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**REVIEW**

WILEY

# Barriers to flexible sigmoidoscopy colorectal cancer screening in low uptake socio-demographic groups: A systematic review

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**Abstract**

**Objective:** To synthesise qualitative evidence related to barriers and facilitators of flexible sigmoidoscopy screening (FSS) intention and uptake, particularly within low socio-demographic uptake groups. FSS uptake is lower amongst women, lower socio-economic status (SES), and Asian ethnic groups within the United Kingdom (UK) and United States of America.

**Methods:** A total of 12 168 articles were identified from searches of four databases: EMBASE, MEDLINE, PsycINFO and Web of Science. Eligibility criteria included: individuals eligible to attend FSS and empirical peer-reviewed studies that analysed qualitative data. The Critical Appraisal Skills Program tool evaluated the methodological quality of included studies, and thematic synthesis was used to analyse the data.

**Results:** Ten qualitative studies met the inclusion criteria. Key barriers to FSS intention and uptake centred upon procedural anxieties. Women, including UK Asian women, reported shame and embarrassment, anticipated pain, perforation risk, and test preparation difficulties to elevate anxiety levels. Religious and cultural-influenced health beliefs amongst UK Asian groups were reported to inhibit FSS intention and uptake. Competing priorities, such as caring commitments, particularly impeded women's ability to attend certain FSS appointments. The review identified a knowledge gap concerning factors especially associated with FSS participation amongst lower SES groups.

**Conclusions:** Studies mostly focussed on barriers and facilitators of intention to participate in FSS, particularly within UK Asian groups. To determine the barriers associated with FSS uptake, and further understand how screening intention translates to behaviour, it is important that future qualitative research is equally directed towards factors associated with screening behaviour.

**KEYWORDS**

barriers, bowel scope, cancer, facilitators, flexible sigmoidoscopy screening, oncology, qualitative

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## 1 | BACKGROUND

An average of 42 042 new cases of colorectal cancer were diagnosed yearly in the United Kingdom (UK) between 2014 and 2016,<sup>1</sup> with 1.80 million cases estimated annually worldwide (2018).<sup>2</sup> Colorectal cancer is the second most common cause of cancer mortality, both in the UK and globally, with around 16 300 deaths reported every year in the UK between 2015 and 2017,<sup>1</sup> and 862 000 worldwide (2018).<sup>2</sup> In 2013, the National Health Service (NHS) England introduced the Bowel Scope Screening Programme (BSSP), within the Bowel Cancer Screening Programme (BCSP). A once-only flexible sigmoidoscopy screening (FSS) procedure offered to men and women in England aged 55, available to be taken up to the age of 60. The sigmoidoscope inspects the rectum and sigmoid colon to identify and remove polyps which can potentially grow and become cancerous; it can also detect whether colorectal cancer is present.<sup>3</sup> The NHS BCSP England,<sup>3</sup> Scotland<sup>4</sup> and Wales<sup>5</sup> also offers men and women aged 60 to 74 (50-74 in Scotland) a home testing kit, comprising of a faecal immunochemical test (FIT) issued for completion every 2 years.<sup>3-5</sup> The FIT has replaced the faecal occult blood test (FOBT), given FIT requires one sample rather than three to be provided and has improved sensitivity.<sup>6</sup> The BSSP and the home testing kit both provide a means of early detection of colorectal cancer, though the primary purpose of FSS is to prevent cancer.<sup>3</sup> A FSS UK trial reported FSS to have long lasting benefits, reducing colorectal cancer incidence by 33% at 10 years, and mortality levels by 43% at 15 years, since trial randomisation.<sup>7</sup> Despite such benefits, FSS uptake was reported in England to be 43.1% during the first 14 months of the BSSP between March 2013 and 8 May 2014 FSS has the lowest participation rate of all organised NHS screening programs, both in comparison with stool-based colorectal cancer testing<sup>8</sup> and in contrast with breast and cervical screening.<sup>9,10</sup> In comparison to the UK, the United States Preventive Services Task Force (USPSTF) recommends colorectal cancer screening to start at 50 years of age, with home tests completed annually and flexible sigmoidoscopy every 3 to 5 years.<sup>11</sup> In 2015, 60.3% of adults in the United States aged 50 and above reported to have had either a sigmoidoscopy in the past 5 years or a colonoscopy in the past 10 years.<sup>12</sup>

Flexible sigmoidoscopy screening uptake has been reported to be lower amongst women,<sup>13-25</sup> in contrast FOBT and FIT colorectal cancer screening, have reported higher uptake among women.<sup>26,27</sup> Consistent with other forms of cancer screening, there is a socio-economic status (SES) gradient in FSS uptake,<sup>28</sup> ranging from 33% to 53% in most to least deprived quintiles in England.<sup>13</sup> A recent review by Kerrison et al.<sup>25</sup> found deprivation,<sup>13,15,20,29-34</sup> low levels of education,<sup>20,23,31,35</sup> low income,<sup>23,36</sup> and being unemployed<sup>30</sup> to be significant barriers to FSS uptake. Studies have highlighted disparities by ethnicity in colorectal cancer screening uptake.<sup>16-18,25,37,38</sup> FSS uptake has been found to be lower among UK Asians (54%) compared to White (69%) or Black (80%) respondents.<sup>37</sup> Study findings did not however show screening intention to differ by ethnicity, further understanding of the factors which contribute to this intention-behaviour gap found within Asian communities in England<sup>37</sup> warrants additional review.

Research in the UK and US found people who perceived fewer barriers<sup>14,15,29,30,39-41</sup> and more benefits<sup>14,15,29,30,42</sup> to the FSS test

were significantly more likely to participate in FSS. More specifically, an unwillingness to complete test preparations, lack of provider recommendation,<sup>31,32</sup> fear of test pain or discomfort,<sup>29,42</sup> and lack of test awareness<sup>43</sup> were reported as key barriers, albeit further research is needed to confirm the significance of these barriers on FSS uptake.<sup>44-47</sup> Furthermore, key health and lifestyle factors found to significantly increase FSS uptake<sup>25</sup> were: having a family history of colorectal cancer,<sup>18,24,30,36,48</sup> good self-reported health,<sup>14,29,30,49</sup> and having health insurance.<sup>18,38</sup> To improve FSS participation, it is imperative to clarify which barriers and facilitators are of most relevance to particular low uptake groups (eg, women, UK Asians). Previous reviews and syntheses of qualitative studies have provided valuable insights into barriers and facilitators to participation in other colorectal cancer screening modalities.<sup>50,51</sup> To date and to our knowledge, no review has provided a synthesis of qualitative literature regarding the factors which impact upon FSS intention and uptake. How the barriers and facilitators to FSS uptake compare to other screening modalities is thus unknown.

While existing review literature<sup>25</sup> is useful in providing confirmation of associations regarding factors which affect FSS uptake and allows comparison to other colorectal cancer screening modalities through cross-sectional evidence, it fails to provide depth of understanding regarding barriers and facilitators identified. In addition, the saliency and relevance of such barriers and facilitators amongst low uptake socio-demographic groups is unknown. Therefore, the current review aimed to:

- 1 Synthesise qualitative evidence to obtain collective insight into and greater depth of understanding of the key barriers and facilitators of FSS intention and uptake.
- 2 Determine how relevant identified barriers and facilitators are amongst low FSS uptake subgroups<sup>25</sup>: women, lower SES (inclusive of high deprivation, low education, low income and unemployed) and Asian minority ethnicity.

## 2 | METHODS

### 2.1 | Registration and guidelines

This review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist<sup>52</sup> and was registered on the PROSPERO international prospective register of systematic reviews (Registration number: CRD42019120446).<sup>53</sup>

### 2.2 | Eligibility criteria and article selection

In accordance with the participants, intervention, control, outcomes and study design (PICOS) framework<sup>54</sup> used to inform the search strategy, eligibility criteria are outlined in Table 1.

ET searched four electronic databases: Ovid Embase (1947-), Ovid Medline (1946-), Ovid PsycINFO (1806-) and ISI Web of Science (1900-), all with end dates up to March 2019. A further search, with end dates up to January 2020, was later completed to include any recent publications.

ET/DOC/LA carefully chose search terms that incorporated all possible phrases in relation to potential barriers and facilitators, socio-demographic factors, colorectal cancer and FSS. Search terms used are provided in Table S1. Factors reported in reviews by Kerrison et al<sup>25</sup> and Smith et al<sup>55</sup> informed this study's search terms, given they provided generic search terms for barriers and facilitators suitable for reuse. ET hand-searched the reference lists within the included articles and within relevant reviews for any further studies which may meet the inclusion criteria. ET used Google Scholar's 'cited by' functionality on included studies, to check for any further studies to include. Searches were also made based on the first and last author within the reference lists of included articles. ET combined search results from each database into a single Endnote file and removed duplicates. A three-stage approach to study screening and selection was employed, whereby titles, then abstracts, then full-texts were examined. Primary reviewer ET screened and captured key exclusion reasons for all titles, and then screened the remaining abstracts. Second reviewer MP screened 20% of titles, and subsequently 100% of the remaining abstracts. ET and MP retrieved and read the full text of all remaining studies to determine inclusion as per the eligibility criteria. Any uncertainties for which eligibility was difficult to determine or disagreements were discussed and resolved. To ensure consensus on inclusion was reached, discussions took place between ET and MP for title and abstract screening, and with the wider review team (DOC, LA) for full-text screening. Cohen's Kappa<sup>56</sup> was used to assess inter-rater reliability scores, calculated for each screening stage, with strong inter-rater reliability at title ( $k = .941$ ), abstract ( $k = .865$ ) and full-text ( $k = .750$ ) stages.

## 2.3 | Data extraction

Data extraction was separated into two stages. The first stage provided a synopsis of the study characteristics captured into a single table, which summarised: research questions/study aims, the setting/theoretical base, country, participant and data collection details, method of analysis and outcome measure(s) for all included studies. The second stage required extraction of data to perform the thematic

**TABLE 1** PICOS eligibility criteria

Participants	<ul style="list-style-type: none"> <li>• General population of any age, eligible to attend FSS for colorectal cancer prevention</li> <li>• Patients, not medical professionals</li> </ul>
Intervention	<ul style="list-style-type: none"> <li>• Not relevant</li> </ul>
Comparators/control	<ul style="list-style-type: none"> <li>• Not relevant</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• Qualitative data specifically reporting barriers and facilitators of FSS intention and uptake</li> </ul>
Study design	<ul style="list-style-type: none"> <li>• Qualitative and mixed-methods empirical study designs</li> </ul>
Other	<ul style="list-style-type: none"> <li>• Published in a peer-reviewed journal</li> <li>• Written in English language</li> </ul>

Abbreviations: FSS, flexible sigmoidoscopy screening; PICOS, participants, intervention, control, outcomes, and study design.

synthesis, where all text labelled as 'results or findings' were extracted as verbatim into NVivo 12 Plus. This ensured both participant quotes and author interpretations from each included study were extracted.

## 2.4 | Quality assessment

The nine-item Critical Appraisal Skills Program (CASP) tool for qualitative research<sup>57</sup> was used to assess the quality of the included studies. Guidance notes for completion were followed, as outlined within the CASP checklist, with responses of yes, cannot tell, and no selected. Second reviewer SM assessed 30% of the included studies, with an inter-rater reliability Cohen's Kappa score of complete reliability ( $k = 1.00$ ). Studies were not excluded from the review based on their quality ratings.

## 2.5 | Method of analysis

This review searched qualitative articles and followed the thematic synthesis model: a three-stage procedure that involves line-by-line coding, the development of descriptive subthemes and the generation of analytical themes.<sup>58</sup> The development of the descriptive subthemes focussed on retaining a close representation of the data itself whilst the creation of analytical themes went a step further and required author interpretation and evaluation to be represented.

## 2.6 | Conducting the thematic synthesis

ET independently coded verbatim data to first group relevant content and create descriptive themes. Following coding completion of the first study, the reviewer then moved to code the next study in turn, using existing descriptive themes where relevant and adding further descriptive themes as necessary. By doing so for all studies, data was collectively themed according to barriers and facilitators of FSS. Line-by-line coding into descriptive subthemes was validated by the review team, resulting in the development of 30 initial descriptive subthemes. ET re-read the verbatim data within each descriptive theme to capture similarities and contradictions. This helped form a line of argument per descriptive subtheme based upon individual views and feelings. Continuing the process of thematic synthesis,<sup>58</sup> ET evaluated the verbatim data under each descriptive theme. Based upon commonality, descriptive themes were synthesised into a tree-like structure with eight overarching analytical themes (see Figure 2).

## 3 | RESULTS

### 3.1 | Study results

A total of 12 168 articles were identified from the database search up until the end of January 2020. After the removal of duplicates and screening, a total of 161 articles were selected for full-text review. A

total of 10 studies were eligible for inclusion. Figure 1 provides a PRISMA flowchart diagram showing exclusion and inclusion of studies at every stage of the screening process.

### 3.2 | Study characteristics

Characteristics of included studies are summarized in Table S2. Included studies shared commonality in research questions/aims proposed, focusing on the barriers and facilitators of FSS. One study<sup>59</sup> specifically aimed to explore gender differences in colorectal cancer screening attitudes, whilst eight studies captured gender sample characteristics.<sup>59-66</sup> Two studies<sup>60,65</sup> focused on how barriers and facilitators to screening varied by ethnicity, reporting views from UK Asian ethnic minority individuals.<sup>60,65</sup> No studies explicitly focused on the influence of lower SES on FSS; however, sample characteristics of seven of the included studies<sup>59-62,64-66</sup> captured views from participants with some degree of lower SES. One article also captured the views of relatives of colorectal cancer patients.<sup>66</sup> Reference to theories as a framework, such as the health belief model,<sup>67</sup> were discussed within some studies to examine behaviour.<sup>60,63,66</sup> Studies were carried out in the UK,<sup>60-63,65,68</sup> the USA<sup>64,66,69</sup> and Canada.<sup>59</sup> Qualitative data collection methods included focus groups,<sup>60,64,66</sup> telephone semi-structured interviews<sup>59,63</sup> and face-to-face semi-structured interviews.<sup>61,62,65,68,69</sup> The method of analysis carried out by many of the included studies was thematic framework analysis.<sup>59-63,66,69</sup> Finally, nine studies<sup>59-66,68</sup> reported outcomes regarding screening intention, while eight studies<sup>61-66,68,69</sup> reported outcomes of screening behaviour.

### 3.3 | Study quality

Full results are provided in Figure S1. The studies generally met the CASP tool criteria and were deemed of overall high methodological quality. All studies provided clear research aims, appropriateness of research design, clear statement of findings, and were of research value. It was clear to identify in all but one study (90%) how data collection had been conducted. The recruitment strategy was deemed appropriate to the aims of the research in most studies (80%). Data analysis was sufficiently rigorous, and the methodology chosen was appropriate for most studies (80%). However, it was not clear in more than half of studies (60%) whether ethical issues had been considered ahead of data collection. Albeit likely that all studies did gain approval in accordance with the ethical principles, this cannot be confirmed. Given the adherence of most studies to high standards of qualitative data analysis, it was surprising to discover only one study (10%) discussed the roles of the researcher and interviewee.<sup>63</sup>

### 3.4 | Thematic synthesis results

Key barriers and facilitators of FSS of high relevance to women and UK Asian communities focussed upon the themes of 'Procedural

anxieties', 'Religious and cultural-influenced health beliefs' and 'Competing priorities'. Other themes highlighted key barriers of FSS intention and uptake in general; however, they were of less relevance to women and UK Asian communities. An illustration of the structure of descriptive subthemes and their relationships with the eight analytical themes are illustrated in Figure 2. This tree diagram shows the relationships between the descriptive themes, displayed as oval and rectangular shapes, and analytical themes, displayed as hexagon shapes. More specifically the oval shapes represent barriers and facilitators of screening intention, and the rectangular shapes represent barriers and facilitators of screening intention and behaviour. Quotes contained within each theme have been stratified into barriers and facilitators of screening intention, see Table S3a-c or barriers and facilitators of screening behaviour, see Table S4a-c. The tables have also been further stratified into general, women and UK Asian ethnicity groupings.

### 3.5 | Barriers and facilitators of screening intention

#### 3.5.1 | Procedural anxieties

'Anxiety regarding test invasiveness' appeared to inhibit FSS intention.<sup>61,63,65,68</sup> Some respondents reported to be horrified at the thought, viewing FSS as an invasion of a private bodily area.<sup>70</sup> Women notably reported more embarrassment regarding the FSS test than with breast or cervical screening.<sup>62,63</sup> 'Medical fear' of doctors, hospitals, and tests in general were also expressed, with the invitation letter perceived negatively, igniting fear, panic and terror for some individuals.<sup>63</sup>

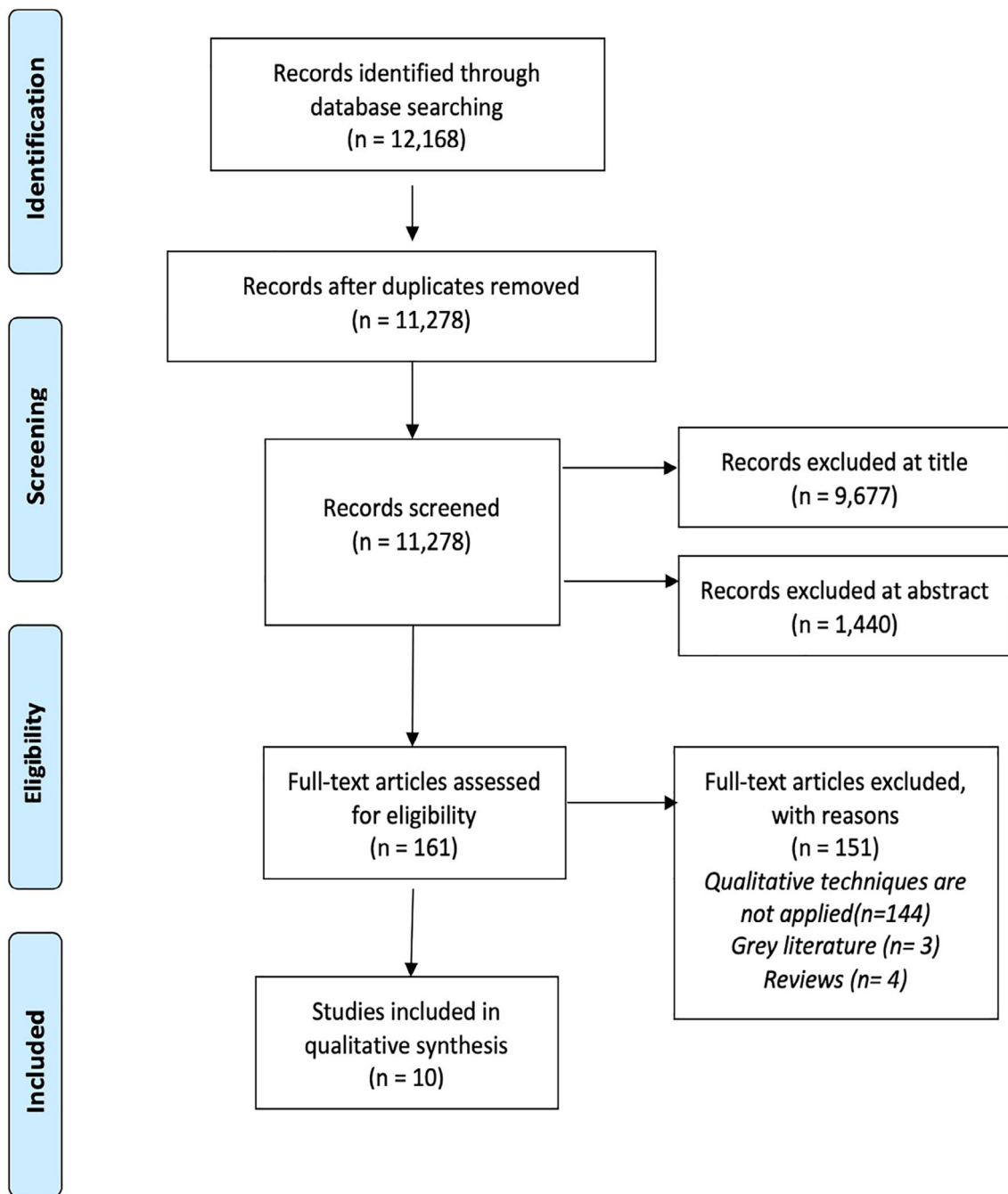
#### 3.5.2 | The power of social role and identity

No quotes were found from low uptake groups regarding this theme; however, the authors provided the following comments. 'Masculinity-associated procrastination' in relation to the procedure was raised as an inhibitory factor amongst men in African-Caribbean communities,<sup>60</sup> with the issue of 'machismo' viewed as an inhibitory factor. FSS was considered a threat to masculinity, with further sexual overtones and views that this was an unnatural procedure voiced, albeit indirect and infrequent.<sup>63</sup>

'Being responsible for your own health' and making healthy lifestyle choices reduced some individuals' perceived personal susceptibility to colorectal cancer.<sup>62</sup> Whilst others felt a real sense of responsibility to use public funding and resources, viewing FSS as a health maintenance procedure.<sup>59</sup>

#### 3.5.3 | The fear of the unknown

'Anxiety surrounding test results' and 'Avoidance due to underlying fatalism' inhibited individuals' intentions to accept FSS invitations.<sup>61,63,66</sup> To leave well alone and prevent psychological harm were



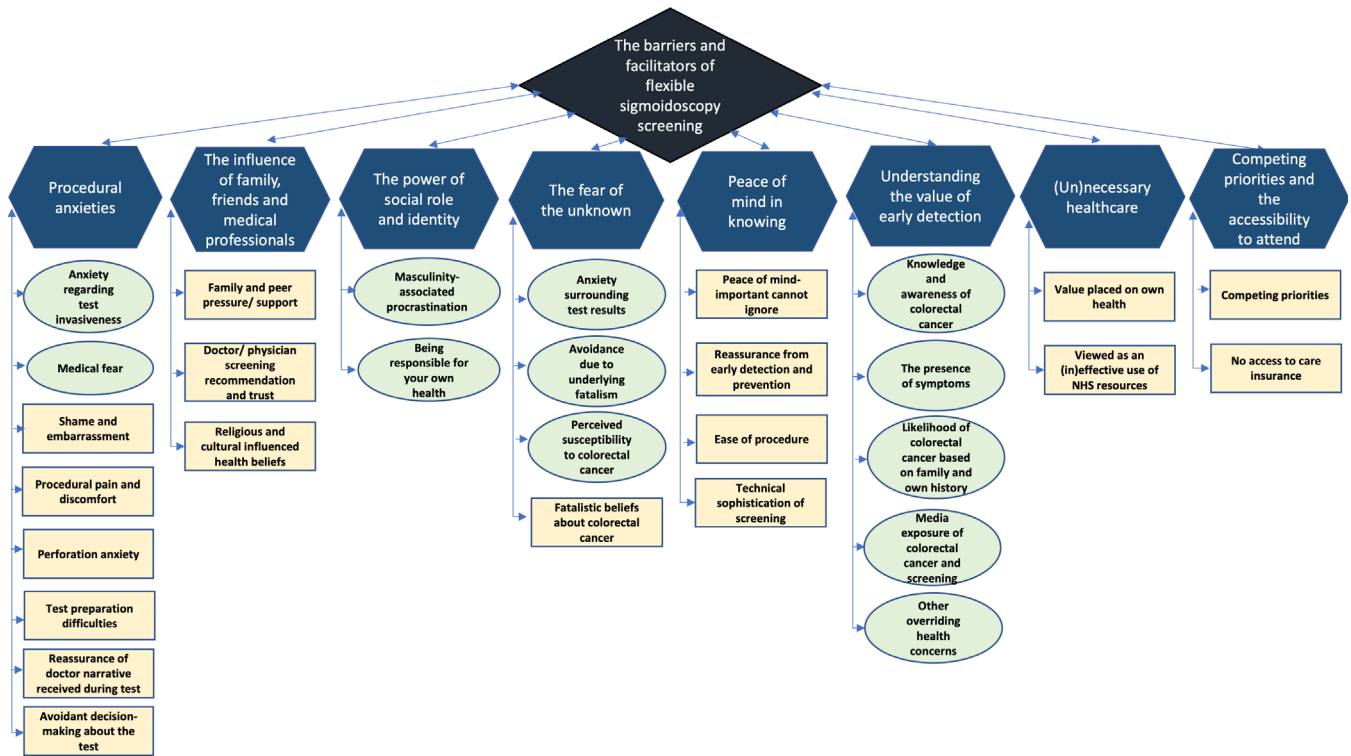
**FIGURE 1** Preferred reporting items for systematic reviews and meta-analyses (PRISMA) flowchart

shared beliefs of respondents who felt screening disturbed their current state of good health and psychological equilibrium.<sup>63</sup> More explicitly, some Pakistani women believed that treatment alone caused cancer to advance.<sup>60</sup> Individuals reported to be unable to cope with a positive diagnosis or the word cancer, stating that they would rather not know.<sup>60</sup> In sum, the anticipation of fear and anxiety was commonly echoed throughout the review literature.

'Perceived susceptibility to colorectal cancer' inhibited screening intention in Gujarati Indian men, given a general lack of awareness of prevalence and that their diet reduced prevalence of colorectal cancer within their community.<sup>60,65</sup>

### 3.5.4 | Understanding the value of early detection

'Knowledge and awareness of colorectal cancer', the associated risks, and the importance of early detection and prevention are factors which can promote screening intention. Thus a lack of knowledge about colorectal cancer by some Pakistani women was viewed as a potential inhibitor of FSS.<sup>60</sup> Furthermore, a lack of test information was viewed by Gujarati Indian men to inflate their test anxiety levels and inhibit screening intention.<sup>60</sup> A lack of awareness by many of the NHS England BSSP reported to bring about reactions of shock and surprise on receiving the screening invitation.<sup>62</sup> Men appeared to be



**FIGURE 2** Tree diagram showing relationships between the descriptive themes (oval and rectangular shapes) and analytical themes (hexagon shapes). Oval shapes represent barriers and facilitators of screening intention, rectangular shapes represent barriers and facilitators of screening intention and behaviour.

[Correction added on 23 July 2020, after first online publication: Figure 2 caption is previously incorrect and has been corrected in this version.]

less aware than women of the colorectal cancer test modalities available to them; however, interestingly, a higher percentage of women were aware but undecided as to whether to partake.<sup>59</sup>

'The presence of symptoms' as a cue to attend screening was identified in several studies,<sup>60,63,64,68</sup> including individuals of Pakistani ethnicity.<sup>60</sup> Furthermore, being asymptomatic was viewed by older women as a valid reason to decline.<sup>63</sup> Gujarati Indian women specifically spoke of the importance of symptoms being present to undergo what they envisaged to be an invasive procedure.<sup>60</sup>

The 'Likelihood of colorectal cancer based on family and own history' of cancer affected FSS intention. For some, adverse family outcomes ignited their own fatalistic beliefs and fears, whilst for others it forged a need to be extra vigilant to detect cancer early given their increased risk.<sup>62,63,66</sup> Personal experience of any type of cancer also heightened sensitivity due to a greater need for reassurance and early detection.<sup>62</sup> For some women, thinking about FSS brought back memories of having had a mastectomy.<sup>63</sup>

### 3.6 | Barriers and facilitators of screening intention and behaviour

#### 3.6.1 | Procedural anxieties

'Shame and embarrassment' were found to inhibit FSS intention<sup>59-61,63-66</sup> based upon general views. For some, however, it did not

inhibit FSS behaviour as it did not affect eventual decision making.<sup>63</sup> Women reported a more personalised and intense expression of embarrassment in relation to medical professionals<sup>59</sup> and a tendency to shy away from the test.<sup>63</sup> Levels of embarrassment were however less common among women who had experienced pregnancy and childbirth.<sup>59,63</sup> A misunderstanding by some women regarding a patient's physical position during the test was found to heighten anticipated levels of embarrassment, thus creating unnecessary concerns with the procedure itself.<sup>64,66</sup> Shame and embarrassment were notably found to inhibit both screening intention and uptake amongst UK Asian groups.<sup>68</sup> Indian and Bangladeshi women revealed embarrassment as the sole reason for not attending screening, even when they had initially accepted.<sup>65</sup>

'Procedural pain and discomfort' anticipated and experienced from FSS was reported within several studies<sup>60,61,65,68,69</sup> and for some this contributed towards a preference for the FOBT.<sup>69</sup> Some screeners reported painful after-effects and difficulties with flatulence,<sup>61,68</sup> while others reported the actual procedure to be uncomfortable yet tolerable.<sup>69</sup> Women's experience of painful mammograms also heightened nervousness to attend the FSS test.<sup>63</sup> 'Perforation anxiety' due to the risk of physical harm,<sup>63,64</sup> specifically bowel perforation, also resulted in some women's decision not to partake.

'Test preparation difficulties' were reported in multiple studies to inhibit FSS intention and uptake.<sup>60-62,64,68</sup> One woman reported this to be the sole reason for not attending her upcoming appointment,<sup>62</sup> with particular difficulties centred around drinking of the fluid laxative diet and enema insertion.<sup>60-62,64,68</sup> Women reported the experience

as extremely unpleasant to administer, self-harm and the cause of increased anxiety.<sup>60</sup> Women spoke of a lack of test preparation information, which affected their confidence and elevated their fears further.<sup>68</sup> Furthermore, one study found discomfort regarding test preparations to impede individuals from repeat screening,<sup>68</sup> this being of relevance to countries such as the US where repeat FSS is recommended every 3 to 5 years.

'The reassurance of the doctor narrative received during the test' and the presence of a professional throughout the procedure positively enhanced patients' personal screening experience.<sup>61,64</sup> The psychological benefits of doctor narrative and presence are likely to promote repeat screens and social encouragement among others to screen,<sup>64</sup> again of relevance to countries such as the United States where repeat FSS is recommended every 3 to 5 years.

'Avoidant decision making about the test' was a strategy adopted by non-responders to not to have to think about the invitation. By pushing it to the back of their minds, temporally at first, then indefinitely, they protected themselves from consciously dealing with the worry and fear of potential health threats that may result from FSS.<sup>63,65</sup>

### 3.6.2 | The influence of family, friends and medical professionals

'Family and peer pressure/support' as factors associated with FSS intention and uptake are multifaceted and dependent upon the perspectives of others within an individual's current social context. Peer pressure, a lack of family support or encouragement were found to both promote and inhibit screening intention and uptake.<sup>64,68</sup> Others mentioned family discussions about screening as commonplace, yet did not perceive themselves as being influenced by their partners.<sup>63,64</sup> The extent to which screening participation was discussed differed by gender. Women discussed screening tests often with friends and family, whose views were largely in line with their own. Men, on the other hand, rarely discussed such matters with friends and family,<sup>63</sup> and were thus potentially less subject to verbal influence or pressure from peers or relatives.

Rather than recommendation from national bodies, patients viewed a 'Doctor/physician screening recommendation', in which personalised invitations from medical professionals promoted screening, to be of direct personal benefit.<sup>66,68,69</sup> Furthermore, in one study, Pakistani men were disinclined to attend unless advised to by their GP.<sup>60</sup> When questioned as to why respondents attended the test, 90% said their physician had recommended the procedure.<sup>69</sup> Overall, the literature supported the value of good doctor-patient relationships and trust to up motivation levels and improve screening intention.<sup>64,68,69</sup>

'Religious and cultural-influenced health beliefs' impacted individuals' perception of their susceptibility to colorectal cancer, particularly amongst minority groups. A fibre-based diet was viewed to reduce risks for colorectal cancer within Indian cultures.<sup>60</sup> Moreover, a misunderstanding that only men are at risk of colorectal cancer was reported by Pakistani and African-Caribbean women.<sup>60</sup> A lack of recognition of cancer was identified among African-Caribbean and Pakistani communities, where cancer was seen as a taboo and not their

cultural way. Finally, Pakistani men and women, in accordance with their religious beliefs, disclosed the requirement for women to be screened by a female endoscopist. In circumstances by which a female endoscopist could not be guaranteed, Pakistani women responded that they would not attend FSS.<sup>60</sup>

### 3.6.3 | The fear of the unknown

'Fatalistic beliefs about colorectal cancer' were demonstrated in women non-screener who had lost family or friends to colorectal cancer.<sup>62</sup> Some respondents concluded that their FSS invitation alone signified an adverse outcome of colorectal cancer.<sup>68</sup>

### 3.6.4 | Peace of mind in knowing

Peace of mind was given as a reason from screeners as to why they attended screening.<sup>62,69</sup> Any experiences of discomfort and embarrassment were felt to be overridden by a personal need for reassurance.<sup>69</sup> Others referred to the importance of taking advantage of potentially life-saving technology, accepting screening to avoid any self-recriminations that could result from not doing so.<sup>64</sup> Furthermore, even intense anxiety about the procedure was reported by some respondents to be negated by the need for reassurance.<sup>62</sup>

Among many respondents, including Pakistani women, 'Reassurance from early detection and prevention' of colorectal cancer provided comfort of knowing and catching cancer at its earlier stage.<sup>60</sup> However, some women non-screener continued to compare the benefits of early detection with the potential threat of an adverse outcome.<sup>62</sup>

The unexpected reality of the test and the 'Ease of the procedure' pleasantly surprised some patients, removing fears of partaking in future FSS tests. Again, of particular relevance to countries such as the United States, where repeat FSS is recommended every 3 to 5 years. Aside from the fear of visualization of polyps, the 'Technical sophistication of screening' was also viewed as interesting, educational, and was provided as a reason for FSS modality preference.<sup>61</sup>

### 3.6.5 | (Un)necessary healthcare

Flexible sigmoidoscopy screening as an 'Unnecessary healthcare' procedure was stated by a female non-screener who disclosed no intention to treat future cancer should it occur.<sup>62</sup> In England, FSS differs from other forms of screening, in that it is not routine and is a once-only procedure. For some individuals, opting to attend FSS was therefore implied to be a deliberate choice requiring greater commitment.<sup>63</sup>

### 3.6.6 | Competing priorities

Childcare, carer, and work commitments were identified as factors impeding some women's ability to free up time to attend certain



screening slots.<sup>63,65,66,68</sup> Particularly caring for ill or disabled children or parents, or conflicting demands such as own ill health obstruct FSS uptake.<sup>62</sup> 'Competing priorities' were exacerbated by difficulties experienced with rescheduling FSS appointments, inhibiting FSS uptake further.<sup>65</sup> The need to request unpaid leave was also viewed as a major barrier for some.<sup>65,68</sup> Yet, for a few women, such difficulties were still secondary to an overall reluctance to attend.<sup>63</sup> For individuals living chaotic lives, common in deprived circumstances, it was suggested that little is left in reserve to deal with potentially negative outcomes of FSS, placing their focus firmly upon their family's immediate health concerns.<sup>62</sup>

## 4 | DISCUSSION

Key barriers to FSS intention and uptake centred upon 'Procedural anxieties'. Notably, 'Shame and embarrassment'<sup>59-61,63-66,68</sup> and, culturally, the gender of medical professionals, were deemed pivotal to the test itself. Feelings of unease were heightened in UK Asian women, who expressed the requirement for a female nurse in order to attend.<sup>60</sup> The themes of embarrassment and feelings of vulnerability, particularly in women, that emerged from this review correspond with findings of procedural anxieties from a previous qualitative review.<sup>50</sup> McLachlan et al<sup>50</sup> reported laxative bowel preparation to be the most burdensome part of having a colonoscopy, the anticipation of pain, and feelings of embarrassment and vulnerability were common amongst patients. 'Anticipated procedural pain and discomfort', and painful after-effects of the test elevated anxiety levels<sup>61,64,66,68</sup> consistent with previous quantitative associations found between anticipated test pain and FSS uptake.<sup>25,42</sup> Moreover, feeling relaxed and comfortable during the procedure was found to be imperative to minimise risk of physical harm.<sup>50</sup> 'Perforation anxiety' was a concern raised by women,<sup>63,64</sup> resulting in decisions for some not to partake. Lower FSS intention and uptake in women due to 'Procedural anxieties', was particularly surprising given many women have previously undergone invasive cervical cancer screening tests. When making direct comparisons between FSS, and cervical and breast cancer screening in terms of embarrassment and intrusiveness, women viewed breast and cervical screening as more easily normalised as part of being a woman.<sup>62</sup> Furthermore, FSS requires invasive bowel preparation procedures to be completed by individuals, which are found to cause additional stress and anxiety.<sup>60-62,64,68</sup>

Social norms and conformity were demonstrated within UK Asian communities and women with regards to FSS intention and uptake. A lack of awareness of cancer was reported among Pakistani communities in which cancer was seen as a taboo and partaking in FSS was not considered their cultural way. Furthermore, in accordance with religious beliefs, UK Asian men and women disclosed the need for women to be screened by a female endoscopist. These findings correspond with a previous qualitative review by Honein-AbouHaidar et al<sup>51</sup> who reported lack of awareness, fear of cancer and misconceptions about colorectal cancer development within Indian, African-Caribbean and Chinese American ethnic groups.

'Competing priorities' were reported to inhibit both FSS intention and uptake. Due to wider family and work commitments, attending

screening was viewed by many women to be beyond their control. To effectively increase FSS uptake, it is necessary to first address these 'Competing priorities' particularly faced by women. A qualitative review by Honein-AbouHaidar et al<sup>51</sup> reported competing life demands of work and family to deter individuals from seeking colorectal cancer screening, particularly within lower SES groups. Given this review did not discover any qualitative studies that reported on factors that influence FSS intention and uptake within lower SES groups, further work is required to understand whether 'competing priorities' is also a barrier faced by lower SES groups, to FSS intention and uptake.

### 4.1 | Study limitations

The methodological approach demonstrated throughout the search and screening procedure was both rigorous and robust. A systematic and comprehensive search strategy was completed in compliance with the PRISMA checklist.<sup>52</sup> To eliminate reviewer bias and to ensure full inclusion, a second reviewer duplicate screened all abstracts and full texts during the screening process.<sup>54</sup> Consistent with other recently published reviews,<sup>55,70</sup> we employed a three-stage screening procedure in which only titles were screened in the first stage. Due to this, and especially as a very high proportion of studies (79.5%) were excluded on the basis of title, it is possible that eligible studies could have been missed at this stage. However, we note that our review included all seven<sup>59,60,62-64,66,69</sup> of the qualitative studies identified in the recent FSS review by Kerrison et al.<sup>25</sup> Moreover, during the peer-review process ET and MP each independently revisited 50% of the excluded titles (n = 4839) and also read the accompanying abstract; there was 100% agreement between the two reviewers that none of the revisited papers were eligible for inclusion in the study. Thus, it is very unlikely that this review failed to include eligible research.

A key review limitation was the inclusion of only published peer-reviewed journals, excluding all grey literature, such as book chapters, theses, and conferences abstracts. Such qualitative literature could have potentially added to the review findings providing a richer understanding of the barriers and facilitators of FSS most pertinent to low uptake groups.<sup>71</sup> Inclusion of grey literature can, however, be challenging given it is time and resource intensive.<sup>72</sup>

All studies highlighted limitations of small sample sizes and or purposeful quota sampling, stating that conclusions drawn from qualitative data alone should remain tentative. Qualitative research principles argue that findings are not intended to be generalisable, but specific to a certain context, time and set of participants.<sup>58</sup> This review therefore echoes caution over generalisation of findings made across different cultural and socio-political contexts.

### 4.2 | Future research and clinical implications

The gap between FSS intention and uptake requires further attention.<sup>29</sup> This review presented data regarding both barriers and facilitators of screening intention and screening behaviour (uptake). Greater

evidence was provided in relation to screening intention, particularly within UK Asian groups. Similar to previous literature, barriers were found to account for a large proportion of screening intention.<sup>73</sup> In order to determine the barriers which explain FSS uptake, it is vital that we direct qualitative research attention towards factors associated with screening behaviour (uptake) in addition to intention.<sup>74</sup>

To address 'Procedural anxieties', clinical action is being taken to trial ways to improve and enhance comfort and modesty during FSS. FSS is an un-sedated procedure; however, sedation can be requested. Early BSSP data has found one in three patients to report moderate to severe discomfort.<sup>75</sup> Screening modifications are thus being trialled to see if post-procedural pain is reduced when using water-assisted, rather than the current CO<sub>2</sub> insufflation for BSSP.<sup>75</sup>

With regards to gender preference of medical professionals, Stoffel et al<sup>76</sup> investigated the preference for women to have a same-gender practitioner. They revealed FSS intention to have a female endoscopist to be significantly greater in disinclined women who were first given the decoy male endoscopist. This compared to disinclined women who were initially given by default a choice to make themselves regarding which gender of practitioner they prefer. This 'nudge technique' thus warrants further trials to explore the 'decoy effect' as an effective means of reducing perceived difficulty in screening decision and the influence on screening behaviour as well as intention.

Results confirmed the value individuals placed on personalised doctor recommendation and how improved FSS intention, particularly within UK Asian groups. Additional targeted primary care interventions within areas with a high UK Asian population could potentially further mobilise FSS interest through targeted GP recommendation and awareness to UK Asian patients when approaching screening age. Appraisal of existing UK-wide NHS interventions to increase FSS uptake, which are largely paper based, require further validation regarding their effectiveness on low uptake groups. Lengthy documents with complex and unfamiliar terminology can challenge groups with low levels of health literacy and may lead to informational avoidance.<sup>77</sup> In order to better understand thought processes on receipt of a written invitation, think-aloud studies on FSS may offer a potential means to further understand the immediate barriers low uptake groups face.<sup>78</sup> Finally, considering efforts to optimize UK Asian ethnic groups' participation in screening, community-based participatory research has been recognised as an important approach to consider when conducting intervention research aimed at improving screening attitude, knowledge and behaviour.<sup>79</sup>

## 5 | CONCLUSIONS

This systematic review has examined and analysed qualitative evidence concerning the barriers and facilitators of FSS intention and uptake. Key barriers centred largely upon procedural anxieties. Women, including UK Asian women, reported shame and embarrassment, anticipated and experienced pain, perforation risk, and test preparation difficulties to elevate their anxiety levels. Religious and cultural-influenced health beliefs amongst UK Asian groups were also

reported to inhibit FSS intention and uptake. Competing priorities such as caring commitments particularly impeded women's ability to attend certain screening appointments. The review exposed a knowledge gap concerning factors that most influence FSS intention and uptake in lower SES groups, inclusive of those populations who are highly deprived, of low income, low educated and unemployed. Foundational qualitative work that builds an understanding of factors associated with FSS intention and uptake amongst UK Asian and lower SES groups is advised.

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## CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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