the worry if they do find anything" [Definitely Not interested] McCaffery et al. (2001).

Fear was also strongly expressed by participants in Bradley et al. (2015), mostly regarding the *shock* provoked by the receipt of the test kit the first time, or fear about the results of the test.

"It's kind of scary and it's all leading up to the result". (Bradley et al., 2015)

Similarly to previous studies, fear of procedures and fear of results were mentioned in Coronado et al. (2015).

"There is risk with that [colonoscopy] when they put you completely under ... you can die right there and then". (Coronado et al., 2015)

In the results of Rogers et al. (2018), fear was associated with the word *cancer* or its *diagnosis*. Participants expressed *fatalistic beliefs* (cancer diagnosis seen as a *death sentence*, *lack of faith in access to medicines*).

"Cancer has become the precedence of fear in a sense. So, when I thought of it, I thought of no medicine, just afraid, this is a very bad disease, deadly disease". (Rogers et al., 2018)

Findings from Besharati et al. (2018) showed a *high anxiety level* related to the *detection of cancer*. Fear of cancer was mentioned by most of the participants as an important barrier. Fear of *being a burden on family members* (economically, psychologically, and physically) was also mentioned by some participants.

"We don't want to bother the family and relatives. We ourselves tolerate the disease, the ultimate result is obvious." (Besharati et al., 2018)

In Goodwin et al. (2019), participants who refused screening (vs intenders) often mentioned a *negative emotional reaction to receiving the kit*. It was seen as a *reminder that they were "getting old"* or *evoked thoughts about their own mortality*. Refusers and intenders expressed *concern over the emotional impact of using the kit*, negative emotions acting as a barrier. *Worry and anxiety around the possibility of receiving a positive result* were often cited by refusers.

"You think I'm old and I may be sick which puts a fear in my mind, which is not pleasant It's invasive in the sense that you are receiving something which, number one, says its only sent to people over a certain age and it reminds you that you are there". [63-year-old female refuser] (Goodwin et al., 2019)

In Hoeck et al. (2020), fear was mentioned in different ways: fear of the result, (*already having had cancer or the negative associations with cancer*) or fear of the broader medical context (*fearing hospitals and medical*

investigations in general) and fear of cancer itself.

“Just the word, colon cancer or cancer, when you hear about it you get in a bad mood. You just don’t want to hear about it”. (Hoeck et al., 2020)

In summary, accounts from included studies show that the screening invitation can induce a strong feeling of fear and anxiety as it brings out the possibility of a cancer diagnosis and a consideration of all the negative consequences associated. This unsolicited invitation tends to be rejected by participants.

3.10. Ignorance is bliss: No screening, no diagnosis. No diagnosis, no disease (reported in 9 studies)

A common preference expressed by participants across studies was to stay ignorant of their own health status.

McCaffery et al. (2001) mentioned the presence of *avoidance beliefs*. A preference for not knowing about problems or “*leave well alone*” was expressed by participants in this study. Two reasons for avoidance were identified: to prevent *psychological harm (unpleasant emotional consequences of screening)* and to prevent *physical harm* (due to the flexible sigmoidoscopy procedure).

“I think a lot of things are best left alone”; “... leave sleeping dogs lie”; “...if it’s not broke then you don’t have to mend it.” (McCaffery et al., 2001)

Not thinking about colorectal cancer was also found in Ruffin et al. (2009).

“I never really thought about being tested.” [female, semi-urban area] (Ruffin et al., 2009)

The implications of knowing the screening results were mentioned in Palmer et al. (2014). Participants expressed a preference for ignoring this information for several reasons. First, participants mentioned the *undesirable implications of a positive result* (colonoscopy, potential cancer diagnosis). Second, participants made a distinction between “*being unwell*” and “*knowing about being unwell*”. A positive screening result would be associated with a need to “*redefine themselves as being unwell, which they did not wish to do because they believed it was unnecessary*”. Thus, according to the authors, participants may have an *alternative reading of screening as an activity that, rather than maintaining good health, may actually be complicit in generating ill health*.

“If there’s something the matter with me now, and I don’t know about it, I’m fine. If somebody says I’ve got a problem, I’m going to worry about it, and I don’t want that, you know you live life as it is now and I don’t want people finding things.” (Palmer et al., 2014)

Findings from Coronado et al. (2015) show similar findings: participants preferred ignoring their health status.

“It’s not something I am ever going to do. I just think if there is nothing wrong that you are aware of then you shouldn’t mess with it, you should just leave things alone. And I have always felt that way about any kind of procedure.” (Coronado et al., 2015)

In line with previous studies, a few participants in Cooper & Gelb study (2016) indicated that *they would prefer to die of cancer without it ever being diagnosed*.

“I don’t want to know if I have cancer.” (Cooper and Gelb, 2016)

The same idea was mentioned by participants in Besharati et al. (2018), colorectal cancer being seen as an *incurable disease*. Consequently, some participants stated that they would prefer to *delay the diagnosis or not know*.

“I saw many who fear to do the test because of a probable positive result; I myself have never done the test. Its treatment is difficult, better not to know.” (Besharati et al., 2018)

A reference to religious beliefs was made in Rogers et al. (2018), “*divine will*” being considered as having an influence on *individual disease and health outcomes*.

“... the doctors here on Earth don’t know how to treat some illnesses like cancer and typically Allah (God) can do it, actually Allah can do it. The way that you get away from diseases or sickness of any sort is that you do good on earth.” (Rogers et al., 2018)

In addition, some participants in Hoeck et al. (2020) had the *firm conviction that one should not intervene preventively and “to let nature take its course”*. Distrust was expressed, due to *negative stories from others*, and *doubts about the validity of the programme and the safety of a potential follow-up colonoscopy*.

“My mother always said ‘when you have no complaints, you should not intervene’.” (Hoeck et al., 2020)

Past experience of cancer and screening can also contribute to encourage or prevent screening participation according to the results of McCaffery et al. (2001) and Bradley et al. (2015). A lot of participants *knew people who had cancer*, but their experiences *often focused on the side effects and futility of treatment*, even if many participants understood the benefits of early treatment.

“A lot of the time it’s too late anyway, I’ve seen what chemo does to someone and that person was going to get 5 years at the most.” (Bradley et al., 2015)

“We both know people who have had early bowel cancer and not survived, and that’s probably one of the reasons that we decided not to have it.” (McCaffery et al., 2001)

In summary, a preference for staying ignorant of a potential cancer diagnosis is expressed for various reasons, such as the avoidance of an undesirable redefinition of own health status, or a fatalism about the outcome of a cancer diagnosis. This preference leads to a negative reaction to the screening invitation.

THEME 3. CONTEXTUAL BARRIERS: PRACTICAL CONSTRAINTS AND HEALTHCARE PROFESSIONALS INFLUENCE

The third theme includes the barriers expressed by non-participants reflecting contextual barriers associated with the healthcare system. Two subthemes explore the practical constraints and the influence of healthcare professionals.

3.11. Practical barriers to screening (reported in 9 studies)

Practical barriers were expressed by participants to explain their non-participation in screening, which might vary according to the screening procedure.

Several practical barriers to flexible sigmoidoscopy screening were mentioned by participants in McCaffery et al. (2001): inadequate timing, having other priorities, problems with taking time off. However, participants acknowledged that any practical problems could be dealt with and were *secondary to their lack of motivation for the test*.

“... my husband ... would take me if I wanted to go.” (McCaffery et al., 2001)

Another practical aspect emerged from Ruffin et al. (2009) about US participants: *insurance as a factor*. A lot of participants mentioned that test cost and insurance coverage *had a direct effect on their test choices*. Costs were also mentioned as a barrier in Coronado et al. (2015) as well as in Cooper and Gelb (2016).

“That’s part of the pain – if you don’t have insurance.” (Ruffin et al., 2009)

“When I received it I said this is cool, you know, I will definitely do this. But like I said, because of my current financial situation, I set this [colorectal cancer screening] kind of on a back burner since I’ve been so preoccupied trying to figure out if I can keep my home” (Coronado et al., 2015)

In Hall et al. (2013) and in Hoeck et al. (2020), *conflicting priorities or events* were also common reasons given to explain non-participation in screening among those who had not actively decided against taking part (e.g. other health priorities, stressful life events, inadequate timing).

“Currently with my wife, with her chemo, I’m not going to be sick as well” (Hoeck et al., 2020).

Similar results were found in Tan et al. (2017) and Tan et al. (2020): *cost of colonoscopy and inconvenience* (e.g. lack of time) were cited as barriers. However, some participants in Tan et al. (2020) felt that the frequently quoted barrier of “inconvenience” is simply down to mindset and inertia.

“We can always make time, it’s our mindset. It’s whether I want or I don’t” (Tan et al., 2020)

Similarly, financial problems (*cost of tests and inadequate insurance coverage*) were expressed by participants in Besharati et al. (2018), especially for low income people. In addition, a *low priority* given to health (*competing priorities*) was also mentioned as a *cultural issue* in the Iranian population.

“The tasks and problems, with which people have dealt every day, stop them visiting doctors or doing tests.” (Besharati et al., 2018)

In summary, practical constraints mainly refer to transportation difficulties, financial aspects, or inadequate timing. However, as expressed by participants themselves, those practical barriers could be overcome with a sufficient motivation.

3.12. The role of healthcare professionals (reported in 6 studies)

Healthcare professionals were often mentioned by participants as being able to influence their motivation to participate in screening. This influence seems to be strongly impacted by the quality of the doctor and patient relationship.

Lack of trust in doctors (e.g. *does not spend enough time with patient*) was cited as a barrier in Coronado et al. (2015). Lack of provider recommendation and *aversion to doctors* was also mentioned in Cooper and Gelb (2016).

“My doctor never told me to be screened.”

“I haven’t seen a doctor in 14 years.” (Cooper and Gelb, 2016)

Tan et al. (2017) found that the *lack of health promotion efforts by medical professionals* is a barrier to colonoscopy screening among first-degree relatives of colorectal cancer patients.

“The doctor mentioned once for the need to have me screened but thereafter, (he) never discussed this again.” (Tan et al., 2017)

Similarly, participants in Rogers et al. study (2018) assigned *responsibilities* to their doctor for providing information about screening. A need for *improved patient-provider rapport* was mentioned. Participants related *anecdotes of physicians being impolite or insensitive*, failing to be caring and to provide *sufficient information about the disease and screening process*. A *mistrust* in healthcare system was also found, with participants assuming that *the medical field is primarily motivated by sales and profit*. Participants suggested more *dialogues* and *education sessions* with physicians.

“... I do have a complete fear of doctors, due to previous bad experiences. So, how do you expect Somalis or even I to make it easier for themselves to go to the doctor for colorectal cancer screening when the doctors themselves are not sensitive and polite?” (Rogers et al., 2018)

Findings from Besharati et al. (2018) also showed *issues related to trust in the health care system in general*, and physicians were cited as influencing factors to *neglect* colorectal cancer screening. More precisely, participants reported a *lack of physician recommendation*, a *distrust of physicians*, and a *poor physician-patient relationship*.

“Physicians don’t know all that’s going on and pay no attention to us.” (Besharati et al., 2018)

Some participants in Hoeck et al. (2020) indicated that *although their GP had already raised the subject, this had not influenced their decision*. A good relationship between the patient and the GP seemed to be essential for patient to follow GP’s recommendation for screening.

Interviewer: “Your GP would leave a stronger impression than such a meeting?”

Participant: “Yes, but only when you have faith in your doctor” (Hoeck et al., 2020)

In summary, this subtheme outlines a general trust issue towards the healthcare system and communication difficulties with healthcare professionals that seem to go beyond the specific topic of colorectal cancer screening.

4. Synthesis

Based on these third order constructs, we developed a line of argument illustrated in Fig. 2. Our interpretation of non-participation in colorectal cancer screening explores several paths leading to non-participation. First, people may have some degree of intention to participate, but fail to translate their intention into action (e.g. due to postponement and procrastination), or might feel that screening is not necessary for them personally. This ambivalence can lead directly to a decision not to take part in screening. Second, people may express an active aversion to screening due to negative emotions and have no intention to participate in screening (so they don’t participate in screening). Third, where ambivalence does not result directly in a non-participation, people might face subsequent barriers such as practical constraints or lack of support from healthcare professionals that would finally result in non-participation.

5. Discussion

5.1. Summary of findings and comparison with other studies

By bringing together qualitative studies focusing on people who have not participated in screening, this meta-ethnography has developed a novel line of argument describing various pathways to non-participation. Our findings highlight the complexity of non-participation, which does not always result from active refusal, but may be due to ambivalence, postponement, practical barriers or lack of support from healthcare professionals.

5.1.1. Differences in motivation related to colorectal cancer screening

The first theme outlined a lack of awareness and knowledge about colorectal cancer and screening. This result is consistent with the findings of several systematic reviews about colorectal cancer screening (Kolahdooz et al., 2014; McLachlan et al., 2012; Wools et al., 2016).

Delaying and forgetting screening is an important result in the present review. According to a qualitative study conducted in Scotland comparing the three organized cancer screening programmes, the colorectal test could be more easily delayed or forgotten than breast or

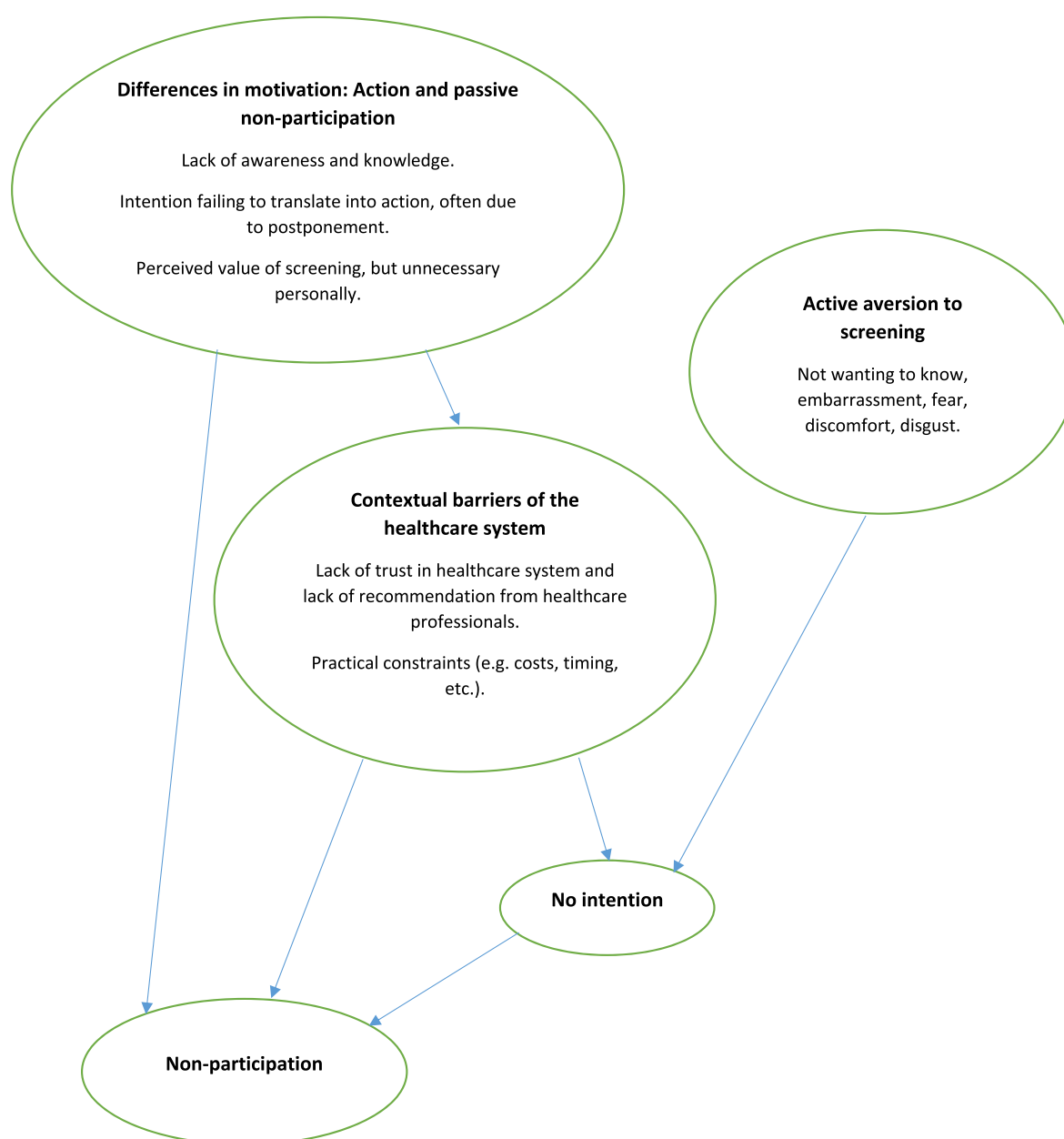


Fig. 2. Line of argument.

cervical screening (Kotzur et al., 2020). Similarly, procrastination was cited as a barrier in a systematic review about patient adherence to publicly funded colorectal cancer screening programmes (Dressler et al., 2021). This phenomenon might be due to the fact that colorectal cancer screening using a faecal test involves several steps (requesting the kit, performing the test, sending back the screening kit to the laboratory) and thus requires a deeper engagement and a stronger motivation than other screening procedures requiring only one step.

Our findings showed that some people have a range of intentions to participate, but still don't take part in screening. In addition, while people invited to participate in screening usually seem to have positive attitudes towards screening, this does not necessarily lead to a subsequent screening participation. Indeed, our results showed that eligible people can feel that although screening is important, they don't feel the need to do it personally as they don't have symptoms. This phenomenon of ambivalence was also found in several studies (Broc et al., 2017; Le Bonniec et al., 2020; Oster et al., 2013).

Therefore, the intention-behaviour gap highlighted in studies about

many health behaviours (Rhodes and de Bruijn, 2013) seem to apply to colorectal cancer screening. In this logic, the distinctions between different kinds of non-participants (e.g. intenders, inclined abstainers, refusers) proposed by the authors of three of the included studies seem particularly relevant (Goodwin et al., 2019; Hall et al., 2013; McCaffery et al., 2001). A similar distinction was made between non-responders, active decliners and non-attenders in a quantitative study conducted in UK about flexible sigmoidoscopy screening (von Wagner et al., 2018). Orbell and Sheeran (1998) introduced the concept of "inclined abstainers" to highlight the inconsistent association between motivation and behaviour. Previous work conducted in France about faecal occult blood test also made a distinction between non-intenders, successful intenders (people who had the intention and then participated in screening) and unsuccessful intenders (people who had the intention to participate in screening but failed to move from intention to action), the latest representing 71% of the quantitative study sample (Le Bonniec et al., 2021).

5.1.2. Active aversion to colorectal cancer screening

The second theme revealed that negative emotions to the screening procedure were often expressed. In accordance with our findings, the negative effects of disgust (Chambers et al., 2016b; Reynolds et al., 2013; Scaglioni et al., 2021) and fear (Adams et al., 2017; Dressler et al., 2021; Majidi et al., 2017; McLachlan et al., 2012) on colorectal cancer screening participation are frequently mentioned in the literature. In the review of Young et al. (2018) about cancer screening attendance in UK, fear was however described as being both a motivator and a barrier to screening participation. In addition, similar to our findings, a preference for ignoring one's own health status was also found in the systematic reviews of Dressler et al. (2021) about colorectal cancer screening and Teo et al. (2016) about health screening procedures in men.

5.1.3. Contextual barriers and influence of healthcare professionals

While practical barriers such as lack of time or financial aspects were interpreted as secondary to a lack of motivation in our meta-ethnography, these are common barriers to screening participation in the literature. Time constraints or costs of colonoscopy were mentioned in the systematic review of Dressler et al. (2021), and having competing priorities was also found as impeding screening participation in an Irish qualitative study about the decision to participate in colorectal cancer screening (Clarke et al., 2016). However, as in our meta-ethnography, having other health concerns, competing life demands or scheduling challenges were categorized as a lack of motivation in the qualitative review of Honein-AbouHaidar et al. (2016).

The last theme highlighted the influence of healthcare professionals. In accordance with our results, relationships with the health services were found as having an influence on cancer screening attendance in the UK (Young et al., 2018). More broadly, receiving a screening recommendation from a healthcare professional has been cited as a facilitator to colorectal cancer screening participation in numerous reviews (Dressler et al., 2021; Honein-AbouHaidar et al., 2016; Peterson et al., 2016; Travis et al., 2020).

5.2. Strengths and limitations

This review provides an important synthesis of non-participation in screening, focusing on an understudied population which is difficult to recruit in research: the non-participants. Another strength is the diversity of studies included in this meta-ethnography, conducted in different countries and about different screening tests, providing a good overview of this complex phenomenon. However, the present review has some limitations that should be highlighted. It is important to acknowledge that participants of included studies chose to take part in a study on this topic, and they may have different views than people who did not want to engage in research. In addition, another source of bias is that we included articles from 2001, and as screening programmes may have changed over time, the barriers expressed by participants may not all reflect the current screening specificities (e.g. the change from FOBT (3 samples) to FIT (1 sample) screening in some countries). Another limitation that must be considered is related to the effect sizes of the included studies. In our analysis, equal weight was given to each study regardless of the number of participants included of each study. This review also inevitably reflects the limitations of the included studies in terms of representativeness and consequently, our findings have limited generalizability.

5.3. Recommendations and future research

This review provides evidence to suggest several cues to action to encourage eligible people to participate in screening: improving knowledge and awareness through media; developing practical approaches to overcome barriers (i.e. people seem to feel more capable to perform a FIT-requiring only one sample and no storage-than a FOBT); providing materials to prompt healthcare professionals to bring up and

follow-up on colorectal cancer screening with their patients; and using persuasive communication highlighting the benefits of screening for people without symptoms. Regarding the faecal tests, the FIT is perceived as less disgusting to complete than the FOBT (Chambers et al., 2016a). Highlighting that the test is hygienic and that the stool sample to be taken is very small might help people to overcome aversion and disgust. In addition, improving knowledge around survival of cancer (cancer not being a death sentence) could overcome the barrier of not wanting to know often mentioned as a reason for non-participation in screening. This could help people to overcome the ambivalence and negative emotions towards screening. Our findings also suggest that different types of interventions might be needed depending on level of intention.

Patient narratives could be used as a strategy to reduce aversion (i.e. disgust) or ambivalence towards screening. A study conducted in the UK showed that adding a narrative leaflet with the standard information had a positive impact on beliefs about colorectal cancer screening, which led to stronger screening intentions (McGregor et al., 2015). However, another randomized control trial conducted in the UK concluded that narratives had a positive effect on knowledge, attitudes and intention but no effect on colorectal cancer screening behaviour (Wardle et al., 2016). It is probable that determinants of behaviour differ from determinants of intention (Wardle et al., 2016).

Developing interventions using techniques of implementation intentions might help people (who have some degrees of intention to participate in screening) to move from intention to action. However, previous interventions using this method showed mixed results regarding its efficacy to increase colorectal cancer screening uptake. A study conducted in UK concluded that preformulated implementation intentions failed to increase colorectal cancer screening uptake (Lo et al., 2014). In contrast, another study conducted in Israel showed that implementation intentions techniques were useful in increasing adherence to colorectal cancer screening, even in a mailed form (Neter et al., 2014). More research is needed to explore these differences in effect.

Finally, a need for a greater use of theory to develop intervention content that targets determinants of screening uptake to specific contexts has been highlighted (Rawl et al., 2012). Our findings suggest multiple routes to non-participation. Overarching frameworks like the COM-B with the Behaviour Change Wheel (Michie et al., 2011) could inform the development of interventions targeted at the various reasons for non-participation.

6. Conclusion

This meta-ethnography gathered and analysed qualitative studies exploring non-participation in colorectal cancer screening. Findings showed that non-participation is a complex phenomenon with multiple paths leading to non-participation ranging from negative attitudes and no intention to participate, to positive intentions but ambivalence or subsequent barriers which result in non-participation. Further studies should evaluate innovative interventions to help people to overcome ambivalence and emotional or practical barriers to screening. Finally, future research should investigate the links between intention and behaviour in colorectal cancer screening.

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Declaration of competing interest

The authors report there are no competing interests to declare.

Data availability

Data will be made available on request.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.socscimed.2023.116022>.

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