Barriers and facilitators to colorectal cancer screening intention and uptake: understanding and addressing patient and practitioner perspectives.

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Submitted in accordance with the requirements for the degree of Doctor of Philosophy.

The University of Leeds

School of Psychology

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Declaration

This thesis is an alternative style doctoral thesis and comprises jointly authored published manuscripts; therefore, the contribution of the candidate, Elizabeth Alex Travis and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others.

Chapter 2 contains the manuscript ‘Barriers and facilitators of flexible sigmoidoscopy screening for colorectal cancer: A systematic review and thematic synthesis of qualitative evidence’ by Elizabeth Travis, Dr Madeleine Pownall, Professor Laura Ashley, and Professor Daryl O’Connor published in *Psycho-Oncology* in 2020 (Travis et al., 2020).

Chapter 3 contains the manuscript, ‘Barriers and facilitators to colonoscopy for cancer detection: patient and practitioner perspectives’ by Elizabeth Travis, Dr Robert Kerrison, Professor Daryl O’Connor and Professor Laura Ashley published in *Psychology and Health* in 2022 (Travis et al., 2022).

Chapter 4 contains the manuscript ‘Effects of a modified invitation letter to follow-up colonoscopy for bowel cancer detection’, by Elizabeth Travis, Dr Professor Laura Ashley, and Professor Daryl O’Connor published in the *British Journal of Health Psychology* in 2023 (Travis et al., 2023).

Chapter 5 contains the manuscript ‘Self-affirmation theory and bowel cancer screening’ by Elizabeth Travis, Dr Professor Laura Ashley, and Professor Daryl O’Connor published in *Psychology and Health* in March 2024 (Travis et al., 2024).

The candidate confirms the material submitted in this thesis complies with the University of Leeds ‘submission of doctoral thesis by alternative format’ guidelines and satisfies the criteria for this submission route therein. The candidate confirms that she is the first author on each of the publications included in this thesis and that each derived from original research undertaken whilst registered as a doctoral student at The University of Leeds.

The thesis is constructed in this format in view of providing the examiner(s) optimum clarity over the variety of research findings derived from the PhD.

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Finally, I would like to dedicate this thesis to my children, Isabelle, and Arthur. I love you; you are my world and my everything.
Abstract

Population-based asymptomatic screening tests can prevent bowel cancer and detect it at an earlier stage. NHS England launched a population-based screening programme for bowel cancer in 2006, called the Bowel Cancer Screening Programme (BCSP). A review by NHS England reported that the BCSP saves almost 9000 lives each year, through early diagnosis and prevention of bowel cancer. Yet levels of uptake of bowel cancer screening in England remain suboptimal. This thesis aimed to further understand the barriers and facilitators to participation in colorectal cancer (CRC) screening and to find potential ways to address these. Specifically, the understudied areas of CRC screening barriers and facilitators, flexible sigmoidoscopy and positive FIT follow-up colonoscopy examination in England were investigated. Through the synthesis of qualitative literature (Study 1) and interviews with patients and nurses (Study 2), patient anxiety was identified as a major barrier to participation in flexible sigmoidoscopy and positive FIT follow-up colonoscopy screening, experienced by patients throughout the screening pathway. Recommendations made by patients and Specialist Screening Practitioners (SSPs) to reduce patient anxiety included suggestions such as the earlier notification of the option for sedation to reduce any patient concerns of pain and discomfort (Study 2). The test of these suggested modifications to the BCSP invitation letter were however found to not be beneficial to patient reported expected levels of anxiety or behavioural intentions to screen (Study 3). Future research ought to seek feedback on tailored invitation materials based on people’s past screening experiences and do so among under-represented groups. The research undertaken in this thesis also experimented with the use of self-affirmation inductions as a novel theory-based intervention to improve responses to bowel cancer screening information materials, yet findings showed no effects on participant expected levels of anxiety, message acceptance or behavioural intentions to screen (Study 4). Cumulatively, the research findings from this thesis improve understanding of the
effectiveness or otherwise of different novel interventions aimed at addressing key patient barriers to different modalities of CRC screening to improve uptake. The findings are promising and highlight the need for future research to endeavour to replicate the current results in larger and more representative samples.
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<td>ANCOVA</td>
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<td>BCSP</td>
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<td>BCW</td>
<td>Behavioural Change Wheel</td>
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<td>National Cancer Intelligence Network</td>
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<td>NHS</td>
<td>National Health Service</td>
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Chapter 1 Introduction

1.1 Colorectal cancer incidence and mortality

1.1.1 Global burden

1.88 million people worldwide were diagnosed with colorectal cancer (CRC, also known as bowel cancer) in 2020 (World Health Organisation, 2024. - a). It is a leading cause of cancer incidence, mortality and is an important barrier to increasing life expectancy in every country in the world (World Health Organisation, 2024. - a). CRC incidence rates are fourfold higher in developed countries for colon cancer (World Health Organisation, 2024. - b). European countries, Australia and America have the highest rates of CRC due to having a greater number of risk factors of CRC, for example, living a more sedentary lifestyle, overconsumption of red processed meats, smoking, and alcohol (Sung et al., 2021). CRC is the second most common cause of cancer death worldwide after lung and bronchus cancer with almost 1 million deaths reported in 2020 (World Health Organisation, 2024. - a). Over the next 20 years (from 2020 to 2040) CRC incidence and mortality is forecast to increase from 1.88M to 3.08M cases and from 916K to 1.59M deaths, due to global demographic changes (World Health Organisation, 2024. - b)

1.1.2 United Kingdom (UK) burden

In the UK, around 42,900 people are diagnosed yearly with CRC (2016-2018), it is the fourth most common cancer accounting for 11% of cancer cases, compared to breast cancer, which is the most common cancer in the UK with 15% of cancer cases. New cases of CRC yearly in the UK are greater in men (23,900 cases) than in women (19,000 cases) (Cancer Research UK, n.d. - a). Approximately 16,800 people die from CRC every year in the UK, of which 9,200 are men and 7,600 are women (2017-2019) (Cancer Research UK, n.d. - a). Incidence rates remained stable between 1993-1995 and 2016-2018 with a slight decrease in females of 2%, and 3% in males (Cancer

1.2 Stages of cancer and survival rates by stage at diagnosis

The most common way of staging CRC is the tumour, nodes, and metastases (TNS) system. Stage 1 is when the cancer is limited to the inner lining of the colon or rectum and has not spread outside the bowel wall. Stage 2 is when the cancer has infiltrated through the outer layer of the bowel wall. Stage 3 is when at least one lymph node has been affected, and Stage 4 when the cancer has metastasised to other parts/ organs of the body (Bowel Cancer UK, n.d. - b).

People who are diagnosed with earlier stages of CRC have a greater chance of survival, however only 13% of CRC cases are currently diagnosed at stage 1, whilst the majority of cases are diagnosed at an advanced stage (52%) in the UK (NCIN, 2010). Approximately 90% of people diagnosed with stage 1 bowel cancer survive five or more years, whilst only 10% with stage 4 bowel cancer survive 5 or more years after diagnosis (Cancer Research UK, n.d. - b). In comparison, more than 55% of people diagnosed with stage 1 lung cancer survive 5 or more years, and less than 5% of people with stage 4 lung cancer will survive five or more years after diagnosis (Cancer Research UK, n.d. - c).

1.3 Population-based asymptomatic screening tests.

Population-based asymptomatic screening tests can both prevent CRC and detect CRC at an earlier stage. People who take part in asymptomatic screening tests are often diagnosed with cancer at an earlier stage and therefore have a greater chance of survival, compared to people who develop CRC symptoms first and are then referred on by their GP for symptomatic screening (Scholefield et al., 2012). A review of four randomized controlled trials, with over 320,000 people found the risk of death caused by CRC to be reduced by 25% in those who participated in at least one round
of organised asymptomatic CRC screening (Hewitson et al., 2008). Population-based asymptomatic screening programmes are now available in most European countries, Canada, and specific regions in North and South America, Asia, and Oceania (Navarro et al., 2017). The most common screening strategies reported in Europe are based on initial home stool test kit; a Faecal immunochemical test (FIT) or Guaiac faecal occult blood test (gFOBt), whilst other European countries such as Italy offer once in a lifetime Flexible Sigmoidoscopy Screening (FSS) at 50 to 58 years, and Poland a colonoscopy screening examination at 55 - 64 years (Senore et al., 2019).

1.4 The current NHS Bowel Cancer Screening Programme (BCSP) and pathway in England

NHS England launched a population-based screening programme for CRC in 2006, called the bowel cancer screening programme (BCSP) (NHS England, 2019). In comparison, the NHS breast screening programme and NHS cervical screening programme launched before the BCSP, in 1988 (NHS England, 2019). A review by NHS England reported that the BCSP saves almost 9000 lives each year, through early diagnosis and prevention of CRC (NHS England, 2019). Full rollout of the BCSP by 2009 allowed screening to be available to all men and women between the age of 60 – 69, the screening age was then further extended to up to 74-year-olds in 2014 (GOV.UK, 2021). Following the discontinuation of bowel scope screening in 2020, the screening age in England has been in the process, since 2021 of being further extended to 50 to 74-year-olds (Halloran, 2009). The current BCSP in England consists of five hubs: the NE Hub - Newcastle, the Eastern Hub - Nottingham, the London Hub, the Southern Hub - Guildford, and the Midlands and the Northwest Hub - Rugby. These hubs issue out and analyse the test kits and provide support to the members of the public via a helpline. The current BCSP care pathway is illustrated in Figure 1.1.
Figure 1.1. The bowel cancer screening care pathway (GOV.UK, 2021)
1.4.1 Stool-based CRC screening.

In 2019 in England and Wales, and in 2017 in Scotland, the gFOBt; a test used to check stool samples for hidden (occult) blood, was replaced in the NHS with the faecal immunochemical test (FIT) (National Institute for Health and Care Excellence; NICE, 2019). The FIT is like the gFOBt in that it checks stool samples for hidden blood, but also has improved sensitivity, allowing for an increased number of pre-cancerous lesions to be detected (Moss et al., 2017). The test is easier for people to complete at home too, as it only requires one sample, not three, to be taken on a stick, which is then contained within a small bottle containing buffer solution, see Figure 1.2. The CRC screening eligible age differs across different countries in the UK. The NHS England bowel cancer screening programme (BCSP) has recently extended the eligible age for asymptomatic screening to people aged 50 and over, available every two years, being rolled out over a 4-year period, since April 2021 (NHS.UK, 2021. - a). The bowel cancer screening eligible age in England will soon be the same as NHS Scotland, available to people aged 50 to 74, and to those people over 75 who self-refer (NHS National Services Scotland, 2023). In comparison in Wales, the current screening eligible age is available to people aged 55 to 74 years old (NHS Wales, n.d.).

![Figure 1.2. The faecal immunochemical test (FIT) and instructions box.](image-url)
1.4.2 Positive FIT follow-up colonoscopy screening

A colonoscopy is an endoscopic examination of the large bowel and involves a long thin flexible tube called a colonoscope with a camera attached, inserted into the large intestine (colon) to look for abnormalities and cancer. People with a positive FIT result are invited, as part of the BCSP to a positive FIT follow-up colonoscopy examination. About 53 in 100 of people with a positive FIT result will have adenomas that need to be removed, and about 9 in 100 will have bowel cancer – see Figure 1.3 (GOV.UK, 2022b). Colonoscopy screening is different from FSS in that it allows for the examination of the entire bowel, not just the rectum and sigmoid colon (NHS.UK, 2022.- b). Colonoscopy is generally considered as the gold standard for the detection of colorectal neoplasia and has been associated with long-term (20–30 years) reduction in CRC mortality (Nishihara et al., 2013). To ensure the bowel is cleared and fully prepared for the examination, patients are required to take a laxative bowel preparation the evening or morning before, and to fast from solid food on the day of the procedure. The examination takes approximately 20 to 30 minutes and is completed by an endoscopist. Patients can be sedated, should they wish to be, to ensure no pain is experienced. Patients who have been sedated need to be accompanied by a family or friend for 24 hours following the procedure. Around 50,000 colonoscopies are currently performed every year on people who test positive on gFOBT/FIT (Richards, 2019).
1.4.3 Flexible sigmoidoscopy screening (FSS) for CRC examination

FSS is an endoscopic examination of the rectum and sigmoid colon. The examination is undertaken in a hospital by an endoscopist using a thin flexible tube with a fibre optic camera attached (See Figure 1.4). The examination is carried out to detect and remove colorectal adenomas before they develop into a cancer (Cancer Research UK, n.d. - d). The incidence of CRC was found in a UK RCT of 40,674 people (71%) who took part in FSS to be reduced by 33% in 10 years, and mortality levels by 43% at 15 years, demonstrating the long-lasting benefits of FSS (Atkin et al., 2010). Between 2013 and 2020, people in England at the age of 55 were invited by NHS England to have a FSS as a one-time procedure, to identify and remove colorectal adenomas. To prepare the bowel for a FSS examination an enema is required to be self-administered by the patient at home, or where assistance is required by a nurse in hospital. Since March 2020, FSS CRC examination (known as bowel
scope screening in England) ceased to be offered by the current NHS England BCSP as routine screening. Bowel scope screening was initially suspended in March 2020 during the Covid-19 pandemic and then stopped indefinitely in September 2020, due to low uptake, and resource and capacity constraints (UK National Screening Committee, 2020; Whyte et al., 2017). In comparison internationally, the U.S. Preventive Services Task Force currently continues to recommend adults aged 45 to 75 to have FSS every 5 years or every 10 years with a FIT every year (Centers for Disease Control and Prevention, 2023).

Figure 1.4. Sigmoidoscopy Exam - (Mayoclinic.org, n.d.)

1.5 CRC screening uptake

The introduction of FIT has shown improvements in the uptake of stool-based testing across 21 population-based screening programmes in Europe. FIT uptake has been reported to be higher (49.5%) than in those European countries still using gFOBt (33.2%) (Senore et al., 2019). When the FIT was first launched in Scotland, uptake was reported at 64%, 8% higher than the gFOBt recorded at 56%, and higher than the Health Improvement standard of 60% (Public Health Scotland, 2021). Prior to the
introduction of the FIT across England, a pilot study in 2014, recorded a 7% increase in FIT uptake compared to gFOBt (Moss et al., 2017). In June 2019, the NHS BCSP implemented FIT across England, as a replacement to gFOBt, available to all patients aged 60-74 (Moss et al., 2017). Data for Quarter 2 (2019 – 2020) reported 67.5% FIT uptake across England, and more recently FIT uptake in England was 71.0% in 2021 (GOV.UK, 2022a). In comparison with other screening programmes in England, cervical screening uptake was reported to be 69.9% and breast cancer screening 62.3% between 2021 -2022 (NHS Digital, n.d. – a, - b).

The increased FIT uptake and FIT sensitivity have led to more people in England being invited for further follow-up tests, in most cases this being a positive FIT follow-up colonoscopy examination (Moss et al., 2017). Screening uptake of colonoscopy six months after positive FIT was 79%, based on an international survey of 35 screening programmes (Selby et al., 2021). Similarly, previous statistics from the bowel cancer screening system database in England showed 6% of 21,106 people with positive (abnormal) test result to not attend the initial nurse appointment despite reminders, and 83% of patients with a positive test to have completed their colonoscopy examination (Logan et al., 2012). Comparatively, in Scotland 84.3% of patients attended colonoscopy following a positive FIT result, compared to 77.5% of English patients, according to English and Scottish pilot databases in 2002 (Alexander & Weller, 2003). In comparison, uptake of bowel scope screening shown in the first 14 months of the bowel scope screening programme in England (BSSP) (2013-2014), was only 43.1% (McGregor et al., 2016). Uptake for bowel scope was lower than any other organised NHS screening programme (McGregor et al., 2016).

1.5.1 Socio-demographic variations in CRC screening uptake

1.5.1.1 Socio-economic variations

Despite improvements in overall CRC uptake, due to the introduction of the FIT there remains a well-established socioeconomic gradient with CRC uptake in the UK.
A 5-year analysis of the BCSP in England found FIT uptake to be nearly 14% lower in the most deprived areas compared to the least deprived areas (Hirst et al., 2018). Key performance indicators (KPIs) published by Public Health Scotland between the period of May 2020 to April 2022 showed a 21% difference between the most (54%) and least (75%) deprived quintiles in Scotland (Public Health Scotland, 2021). The socioeconomic gradient with CRC uptake has been shown to apply to all CRC screening tests, including positive FIT follow-up colonoscopy examination. Morris and colleagues (2012) used BCSP data for England to report small but significant variations between quintiles of area deprivation, ranging from 86.4% to 89.5% in colonoscopy CRC screening uptake. Furthermore, Dalton (2018) showed individuals whose first language was not the predominant language of the country they lived in, and individuals who belonged to lower socio-economic position groups, to have lower uptake rates of colonoscopy examination.

1.5.1.2 Ethnic variations

Minority ethnic groups have been found to partake less in initial stool-based screening tests (FIT/gFOBt), positive FIT follow-up colonoscopy screening and FSS. A 5-year analysis of the BCSP in England found FIT uptake to be almost 16% lower in the most ethnically diverse areas, compared to the least ethnically diverse areas (Hirst et al., 2018). In Scotland, FIT uptake was reported to be lower in South Asian populations compared to White Scottish populations, and higher among the Chinese and White British populations (Campbell et al., 2020). FSS intentions to take part in the UK were high, with 80% of participants reporting being ‘definitely’ or ‘probably interested’ in taking part across different ethnic groups (White, Black, Asian) (Robb et al., 2008a). Yet, a second sample of 4,303 UK adults, found FSS uptake to be significantly lower among Asian populations (54%), compared to White (69%) and Black populations (80%) (Robb et al., 2008a). Furthermore, Dalton (2018), in a review of 63 studies internationally, found minority ethnic groups to have lower uptake in
positive FIT follow-up colonoscopy examination, with South Asian groups specifically lower in uptake for the UK.

1.6 Barriers and facilitators to CRC intention and uptake

Barriers and facilitators of colorectal, breast and cervical screening uptake have been extensively examined in previous research (Kiviniemi et al., 2011; Kotzur et al., 2022; Lo et al., 2013; Vedel et al., 2011; Wools et al., 2016; Young & Robb, 2021) and have many common barriers and facilitators, these include socio demographic, psychological (including perceived barriers), practical and service barriers and facilitators. Lo et al. (2013) compared barriers to CRC screening with barriers to breast and cervical screening, among 890 women in the UK. Their findings showed cancer screening tests to have many shared barriers, yet a dislike for the gFOBt specifically was greater in women non-screeners (of CRC, breast and/or cervical screening), compared to other screening tests (Lo et al., 2013).

1.6.1 Practical barriers

Practical barriers have been reported in previous work to inhibit the intention and uptake in CRC screening tests. For example, Goodwin et al. (2021) in a recent online survey based on 427 Australian adults cited common barriers for not completing and returning home bowel cancer screening kits to include people forgetting to complete the test, lack of planning the time to complete, hygiene concerns and embarrassment. Furthermore, common barriers to using FITs were recently investigated by Kotzur et al. (2022) in Scotland, who recruited 2387 participants that had completed a FIT and 359 participants that had not completed a FIT (through the Scottish bowel cancer screening programme). Frequently endorsed barriers included practical (e.g., ‘I never get round to doing it’). A review of 94 qualitative studies, mostly conducted in the US (n=61), reported specific barriers within low uptake groups which included language barriers, logistical issues with attending screening tests, and cultural beliefs (Honein-AbouHaidar et al., 2016). The impact of having a chronic disease on CRC uptake was also investigated by Guiriguet et al. (2017), using general population
Data of 36,208 individuals invited to take part in the Barcelona population-based colorectal cancer screening programme. Those individuals invited who had three or more major chronic diseases (for e.g., heart failure, diabetes) were found to be less likely to return their FIT kit (Guiriguet et al., 2017). McLachlan et al. (2012) reviewed 56 studies, conducted mainly in the US, that reported bowel preparation to be the most burdensome part of a colonoscopy, with moderate discomfort from the laxative bowel preparation.

### 1.6.2 Socio-demographic barriers

Gender and socioeconomic inequalities in the participation in CRC screening were recently highlighted in a review by Mosquera et al. (2020). Findings from the review of 96 studies, mainly conducted in the UK (n=29) and US (n=18), showed being male and higher levels of deprivation to be associated with lower participation in CRC screening. Moreover, in a rapid review of 42 articles, conducted mostly in the US (n = 21) and UK (n=13), Kerrison and colleagues (2019) reported high levels of deprivation, low levels of education and income, and being unemployed to all inhibit FSS participation. Previous qualitative research by Green and colleagues (2008) interviewed 40 low-income Latino and White patients from Massachusetts in the US, reporting system barriers of scheduling, financial cost, transportation, and language difficulties. Furthermore, Smith and colleagues (2012) highlighted in a sample of 765 older American participants difficulties in the understanding of a bowel preparatory instruction leaflet for a colonoscopy, with poor comprehension amongst individuals with low literacy.

### 1.6.3 Psychological barriers

Psychological barriers have in previous work been classified into four types: feelings of disgust in completing the test, avoidance due to fear of, and the tendency to focus on negative outcomes, a lack of autonomy in deciding whether to take part, and difficulty in completing and returning the kit (Goodwin et al., 2021). Kotzur et al. (2022) also identified frequently endorsed barriers to include emotional factors (e.g., I’m
worried about the results’), and self-efficacy (e.g., ‘I'm unsure how to do it’) barriers, regardless of people’s previous screening history (Kotzur et al., 2022). Furthermore, according to a review by Kerrison et al. (2019) individuals who perceive more benefits and less barriers to FSS are more likely to attend FSS. Known barriers to attending FSS reviewed by Kerrison and colleagues (2019) included being reluctant to complete bowel preparation procedures (in most cases this was an enema), procedural concerns with pain or discomfort, and lack of procedural awareness (Lewis & Jensen, 1996; Power et al., 2008; Van Dam et al., 2013). A recent review by Kayal and colleagues (2023) of the quantitative literature found six UK studies that reported on patient experiences of having a positive FIT follow-up colonoscopy examination (Plumb et al., 2017; Ghanouni et al., 2016; Gupta et al., 2012; Sarkar et al., 2012), one in Spain (Burón et al., 2017), and one in the Netherlands (Denters et al., 2013). Notably one of the UK studies by Plumb et al. (2017) analysed 52,805 positive FIT follow-up colonoscopy screener responses to a standard post 30-day colonoscopy questionnaire. These authors found struggles with procedural related concerns with pain and risk, and problems with bowel preparation procedures to be key barriers.

1.7 The use of theory-based frameworks to understand psychological barriers to CRC screening.

1.7.1 Social cognition models

Social cognition models have been used to understand CRC screening intention and behaviour, these include the Health Belief Model (HBM; Becker, 1974), Social Cognitive Theory (SCT; Bandura, 1998) and Theory of Planned Behaviour (TPB; Ajzen, 1991). As social cognition models they suggest that cognitions, such as attitudes and beliefs are determinants of behaviour, via intention. In accordance with the Health Belief Model, previous work has shown high perceived benefits and low perceived barriers to be independently associated with CRC screening uptake (James et al., 2002; Manne et al., 2002; Wardle et al., 2000). Harewood et al. (2002) specifically applied the Health Belief Model as a framework to examine decisions to participate in
colonoscopy screening. In a review of studies of work which have applied the TPB to screening behaviours, Godkin and colleagues (1996) found attitudes to be associated with intentions ($r = 0.51$) to take part in screening. Moreover, in a FSS trial of 2,969 English participants, Power et al. (2008) found social cognition variables to be associated with FSS CRC screening intentions and to be significant predictors of FSS CRC screening uptake. Previous studies which have used SCT to understand CRC screening behaviours have shown people with positive outcome expectancies and higher self-efficacy to have higher CRC screening intentions (goals) (Sun et al., 2004; Watts et al., 2003).

1.7.2 Integrative models of behaviour

An integrative model of behaviour and framework that incorporates a range of models and constructs including the HBM, SCT, and TPB, allowing for the inclusion of other correlates of behaviour and important wider social determinants is the Behaviour Change Wheel (BCW) (Michie et al., 2011). At the core of the BCW are capability, opportunity, and motivation, which are constructs that when changed can achieve desired behaviours (COM-B). Psychological barriers to CRC screening uptake have recently been reviewed in accordance with the COM-B model, Young and Robb (2021) reported capability factors of knowledge and health literacy, opportunity factors of social norms and stigma, and motivation factors of habits and perceived risk.

The recent introduction of the Integrated Screening Action Model (I-SAM) by Robb (2021) incorporates existing models of health behaviour and aims to improve access to cancer screening specifically. As shown in Figure 1.5, the I-SAM includes the different stages of cancer screening an individual goes through, and how a person’s behaviour can be affected by participant and environmental influences. Targets for intervention can then be informed by these sources of behaviour; ‘capability’, ‘opportunity’ and ‘motivation’ (the COM-B model; Michie et al., 2011) to facilitate screening intention and uptake (Robb, 2021). These sources of behaviour have been organised into participant and environmental influences, thought to enable, or inhibit
cancer screening participation, these are: automatic motivation, reflective motivation, psychological capability, physical capability, social opportunity, and physical opportunity (Robb, 2021)

Figure 1.5. The Integrated Screening Action Model (I-SAM) (Robb, 2021)

1.8 Proposed research to further understand barriers and facilitators to CRC Screening.

Further research to identify the relative importance of the barriers identified for FSS uptake has been recommended (Kerrison et al., 2019; Wardle et al., 2003). Enablers that increase FSS participation also require further investigation, including having a family history of CRC, good self-reported health, and having health insurance (Kerrison et al., 2019). Understanding the barriers and facilitators of most relevance to the known low uptake groups, namely women and Asians groups is vital to the development and tailoring of interventions that would increase intention and uptake of FSS in England (as part of the bowel scope screening programme). No review has provided a synthesis of qualitative literature globally concerning the barriers and facilitators to FSS participation. The comparisons of barriers and facilitators of FSS with other screening modalities are also required. Kerrison et al.’s (2019) rapid review of the quantitative literature provided confirmation of associations between barriers and
facilitators and FSS uptake, however the existing research lacked a depth of understanding concerning how these named factors affected FSS participation. Furthermore, the relevance of these barriers and facilitators amongst low uptake groups was unknown. Therefore, the first aim of the current thesis was to synthesise existing qualitative evidence to understand key barriers and facilitators to intention and uptake of flexible sigmoidoscopy screening (FSS) for CRC prevention and detection, and to identify those barriers to FSS intention and uptake amongst lower uptake groups.

Previous research findings have been helpful in identifying the factors which affect positive FIT follow-up colonoscopy uptake, but they do not explain the reasons why, nor do they provide an insight into the practical and emotional difficulties anticipated and faced during the test procedure. Additionally, how these barriers were inter-related, for instance, how individuals deal with practical barriers of competing priorities alongside managing bowel preparation procedures at home is unknown. Other reviews and studies internationally have investigated the barriers to colonoscopy screening when undertaken as an initial, rather than as a follow-up test based on a positive FIT (Green et al., 2008; Kerrison et al., 2021a; McLachlan et al. (2012). Only two qualitative studies have investigated the barriers to positive FIT follow-up colonoscopy, neither of these studies were however conducted on UK participants (Bertels et al., 2020, 2022). A comparison with previous findings and a deeper exploration of the associated logistical and emotional challenges which patients face, and how these are discussed and resolved with medical professionals at the screening centre, is needed to be investigated. Qualitative research provides an avenue to understand both patient and medical specialist narratives, on multiple patient factors associated with non-attendance. Therefore, the second aim of the current thesis was to understand patient barriers and facilitators to attending positive FIT follow-up colonoscopy examination in England, and to provide key procedural recommendations, suggested by patients that focussed on reducing patient barriers.
1.8.1 Specialist Screening Practitioners (SSPs)

SSPs are specialist nurses who frequently interface with BCSP patients, initially in person through a scheduled appointment ahead of their colonoscopy screening examination. The SSPs apply their expert clinical knowledge and experience alongside evidence-based decision-making skills to support patients through the bowel screening procedure (Kerrison et al., 2021b). The role of the SSP is multifaceted, and as an advanced nursing role, it is pivotal in providing patients with a high level of support and advice needed (Kerrison et al., 2021b). The views, experiences, perspectives, and suggestions of the SSPs regarding the barriers, facilitators contributing to the intention and uptake of positive FIT follow-up colonoscopy screening of patients referred were yet to be explored qualitatively in research. The SSPs provide a channel for us to improve our understanding of how patient barriers, needs, experiences differ by socio-demographic groups, and more specifically, for those patients lower in intention and uptake of positive FIT follow-up colonoscopy screening. Therefore, the second aim of the current thesis was also to understand patient barriers and facilitators to attending positive FIT follow-up colonoscopy examination, observed and reported by SSPs in England, and to provide key procedural recommendations suggested by SSPs that focussed on reducing patient barriers.

1.9 Interventions to address barriers to CRC screening uptake.

A recent review of 102 randomised controlled trials (RCTs) that aimed to improve CRC screening uptake, showed significant benefit of all interventions combined (Tsipa et al., 2021). Interventions reviewed were mainly conducted in the USA (75) and Europe (17), using non-endoscopic screening, delivered remotely on an individual basis using paper-based educational materials, and through primary care settings (Tsipa et al., 2021). Interventions to improve participation in organised screening programmes, such as those offered in England, have been broadly categorised according to six intervention types by researchers, which can be delivered at six different intervention timepoints (Duffy et al., 2017; Figure 1.6). Duffy and
colleagues (2017) reviewed the effectiveness of these intervention categories and timepoints on participation in cancer screening services. Pre-screening reminders, GP endorsement and more personalised reminders for non-attenders were all consistently found in bowel and cervical screening to increase uptake (Duffy et al., 2017). Text message reminders have been shown to increase gFOBt uptake by 5.6% among 8,269 first-time invitees across 141 GPs in London, England (Hirst et al., 2017). Repeat invitations have also been tested to be effective at increasing gFOBt uptake and positive gFOBt follow-up colonoscopy, by 8% over three rounds of 510,990 screening episodes in patients in east and northeast Scotland (Steele et al., 2010b). A RCT in England based on 1288 patients registered with 20 GPs, showed GP endorsement letters and an enhanced procedural leaflet to increase uptake in gFOBt by 6% (Hewitson et al., 2011).

Figure 1.6. Schematic diagram showing the categories of interventions and time points (Duffy et al., 2017).

1.9.1 Varying invitation materials to improve CRC screening uptake.

Duffy and colleagues’ (2017) rapid review investigated the effects of interventions that vary invitation materials on CRC screening uptake, reporting mixed findings. Eighteen intervention studies which all varied invitation materials were
reviewed, eleven studies of which were in CRC screening, four in breast screening, one cervical screening, one in breast and cervical screening and one in melanoma screening. Thirteen of the interventions were found to be associated with increased screening uptake. While in other studies, for example, Watson and colleagues (2013) who provided an additional research study questionnaire that included demographic, medical and lifestyle questions, 5,857 English participants did not show improvements in CRC uptake. Their survey was designed to investigate the characteristics of people with a false-positive gFOBt result, and findings showed significantly lower gFOBt uptake in those who received study questionnaire than in those who did not, particularly in areas of higher deprivation (Watson et al., 2013).

1.9.1.1 Advance notification letters

Advance notification letters have been used to prepare individuals of their upcoming invitation, transitioning individuals from a stage of pre-contemplation to a stage of contemplation or readiness (Cole et al., 2007; Zajac et al., 2016). Three RCTs have reported advance notifications to be associated with increased uptake in gFOBt and FIT screening (Cole et al., 2007; Libby et al., 2011; Van Roon et al., 2011), and one RCT to increase uptake in FSS (Senore et al., 2015). In a recent RCT, Goshgarian et al. (2022) tested the effect of patient portal messaging before mailing the FIT kit, on 2339 patients in the US, resulting in a significant increase in CRC uptake by 6% in the intervention group, compared to the control group.

1.9.1.2 Educational written invitation interventions

Mailed education interventions have been shown to increase patient adherence. For example, in a sample of 781 US patients who received an informational brochure for screening colonoscopy, 11% more patients compared to the control group, completed the procedure (Denberg et al., 2006). Behaviour change theory has been applied in research to develop new written-based interventions, testing the effects on CRC screening intention and uptake measured. For example, work based on a sample from four general practices in the North of England, by researchers Smith and
colleagues (2015b) tested the effects of a ‘Gist’ theory-based leaflet in addition to standard written invitation materials for gFOBt. The ‘Gist’ based leaflet improved knowledge and patient engagement with gFObt screening, however no significant differences were found in gFOBt intention to screen for the 4,452 individuals tested (Smith et al., 2015b). Moreover, Kerrison and colleagues (2018) developed a theory-based leaflet, designed using the BCW in a RCT aimed to increase uptake in FSS, in the English bowel scope screening programme. Findings showed a greater number of individuals who received the theory-based leaflet, and a reminder (12- and 24-month reminder combined) to attend screening (21.5%), compared to those in the control group (0.7%) (Kerrison et al., 2018).

Wider international work has demonstrated the effectiveness of modifications to written materials regarding having a colonoscopy for CRC screening, by providing procedure-related information about the colonoscopy, showing reductions in patient self-reported pain, procedural-related anxiety and improvements in adherence to screening (Denberg et al., 2006; Hsueh et al., 2016; Shaikh et al., 2010). Recommendations based on research undertaken in Canada for well-designed educational materials to improve patient knowledge and understanding, were suggested to be particularly beneficial to patients who have no previous history of having a colonoscopy, given they have known higher levels of procedural anxiety, compared to repeat screeners (Shafer et al., 2018).

1.9.2 Proposed research to improve CRC screening uptake.

1.9.3 Modifications to written-based invitation materials.

The effects of providing modified NHS written invitation materials on positive FIT follow-up colonoscopy screening, on English patients, based on self-reported patient barriers to positive FIT follow-up colonoscopy screening intention uptake, reported in Chapter 3, had not been investigated. For example, the effects of modified invitation materials on procedural-related anxieties, such as pain and discomfort, were highlighted as a key barrier by Travis and colleagues (2022) - see Chapter 3, however
these were yet to be tested. Therefore, the third aim of the current thesis was to explore whether providing modified written NHS invitation information to attending positive FIT follow-up colonoscopy examination, in England reduced participant reported barriers, concerns and improved intention levels to attend a nurse appointment to discuss further medical tests.

As mentioned earlier, the I-SAM is a recently developed framework to improve participation in cancer screening, it outlines the sequence of stages a person goes through when engaging in a screening behaviour (Robb, 2021). The model shows how individuals at different screening stages will experience different barriers and health beliefs and therefore require different interventions (Robb, 2021). The effects of a patient's screening history on their responses to NHS written invitation materials were yet to be investigated and were therefore included within the third aim of this thesis. Furthermore, it was unknown whether providing further information about a colonoscopy procedure in the invitation letter, such as the option of pain relief during the examination, would affect participant levels of capability and motivation (participant influences) as per the I-SAM Framework (Robb, 2021) measured through participant expected levels of anxiety (negative emotional responses) and behavioural intentions to attend the nurse appointment when invited to attend further tests.

1.9.4 The use self-affirmation theory.

Reading health-related invitation materials which explain the risks of a disease, and potential benefits of taking part in early detection tests, such as bowel cancer screening, can pose as a health threat to people receiving them. People’s acceptance of the content provided in CRC screening invitation materials is therefore likely to influence their decision to participate in screening. Recent research by Clarke et al. (2023) has indicated that a major barrier to CRC screening uptake relates to individuals being frightened and defensive and associations between lower defensive information processing and higher CRC screening uptake (Clarke et al., 2023). One theory that offers promise to reduce defensive processing is self-affirmation theory. Steele (1988)
first proposed the theory of self-affirmation. As individuals our self-system tries to protect our perceived image of self-integrity (Steele, 1988). During everyday life, we as individuals receive many threats to our self-integrity, which is our sense of being good, virtuous, successful, and able to control important life outcomes (Sherman & Cohen, 2006; Steele, 1988), and our coping responses to restore our self-worth can often be maladaptive and defensive. Understanding how we can restore our sense of self by using alternative sources of self-integrity that demonstrate our moral and adaptive adequacy, is the act of self-affirmation (Steele, 1988). Reading health information which highlights the risks of unhealthy behaviours, such as smoking or drinking alcohol can threaten our self-integrity. In response to these threats, individuals can alternatively practice the act of self-affirmation. Sherman et al. (2000) investigated the effects of self-affirmation in a study which involved 60 female students from Stanford University (coffee drinkers and non-coffee drinkers) asked to read health information about caffeine consumption and increased breast cancer risk. Findings showed affirmed coffee drinkers to be less defensive and more willing to change their behaviour than affirmed non-coffee drinkers (Sherman et al., 2000). A meta-analysis of 45 tests by Good and Abraham (2007) measured defensive responses to threatening messages, reporting increased message acceptance in affirmed participants. A later meta-analysis by Epton et al. (2015) found receiving a self-affirmation induction alongside persuasive health information to promote message acceptance, intention to engage in health behaviours, and actual behaviour. With regards to CRC screening, Klein et al. (2010) found CRC screening intentions of 141 US participants at 6-month follow-up, to vary and be dependent on their optimistic and realistic beliefs about their bowel cancer risk. For example, unrealistically optimistic individuals who self-affirmed about their health before reading CRC screening risk information, self-reported greater intentions to screen than controls (Klein et al., 2010).

Self-affirmation is a theory and mechanism for intervention yet to be fully investigated or tested in terms of CRC cancer screening intention and uptake. Only one
study (Klein et al., 2010) to our knowledge has tested the effects of self-affirmation on individuals receiving CRC screening information. The act of self-affirming is therefore a novel and an alternative intervention which requires exploration, as to its effects on CRC screening intention and uptake. Self-affirmation is a theory-based intervention we investigated in this thesis. The fourth and final aim of the current thesis was to examine the effects of a self-affirmation intervention on responses to bowel cancer screening information provided to adults in England, measured through levels of message acceptance, intention to screen, and state anxiety.

Whether the effectiveness of self-affirmation interventions on responses to bowel cancer screening information is moderated by trait self-esteem and the extent one spontaneously makes self-affirmations, had also never been investigated within a bowel cancer screening context before. In previous work, Creswell et al. (2005) found self-affirmation to be most effective in lowering stress in people with a positive dispositional self-concept (i.e., high in self-resources such as trait self-esteem and optimism) yet increasing stress in those with a negative dispositional self-concept (i.e., low in self-resources). Harris and colleagues (2019) showed that individuals who make spontaneous self-affirmations have lower levels of depression, anxiety and higher levels of wellbeing and message acceptance. Furthermore, spontaneous self-affirmation is thought to function in a similar way to experimentally induced self-affirmation by resulting in greater open-mindedness and readiness to engage in behavior change (Harris et al., 2019). In recent work, Jessop and colleagues (2023) also showed that a values self-affirmation induction moderated the association between spontaneous self-affirmation and well-being, such that the self-affirmation induction boosted state wellbeing scores in participants with lower spontaneous self-affirmation. Taken together, the final aim of the current thesis, through secondary analyses, was to explore and investigate for the first time the effects of trait self-esteem and spontaneous self-affirmation on responses to bowel cancer screening information.
1.10 Thesis aims and overview.

The overall aim of this thesis was to further understand the barriers and facilitators to participation in colorectal cancer (CRC) screening and to find potential ways to address these. Specifically, the understudied areas of CRC screening barriers and facilitators; flexible sigmoidoscopy and positive FIT follow-up colonoscopy examination in England were investigated. This thesis also aimed to test novel interventions that could potentially reduce barriers and promote facilitators to intention and uptake of CRC screening in adults eligible for screening who live in England. The different types of CRC screening available at the time of this doctoral research as part of the current bowel cancer screening programme (BCSP) in England were investigated and analysed in this thesis.

The specific aims of this thesis were to:

1. synthesise existing qualitative evidence to:
   a. understand key barriers and facilitators to intention and uptake of flexible sigmoidoscopy screening (FSS) for CRC prevention and detection.
   b. to identify those barriers to FSS intention and uptake amongst lower uptake groups.

2. understand barriers and facilitators to attending positive FIT follow-up colonoscopy examination in England, and to provide key procedural recommendations that focussed on reducing patient barriers.

3. explore whether providing modified written invitation information to attending positive FIT follow-up colonoscopy examination, in England reduced participant reported barriers, and improved intention levels to attend a nurse appointment to discuss further medical tests.
4. examine the effects of a self-affirmation intervention on responses to bowel cancer screening information provided to adults in England, measured through levels of message acceptance, intention to screen, and state anxiety.

How these four thesis aims relate to one another is outlined in Figure 1.7 below.

![Figure 1.7. Thesis aims](image-url)
1.11 Thesis outline

1.11.1 Chapter 2

This chapter presents the manuscript entitled ‘Barriers to flexible sigmoidoscopy colorectal cancer screening in low uptake socio-demographic groups: A systematic review’, published in the journal *Psycho-oncology* in 2020 is detailed (Travis et al., 2020). This systematic review included 10 qualitative studies internationally that investigated barriers and facilitators to flexible sigmoidoscopy colorectal cancer screening. Thematic synthesis of the data identified procedural anxiety as a key barrier to screening intention and uptake. Heightened anxiety levels in women were associated with shame and embarrassment, anticipated pain, perforation risk, and test preparation difficulties. Religious and cultural-influenced health beliefs acted as a barrier to FSS amongst UK Asian groups. Competing priorities, such as caring commitments, particularly for women made attending FSS screening difficult for some.

1.11.2 Chapter 3

In this chapter, the manuscript entitled ‘Barriers and facilitators to colonoscopy for cancer detection: patient and practitioner perspectives’ published in *Psychology and Health* in 2022 is outlined (Travis et al., 2022). This study explored patient barriers and facilitators experienced in patients attending positive FIT follow-up colonoscopy screening in England, from both the patient and SSP perspective. Qualitative semi-structured interviews were conducted with 32 participants, consisting of 20 English patients and 12 SSPs. Framework analysis included the use of inductive and deductive coding. Practically orientated strategies were suggested by patients and SSPs to address the patient barriers identified.

1.11.3 Chapter 4

In this chapter, the manuscript entitled ‘Effects of a modified invitation letter to follow-up colonoscopy for bowel cancer detection’ published in the *British Journal of Health Psychology* in 2023, is presented (Travis et al., 2023). The study investigated
whether providing modified information to the current BCSP invitation letter to English participants for positive FIT follow-up colonoscopy, after reading reduced participant self-reported state anxiety and increased behavioural intention levels to attend the nurse appointment to discuss further medical tests. The study also tested the effect of history of colonoscopy invitation on levels of state anxiety, behavioural intention, and colonoscopy concerns per letter condition.

1.11.4 Chapter 5

In this chapter, the manuscript ‘Effects of a self-affirmation intervention on responses to bowel cancer screening information’ published in *Psychology and Health* in 2024 is outlined (Travis et al., 2024). The study examined whether self-affirming about health and values before reading health threatening information, in the format of a CRC screening information leaflet for adults in England, reduced participant state anxiety and increased message acceptance and behavioural intention to screen for CRC. The study also investigated moderating effects of history of friends and family with bowel cancer, self-esteem, and spontaneous self-affirmation on participants levels of state anxiety, message acceptance and behavioural intention.

1.11.5 Chapter 6

This chapter comprises of a discussion of the findings from the systematic review and empirical studies from this thesis within the context of barriers and facilitators to CRC screening and the effects of novel interventions to improve intention and uptake, along with the associated literature. The strengths and limitations of the thesis are considered and areas for future research are identified.
Chapter 2 Barriers and facilitators of flexible sigmoidoscopy screening for colorectal cancer: A systematic review and thematic synthesis of qualitative evidence.

2.1 Abstract

Objective: To synthesise qualitative evidence related to barriers and facilitators of flexible sigmoidoscopy screening (FSS) intention and uptake, particularly within low 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: 12,168 articles were identified from searches of four databases: EMBASE, MEDLINE, PsychINFO, 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.
2.2 Background

An average of 42,042 new cases of colorectal cancer were diagnosed yearly in the United Kingdom (UK) between 2014-2016 (Cancer research UK, n.d. - a), with 1.80 million cases estimated annually worldwide (WHO, 2018). 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 2015-2017 (Cancer research UK, n.d. - a), and 862,000 worldwide (WHO, 2018). 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 (NHS.UK, 2022- b). The NHS BCSP England (NHS.UK, 2021- a), Scotland (Public Health Scotland, 2021) and Wales (NHS Wales, n.d.) also offers men and women aged 60-74 (50-74 in Scotland) a home testing kit, comprising of a faecal immunochemical test (FIT) issued for completion every two years (NHS.UK, 2021- a; Public Health Scotland, 2021; NHS Wales, n.d.). 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 (Young et al., 2015). 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 (NHS.UK, 2021- a). 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 (Atkin et al., 2010). 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 May 2014 (McGregor et al., 2016). FSS has the lowest participation rate of all organised NHS screening programs, both in comparison with stool-based colorectal cancer testing and in contrast with breast and cervical
screening (GOV.UK, 2018a, 2018b; Bibbins-Domingo et al., 2016). 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 (USPSTF, 2021). In 2015, 60.3% of adults in the US aged 50 and above reported to have had either a sigmoidoscopy in the past 5 years or a colonoscopy in the past 10 years (McGregor et al., 2016).

FSS uptake has been reported to be lower amongst women (Kerrison et al., 2019; Littlejohn et al., 2012; McCaffery, 2002; Sutton et al., 2000), in contrast FOBT and FIT colorectal cancer screening, have reported higher uptake among women (Steele et al., 2010a; Von Wagner et al., 2011). Consistent with other forms of cancer screening, there is a socio-economic status (SES) gradient in FSS uptake (Wardle et al., 2016), ranging from 33% to 53% in most to least deprived quintiles in England (Littlejohn et al., 2012). A recent review by Kerrison et al. (2019) found deprivation (Lawsin et al., 2007; Littlejohn et al., 2012; Power et al., 2008; Robb et al., 2010; V. Taylor et al., 2003a; Van Jaarsveld et al., 2006; Wardle et al., 2005; Whitaker et al., 2011; Yip et al., 2006) low levels of education (Van Jaarsveld et al., 2006; Bostick et al., 1993; Lawsin et al., 2007; Kang & Bloom, 1993), low income (Blom et al., 2008; Bostick et al., 1993), and being unemployed (Wardle et al., 2005) to be significant barriers to FSS uptake.

Studies have highlighted disparities by ethnicity in colorectal cancer screening uptake (Janz et al., 2003; Kerrison et al., 2019; Ko et al., 2005; Robb et al., 2008a; Walsh et al., 2002; 2004). FSS uptake has been found to be lower among UK Asians (54%) compared to White (69%) or Black (80%) respondents (Robb et al., 2008a). 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 (Robb et al., 2008a) warrants additional review.

Research in the UK and US found people who perceived fewer barriers (Brenes & Paskett, 2000; Power et al., 2008; Rowl et al., 2005; Sutton et al., 2000; Tang et al.,
to the FSS test were significantly more likely to participate in FSS. More specifically, an unwillingness to complete test preparations, lack of provider recommendation (Lawsin et al., 2007; V. Taylor et al., 2003a) fear of test pain or discomfort (Lewis & Jensen, 1996; Power et al., 2008) and lack of test awareness (Van Dam et al., 2013) were reported as key barriers, albeit further research is needed to confirm the significance of these barriers on FSS uptake (Kerrison et al., 2016, 2017, 2018; Wardle et al., 2003). Furthermore, key health and lifestyle factors found to significantly increase FSS uptake (Kerrison et al., 2019) were: having a family history of colorectal cancer (Blom et al., 2008; Gölder et al., 2007; McCarthy & Moskowitz, 1993; Walsh et al., 2002; Wardle et al., 2005), good self-reported health (Power et al., 2008; Richardson et al., 1995; Sutton et al., 2000; Wardle et al., 2005) and having health insurance (Walsh et al., 2002, 2004). To improve FSS participation, it is imperative to clarify which barriers and facilitators are of most relevance to particular low uptake groups (e.g. 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 (Honein-AbouHaidar et al., 2016; McLachlan et al., 2012). 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 (Kerrison et al., 2019) 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 sociodemographic 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 (Kerrison et al., 2019): women, lower SES (inclusive of high deprivation, low education, low income and unemployed) and Asian minority ethnicity.

2.3 Methods

2.3.1 Registration and guidelines
This review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Moher et al., 2010) and was registered on the PROSPERO international prospective register of systematic reviews (Registration number: CRD42019120446).

2.3.2 Eligibility criteria and article selection
In accordance with the Participants, Intervention, Control, Outcomes, and Study design (PICOS) framework (Higgins et al., 2011) used to inform the search strategy, eligibility criteria are outlined in Table 1.

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>PICOS Eligibility Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participants</strong></td>
<td>• General population of any age, eligible to attend FSS for colorectal cancer prevention.</td>
</tr>
<tr>
<td></td>
<td>• Patients, not medical professionals.</td>
</tr>
<tr>
<td><strong>Intervention</strong></td>
<td>• Not relevant.</td>
</tr>
<tr>
<td><strong>Comparators/Control</strong></td>
<td>• Not relevant.</td>
</tr>
<tr>
<td><strong>Outcomes</strong></td>
<td>• Qualitative data specifically reporting barriers and facilitators of FSS intention and uptake.</td>
</tr>
</tbody>
</table>
Study Design

- Qualitative and mixed-methods empirical study designs

Other

- Published in a peer-reviewed journal.
- Written in English language.

ET searched four electronic databases: Ovid Embase (1947-), Ovid Medline (1946-), Ovid PsychINFO (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 supplementary table 1 of the Supporting Information. Factors reported in reviews by Kerrison et al. (2019) and Smith et al. (2016) 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 (Upton & Cook, 2014) 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.

2.3.3 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 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.

2.3.4 Quality assessment

The nine-item Critical Appraisal Skills Program (CASP) tool for qualitative research (CASP, 2018) 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, can’t 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.

2.3.5 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 (Thomas & Harden, 2008). 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.

### 2.3.6 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 (Thomas & Harden, 2008), 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).

### 2.4 Results

#### 2.4.1 Study results

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 ten 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.
FIGURE 1  Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flowchart.

2.4.2 Study Characteristics

Characteristics of included studies are summarized in supplementary table 2 of the Supporting Information. Included studies shared commonality in research questions/aims proposed, focusing on the barriers and facilitators of FSS. One study (Ritvo et al., 2013) specifically aimed to explore gender differences in colorectal cancer screening attitudes, whilst eight studies captured gender sample characteristics (Austin et al., 2009; Frew et al., 2005; Hall et al., 2016; McCaffery et al., 2001; Ritvo et al., 2013; Robb et al., 2008b; Rawl et al., 2000; Weitzman et al., 2001). Two studies
(Austin et al., 2009; Robb et al., 2008b) focused on how barriers and facilitators to screening varied by ethnicity, reporting views from UK Asian ethnic minority individuals (Austin et al., 2009; Robb et al., 2008b). No studies explicitly focused on the influence of lower SES on FSS; however, sample characteristics of seven of the included studies (Austin et al., 2009; Frew et al., 2005; Hall et al., 2016; Rawl et al., 2000; Ritvo et al., 2013; Robb et al., 2008b; Weitzman et al., 2001) captured views from participants with some degree of lower SES. One article also captured the views of relatives of colorectal cancer patients (Rawl et al., 2000). Reference to theories as a framework, such as the health belief model (Rosenstock, 1974), were discussed within some studies to examine behaviour (Austin et al., 2009; McCaffery et al., 2001; Rawl et al., 2000). Studies were carried out in the UK (Austin et al., 2009; Frew et al., 2005; Hall et al., 2016; McCaffery et al., 2001; Robb et al., 2008b; Gray & Snadden, 1999), the USA (Weitzman et al., 2001; Rawl et al., 2000; Holt, 1991) and Canada (Ritvo et al., 2013). Qualitative data collection methods included focus groups (Austin et al., 2009; Rawl et al., 2000; Weitzman et al., 2001), telephone semi-structured interviews (McCaffery et al., 2001; Ritvo et al., 2013) and face-to-face semi-structured interviews (Frew et al., 2005; Gray & Snadden, 1999; Hall et al., 2016; Holt, 1991; Robb et al., 2008b). The method of analysis carried out by many of the included studies was thematic framework analysis (Austin et al., 2009; Frew et al., 2005; Hall et al., 2016; Holt, 1991; McCaffery et al., 2001; Rawl et al., 2000; Ritvo et al., 2013). Finally, nine studies (Austin et al., 2009; Frew et al., 2005; Gray & Snadden, 1999; Hall et al., 2016; McCaffery et al., 2001; Rawl et al., 2000; Ritvo et al., 2013; Robb et al., 2008b; Weitzman et al., 2001) reported outcomes regarding screening intention, while eight studies (Frew et al., 2005; Hall et al., 2016; McCaffery et al., 2001; Weitzman et al., 2001; Robb et al., 2008b; Rawl et al., 2000; Gray & Snadden, 1999; Holt, 1991) reported outcomes of screening behaviour.
2.4.3 Study quality

Full results are provided in supplementary figure 1 of the Supporting Information. 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 (McCaffery et al., 2001).

2.4.4 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 supplementary table 3a,b,c or barriers and facilitators of screening behaviour, see
supplementary table 4a,b,c of the Supporting Information. The tables have also been further stratified into general, women and UK Asian ethnicity groupings.
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.
2.4.4.1 Barriers and facilitators of screening intention

2.4.4.1.1 Procedural anxieties
‘Anxiety regarding test invasiveness’ appeared to inhibit FSS intention (Frew et al., 2005; McCaffery et al., 2001; Robb et al., 2008b; Gray & Snadden, 1999). Some respondents reported to be horrified at the thought, viewing FSS as an invasion of a private bodily area (Seitz et al., 2009). Women notably reported more embarrassment regarding the FSS test than with breast or cervical screening (Hall et al., 2016; McCaffery et al., 2001). ‘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 (McCaffery et al., 2001).

2.4.4.1.2 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 (Austin et al., 2009), 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 (McCaffery et al., 2001).

‘Being responsible for your own health’ and making healthy lifestyle choices reduced some individuals’ perceived personal susceptibility to colorectal cancer (Hall et al., 2016). Whilst others felt a real sense of responsibility to use public funding and resources, viewing FSS as a health maintenance procedure (Ritvo et al., 2013).

2.4.4.1.3 The fear of the unknown
‘Anxiety surrounding test results’ and ‘Avoidance due to underlying fatalism’ inhibited individuals’ intentions to accept FSS invitations (Frew et al., 2005; McCaffery et al., 2001; Rawl et al., 2000). To leave well alone and prevent psychological harm were shared beliefs of respondents who felt screening disturbed their current state of good
health and psychological equilibrium (McCaffery et al., 2001). More explicitly, some Pakistani women believed that treatment alone caused cancer to advance (Austin et al., 2009). Individuals reported to be unable to cope with a positive diagnosis or the word cancer, stating that they would rather not know (Austin et al., 2009). 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 (Austin et al., 2009; Robb et al., 2008b).

2.4.4.1.4 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 (Austin et al., 2009). Furthermore, a lack of test information was viewed by Gujarati Indian men to inflate their test anxiety levels and inhibit screening intention (Austin et al., 2009). 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 (Hall et al., 2016). Men appeared to be 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 (Ritvo et al., 2013).

‘The presence of symptoms’ as a cue to attend screening was identified in several studies (Austin et al., 2009; Gray & Snadden, 1999; McCaffery et al., 2001; Weitzman et al., 2001), including individuals of Pakistani ethnicity (Austin et al., 2009). Furthermore, being asymptomatic was viewed by older women as a valid reason to decline (McCaffery et al., 2001). Gujarati Indian women specifically spoke of the
importance of symptoms being present to undergo what they envisaged to be an invasive procedure (Austin et al., 2009).

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 (Hall et al., 2016; McCaffery et al., 2001; Rawl et al., 2000). Personal experience of any type of cancer also heightened sensitivity due to a greater need for reassurance and early detection (Hall et al., 2016). For some women, thinking about FSS brought back memories of having had a mastectomy (McCaffery et al., 2001).

2.4.4.2 Barriers and facilitators of screening intention and behaviour

2.4.4.2.1 Procedural anxieties

‘Shame and embarrassment’ were found to inhibit FSS intention (Austin et al., 2009; Frew et al., 2005; McCaffery et al., 2001; Rawl et al., 2000; Ritvo et al., 2013; Robb et al., 2008b; Weitzman et al., 2001) based upon general views. For some, however, it did not inhibit FSS behaviour as it did not affect eventual decision making (McCaffery et al., 2001). Women reported a more personalised and intense expression of embarrassment in relation to medical professionals (Ritvo et al., 2013) and a tendency to shy away from the test (McCaffery et al., 2001). Levels of embarrassment were however less common among women who had experienced pregnancy and childbirth (McCaffery et al., 2001; Ritvo et al., 2013). 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 (Rawl et al., 2000; Weitzman et al., 2001). Shame and embarrassment were notably found to inhibit both screening intention and uptake amongst UK Asian groups (Gray & Snadden, 1999). Indian and Bangladeshi women revealed embarrassment as the sole
reason for not attending screening, even when they had initially accepted (Robb et al., 2008b).

‘Procedural pain and discomfort’ anticipated and experienced from FSS was reported within several studies (Austin et al., 2009; Frew et al., 2005; Robb et al., 2008b; Gray & Snadden, 1999; Holt, 1991) and for some this contributed towards a preference for the FOBt (Holt, 1991). Some screeners reported painful after-effects and difficulties with flatulence (Frew et al., 2005; Gray & Snadden, 1999), while others reported the actual procedure to be uncomfortable yet tolerable (Holt, 1991). Women’s experience of painful mammograms also heightened nervousness to attend the FSS test (McCaffery et al., 2001). ‘Perforation anxiety’ due to the risk of physical harm (McCaffery et al., 2001; Weitzman et al., 2001), 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 (Austin et al., 2009; Frew et al., 2005; Hall et al., 2016; Weitzman et al., 2001; Gray & Snadden, 1999). One woman reported this to be the sole reason for not attending her upcoming appointment (Hall et al., 2016), with particular difficulties centred around drinking of the fluid laxative diet and enema insertion (Austin et al., 2009; Frew et al., 2005; Hall et al., 2016; Weitzman et al., 2001; Gray & Snadden, 1999). Women reported the experience as extremely unpleasant to administer, self-harm, and the cause of increased anxiety (Austin et al., 2009). Women spoke of a lack of test preparation information, which affected their confidence and elevated their fears further (Gray & Snadden, 1999). Furthermore, one study found discomfort regarding test preparations to impede individuals from repeat screening (Gray & Snadden, 1999), 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 (Frew et al., 2005; Weitzman et al., 2001). The psychological benefits of doctor narrative and presence are likely to promote repeat screens and social encouragement among others to screen (Weitzman et al., 2001), again of relevance to countries such as the US 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 (McCaffery et al., 2001; Robb et al., 2008b).

2.4.4.2.2 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 (Weitzman et al., 2001; Gray & Snadden, 1999). Others mentioned family discussions about screening as commonplace, yet did not perceive themselves as being influenced by their partners (McCaffery et al., 2001; Weitzman et al., 2001). 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 (McCaffery et al., 2001), 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 (Gray & Snadden, 1999; Holt, 1991; Rawl et al., 2000). Furthermore, in one study, Pakistani men were disinclined to attend unless advised to by their GP (Austin et al., 2009). When questioned as to why respondents attended the test, 90% said their physician had recommended the procedure (Holt, 1991). Overall, the literature supported the value of good doctor-patient relationships and trust to up motivation levels and improve screening intention (Weitzman et al., 2001; Gray & Snadden, 1999; Holt, 1991).

‘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 (Austin et al., 2009). Moreover, a misunderstanding that only men are at risk of colorectal cancer was reported by Pakistani and African Caribbean women (Austin et al., 2009). 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 (Austin et al., 2009).

2.4.4.2.3 The fear of the unknown
‘Fatalistic beliefs about colorectal cancer’ were demonstrated in women non-screeners who had lost family or friends to colorectal cancer (Hall et al., 2016). Some respondents concluded that their FSS invitation alone signified an adverse outcome of colorectal cancer (Gray & Snadden, 1999).

2.4.4.2.4 Peace of mind in knowing
Peace of mind was given as a reason from screeners as to why they attended screening (Hall et al., 2016; Holt, 1991). Any experiences of discomfort and embarrassment were felt to be overridden by a personal need for reassurance (Holt,
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 (Weitzman et al., 2001). Furthermore, even intense anxiety about the procedure was reported by some respondents to be negated by the need for reassurance (Hall et al., 2016).

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 (Austin et al., 2009). However, some women non-screeners continued to compare the benefits of early detection with the potential threat of an adverse outcome (Hall et al., 2016).

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 US, 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 (Frew et al., 2005).

2.4.4.2.5 (Un)necessary healthcare
FSS as an ‘Unnecessary healthcare’ procedure was stated by a female non-screener who disclosed no intention to treat future cancer should it occur (Hall et al., 2016). 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 (McCaffery et al., 2001).

2.4.4.2.6 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 (McCaffery et al., 2001; Robb et al., 2008b; Rawl et al., 2000; Gray & Snadden, 1999). Particularly caring for ill or disabled children or parents, or conflicting demands such as
own ill health obstruct FSS uptake (Hall et al., 2016). ‘Competing priorities’ were exacerbated by difficulties experienced with rescheduling FSS appointments, inhibiting FSS uptake further (Robb et al., 2008b). The need to request unpaid leave was also viewed as a major barrier for some (Robb et al., 2008b; Gray & Snadden, 1999). Yet, for a few women, such difficulties were still secondary to an overall reluctance to attend ((McCaffery et al., 2001). 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 (Hall et al., 2016).

2.5 Discussion

Key barriers to FSS intention and uptake centred upon ‘Procedural anxieties’. Notably, ‘Shame and embarrassment’ (Ritvo et al., 2013; Austin et al., 2009; Frew et al., 2005; McCaffery et al., 2001; Weitzman et al., 2001; Robb et al., 2008b; Rawl et al., 2000; Gray & Snadden, 1999) 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 (Austin et al., 2009). 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 (McLachlan et al., 2012). McLachlan et al. (2012) 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 (Frew et al., 2005; Gray & Snadden, 1999; Rawl et al., 2000; Weitzman et al., 2001) consistent with previous quantitative associations found between anticipated test pain and FSS uptake (Kerrison et al., 2019; Lewis & Jensen, 1996). Moreover, feeling relaxed and comfortable during the procedure was found to be imperative to minimise risk of physical harm (McLachlan et al., 2012). ‘Perforation anxiety’ was a concern raised by
women (McCaffery et al., 2001; Weitzman et al., 2001), 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 (Hall et al., 2016). Furthermore, FSS requires invasive bowel preparation procedures to be completed by individuals, which are found to cause additional stress and anxiety (Austin et al., 2009; Frew et al., 2005; Gray & Snadden, 1999; Hall et al., 2016; Weitzman et al., 2001).

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. (2016) 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. (2016) 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.

2.5.1 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 (Moher et al., 2010). To eliminate reviewer bias and to ensure full inclusion, a second reviewer duplicate screened all abstracts and full texts during the screening process (Higgins et al., 2011). Consistent with other recently published reviews (Smith et al., 2016; Seitz et al., 2009), 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 (Ritvo et al., 2013; Austin et al., 2009; Hall et al., 2016; McCaffery et al., 2001; Weitzman et al., 2001; Rawl et al., 2000; Holt, 1991) of the qualitative studies identified in the recent FSS review by Kerrison et al. (2019). Moreover, during the peer-review process ET and MP each independently revisited 50% of the excluded titles (n= 4,839) 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 (Mahood et al., 2014). Inclusion of grey literature can, however, be challenging given it is time and resource intensive (Benzies et al., 2006).
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 (Thomas & Harden, 2008). This review therefore echoes caution over generalisation of findings made across different cultural and socio-political contexts.

2.5.2 Future research and clinical implications

The gap between FSS intention and uptake requires further attention (Power et al., 2008). 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 (Kiviniemi et al., 2011). 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 (Von Wagner et al., 2019b).

To address ‘Procedural anxieties’, clinical action is being taken to trial ways to improve the bowel preparation process 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 (Beintaris et al., 2019). Screening modifications are thus being trialled to see if post-procedural pain is reduced when using water-assisted, rather than the current CO₂ insufflation for BSSP (Beintaris et al., 2019).

With regards to gender preference of medical professionals, Stoffel et al. (2020) 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 (Von Wagner et al., 2009). 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 (Smith et al., 2015a). 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 (Bellhouse et al., 2018).

2.6 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.
Chapter 3 Barriers and facilitators to colonoscopy for cancer detection: Patient and Practitioner perspectives.

3.1 Abstract

Objective: To further understand the barriers and facilitators to attending colonoscopy examination following a positive routinely offered stool test result, from the perspective of patients and Specialist Screening Practitioners (SSPs).

Methods: Qualitative semi-structured interviews were conducted. Participants (N= 32) were patients (n = 20) who, as part of the Bowel Cancer Screening Programme (BCSP) in England, were invited to attend a colonoscopy examination, and SSPs (n= 12), who worked for the BCSP in England. Framework analysis included inductive and deductive coding.

Results: Anxiety was a key barrier cited by patients and SSPs, arising from the moment the patient received the invitation letter. Notably, procedural-related anxieties centred upon the fear of pain and discomfort and test invasiveness. The role of family, friends and the SSP were recognised by patients and SSPs to facilitate participation. Many patients, yet not SSPs, emphasised an obligation to attend all medical test invitations.

Conclusion: Practically-orientated strategies suggested by patients and SSPs address the patient barriers identified. These include earlier information to patients on the option of sedation for pain relief, earlier notification of potential financial support for patients unable to fund their own travel costs, and fewer uses of the term cancer within written materials.
Colorectal cancer (CRC), also known as bowel cancer is a leading cause of cancer morbidity and mortality worldwide, with 10% of all cancer cases diagnosed being CRC (Sung et al., 2021). It is the second most common cause of cancer death in the UK, accounting for 16,571 deaths yearly in the UK (Cancer Research UK, n.d. - a).

Organised asymptomatic CRC screening includes fecal immunochemical testing (FIT); a test that looks for traces of blood in a feces sample, and follow-up colonoscopy examination; a flexible tube called a colonoscope with a camera attached, inserted into the large intestine (colon) to look for abnormalities. CRC Screening programmes are available in most European countries, Canada, regions in North and South America, Asia, and Oceania (Schreuders et al., 2015). The FIT is the most widely used screening test worldwide, producing increased participation rates and the detection of positive results compared with other tests like the guaiac fecal occult blood test (Navarro et al., 2017). If a patient receives a positive FIT result, in many national screening programmes, they will be invited to a follow-up colonoscopy (Navarro et al., 2017). Colonoscopy is generally considered the gold standard for the detection of colorectal neoplasia and has been associated with long-term (20–30 years) reduction in CRC mortality (Nishihara et al., 2013).

Inadequate follow-up of a positive FIT result with a colonoscopy examination has the potential to undermine the effectiveness of screening programmes in reducing CRC morbidity and mortality. Based on an international survey of 35 FIT screening programmes, Selby and colleagues (2021) reported a mean proportion of 79% (ranging from 39 – 100%) of participants with a positive FIT attending colonoscopy as a follow-up examination test.

Colonoscopy examination as a diagnostic test, following a routinely offered positive FIT result, is provisioned by the National Health Service (NHS.UK, 2022- b) in England as part of the BCSP. Specialist Screening Practitioners (SSPs) play a key role as nurses who provide support and advice to FIT-positive patients, assessing patient
suitability for colonoscopy examination. See Figure 1 for an overview of the patient colonoscopy examination pathway and the SSP role within this pathway.

Empirical evidence on barriers to colorectal cancer screening include several systematic and rapid reviews among practitioners or patients regarding colonoscopy examination for primary colorectal cancer screening (Kerrison et al., 2021a; McLachlan et al., 2012; Green et al., 2008). Previous studies and reviews have focused largely on colonoscopy as a primary screening test, with only two studies looking at barriers to colonoscopy as a follow-up test for a positive stool-based test result (Bertels et al., 2020, 2022), specifically, neither of these two studies were conducted in England. The current study is therefore novel given it investigated patient barriers and facilitators to colonoscopy as a follow-up test as opposed to as a primary screening examination, which has never been investigated through qualitative research methods in England before. The current study is the first to continue and extend this work provided by Kerrison et al. (2021b) by incorporating and comparing patient to SSP known barriers and facilitators. Kerrison and colleagues (2021b) investigated the barriers to colonoscopy attendance following a positive FIT result, from the viewpoint of SSPs. Patient concerns about the procedure, bowel preparation, and pain and discomfort were frequently cited by Kerrison and colleagues (2021b), as psychological factors including emotional responses during the assessment, anxiety and denial about the accuracy of the FIT result. Furthermore, Mog et al. (2022) interviewed 17 gastroenterology providers and staff, reported perceived patient barriers included concerns about the safety and invasiveness of the procedure, patient embarrassment and lack of social support.

While a useful first step, Kerrison et al. (2021b) and Mog et al.’s (2022) research may not have fully captured patient barriers, as there may be some, or many barriers, patients do not disclose to health care professionals. Inclusion of patients within the current study allowed for direct accounts of the barriers faced to be captured, and it was deemed likely that patients who attended screening would share other
issues, not discussed at the time with their SSP. It was also anticipated that patients would provide greater insight into the facilitators that motivated and enabled them to attend a colonoscopy examination.

Patient questions within the interview schedule were informed by the Theoretical Domains Framework (TDF) (Atkins et al., 2017), whereby each question and prompt was mapped to one or more of the domains ahead of data collection. As guided by Michie et al. (2005) this facilitated a comprehensive assessment of the determinants of the barriers to and facilitators of behaviour change, allowing questions and prompts to gain a broad understanding of the barriers and facilitators patients experienced. A recent review by McGowan et al. (2020) reported many other qualitative studies (n=38) to have also used the TDF to inform data collection.

The current study aimed to:

1. undertake qualitative interviews to advance our understanding of the barriers and facilitators to attending colonoscopy examination, following a routinely offered positive FIT result, from both the perspective of patients and SSPs.

2. provide key procedural recommendations for consideration to reduce patient barriers which specifically focus on improving the NHS information and service provided to patients invited to attend further tests for CRC detection.
Figure 1

The Colonoscopy Examination Pathway

Note. Illustrates the colonoscopy pathway of the typical patient flow through the screening programme and the involvement of the Specialist Screening Practitioner (Kerrison et al., 2021b; adapted from Plumb et al., 2017)
3.2 Methods

3.2.1 Participant eligibility criteria.

Patients were members of the public who at bowel cancer screening age (60-74) had received an invitation to attend a colonoscopy examination (within the last 10 years), following a positive routinely offered stool test result. Both patients who had accepted this invitation and attended a colonoscopy examination and those patients who had declined this invitation were eligible participants. SSPs were employed by (or had been within the last 12 months) the NHS BCSP in England in which they support patients referred for a colonoscopy. Both patients and SSPs were able to speak and understand English and had the capacity to consent to the interview. All Interested participants were sent a participant information sheet (explaining the purpose of the study) and consent form to read. For those who wished to proceed, a discussion via email took place to allow the researcher to check the participant’s eligibility. Approval was obtained from the University of Leeds Ethics committee (Reference: PSYC-134). None of the participants dropped out or withdrew from the study. The reporting of the current study adheres to the CONsolidated criteria for REporting Qualitative (COREQ) guidelines (Tong et al., 2007)

3.2.2 Sampling and recruitment

3.2.2.1 Patients

A variety of social media platforms were used with Facebook’s local community forums, and bowel cancer support groups found to be the most responsive. Leaflets were sent to members of the public living in deprived and ethnic minority communities in the North of England, issued with food parcels and on newsletters. To aim to achieve ethnic diversity in sample with regards to patient characteristics, advertisement also took place on a local Asian radio station within the North of England.

3.2.2.2 Specialist Screening Practitioner (SSPs)
Snowball sampling via word of mouth was used to recruit SSPs, first initiated via the social media platform, Twitter. No recruitment of SSPs took place via formal NHS communication channels.

3.2.3 The research team

The research team consisted of four researchers with an average of 13 years in academia and applied health psychology research. The team are highly experienced in researching cancer screening behaviours using various qualitative and quantitative research methods. All members of the team are non-clinical and have no direct lived experience of being invited to or have attended a colonoscopy examination for any medical reason.

3.2.4 Data collection

Semi-structured interviews were conducted by (ET). Topic guides were broken down into the timeline of events known to occur for patients, from receipt of the initial invitation to receiving their colonoscopy test result. The patient interview questions and prompts were informed by and mapped to the Theoretical Domains Network (TDF) (Atkins et al., 2017) to gain a comprehensive coverage and understanding of barriers and facilitators. Furthermore, the interview was structured to allow patients to easily share their experiences as a journey they had recently undertaken (see supplementary interview guide). Due to the reports of improved quality of interviews conducted online regarding sensitive health related topics (Thunberg & Arnell, 2021) and Covid restrictions on face-to-face data collection, interviews were conducted and audio-recorded by the researcher (ET): via video call (in homes or private office spaces) or telephone, depending on the participant's preference (field notes were not taken during and or after the interviews). Patients gave their consent and completed a participant demographics form together with the researcher who recorded responses before the interview began. Patients were given a £20 AMAZON voucher as a thank you for their time and contribution.
3.2.5 Data analysis

Data analysis was begun in parallel with data collection, to inform subsequent data collection and for the researchers to determine when sufficient data saturation was achieved to address the research questions. Framework analysis followed an iterative process in accordance with the 7 stage guidelines outlined by Gale et al. (2013) and as described below.

The initial development of codes

Stage 1: Transcription. Verbatim transcription of the interviews was carried out by the primary researcher (ET), who also conducted the interviews. Stage 2: Familiarisation with the interview data. Transcripts were read and re-read, and handwritten reflections of initial thoughts and observations were captured in the page margins by the primary researcher (ET). Stage 3: Coding. Codes were developed to help describe and classify the data with reference to the research questions (i.e., a sentence or passage may be labelled ‘Level of cancer fear’ or ‘Early detection of cancer’). Two researchers (ET, RK) initially independently developed ideas for codes using the same sample of 6 transcripts (3 patient, 3 SSP). Codes were generated inductively (i.e., from the data), but also by using Kerrison et al.’s (2021b) coding framework to assist with this (i.e., codes were used/adapted from Kerrison et al.’s list of codes as and when relevant to the current data). Stage 4: Development of a working analytical framework. Researchers (ET, RK) met to compare their independently generated ideas for codes and through discussion consensually agreed on a working analytical framework (i.e., a ‘final’ set of 86 code names and the meaning of each).

The application of codes

Stage 5: Applying the analytical framework. The primary researcher (ET) then applied the agreed-upon codes to all transcripts. Where a new transcript was judged to contain text that could not be satisfactorily coded using the existing codes, new code(s)
were created, 14 new codes in total were created. The transcript number at which new codes were developed was logged. The researcher (ET) subsequently revisited all transcripts to apply the new code(s) if relevant.

*The use of the coded material to develop themes.*

Stage 6: Charting data into the framework matrix. The data were charted into a framework matrix, to provide a summary of the transcript material assigned to each code per participant (i.e., some cells could be blank should no material exist in a transcript labelled with that code). All researchers (ET, RK, DOC, LA) then used the charted framework matrix, and examination of interview transcripts or excerpts, to help develop themes. All stages of coding and data analysis were carried out in MS Excel.

Stage 7: Interpreting the data. Themes were developed to delineate key messages in the data relevant the research questions. Data interpretation involved making comparisons between the barriers and facilitators reported by patients and SSPs. Theme development was iterative and involved all researchers, who reached a consensus through discussion on the final content and organisation of themes.

### 3.2.6 Rigor

The current study was guided by four fundamental dimensions of rigor for qualitative work, according to the Trust, Auditability, Credibility and Transferability (TACT) framework (Daniel, 2019). A description of each of the four dimensions according to Daniel (2019) and how the current study specifically applied these is included in Supplementary table 2. As requested during peer-review, a different researcher (RK) to the primary researcher (who undertook stage 5 described above) judged the comprehensiveness of the final analytical framework (i.e., the final 100 codes developed after applying the initial/working coding framework to all transcripts). The researcher (RK) independently applied the final code list to two transcripts (different to the original 6 used to develop the initial/working coding framework), and
judged it to be sufficient (i.e., no new codes were required to adequately label the transcripts).

3.3 Results

3.3.1 Participant characteristics and data collection

Patient and SSP numbers and characteristics are summarised in Table 1. Interviews ranged from 29 to 76 minutes. Only patients who accepted the invitation and attended a colonoscopy examination were recruited, meaning no patients who chose to decline the invitation to attend further tests were interviewed. No participants dropped out or decided to withdraw their data. All data were collected by one researcher (ET) over a 6-month period, from December 2020 to May 2021.

Table 1

*Participant numbers and characteristics (N = 32)*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients who screened <em>(n = 20)</em></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>12 (60)</td>
</tr>
<tr>
<td>Age, mean <em>(range)</em></td>
<td>67.4 <em>(60 – 75)</em></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>18 (90)</td>
</tr>
<tr>
<td>White Irish</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Black British - Caribbean</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Highest level of education completed</td>
<td></td>
</tr>
<tr>
<td>No schooling completed</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Secondary Education <em>(GCSE/O - Levels)</em></td>
<td>8 (40)</td>
</tr>
<tr>
<td>Post-Secondary Education <em>(College, A-levels, NVQ3 or below, or similar)</em></td>
<td>5 (25)</td>
</tr>
<tr>
<td>Undergraduate Degree <em>(BA, BSc etc.)</em></td>
<td>3 (15)</td>
</tr>
<tr>
<td>Post-graduate Degree</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Other <em>(Doctor)</em></td>
<td>1 (5)</td>
</tr>
<tr>
<td>Number of different Regions of England</td>
<td>5</td>
</tr>
<tr>
<td>Socio Economic Status- Index of multiple deprivation</td>
<td></td>
</tr>
</tbody>
</table>
Quintiles

<table>
<thead>
<tr>
<th>Quintile</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (Most deprived)</td>
<td>15</td>
</tr>
<tr>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>4</td>
<td>30</td>
</tr>
<tr>
<td>5 (Least deprived)</td>
<td>25</td>
</tr>
</tbody>
</table>

Time period lapsed since colonoscopy mean *(range)* 27 months (1 day – 8 years)

**Specialist Screening Practitioners (*n* = 12)**

Female 11 *(91.6)*

**Occupation**

- Lead SSP 2 *(16.7)*
- SSP 10 *(83.3)*

Number of different Screening Centre's 6

Number of different Regions of England 5

*Note. Patients who screened had attended a colonoscopy following a positive routinely offered stool test result, meaning no patients recruited chose to decline the invitation to attend further tests.*

### 3.3.2 Description of themes

Based on the data analysis of barriers and facilitators coded, three key themes with subthemes were developed: (1) *patient anxiety throughout the colonoscopy pathway*, (2) *psychosocial facilitators assisting participation*, and (3) *The need for earlier tailored patient advice and support* (see Figure 2).
Figure 2
Themes and the hierarchy of sub-themes.
3.3.2.1 Theme one: Patient anxiety throughout the colonoscopy pathway.

Most patients and SSPs reported feelings of anxiety from the moment they (patients) received the invitation letter to attend further tests. Patient anxiety continued to be raised as a key barrier throughout all stages of the colonoscopy examination.

“I was quite shocked and obviously it made me anxious” P4

“They are instantly worried” SSP2

3.3.2.1.1 Patient anxiety about the risk of bowel cancer

For some patients, a fear of having bowel cancer was triggered on immediate receipt of their invitation letter. Likewise, SSPs reported patients read the word cancer on the letter and jump to conclusions. Depending on the patient’s level of cancer fear, it was thought that this could inhibit or assist patient participation. Anxiety levels were reported to be lower in patients that had no symptoms or who provided alternative explanations, such as piles.

“I didn’t think it was cancer, but that was the first thing that came into my mind” P6

“Someone who sees the word cancer, that’s it, you see that C bomb dropped, that’s it...I find people tend to go into sort of overdrive” SSP12

“One part of me’ I’d obviously read the letter thinks ‘9 out of 10 abnormal so just piles’ which I did have piles ‘or polyps, but the other part is worried” P13

SSPs and patients recognised that existing written materials were designed to reduce patient anxiety, by providing statistics on the low levels of bowel cancer risk. Some SSPs explained that an optimal level of reassurance in written materials is impossible to achieve, given its dependence on the patient’s own anxiety levels at the time of reading.

“I have to say reading the leaflet that came with it, was quite reassuring” P4
“The problem is, you don’t want people to get a letter and to absolutely terrify them, but then you don’t want it to give them more reason to think that they don’t need to come and have the test” SSP3

3.3.2.1.2 Patient anxiety about the bowel preparation procedure

Many patients tolerated the laxative drink well, surprisingly given their initial concerns about the bowel preparation. SSPs, in contrast, continued to view the bowel preparation as more unpleasant than the colonoscopy examination itself, for patients. Patients and SSPs equally recognised that hearing of other people’s unpleasant bowel preparation experiences contributed to these initial concerns, discouraging patient participation.

“I found it okay. I’ve spoken to some people who say ‘Oh it’s horrible, it’s horrible’ but I didn’t mind it” P16

“The prep generally is worse than having the procedure done. So, by the time you actually come into hospital to have your test done, you’ve been through the worst of it” SSP2

Due to the laxatives patients had taken, concerns of a bowel accident enroute to the hospital were shared by some patients. Some patients were relieved and encouraged knowing that their appointment was in the morning having taken the laxative fluid the evening before.

“I think it’s a worry that I would probably think about if I wasn’t in the profession” SSP1

“I don’t think I would like a colonoscopy in the afternoon. Having to have to take the bowel preparation stuff in the morning, because I wouldn’t want to be leaving the flat not certain that, that something else was suddenly going to appear” P1

3.3.2.1.3 Patient anxiety about the colonoscopy procedure
Many patients and SSPs spoke of greater levels of anxiety about attending the procedure compared to their risk of bowel cancer, particularly the case in patients who had never had a colonoscopy before. Morning appointments were often reported by patients and SSPs to be preferred, particularly encouraging to those patients where it was their first colonoscopy. Many reported patient nerves on arrival for their colonoscopy, any delays in their waiting time increased their anxiety.

“I was probably more anxious about having the colonoscopy than having the result” P12

“I was anxious because I was doing something that I have never done before” P5

“I wake up, I think right I’m going. Where if it’s in the afternoon, I’m sat all morning thinking about it” P3

“But some people are very quiet. Some people can be angry and often, just nervous is the most common” SSP2

Anxiety about the colonoscopy procedure itself has been broken down into the following areas of concern, acting as barriers to patient participation raised by both patients and SSPs.

3.3.2.1.4 Patient concerns about pain and discomfort

For most patients, the expectation of pain and discomfort were often reported, by both patients and SSPs, to be greater than the pain experienced during the procedure. For those where it was their first colonoscopy, hearing painful colonoscopy experiences from friends heightened any initial anxiety, discouraging participation.

“You’re just terrified of what they are going to do and if it’s going to hurt… but there wasn’t any pain so...the unknown, you don’t know what they are going to do, do you.” P3

“[Patient says] ‘I was really worried, but it was a really painless procedure’” SSP5
“She just said it was that painful that she had to have painkiller, and the painkiller didn’t do anything” P5

The availability of pain relief was reported to reduce patients’ concerns and encourage participation. Yet SSPs explained that the option of sedation was not always available to patients, should they live alone, need to care for a family member, or have work commitments the next day. Patients interviewed did not however share such barriers concerning their living or work circumstances. Providing distractions during the test were reported by both SSPs and patients as effective ways to reduce the anxiety and pain experienced.

“If you think you’re going to get a bit anxious, tell them they’ll give you a sedative, you’ll feel fine” P12

“You need somebody to look after you, if you have sedation. I believe that this is a barrier, because they say, ‘Oh I don’t have anybody then, I’m not going to be able to come’” SSP9

“I was able to look at the screen, to see what they were doing, that was a distraction” P11

One patient’s experience of a previous painful colonoscopy fostered higher levels of anxiety and inhibited participation. Likewise, SSPs recalled similar patient examples.

“I made a mental note on paper that I was never going there again, and that was the last time I was having that” P7

“You do get a few who’ve had bad experiences and they have found it uncomfortable before and obviously those we would try and explain to them that each colonoscopy can be very different”. SSP3

3.3.2.1.5 Patient concerns with test invasiveness and embarrassment.

Concerns with test invasiveness were reported to inhibit patient participation by patients and SSPs, a greater issue for men than women. Childbirth, and being older in
age may partially explain why women reported less embarrassment than men. Interestingly, one male went so far as to say the procedure was not something men should do, suggesting underlying reasons of homophobia.

“I’m 70 and I have had two children, there is not much that embarrasses me now!” P5

“The initial embarrassment of having your bottom exposed. You don’t do that sort of thing... it was a strange sort of thing to be doing” P20

“I’ve got a camera being shoved up my backside, potentially by another man, hang on, woooo! it could be a homosexuality kind of thing” SSP12

For one patient with a history of sexual abuse, the thought of having a colonoscopy caused high levels of anxiety. The patient and SSPs provided details of the personalised care provided to those (patients) who had previous experiences of sexual abuse, to reduce anxiety and assist participation.

“I was scared of my reaction to the colonoscopy, that I would have attacked somebody, or hit somebody. That was my fear...They arranged an all-female team, which I thought was amazing.” P14

“She just wanted me to hold her hand, and I think that was it” SSP4

3.3.2.1.6 Patient anxiety about potential further surgery

A fear of the need for a colostomy stoma, should an operation to remove a tumor result in a stoma being required, was recognised as a potential barrier for other patients, yet not personally to those interviewed.

“I think it is other things like perforation, and stoma bags, which patients probably ask about more” SSP2

“Better a bag than a body” P19

3.3.2.1.7 Patient and relative’s anxiety from receiving news of bowel cancer
Patients and SSPs reported a mixture of emotions when they (patients) received news of bowel cancer. Often, patients and SSPs cited more concern about the reactions of loved ones.

“It tends to be the relatives that get upset, more than the patient themselves” SSP7

“My main thing was, how on earth am I going to tell <wife’s name>. That was my main concern” P18

3.3.2.1.8 Patient anxiety related to Covid-19 measures

At the time of colonoscopy examination, the additional burden of having to adhere to Covid measures was experienced by many patients and SSPs, increasing patient anxiety and hindering participation.

“We’ve been so careful all the way through. I just felt very nervous, just going into the hospital situation” P9

“A lot of people, say oh I’ll wait until I’ve had my vaccine” SSP7

“Because of Covid you can’t have anybody with you. So, you're on your own. Yeah, not good. I cried” P14

3.3.2.2 Theme two: Psychosocial facilitators assisting participation

This theme considered the key facilitators for patient participation. The role of family and friends, the SSP, and themselves situated as the ‘patient’ were reported to influence patient’s decision. Given the continual involvement of family, friends and the SSP, patients reported these facilitators to occur throughout the colonoscopy examination pathway.

3.3.2.2.1 The role of family and friends – encouraging participation

The support and influence of loved ones

The reassurance provided by family and friends encouraged patient participation and lowered initial concerns of the risk of bowel cancer and procedural
anxieties. Having similar attitudes to friends and the support of family members on the
day of the procedure, both in terms of travel and whilst in hospital assisted patients.

“I spoke to one of my colleagues and he said, ‘Oh I’ve had one of them, no need to
worry about that...it’s nowt, very little chance of anything being found, the percentage is
so low’...so I thought, we’ll go and see what happens” P17

“My brother is 70 this year. We’re of the same opinion, in family discussions, we talked
about this” P7

“No, my husband drove. I could have driven myself, but you know, he would have
wanted to drive me to make sure it was alright, especially to drive me back, so he
drove and waited”. P11

Coercion by family members was cited by almost all SSPs, who described
instances of patients pressurised to have a colonoscopy. SSPs described how they
intervened to remind relatives that it was the patient’s decision. Equally, a patient
shared pressures to attend received from their spouse.

“I just say you’ve got to stop for a minute, this is about your relative and it’s about them
they’re making the decision, not you, and if this does carry on, I am going to have to
ask you to leave”. SSP5

“I can’t fight my wife, she made me do it. Nagging me to do it…She came with me,
yeah. She made sure I went, to tell you the truth.” P20

History of cancer and the need for early diagnosis.

Patients who have experienced cancer with a family member or spouse
explained how this encouraged their participation. Patients acted quickly for the early
detection and prevention of any potential cancers. Likewise, SSPs confirmed ‘having a
family history of cancer’ to assist patient participation.
“My brother had died in 2006 at the age of 56 with rectal cancer, and so it was it was a no brainer really. I just went. I truly believe that early diagnosis is the key to anything.”

P12

“My mother died of bowel cancer, so that sort of raised the awareness in me” P15

“They say ‘oh my mom had it, my dad had it, or my brother, and the experience with them, they delayed it and you know, and then they found it at the final stage, and I don’t want this to happen to me’” SSP8

3.3.2.2 The role of the SSP – Providing knowledge and reassurance

Before attending the SSP assessment, many patients reported knowing little about bowel cancer screening. During the assessment patients reported gaining understanding of the procedure and associated risks, according to SSPs this assisted patient participation. Patients recalled feeling reassured both following the assessment and on the day of the procedure.

“I had no idea about how it would be performed. I didn’t know if it was one person or half a dozen” P1

“They’ve come in saying they don’t want it, but actually maybe they do want it, and they just need that bit more information” SSP5

“She’d gone through everything from start to finish. She was just so reassuring about it, and I knew I could call her if I have any questions” P2

“Those nurses, fantastic, in that room. They really put you at ease” P8

3.3.2.3 The role of the patient- knowing the importance of screening

It’s okay, it’s not my first time

Patients who had previously attended medical or screening tests, had a medical work background or went through childbirth demonstrated knowledge of the purpose and benefit of further screening tests, assisting in their participation. A patient’s medical background was not discussed by SSPs.
“Well, I had no hesitation, but you see, I suppose it’s partly to do with my background, in that I knew it was important” P12

“It’s an alien environment. The whole thing is, but for me, it’s not an alien environment really” P4

**A need for the certainty of a diagnosis or not**

Many patients explained that their reason for participation was due to a need for the certainty of a diagnosis or not, providing peace of mind. Similarly, a few SSPs shared their understanding and appreciation of patients' innate need to know either way.

“Just to find out what was what. If you don’t go you don’t find out. And if you don’t find out what it is then the worst can happen. If you don’t go and find out, it could become untreatable” P16

“I thought, no, I need to have it, because if I don’t have it, I would worry” P13

“That need to know, I think, just being human. We need to know what the answer is” SSP7

‘*Just do it*’ - *Feeling obliged to look after yourself*

Almost all patients demonstrated an obligation to attend anything medical or health related. Patients did not view their invitation as optional, given their initial participation. Many patients put their concerns or other priorities to one side, focusing on the necessity of medical-related tests. In comparison, a patient’s obligation to attend medical tests was not reported by SSPs.

“I just did it. I didn’t think, have I to, or haven’t I to. I just met this nurse, I got on with it!” P3

“If you’ve got a result, then I don’t see that as optional, I see that as you’ve got to do something about it. That was my view, I need to do something about it” P10
“I’m just one of these that if they say something has got to be done, it’s got to be done, regardless of whether I feel a little bit apprehensive about it. This is all about my well-being” P2

3.3.2.3 Theme three: The need for earlier tailored patient advice and support.

This theme considered the timing of and need for tailored advice and support to further encourage patient participation. According to SSPs and patients, patient barriers were currently addressed during the SSP assessment, not earlier in the colonoscopy pathway. SSPs perceived patient nonattendance to be greater at the initial assessment stage, indicating a requirement for the earlier provision of advice and support.

“We have far more Do Not Attends (DNAs) for patients who are coming in for assessments. Then, once they’ve come for the assessment, generally, they come for the colonoscopy” SSP1

3.3.2.3.1 A need to know earlier about...

The patient knowing earlier in the colonoscopy pathway of the options available to them was suggested by patients and SSPs to reduce anxieties, overcome accessibility issues, and assist participation.

“Maybe they don’t, at this stage, know enough about it, you don’t get to find out really what it is, until you go to the nurse, do you” P12

The option of sedation.

It was not until the assessment that patients and SSPs cited concerns raised of expected pain and discomfort. The potential administration of sedation is briefly mentioned in the booklet sent to patients, however to reduce immediate concerns of pain and discomfort and encourage participation it was suggested that the invitation letter signposts to patients the option of sedation.
“She effectively talked to me about what the procedure was, how it worked. What my options were in terms of sedation and pain relief” P15

“If people think it’s going to hurt them, they might not go... maybe if people knew they could have a sedative right from the beginning, they might go” P12

**Alternative examination options.**

It was not until the assessment that patients and SSPs cited discussions of co-morbidities, previous unpleasant medical experiences, or concerns of test invasiveness. Alternative examination methods (a Computerised Tomography Colonography) was cited by a patient to be briefly mentioned in the booklet.

“I didn’t want the test, because of what happened previously, so I rang them up. I spoke to a nurse” P7

“In the initial stage. You shouldn’t be able to say to people, you need to go for colonoscopy, if there are alternatives, they should be offered it, definitely. Or they should know that there are alternatives” P14

**The option to request a same sex endoscopist**

According to SSPs prior to the assessment most patients had no initial awareness of the option to have a same sex endoscopist. SSPs and one patient questioned how many individuals immediately decline further tests, without sharing their reason or making specific requests of the screening team.

“Woman in Muslim cultures they don’t want to be scoped by a male endoscopist. They want a female endoscopist, which we make arrangements for that” SSP8

“She’d had some kind of sexual abuse experience, which is why she particularly wanted a woman” SSP3

“A cultural, kind of like a barrier really. They don’t ever really say what it is, but we do find that sometimes they just don’t participate” SSP6
Potential travel provision

According to SSPs the assessment is the first opportunity a patient has to request financial support with travel costs. To attend this assessment, it was recognised by SSPs that the patient would need sufficient funds to travel. For the invitation letter to notify patients of potential financial support with travel costs, SSPs advised that funding would need to be sourced at a programme level. Patients interviewed recognised this to be an issue for others (not themselves) in participation.

“Some people don't have money, and I know it's incredible in this day and age to think that somebody can't get to a place because of the money” P12

“On a case-by-case basis, we can make an argument for this person to be given a funded taxi...a few occasions where that's happened, but it puts a lot of work on to the SSP to actually make that argument, fire off all those emails, collate everything, arrange the taxi, it's not a streamlined process” SSP11

3.3.2.3.2 A need for tailored patient care

Many patients recognised the tailored information they had received from their SSP. SSPs explained that the need for information was very individualised, with some patients preferring to know very little indeed about the procedure.

“She'd gone through everything from start to finish. She was just so reassuring about it, and I knew I could call her if I had any questions” P2

“There's only so much you can do, only so much information that you can give people without scaring them, that sort of fine line, between what's enough and what's too much information” SSP6

Fewer uses of the term ‘Cancer' within written invitation materials

The inclusion of the word cancer both within the programme title (BCSP) and written materials was cited by SSPs and patients to heighten anxiety and inhibit patient
participation. It was advised that written materials should be revised given the aim of a colonoscopy examination is to look for changes and abnormalities in the large bowel.

“They just see the word cancer and that's... I mean if you think about all the other screening programmes that are out there, they don't actually have cancer in the title” SSP5

“You’re looking for abnormalities rather than cancer. I don’t think cancer should be on that letter anywhere. I think it should be abnormalities or irregularities or something. But not cancer, because that would put people off”. P14

**Improved patient understanding of the need to request an interpreter**

SSPs shared examples of patients who had arrived for their assessment without requesting an interpreter, leading to the rescheduling of their appointment. A few SSPs questioned whether the standard invitation letter was only issued to patients in English, requiring the patient to have local resources to help them interpret and know to request an interpreter. English was the first language of all patients interviewed; therefore, no patients had experienced language barriers.

“They don't always call us, but they might not be able to read all the information on there, anyway. If their English isn't very good” SSP4

“[the patient] turned up and, like the son or daughter or the friend or whoever will turn around and say oh yeah, I'm happy to translate, and you go I'm now going to have to rebook this appointment”. SSP12

“I'm not sure whether they have this letter, sent out in their native language?” SSP10

**Greater flexibility in appointments times offered.**

Due to the bowel cancer screening age extension to 56 years (as of 2021), SSPs noted that the increase in patients with work commitments will create greater
need for appointment flexibility and the option of out-of-hour appointments. A few SSPs shared how their screening centres had started offering evening appointments for the colonoscopy procedure, but not for the assessment.

“With the age extension coming in, a lot of the younger people are going to still be working and I know that that is starting to become a factor” SSP 11

“We do have evening appointments. We have a five to nine appointments, not for clinic but for colonoscopy. We are thinking about doing out of hours Saturday lists for colonoscopy” SSP10

**Earlier access to patient contact details**

SSPs explained that it is not until the patient has given their consent at assessment that they have the patient’s contact details. Should earlier access to patient details be possible, SSPs suggested the use of text messages as a helpful reminder to patients of their assessment and for bowel preparation timings. Text reminders were not discussed with patients interviewed to gather initial reactions of their potential benefit.

“Until they come to you, we don’t know anything about them. We have no idea about their health, any problems or anything which you know which is really frustrating” SSP10

“For some people it’s [text messages] going to remind them of their appointment...Text reminders to start your prep I would love that, that would be amazing” SSP12

### 3.4 Discussion

This study is the first qualitative study to examine patient barriers and facilitators experienced in attending colonoscopy examination, following a routinely offered positive FIT result, from both the perspective of patients and SSPs. These findings corroborate and extend earlier work by Kerrison et al. (2021b) in SSPs only, and Mog et al. (2022) in gastroenterology providers strengthening the validity of known
barriers and facilitators, while also providing a greater insight into facilitators, namely the role of family, friends and the SSP and how these social and professional influences have motivated and enabled patients to attend follow-up colonoscopy.

Study findings were developed into three key themes. (1) Patient anxiety throughout the colonoscopy pathway. Anxiety was frequently cited by patients and SSPs as a key barrier, arising from the moment the patient received the invitation letter to discuss further tests. Notably, procedural-related anxieties centred upon the fear of pain and discomfort and test invasiveness. (2) Psychosocial facilitators assisting participation. The role of family, friends and the SSP were recognised to assist and in some instances force participation. Almost all patients felt obliged to attend all medical test invitations and expressed a need for the certainty of a diagnosis or not. (3) The need for earlier tailored patient advice and support to lower anxieties, make earlier contact with patients, and reduce accessibility barriers such as travel costs. Suggestions made by SSPs and patients for this additional advice and support were mostly required earlier on in the colonoscopy pathway.

Findings from reviews by Yang et al. (2018) and Travis et al. (2020) similarly focussed on procedural-related anxieties in patients who had undergone a colonoscopy or flexible sigmoidoscopy, with alike concerns of bowel preparation, the procedure itself, and diagnosis of cancer. Recent charity campaigns have attempted to reduce the public's anxieties about having a colonoscopy through online videos, fact sheets and leaflets (Bowel Cancer UK, n.d. - a). Patients in the current study demonstrated a sense of obligation to act soon for the early detection and prevention of any potential cancers. Further to this, Bertels et al. (2022) recently found that when a patient’s decision-making process to participate in a colonoscopy examination was immediate, this was associated with high-risk perception, worry, and emotional turmoil. Family influenced participation beyond the provision of practical and emotional support, first reported by Kerrison et al. (2021b) was again further evidenced by SSPs in the current study. There were several barriers and facilitators SSPs raised which were not
reported by patients and vice versa. For example, cultural and language barriers to colonoscopy examination previously reported by Kerrison et al. (2021b), were highlighted in the current study as a patient barrier by SSPs. Patients interviewed in the current study did not however report any issues experienced with their own cultural beliefs. English was the first language of all patients interviewed; therefore, no patients had experienced language barriers. Most patients explained how they felt obliged to attend all medical tests facilitating their participation, this was not something reported by SSPs. For a full comparison of all individual barriers and facilitators raised by SSPs compared to those raised by patients see Supplementary table. This table categorises each barrier and facilitator coded according to the psychological, sociocultural, health-related, practical and Covid-related factors reported with Kerrison et al.’s, (2021) coding framework.

3.4.1 Limitations

This study also has several limitations. (1) It was our intention to recruit patients who have accepted and declined an invitation to attend further diagnostic tests. Despite extensive methods of recruitment, the sample did not include patient decliners. Questions were included within the interview topic guides (see supplementary interview guide) to specifically ask patients and SSPs why they thought other patients choose not to attend the SSP appointment/follow-up tests. Suggested reasons as to why patients do not attend further tests, were then analysed and coded within the data as barriers and facilitators. SSPs have regular contact with patients, this enables them to share valuable insights as to the reasons decliners report to them for not attending. (2) Nearly all patients were of White British or White Irish ethnicity. Recruitment of decliners and minority ethnic groups for health research is a common issue recognised and experienced by researchers unable to engage ‘hard to reach’ groups to find out why they are not accessing certain healthcare services (Rockliffe et al., 2018).

3.4.2 Recommendations and implications for future research
Future qualitative research should work with an ethnic minority group sample to establish to what extent the collective findings thus far are generalisable, allowing for the identification of additional barriers distinct to ethnic minority groups. Future qualitative work should also target patient decliners to understand the magnitude of key barriers identified in the current study, particularly the barriers surrounding patient anxiety. Based on findings outlined, Table 2 summarises key recommendations for consideration to further encourage patient participation through the improvement of the information and service provided.

Consistent with recent recommendations for using the TDF in qualitative studies (McGowan et al., 2020) the current study adopted flexible and optimised use of the TDF. The TDF informed the patient interview questions, yet data analysis was guided by the framework method stages and recommendations set out by Gale et al. (2013). This allowed codes to be derived from the data and not predetermined or restricted to the TDF. All recommendations suggested were obtained directly from the SSP and patient interviews, not from suggestions developed by the researchers through further analysis or consideration of barriers reported. It is recommended that future work is now informed by behaviour change techniques and their mechanisms of action; processes which influence behaviour (Carey et al., 2019; Connell et al., 2019) or the integrated screening action model (Robb, 2021) to identify effective theory-based behavioural interventions to overcome other barriers raised by SSPs and patients. To our knowledge, this is the most comprehensive single list of such recommendations and accompanying potential strategies for consideration. The strategies have the potential to improve future equality, diversity, and inclusion of patients attending a colonoscopy examination. For instance, earlier notification of potential financial support for patients unable to fund their own travel costs, improved patient understanding of the need to request an interpreter and having greater flexibility in appointments times offered. It is advised that future research findings and chosen strategies be externally audited for validation and further development with patients, SSPs, and programme
managers to ensure they are both feasible and accepted by stakeholders prior to wider programme level rollout.
### Table 2

Key recommendations for consideration to reduce patient barriers through the improvement of NHS procedural information and services provided to patients invited to attend further tests for CRC detection.

<table>
<thead>
<tr>
<th>Patient barriers to attending further tests</th>
<th>Recommendations</th>
<th>Suggestions for implementation</th>
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</thead>
<tbody>
<tr>
<td>Patient anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anticipated pain and discomfort</td>
<td>Patients know earlier about the option of sedation</td>
<td>• Use the invitation letter to signpost and provide information regarding patient options, to immediately address patient concerns/anxiety. *Note the booklet briefly mentions the potential use of sedation and occasional need for CTC due to health issues.</td>
</tr>
<tr>
<td></td>
<td>Patients know earlier about alternative screening options (CTC).</td>
<td>• Provide a short video/YouTube clip of an SSP explaining 'Patient concerns about colonoscopy'.</td>
</tr>
<tr>
<td>Concerns with test invasiveness</td>
<td>Patients know earlier about the option to request same sex endoscopist</td>
<td>• Give patient’s the option to phone an SSP to discuss their immediate concerns and or ask questions ahead of their appointment.</td>
</tr>
<tr>
<td>Anxiety about the risk of bowel cancer</td>
<td>Increase patient understanding that the risk of bowel cancer is low and that further tests are looking for abnormalities/irregularities.</td>
<td>• Fewer uses of the term cancer within the invitation letter, replace with ‘the purpose of further tests is to look for abnormalities/irregularities’ rather than cancer.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Remove the term cancer from NHS Bowel Cancer Screening title. The word cancer is not included in the NHS Breast screening, NHS Cervical</td>
</tr>
<tr>
<td>Anticipated concerns with the bowel preparation</td>
<td>Widen patient communication channels regarding what to expect with bowel preparation.</td>
<td>Make available SSP top tips on bowel preparation to patients (in a YouTube video clip, or leaflet)</td>
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<tr>
<td>Accessibility to attend hospital</td>
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<td>Source and distribute funding for travel costs at a programme level.</td>
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<tr>
<td>Travel costs</td>
<td>Offer and improve the awareness of travel provision to patients who are unable to fund their own travel costs.</td>
<td>Obtain details of patient's native language in order to issue out invitation letters in patient's native language.</td>
</tr>
<tr>
<td>Language barriers reading the letter</td>
<td>Improve patient understanding of the need to request an interpreter when English is not the patient's first language.</td>
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</tr>
</tbody>
</table>
Work or family commitments

Offer flexibility in timings of appointments/further tests where work or family commitments possible.

- Make out of hours/weekend SSP and colonoscopy test appointments (more) available, as part of normal service across all screening centres.
- Ask patients who phone to reschedule if this is due to work or family commitments, if so, offer out of hours/weekend appointments.
- Notify the patients in advance, on the invitation letter that the appointment is 45 minutes long, to ensure they allocate sufficient time and parking charges to attend.

Patient communication

Send text reminders to patients to:

- Notify them of their appointment time.
- Provide a phone number should they have any immediate concerns to discuss.
- Provide a phone number should they wish to reschedule.
- To remind them of bowel preparation timings.

- Include a tick option on the FIT test for patients to consent for the NHS to make contact via telephone should further communication and tests be required.
- Grant earlier access to patient phone contact details prior to 'consent for further tests' taken at the initial assessment.

Unable to contact patients who Do Not Attend

Note. CTC- Computed Tomography Colonography. SSP – Specialist Screening Practitioner. FIT- Fecal Immunochemical cancer screening Test
3.5 Conclusion

Inadequate follow-up of positive FIT has the potential to undermine the effectiveness of screening programmes in reducing CRC morbidity and mortality. Our findings provide in depth reports of procedural-related anxiety experienced by patients who, as part of the BCSP in England, were invited to attend a colonoscopy examination. Our findings suggest there are many practically orientated strategies for onward consideration, intended to improve the equality, diversity, and inclusion of patients attending a colonoscopy examination in the future.
Chapter 4 Effects of a modified invitation letter to follow-up colonoscopy for bowel cancer detection.

4.1 Abstract

Objective: To investigate whether modifications made to the current National Health Service (NHS) invitation letter for follow-up colonoscopy examination affect participant state anxiety and behavioural intentions to attend.

Methods: 538 adults of bowel cancer eligible screening age (56-74) were randomised to receive the current NHS invitation letter or the modified version of the letter as a hypothetical scenario. Modifications to the letter included fewer uses of the term cancer and awareness of alternative screening options. History of colonoscopy invitation, anticipated state anxiety, behavioural intention to attend the nurse appointment, and colonoscopy concerns upon reading the letter were measured.

Results: Behavioural intentions were high in both conditions, however participants reading the current letter reported significantly higher behavioural intentions compared to the modified letter. There was no main effect of previous invite status, or interaction between previous invite status and letter condition on behavioural intentions. However, the effect of the letter on levels of anxiety depended on the participant's invitation history. Those never invited for a colonoscopy were more anxious when reading the modified letter compared to the current letter. Conversely, previous colonoscopy invitees were less anxious following reading the modified letter than those reading the current letter. Those never invited for a colonoscopy were more concerned about embarrassment and test invasiveness. All findings remained the same when controlling for age and education.

Conclusion: Modifications to the invitation letter were not beneficial to levels of screening intention or anxiety.

KEYWORDS: Colonoscopy; Early diagnosis; Cancer screening; Fecal immunochemical test; Patient anxiety.
4.2 Introduction

Colorectal cancer (CRC), also known as bowel cancer, is among the leading causes of cancer morbidity and mortality worldwide. It is the second most common cause of cancer death in the UK resulting in 16,800 deaths yearly (Cancer Research UK, n.d.-a). The relative risk of CRC mortality has been reported to be reduced by 25% through patient attendance in at least one round of organised asymptomatic CRC screening (Hewitson et al., 2008). Asymptomatic CRC screening now includes initial fecal immunochemical testing (FIT); a test that looks for traces of blood in a feces sample, and follow-up colonoscopy examination; a flexible tube called a colonoscope with a camera attached, inserted into the bowel to look for abnormalities. Colonoscopy is the gold standard for the detection of colorectal neoplasia and has been attributed to the long-term reduction in CRC mortality (Nishihara et al., 2013). Colonoscopy examination is currently provisioned by the National Health Service (NHS) in England as part of the Bowel Cancer Screening Programme (BCSP) to screen for abnormalities, following a routinely offered positive FIT result.

In a recent international survey completed by 35 screening programmes the mean colonoscopy completion at six months after positive FIT was 79% (Selby et al., 2021). Likewise earlier findings by Logan et al. (2012) found 83% of 21,106 patients in England with an abnormal test to undergo colonoscopy, with 6% of patients not attending the initial specialist screening practitioner clinic despite reminders. Given individuals with a positive FIT result are at a heightened risk of CRC, inadequate uptake of follow-up colonoscopy examination undermines the effectiveness of organised asymptomatic screening programmes to reduce CRC morbidity and mortality.

Previous quantitative research provides insight into patient emotional and practical barriers to follow-up colonoscopy (Kaushal et al., 2020; Plumb et al., 2017). For example, Kaushal and colleagues (2020) conducted a hypothetical online vignette survey with 953 English participants asked to imagine they had received a positive
fecal occult blood test (FOBt). Barriers to having a follow-up investigation included time constraints, more frequently cited in participants in employment or from ethnic minority groups, and difficulties with transport among participants living in areas of higher deprivation. To our knowledge only two qualitative studies in England have investigated the reasons for (non)participation in follow-up colonoscopy examination offered by the BCSP (Kerrison et al., 2021b; Travis et al., 2022). Patient anxieties were found to be a key barrier in follow-up colonoscopy attributed to the fear of a CRC diagnosis and procedural related anxieties such as pain and discomfort, bowel preparation procedures, and embarrassment. To our knowledge, these findings were consistent with only two other studies outside of the UK looking at barriers to follow-up colonoscopy examination in people in Denmark (Bertels et al., 2020, 2022). Through interviews with follow-up colonoscopy attenders and specialist screening practitioners, Travis and colleagues (2022) also captured recommendations to improve the delivery of NHS procedural information and services. Recommendations included the suggestion that information should be provided earlier to patients within written invitation materials about: 1) the option of pain relief (known as sedation) during the colonoscopy, 2) the possibility to request a same-gender NHS team to carry out the colonoscopy, and 3) it might reduce anxiety levels by including fewer uses of the term cancer within the letter.

To our knowledge interventions including modifications to written materials in England that relate specifically to follow-up colonoscopy invitation are yet to be trialled. The effects of alternate written materials on levels of patient anxiety and behavioural intention to attend follow-up colonoscopy is therefore currently unknown. The current study is informed by wider international work that demonstrates the effectiveness of providing procedural information and education in reducing procedural-related anxiety, pain, and adherence to colonoscopy (Denberg et al., 2006; Hsueh et al., 2016; Shaikh et al., 2010). Having no previous history of undergoing a colonoscopy has also been found to be associated with higher levels of procedural anxiety, with recommendations
for well-designed education materials to improve patient understanding of the procedure (Coombes et al., 2008; Shafer et al., 2018). This study therefore sought to investigate and compare the effect of screening history on patient anxiety and intention, following reading invitation material. Supporting theory which specifically considers the sequence of screening behaviour that an individual goes through is the integrated screening action model (I-SAM) introduced by Robb (2021). The I-SAM aims to improve uptake of cancer screening by providing a framework that outlines the sequence of stages a person passes through when engaging in a screening behaviour. These include participants being unaware of screening, repeating a screening behaviour through re-invitation or deciding not to screen. The I-SAM is directly informed by the Precaution Adoption Process Model (Weinstein et al., 2020) to explain how individuals at the same screening stage face common barriers to one another and therefore that interventions should be targeted per screening stage. Furthermore, individuals at different screening stages will face different barriers and health beliefs and therefore require different interventions (Robb, 2021). This integrated model draws upon behaviour change theory to identify potential targets and policies to increase access to screening, derived from the Capability, Opportunity, Motivation- Behaviour (COM-B) model (Michie et al., 2011) and other existing literature. This study sought to investigate whether providing additional procedural related information, such as the option of pain relief during the colonoscopy, would as per the I-SAM framework (Robb, 2021), change participant levels of motivation and capability (participant influences), measured through participant expected levels of anxiety (negative emotional responses) and behavioural intentions to attend the nurse appointment when invited to attend further tests.

To examine whether modifying the letter could positively impact levels of behavioural intention and anxiety we made a series of modifications to the current NHS BCSP invitation letter, following a positive FIT result. These modifications were based on recent qualitative research by Travis and colleagues (2022) which outlined
suggestions from specialist screening practitioners and colonoscopy screening patients within the BCSP. Suggestions were specifically informed by the barriers and facilitators patients experienced, and observed by nurses, when patients were invited and attended a colonoscopy following a routine positive FIT result (Travis et al., 2022). Modifications included fewer uses of the term cancer, making it known that pain relief was an option (known as sedation) during the colonoscopy, highlighting that there was an option to request a same-gender NHS team to carry out the colonoscopy and that alternative screening options are available should (for whatever reason) having a colonoscopy be of concern to the participant.

The current study is novel in its aim to investigate whether providing modified information to the current NHS Bowel Cancer Screening Programme (BCSP) invitation letter for follow-up colonoscopy reduced participant self-reported state anxiety and increased behavioural intention levels to attend the nurse appointment to discuss further medical tests. For exploratory reasons, the study also investigated whether history of colonoscopy invitation (for any medical reason) affected self-reported state anxiety and behavioural intention levels to attend the nurse appointment by letter condition. Specifically, it was hypothesised that participants who receive the modified invitation letter will report significantly lower levels of state anxiety, higher levels of behavioural intention, and significantly lower levels of concern regarding different aspects of the colonoscopy procedure (e.g., pain and discomfort, the gender of the NHS staff performing the colonoscopy, test invasiveness) compared to those participants who receive the current NHS BCSP invitation letter.

4.3 Methods

4.3.1 Design and participants

The current study used a between-participants cross-sectional online questionnaire design. Participants were recruited using an online participant database (Prolific) and were required to be aged 56 -74 years old (the existing BCSP eligible
screening age for CRC) and to currently live in the United Kingdom. No other eligibility criteria were specified. Participants were randomised, using the Qualtrics questionnaire randomizer function to receive, and read one of two letter conditions: The current NHS BCSP letter or a modified version of the NHS BCSP letter. Participants were given a hypothetical situation in which they were asked to imagine that they had received the letter in the post inviting them to attend a nurse appointment to talk about having a colonoscopy. After reading the letter participants were asked to rate their expected levels of state anxiety, behavioural intention, and the nature of concerns with being invited to attend a nurse appointment to talk about having a colonoscopy. Note that prior to the study commencing, patient and public engagement work was carried out with 15 adults of eligible screening age (between 56-74), to gain further feedback on both the current NHS and the modified invitation letter with minor changes made to the modified letter. For the current NHS letter and the modified version of the NHS BCSP letter, see Supporting information file. The study received ethical approval from the University of Leeds Ethics committee on the 21st of March 2022 (Reference: PSYC-501) and was preregistered on AsPredicted (#97222) on the 16th of May 2022 ahead of data collection. Data was collected twice due to a technical error with the position of the behavioural intention anchors on the questionnaire being incorrect. The questionnaire was repeated with the behavioural intention scale anchors corrected. Data from both questionnaires was combined to analyse the state anxiety and colonoscopy concerns scales (n= 538), whilst only data from the repeated second questionnaire was used to analyse the behavioural intention scale (n= 268). Participant characteristics are shown in Table 1.

### 4.3.2 Sample size justification

Given there were no previous studies, the sample size calculation was informed by a related study that measured the effect of social norm messages on screening intention for endoscopic screening for CRC (Von Wagner et al., 2019a). This study reported odds ratios of 2.38 and 5.34 for two messages compared to the control.
condition (Von Wagner et al., 2019a). Therefore, using G*Power, the current study used the smaller effect size to calculate the sample size for analysis of covariance (ANCOVA) and multivariate analysis of covariance (MANOVA). The analyses suggested a total sample size of 230 respondents would be required to achieve 80% power at alpha = 0.05. The researchers then added 20 participants per condition to account for any missing data or unforeseen technical difficulties. The overall target sample size was 270. See Table 1 for participant characteristics.

4.3.3 Measures

*History of colonoscopy invitation* recorded whether participants had ever been invited for a colonoscopy for any medical reason. Options of response were (1) I have never been invited for a colonoscopy, (2) I have previously been invited for a colonoscopy but did NOT attend or (3) I have previously been invited for and have attended a colonoscopy. Participants who had previously attended a colonoscopy and those who had been invited but did not attend were grouped together as previous invitees. This allowed for a direct comparison based on different stages of screening, comparing the effects on first-time invitees and invitees repeating a screening behaviour through re-invitation.

*State Anxiety* was assessed using the Spielberger six-item short form state anxiety inventory (STAI-6) scale (Marteau & Bekker, 1992). This scale measures state anxiety levels “right now” on a 4-point Likert scale (not at all (0), somewhat (1), moderately (2) and very much (3)). A mean state anxiety score was computed. The Cronbach’s alpha for this scale in the current sample was $\alpha = .92$.

*Behavioural intention* to attend the nurse appointment to discuss further medical tests was measured using 4 item statements rated on a 11-point Likert scale (ranging from strongly disagree- 0 to strongly agree- 10). For example, ‘I will go to the nurse appointment’, ‘I plan to go to the nurse appointment’. A mean behavioural intention
score was computed. The Cronbach’s alpha for this scale in the current sample was $\alpha = .84$

Colonoscopy concerns were assessed using eight items rated on an 8-point Likert scale (0 - not at all to 7 - very much). Colonoscopy concerns were taken from key barriers reported by patients in previous literature when invited to attend follow-up colonoscopy (Kerrison et al., 2021b; Travis et al., 2022). For example, participants were asked to what degree they would be concerned about different aspects of the colonoscopy procedure such as pain and discomfort, test invasiveness, and also about being at risk of bowel cancer. A mean colonoscopy concerns score was computed. The Cronbach’s alpha for this scale in the current sample was $\alpha = .80$.

All measures with Likert scales and scoring used in the questionnaire can be found in the supporting information file.

4.3.4 Data analysis
A 2 (current letter vs modified letter) X 2 (previously invited vs never invited for a colonoscopy) between-participants analysis of variance (ANOVA) was used with level of self-reported state anxiety and behavioural intention as the dependent variables. Note that one-way ANOVAs and multivariate analysis of variances (MANOVAs) were preregistered as the planned analyses on AsPredicted, however for exploratory reasons the current study also included the participant’s previous history of colonoscopy invitation as a factor in the main analyses. The analyses were run a second time controlling for covariates, using analysis of covariance (ANCOVA). Finally, a 2 (current letter vs modified letter) X 2 (previously invited vs never invited for a colonoscopy) between-participants MANOVA was conducted on the eight colonoscopy concerns items. These analyses were also run a second time controlling for covariates, using multivariate analysis of covariance (MANCOVA).

4.3.5 Treatment of data
Histograms and box plots of outcome variables were run to check for data normality and identify potential outliers (Mishra et al., 2019). To limit the effect of any outliers we used a form of Winsorisation and replaced outliers with the mean plus 3 standard deviations (Kennedy et al., 1992; Kwak & Kim, 2017). We chose mean plus 3 standard deviations as this approach ensures that the outlier is replaced by the value of the data at the 97.5th percentile (Kennedy et al., 1992; Kwak & Kim, 2017).

Assumptions for MANOVA included the check for the absence of multivariate outliers, multicollinearity, linear relationship between groups and test of equality of covariance (Pituch & Stevens, 2015). Assumptions for MANOVA were satisfied. Data remained heavily skewed after removing outliers and a logarithmic transformation was applied (i.e., log 10) for the behavioural intention and colonoscopy concerns scales (Osborne, 2010). We ran the analyses in datasets with and without transformations and the results were substantively the same. Therefore, we elected to report the results based on these data with the outliers removed.

Before reading the letter, the statement ‘Please take your time to read the letter from start to finish’ was included in bold, the participant then had to click the next button to continue with the survey after reading the letter. The questionnaire included an attention check. An attention check identifies participants who are not engaged with the questions and allows researchers to screen out those participants prior to conducting analyses (Maniaci & Rogge, 2014). The attention check had to be completed by the participant for the data to be included. The attention check specifically stated “Please type the word ‘letter’ into the box below”, participants could choose whether to read and complete this task or not, and when to click next to continue with the survey. Two participants were removed from the data because they did not complete the attention check, shown on the data output as a blank field.
4.4 Results

4.4.1 Descriptive statistics

The means and standard deviations for main study variables by each condition are shown in Table 2. For both letter conditions, the average state anxiety was scored ‘somewhat’ to ‘moderately’ (M = 1.76 SD = .83). The average behavioural intention was scored high (M = 8.70 SD = 1.65). Being at risk of bowel cancer was scored to be of greatest concern to participants in both conditions (M= 5.10 SD= 1.84), then procedural related concerns, with little concern given for practical issues (travel costs and other commitments).
Participant characteristics
See Table 1 for participant characteristics, n (%)

<table>
<thead>
<tr>
<th>Participants Characteristics</th>
<th>Study 1 ( (N = 270) )</th>
<th>Study 2 ( (N = 268) )</th>
<th>Total ( (N= 538) )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>154 (57.0)</td>
<td>136 (50.7)</td>
<td>290 (53.9)</td>
</tr>
<tr>
<td>Male</td>
<td>116 (42.9)</td>
<td>132 (49.3)</td>
<td>248 (46.1)</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (range)</td>
<td>61.87 (56-74)</td>
<td>61.85 (56-74)</td>
<td>61.86 (56 - 74)</td>
</tr>
<tr>
<td>History of colonoscopy invitation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previously been invited to attend a colonoscopy</td>
<td>91 (33.7)</td>
<td>103 (38.4)</td>
<td>194 (36.1)</td>
</tr>
<tr>
<td>Never been invited to attend a colonoscopy</td>
<td>179 (66.3)</td>
<td>165 (61.6)</td>
<td>344 (63.9)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British or White other</td>
<td>259 (95.9)</td>
<td>261 (97.4)</td>
<td>520 (96.7)</td>
</tr>
<tr>
<td>Black or mixed Black or Black other</td>
<td>5 (1.9)</td>
<td>4 (1.5)</td>
<td>9 (1.7)</td>
</tr>
<tr>
<td>Asian or mixed Asian or Asian other</td>
<td>5 (1.9)</td>
<td>1 (0.4)</td>
<td>6 (1.1)</td>
</tr>
<tr>
<td>Any other ethnic group</td>
<td>1 (0.4)</td>
<td>2 (0.7)</td>
<td>3 (0.6)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below degree level educated</td>
<td>147 (54.4)</td>
<td>137 (51.1)</td>
<td>284 (52.8)</td>
</tr>
<tr>
<td>Degree level educated and above</td>
<td>123 (45.6)</td>
<td>131 (48.9)</td>
<td>254 (47.2)</td>
</tr>
<tr>
<td>Employment status (last 7 days)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Employed</td>
<td>127 (47.0)</td>
<td>131 (48.9)</td>
<td>258 (48.0)</td>
</tr>
<tr>
<td>Retired</td>
<td>92 (34.1)</td>
<td>93 (34.7)</td>
<td>185 (34.4)</td>
</tr>
<tr>
<td>Looking after home or family</td>
<td>23 (8.5)</td>
<td>22 (8.2)</td>
<td>45 (8.4)</td>
</tr>
<tr>
<td>Long term sick or disabled</td>
<td>12 (4.4)</td>
<td>10 (3.7)</td>
<td>22 (4.1)</td>
</tr>
<tr>
<td>Other</td>
<td>16 (5.9)</td>
<td>12 (4.5)</td>
<td>28 (5.2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Legal marital or registered civil partnership status</th>
<th></th>
<th></th>
<th></th>
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<tbody>
<tr>
<td>In a relationship</td>
<td>158 (58.5)</td>
<td>169 (63.1)</td>
<td>327 (60.8)</td>
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<tr>
<td>Single</td>
<td>104 (38.5)</td>
<td>89 (33.2)</td>
<td>193 (35.9)</td>
</tr>
<tr>
<td>Widowed</td>
<td>8 (3.0)</td>
<td>10 (3.7)</td>
<td>18 (3.3)</td>
</tr>
</tbody>
</table>

Table 1. Participant characteristics for each study and for total sample.
Table 2. Means and standard deviations for state anxiety, behavioural intention, and colonoscopy concerns measures by letter condition.

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>Total</th>
<th>Letter 1 - Existing Letter.</th>
<th>Letter 2 - Modified Letter.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td><strong>State anxiety</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>538</td>
<td>1.76</td>
<td>0.83</td>
</tr>
<tr>
<td>Previously invited to attend a colonoscopy</td>
<td>194</td>
<td>1.61</td>
<td>0.88</td>
</tr>
<tr>
<td>Never been invited to attend a colonoscopy</td>
<td>344</td>
<td>1.84</td>
<td>0.78</td>
</tr>
<tr>
<td><strong>Behavioural intention</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>268</td>
<td>8.70</td>
<td>1.65</td>
</tr>
<tr>
<td>Previously invited to attend a colonoscopy</td>
<td>103</td>
<td>8.91</td>
<td>1.61</td>
</tr>
<tr>
<td>Never been invited to attend a colonoscopy</td>
<td>165</td>
<td>8.56</td>
<td>1.67</td>
</tr>
<tr>
<td><strong>Colonoscopy concerns</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>STUDY</td>
<td>Mean</td>
<td>STDEV</td>
<td>N</td>
</tr>
<tr>
<td>-------</td>
<td>------</td>
<td>-------</td>
<td>---</td>
</tr>
<tr>
<td>Being at risk of bowel cancer</td>
<td>5.10</td>
<td>1.84</td>
<td>269</td>
</tr>
<tr>
<td>Pain and discomfort</td>
<td>3.83</td>
<td>2.25</td>
<td>269</td>
</tr>
<tr>
<td>Test invasiveness</td>
<td>3.61</td>
<td>2.45</td>
<td>269</td>
</tr>
<tr>
<td>Bowel preparation</td>
<td>3.25</td>
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<tr>
<td>Embarrassment</td>
<td>2.80</td>
<td>2.48</td>
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<tr>
<td>Gender of NHS nurse</td>
<td>1.45</td>
<td>2.04</td>
<td>269</td>
</tr>
<tr>
<td>Travel costs</td>
<td>1.10</td>
<td>1.74</td>
<td>269</td>
</tr>
<tr>
<td>Other commitments</td>
<td>0.84</td>
<td>1.54</td>
<td>269</td>
</tr>
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</table>

Previously invited to attend a colonoscopy

<table>
<thead>
<tr>
<th>STUDY</th>
<th>Mean</th>
<th>STDEV</th>
<th>N</th>
<th>Mean</th>
<th>STDEV</th>
<th>N</th>
<th>Mean</th>
<th>STDEV</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being at risk of bowel cancer</td>
<td>4.96</td>
<td>1.88</td>
<td>93</td>
<td>5.09</td>
<td>1.78</td>
<td>101</td>
<td>4.84</td>
<td>1.97</td>
<td>101</td>
</tr>
<tr>
<td>Pain and discomfort</td>
<td>3.71</td>
<td>2.34</td>
<td>93</td>
<td>3.75</td>
<td>2.40</td>
<td>101</td>
<td>3.67</td>
<td>2.30</td>
<td>101</td>
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<tr>
<td>Test invasiveness</td>
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<td>2.47</td>
<td>93</td>
<td>3.24</td>
<td>2.43</td>
<td>101</td>
<td>3.16</td>
<td>2.51</td>
<td>101</td>
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<tr>
<td>Bowel preparation</td>
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<td>2.46</td>
<td>93</td>
<td>3.33</td>
<td>2.55</td>
<td>101</td>
<td>3.24</td>
<td>2.40</td>
<td>101</td>
</tr>
<tr>
<td>Embarrassment</td>
<td>2.28</td>
<td>2.33</td>
<td>93</td>
<td>2.28</td>
<td>2.37</td>
<td>101</td>
<td>2.29</td>
<td>2.31</td>
<td>101</td>
</tr>
<tr>
<td>Gender of NHS nurse</td>
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<td>93</td>
<td>1.52</td>
<td>2.30</td>
<td>101</td>
<td>1.04</td>
<td>1.71</td>
<td>101</td>
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<tr>
<td>Travel costs</td>
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<td>93</td>
<td>1.38</td>
<td>2.02</td>
<td>101</td>
<td>1.34</td>
<td>1.87</td>
<td>101</td>
</tr>
<tr>
<td>Other commitments</td>
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<td>93</td>
<td>1.08</td>
<td>1.82</td>
<td>101</td>
<td>0.69</td>
<td>1.38</td>
<td>101</td>
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</tbody>
</table>

Never been invited to attend a colonoscopy
<table>
<thead>
<tr>
<th>Category</th>
<th>Mean</th>
<th>SD</th>
<th>Mean</th>
<th>SD</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being at risk of bowel cancer</td>
<td>5.18</td>
<td>1.82</td>
<td>5.05</td>
<td>1.86</td>
<td>5.32</td>
<td>1.77</td>
</tr>
<tr>
<td>Pain and discomfort</td>
<td>3.89</td>
<td>2.20</td>
<td>3.93</td>
<td>2.15</td>
<td>3.85</td>
<td>2.25</td>
</tr>
<tr>
<td>Test invasiveness</td>
<td>3.84</td>
<td>2.41</td>
<td>3.77</td>
<td>2.41</td>
<td>3.92</td>
<td>2.42</td>
</tr>
<tr>
<td>Bowel preparation</td>
<td>3.24</td>
<td>2.37</td>
<td>3.19</td>
<td>2.34</td>
<td>3.29</td>
<td>2.41</td>
</tr>
<tr>
<td>Embarrassment</td>
<td>3.10</td>
<td>2.51</td>
<td>3.15</td>
<td>2.58</td>
<td>3.05</td>
<td>2.45</td>
</tr>
<tr>
<td>Gender of NHS nurse</td>
<td>1.55</td>
<td>2.04</td>
<td>1.60</td>
<td>2.15</td>
<td>1.50</td>
<td>1.94</td>
</tr>
<tr>
<td>Travel costs</td>
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</tr>
<tr>
<td>Other commitments</td>
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<td>0.75</td>
<td>1.41</td>
<td>0.89</td>
<td>1.58</td>
</tr>
</tbody>
</table>
4.4.2 Effects of letter condition and previous invitation status on state anxiety levels

A 2 (current letter vs modified letter) x 2 (previously invited vs never been invited for a colonoscopy) factorial ANOVA found no main effect of letter condition $F(1, 534) = .17, p = .68, \eta_p^2 = .00$ on state anxiety levels (current letter: $M = 1.74, SE = .05$; modified letter: $M = 1.71, SE = .05$). However, a main effect of history of colonoscopy invitation, $F(1, 534) = 9.94, p = .002, \eta_p^2 = .02$ was found on state anxiety, with anxiety significantly higher in previous invitees ($M = 1.85, SE = .04$) than those never invited ($M = 1.61, SE = .06$). The interaction between letter condition and history of colonoscopy invitation was also significant, $F(1, 534) = 8.01, p = .005, \eta_p^2 = .02$. As shown in Figure 1 and through follow-up simple effects analysis, previous invitees were significantly less anxious when reading the modified letter ($M = 1.49, SE = .08$) than those reading the current letter ($M = 1.73, SE = .08$), $F(1, 534) = 4.13, p = .043$. Conversely, those never invited were significantly more anxious when reading the modified letter ($M = 1.93, SE = .06$) compared to the current letter ($M = 1.76, SE = .06$) $F(1, 534) = 4.10, p = .043$. When controlling for age and education level, there continued to be no main effect of letter condition $F(1, 532) = .63, p = .63, \eta_p^2 = .00$. The main effect of history of colonoscopy invitation $F(1, 532) = 9.48, p = .002, \eta_p^2 = .02$ remained statistically significant, as did the interaction effect between history of colonoscopy invitation and letter condition $F(1, 532) = 8.21, p = .004, \eta_p^2 = .02$. 

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4.4.3 Effects of letter condition and previous invitation status on behavioural intention

A 2 (current letter vs modified letter) x 2 (previously invited vs never been invited for a colonoscopy) factorial ANOVA found a main effect of letter condition on behavioural intention $F(1, 264) = 5.15 \, p = .024 \, \eta_p^2 = .02$ with intention significantly higher in the current letter ($M = 8.98 \, SE = .15$) compared to the modified letter condition ($M = 8.51 \, SE = .14$). There was no main effect of history of colonoscopy invitation, $F(1, 264) = .3.27 \, p = .072 \, \eta_p^2 = .01$, between previous invitees ($M = 8.93 \, SE = .16$) and those never invited ($M = 8.56 \, SE = .13$) on behavioural intention. There was also no interaction effect between history of colonoscopy invitation and letter condition on behavioural intention, $F(1, 264) = 2.31 \, p = .130 \, \eta_p^2 = .01$. When controlling for age and education there continued to be a main effect of letter condition $F(1, 262) = .5.10 \, p = .025 \, \eta_p^2 = .02$, and a main effect of history of colonoscopy invitation $F(1, 262) = 3.23 \, p = .073 \, \eta_p^2 = .01$. There also continued to be no interaction between letter condition and history of colonoscopy invitation $F(1, 262) = 2.32 \, p = .129 \, \eta_p^2 = .01$. 

Figure 1. The interaction between letter condition and history of colonoscopy invitation on state anxiety.
4.4.4 Colonoscopy concerns

A 2 (current letter vs modified letter) x 2 (previously invited vs never been invited for a colonoscopy) factorial MANOVA found no overall effect of letter condition \( F(8, 527) = .544 \ p = .824 \eta^2 = .01 \), on the colonoscopy concerns. An overall effect of history of colonoscopy invitation, \( F(7, 527) = 4.26 \ p < .001 \eta^2 = .06 \) was found on colonoscopy concerns, with concerns about embarrassment significantly higher for those never invited (\( M = 3.10 \ SD = 2.51 \)) than those previously invited (\( M = 2.28 \ SD = 2.33 \)) \( F(1, 534) = 13.64 \ p < .001 \eta^2 = .03 \). Concerns of test invasiveness were significantly higher for those never invited (\( M = 3.84 \ SD = 2.41 \)) than those previously invited (\( M = 3.20 \ SD = 2.47 \)) \( F(1, 534) = 8.68 \ p = .003 \eta^2 = .02 \). Concerns of travel cost were in contrast significantly lower for those never invited (\( M = .95 \ SD = 1.60 \)) than those previously invited (\( M = 1.36 \ SD = 1.94 \)) \( F(1, 534) = 6.80 \ p = .009 \eta^2 = .01 \). Concerns of pain and discomfort, being at risk of bowel cancer, bowel preparation and the gender of the NHS nurse found no significant differences of the effect of history of colonoscopy invitation. There was no interaction effect between letter condition and history of colonoscopy invitation \( F(8,527) = 1.09 \ p = .370 \eta^2 = .01 \). When controlling for age and education there continued to be no overall effect of letter condition \( F(8, 525) = .611 \ p = .769 \eta^2 = .01 \), an overall effect of history of colonoscopy invitation \( F(8, 525) = 4.40 \ p < .001 \eta^2 = .06 \) and no interaction effect \( F(8, 525) = 1.11 \ p = .354 \eta^2 = .02 \) on colonoscopy concerns.

4.5 Discussion

This study is the first quantitative study to examine whether providing modified information to the current NHS Bowel Cancer Screening Programme (BCSP) letter inviting participants for follow-up colonoscopy reduced participant self-reported state anxiety and increased behavioural intention levels to attend the nurse appointment to discuss further medical tests. It is also the first study to investigate the effect of history of colonoscopy invitation on participants levels of state anxiety, behavioural intention,
and colonoscopy concerns within the context of being invited to attend follow-up colonoscopy for bowel cancer detection.

A key finding of the current study was that behavioural intentions to attend the nurse appointment were scored lower by participants who received the modified letter compared to the current letter. Modifications to the letter included fewer uses of the term cancer, which may have reduced the perceived need for, and importance placed by some participants in attending the appointment. An individual’s perceived susceptibility to a threat is a key component of many health behaviour change theories and is both a theoretical and empirical driver of health behaviour (Dillard et al., 2012; Ferrer et al., 2016; Sheeran et al., 2014). For example, Dillard and colleagues (2012) found risk perception to be positively correlated with intention and attitudes in 3,689 participants, all due for CRC screening, who were asked to read an online message about the importance of screening in reducing their chance of cancer. Recent theory has introduced and tested a tripartite model of risk perception to consider deliberative, affective, and experiential components of risk perception (Ferrer et al., 2016). Findings recommend a need to consider different ways to target risk perception in future health behaviour change interventions and communications (Ferrer et al., 2016). Intention levels however in the current study for both letter conditions irrespective of previous invite status were high. It is possible that a ceiling effect in behavioural intention score ratings could have occurred, given most of the data was skewed towards the upper limit of the 11-point behavioural intention scale used, with 87% of participants scoring intention high between 7 to 10 (Cramer & Howitt, 2004). Caution is therefore advised when drawing conclusions from the effect of letter condition found on behavioural intention. Future work should explore the use of alternative scales for measuring behavioural intention and look to also measure intention to attend the colonoscopy procedure, in addition to the initial nurse appointment. A suggested reason for the high behavioural intention ratings could be taken from Construal-Level Theory, which states that events in the future, such as, taking part in screening for the detection of CRC, are
viewed by people in abstract and desirable (as opposed to concrete) terms (Trope & Liberman, 2010; Von Wagner et al., 2010). Furthermore, participants in the current study were older in age (56-74 years) and age has been found to be associated with higher levels of uptake in CRC screening (Young & Robb, 2021).

Depending on previous colonoscopy invitee status, modifications to the current NHS letter were found to significantly influence state anxiety levels. Previous colonoscopy invitees were significantly less anxious when reading the modified letter than those reading the current NHS letter. Conversely, those never invited for a colonoscopy were significantly more anxious when reading the modified letter compared to the current NHS letter. Suggestions for modifications to the current NHS letter were taken from interviews with nurses and previous invitees of colonoscopy (Travis et al., 2022). Reflections and views were therefore informed by the issues and barriers they (previous invitees) had faced when invited and attended a colonoscopy.

Two in one hundred people who complete the FIT kit will have a positive result, meaning approximately 2% of all screeners will also have previous colonoscopy invitee status (GOV.UK, 2022c). In comparison, 36.1% of participants in the current sample had previous colonoscopy invitee status, and 63.9% of participants had never been invited to a colonoscopy before. For those never invited before, providing information on procedural related concerns such as pain and discomfort, test invasiveness, the gender of the NHS team may not have been instinctively of immediate concern. Bringing other concerns to the participants’ attention, as presented within the modified letter, may have resulted in raised levels of state anxiety. Whether the modified letter provides participants never invited to colonoscopy with too much medical information and thus is a contributing factor to increased levels of state anxiety should be investigated further. For first-time invitees, additional procedural information and risks about colonoscopy may be best to be continued to be handled through in-person consultation. The role of the specialist screening practitioner is multifaceted, and as an advanced nursing role, it is pivotal in providing patients with the information and
reassurance needed (Kerrison et al., 2021b). During the patient appointment, the specialist screening practitioner explains the bowel preparation procedure and provides instructions, providing the required medication to the patient. The specialist screening practitioner also explains the colonoscopy screening test itself and confirms that the patient is medically suitable to undergo the procedure. Conducting a think aloud study on tailored invitation materials would allow for immediate utterances, thoughts, and comparisons to be drawn from participants with and without past screening experience (Smith et al., 2015a). Findings suggest that there may be a need to tailor future invitation materials based on colonoscopy invitation history. Future research ought to further explore the feasibility and acceptability of tailoring invitation materials to individuals' past screening experiences.

Those never invited for a colonoscopy were found to be significantly more concerned about embarrassment and test invasiveness, yet they were significantly less concerned about travel cost compared to previous invitees. These findings are consistent with Shafer et al. (2018) who reported patients with no previous history of a colonoscopy to have higher levels of procedural anxiety. There is a lack of research into the effect of previous invitee status on colonoscopy concerns, and future work should aim to explore and compare the nature of concerns based on people’s previous colonoscopy invitee status. For both letters, being at risk of bowel cancer was scored of greatest concern to participants, then procedural related concerns, with lowest levels of concern scored for practical issues (travel costs and other commitments). Higher levels of concern attributed to being at risk of cancer and procedural-related anxieties by patients invited to follow-up colonoscopy are consistent with previous quantitative and qualitative findings (Kerrison et al., 2021b; Plumb et al., 2017; Travis et al., 2022). Taken together with the previous research, it is important that potential future interventions explore ways to reduce these concerns and mitigate known barriers.

It is important that the identification of future interventions also draw upon existing theory (O’Cathain et al., 2019). The recent introduction of the integrated
screening action model (I-SAM) aims to predict screening behaviour and support the development of interventions that improve the screening process (Robb, 2021). The Precaution Adoption Process Model (PAPM) (Weinstein et al., 2020) is a key component of I-SAM, and describes the stages that people pass through from ‘unaware’ to ‘unengaged’ to ‘deciding’ to ‘intending’ to ‘acting’ to ‘repeat’. Adopting a behaviour for the first time, such as participants in the current study who had never invited for a colonoscopy, is very different to repeating the behaviour. It is therefore advised that researchers take this into consideration when developing interventions (Weinstein et al., 2020).

4.5.1 Strengths and limitations

A key strength of the current study is that data were collected from an equal representation of male and female participants with a full range of screening appropriate age, and participants had varying levels of education attainment, and a good representation employed compared to retired (see Table 1). It was unfortunately not possible to assess indices of multiple deprivation (IMD) as a measure of relative deprivation in areas of the UK, due to the collection of participant postcodes not being permitted on Prolific. The current study has three additional limitations: First, participants were given a hypothetical situation in which they were asked to imagine that they had received the letter in the post; findings therefore may lack ecological validity. Upon reading, participants were asked to rate their expected levels of state anxiety, behavioural intention, and the nature of concerns they would have. For instance, participants were asked to imagine and rate their expected concern about travel costs to a hypothetical place they may have never visited before, and also asked to record anticipated rather than actual state anxiety experiences. However, it is worth noting that other recent research has successfully adopted a similar design to the current study, asking participants to imagine they had received a positive FOBT or to imagine cancer symptom presentation (Goodwin et al., 2021; Kaushal et al., 2020; Marcu et al., 2019; Saab et al., 2021). Moreover, conducting research with this
particular patient population in real life is challenging given the reduced number of people invited to attend further tests following routine screening, therefore, utilizing hypothetical vignette approaches represents a useful research tool in this context. Second, participants were only recruited through the Prolific platform which may not be representative of the screening population. Participants of Prolific are required to have internet access and possess a certain level of literacy to allow them to be part of the panel. In a recent review by Dalton (2018) patient characteristics of incomplete diagnostic follow-up after positive colorectal cancer screening tests showed minority ethnic groups to have lower uptake, with evidence from South Asian groups in the UK. Furthermore, those whose first language was not the predominant language, and those belonging to lower socio-economic position groups were also associated with lower uptake rates (Dalton, 2018). The current study included 24 participants (4.5%) who had previously been invited for a colonoscopy but did NOT attend, providing a degree of input from non-attenders. Third, almost all participants (96%) were White, which is not fully representative of the screening population in England, given 81% of the population in England identify as White (Office for National Statistics, 2022). Under-recruitment of minority ethnic groups in health research is a commonly experienced difficulty (Ashley et al., 2021; Rockliffe et al., 2018; Shaghaghi et al., 2011; Wilding et al., 2022). Nevertheless, uptake for follow-up colonoscopy has been shown to be lower among those with an ethnic minority background compared to those with a white British ethnicity (Morris et al., 2012), future research should aim to work with an ethnic minority group sample to establish to what extent the collective findings thus far are generalisable or differ.

4.6 Conclusion

Behavioural intentions to attend the nurse appointment were rated lower by participants who received the modified letter compared to the current letter, intention was however high for both letter conditions. Modifications to the letter may have reduced the perceived need for and importance some participants placed on attending
the appointment. Depending on previous colonoscopy invitation status, modifications to
the current NHS letter were found to significantly influence state anxiety levels. For
first-time invitees, procedural information about colonoscopy and risks may be best
handled through in-person consultation as opposed to written forms of communication.
Future research ought to seek further feedback on tailored invitation materials based
on people’s past screening experiences and do so among under-represented groups.
Chapter 5 Effects of a self-affirmation intervention on responses to bowel cancer screening information.

5.1 Abstract

Objective: To investigate the effect of two brief self-affirmation interventions, immediately prior to reading standard information about bowel cancer screening, on state anxiety, message acceptance and behavioural intention to screen for bowel cancer.

Methods: 242 adults aged 49 were randomised to one of two self-affirmation interventions (health or values) or one of two control conditions, before reading an NHS England bowel cancer screening leaflet. Participant friend and family history of bowel cancer, state anxiety, message acceptance, behavioural intention to screen, trait self-esteem and spontaneous self-affirmation were measured. Data were analysed using between-participants analysis of variance, planned contrasts and moderated regression.

Results: No main effects of experimental condition on levels of state anxiety, message acceptance and behavioural intention were found. However, planned contrasts showed participants who self-affirmed about their health or values (conditions-collapsed) were significantly less anxious and reported significantly higher behavioural intentions compared to participants in the controls (conditions-collapsed). Irrespective of condition, higher levels of spontaneous self-affirmation and trait self-esteem were correlated with lower anxiety, higher intentions, and message acceptance.

Conclusion: No main effects of experimental condition on levels of state anxiety, message acceptance and behavioural intention were found.

Keywords: Bowel cancer screening; Self-affirmation; Fecal immunochemical test; Patient anxiety; Message acceptance; Behavioural Intention.
5.2 Introduction

1.9 million new cases of colorectal cancer, also known as bowel cancer, were reported in 2020 worldwide (World Health Organisation, 2024- a) and 42,886 new cases are reported yearly in the United Kingdom (UK) (2016-2018 average) (Cancer Research UK, n.d. - a). Bowel cancer is a leading cause of cancer death accounting for 10% of all cancer deaths in the UK, with more than nine out of ten cases diagnosed in people over the age of 50 (Cancer Research UK, n.d. - a). The National Health Service (NHS) England bowel cancer screening programme (BCSP) has recently extended from over 60 years for the eligible age for asymptomatic screening to people aged 50 and over, being rolled out over the next 4 years, available every two years (NHS.UK, 2021- a). Population screening has been found to reduce the risk of death caused by bowel cancer by 25%, in people who participate in at least one round of organised asymptomatic bowel cancer screening (Hewitson et al., 2008). Asymptomatic bowel cancer screening involves initial fecal immunochemical testing (FIT); a test that looks for traces of blood in a feces sample (NHS.UK, 2021- a). Since the introduction of the FIT in 2019, uptake of bowel cancer screening in England was reported to be 71.0% in 2021 (GOV.UK, 2022a), nevertheless, the levels of uptake remain suboptimal.

In England people aged 50 years and over are mailed an NHS leaflet about bowel cancer screening, followed by a FIT kit for their completion two weeks later (see supplementary file 1). When people receive health threatening information, such as a leaflet about bowel cancer screening, they can feel anxious, upset, or defensive. Studies have shown levels of message acceptance, stress and behavioural intention vary considerably in participants informed of their increased risk of cancer due to their current health behaviours (Creswell et al., 2005; Klein et al., 2010; Sherman et al., 2000, 2009).

We are faced daily with numerous threats to our self-integrity; our sense of being good, virtuous, successful, and able to control important life outcomes (Sherman & Cohen, 2006; Steele, 1988). Understanding how we maintain our integrity of the self
when under psychological threat, forms the basis of self-affirmation; an act where we as individuals can use alternative sources of self-integrity that demonstrate one’s moral and adaptive adequacy (Steele, 1988). The act of self-affirming is understood to restore our sense of self, enabling us to be more willing to process threatening information (Cohen & Sherman, 2014).

Message acceptance has been found to increase in participants undertaking affirmation conditions, in a meta-analysis of 45 tests (Good & Abraham, 2007). Likewise, a later review by Epton and colleagues (2015) reported positive effects of self-affirmation, induced by people reflecting upon important values, across 34 tests of message acceptance, 64 tests of intention to engage in health behaviours and 46 tests of actual behaviour. Participants who affirm about their values have been shown to have lower cortisol responses to stress, compared to controls (Creswell et al., 2005; Dutcher et al., 2020). Self-affirmation inductions carried out as experimental manipulations have largely involved participants choosing a value that is most important to themselves, in a domain unrelated to the threat, writing in essay form or by answering values related yes/no questions as to why that value is important to them (Armitage et al., 2011; Reed & Aspinwall, 1998). It has been suggested that self-affirming in a domain unrelated to the threat (e.g., health) is more effective, given it encourages the mind to focus on their self-integrity beyond the threat (Cohen & Sherman, 2014). Yet, other findings have suggested that affirming values related to the threat domain can also be effective (Klein et al., 2010; Wiesenfeld et al., 2001). It is therefore important that research investigates and compares the effects of self-affirming in a domain related and unrelated to the threat.

A recent study by Iles and colleagues (2022), based on 1,056 women in the US, measured the effectiveness of health versus general values self-affirmation inductions and essay writing versus questionnaires toward threatening health messages. Findings showed no differences in intention to reduce alcohol intake in those who affirmed health versus non-health values, and higher breast cancer worry and intentions to
reduce alcohol consumption in essay versus questionnaire-based inductions. No differences in those who affirmed health versus non-health values on message acceptance measures were found (Iles et al., 2022). Replication of their findings is recommended by Iles et al. (2022) in a non-US participant pool, given that health affirmations could significantly facilitate dissemination of health-risk information. The current study therefore aims to continue to compare the effectiveness of health versus general values self-affirmation inductions, and to do so, item question wording in the current study for the questionnaire inductions used were taken and adapted from the previous inductions tested by Iles et al. (2022).

To our knowledge only one study to date has examined the effects of a self-affirmation intervention on responses to information about bowel cancer screening and risk. Klein and colleagues (2010) examined whether maintaining good health would facilitate bowel cancer screening intentions and subsequent screening behaviour at a 6-month follow-up. Findings were mixed, with intentions to screen dependent on participant’s optimistic and realistic beliefs about their bowel cancer risk. Specifically, unrealistically optimistic participants who affirmed (compared to controls) about their health prior to receiving bowel cancer screening risk information had greater intentions to screen (Klein et al., 2010). In recent work Clarke and colleagues (2023) found higher levels of defensive information processing to be associated with lower bowel cancer screening uptake. Denying the immediacy to be tested and self-exempting oneself have been suggested as key barriers to FIT uptake (Clarke et al., 2023). Interventions such as self-affirmation which are known to reduce defensiveness (Good & Abraham, 2007) should now be tested to investigate the effects on bowel cancer screening intention and uptake.

Ferrer and Cohen (2019) proposed three conditions thought to facilitate the effectiveness of self-affirmation inductions; the presence of a psychological threat, resources to foster change, and timeliness of self-affirmation with respect to a health threat and resources. The sample age for participants in the current study was chosen
to be 49 years old to ensure the majority of participants had no previous direct exposure yet relevance and salience of the health information. Participants at this age group were likely to receive their first invitation to screen for bowel cancer the following year and this was explained to participants. It is important to examine other factors that may moderate the effectiveness of self-affirmation inductions. Factors include having a history of friends and family with bowel cancer, trait self-esteem and spontaneous self-affirmation. According to a previous review, the risk of developing bowel cancer is double in individuals with one or more first degree relative affected (Butterworth et al., 2006). Having greater proximity to cancer is known to increase fear and motivation levels to screen (Vrinten et al., 2017). This increases the practical importance of finding an affirmation intervention to reduce anxiety and increase intentions within this participant group. A secondary aim of the current study was therefore to explore whether having a history of friends and family with bowel cancer moderates the effectiveness of the self-affirmation interventions. This study also wanted to investigate whether trait self-esteem and the extent to which one spontaneously makes self-affirmations moderated the effectiveness of the interventions and to explore whether these variables were associated with the key outcome variables (anxiety, message acceptance and behavioural intention). Trait self-esteem has been found to moderate the relationship between values affirmation and psychological stress responses to a laboratory stressor, whereby affirmed participants with high self-esteem reported lower stress responses (Creswell et al., 2005). Creswell et al. (2005) suggest that self-affirmation may be most effective in reducing stress in people with a positive dispositional self-concept (i.e., high in self-resources such as trait self-esteem and optimism) yet increase stress in those with a negative dispositional self-concept (i.e., low in self-resources). Harris and colleagues (2019) showed that individuals who have a tendency to make spontaneous self-affirmations have lower levels of depression, anxiety and higher levels of wellbeing and message acceptance. Harris et al. (2019) also explained that spontaneous self-affirmation functions in a way that is similar to
experimentally induced self-affirmation by resulting in greater open-mindedness and readiness to engage in behavior change. Further to this, it was reported by Jessop and colleagues (2023) that a values self-affirmation induction moderated the association between spontaneous self-affirmation and well-being, such that the self-affirmation induction boosted state wellbeing scores in participants with lower spontaneous self-affirmation.

The current study hypothesised:

(1) participants who completed a health or values based self-affirmation task before reading an information leaflet about bowel cancer screening would report lower levels of state anxiety and higher levels of message acceptance and behavioural intention, compared to those participants in non-active or active control conditions.

(2) the effectiveness of the self-affirmation interventions would be moderated by history of friends or family with bowel cancer, such that intervention effects would be stronger for participants with a history of friends or family with bowel cancer.

(3) Irrespective of the self-affirmation intervention, participants who have a history of friends or family with bowel cancer will report higher levels of anxiety, message acceptance and behavioural intention, compared to those with no history of friends or family with bowel cancer.

In secondary analyses, the current study also investigated whether the effectiveness of the self-affirmation interventions would be moderated by self-esteem and spontaneous self-affirmation. The study predicted that participants who have higher self-esteem or spontaneous self-affirmation and who have affirmed health or values before reading an information leaflet about bowel cancer screening, will report lower levels of anxiety, and higher levels of message acceptance and behavioural intention. Furthermore, it was predicted that irrespective of the self-affirmation
levels of self-esteem and spontaneous self-affirmation would be associated with levels of anxiety, message acceptance and behavioural intention.

5.3 Methods

5.3.1 Design and participants

The current study used a between-participants cross-sectional online questionnaire design. Participants were recruited using an online participant database (Prolific) and were required to be aged 49 years old. This age group were chosen to ensure the majority of participants had no previous exposure to the information and were one year younger than the pre-existing UK NHS Bowel Cancer Screening Programme eligible screening age for bowel cancer. Participants were required to currently live in the United Kingdom and have no previous bowel cancer screening experience. Participants were evenly randomised, using the Qualtrics questionnaire randomizer function to one of two self-affirmation conditions or one of two control conditions. Participants were then informed that the NHS information leaflet they were about to read was a leaflet they would receive from the NHS in less than 12 months regarding bowel cancer screening. After reading the information leaflet about bowel cancer screening, participants were asked to rate their levels of state anxiety, message acceptance, behavioural intention to screen, self-esteem, and spontaneous self-affirmation. The study received ethical approval from the University of (Leeds) Ethics committee on the 17th of February 2023 (Reference: PSYC-831) and was preregistered on AsPredicted (#122350) on the 20th of February 2023 ahead of data collection (https://aspredicted.org/2G2_LTV).

5.3.2 Sample size justification

The sample size calculation was informed by two meta-analyses: Good and Abraham's (2007) review of self-affirmation interventions and defensive responses, and Epton et al.'s (2015) review of self-affirmation interventions and health behaviour change. Based on effect sizes reported in these reviews (f = .38 and f = .085
(retrospectively) we calculated a mean effect size of \( f = .23 \). A power analysis using G*Power determined 211 participants would be required to achieve 80% power at alpha = 0.05. We added 20 additional participants per condition to account for participants who may fail the attention check or who may report previous bowel cancer screening experience. The overall target sample size was 291, aimed to be of equal numbers of male and female.

5.3.3 Experimental conditions

The 4 experimental conditions in this study are described below. The item wording for the conditions were taken and adapted from Iles et al. (2022), and in line with previous research previous studies (Armitage et al., 2011; Armitage & Rowe, 2011). To avoid participants replying with a ‘no’ response and providing no explanation, the item questions taken from Iles et al. (2022) were rephrased to begin “Please write about a…”. Instructions were provided to participants in all conditions except in non-active to encourage participants to type their immediate thoughts and reflections as they come to mind. Instructions provided were:

‘Writing and reflecting on what matters to you has been shown to be beneficial for lots of reasons. We would like you to write a couple of sentences in response to the four questions below. Do not worry about spelling, punctuation of grammar, just jot down your immediate thoughts and reflections that come to mind.’

Values-based affirmation questionnaire

Participants in this condition answered four open questions which have been found to generate largely affirmative responses (Iles et al., 2022; Armitage et al., 2011), these were:

‘Please write about a time when you have done something to help another person (in the past year)’. ‘Please write about a time when you have done something that you are particularly proud of (in the past year)’. ‘Please write about a time when someone paid you a particularly nice compliment (in the past year)’. ‘Please write about an aspect of your personality that you particularly like’.
Health-based affirmation questionnaire

The health-based affirmation condition did not ask participants about the threat itself (the risk of bowel cancer). Participants in this condition answered four open questions designed to generate affirmative responses to their health specifically (Illes et al., 2022), these were:

‘Please write about an aspect of your personality that you think will help you to live longer’. ‘Please write about something you are doing right now to maintain your health’. ‘Please write about a time when you have done exercise that caused you to break a sweat (in the past year)’. ‘Please write about a time when you found yourself saying ‘no’ when offered an unhealthy food (in the past year)’.

Non-active

Participants in this condition were not asked to answer any questions and were immediately presented with the bowel cancer screening leaflet to read.

Active control questionnaire

Participants in this condition answered four open questions about negative aspects of the self which should not affirm the self (Illes et al., 2022), these were:

‘Please write about a time when you have done something to hurt someone’s feelings (in the past year)’.

‘Please write about a time when you have done something that you wished you had done better (in the past year)’. ‘Please write about a time when someone said something critical about you (in the past year)’. ‘Please write about an aspect of your personality that you wish was different’.

5.3.4 Measures

State Anxiety was assessed using the Spielberger six-item short form state anxiety inventory (STAI-6) scale (Marteau & Bekker, 1992). This scale measures state anxiety levels “right now” on a 4-point Likert scale (not at all (0), somewhat (1), moderately (2) and very much (3)). Items statements included “I feel calm’, ‘I am tense’. 
A mean state anxiety score was computed. The Cronbach’s alpha for this scale in the current sample was $\alpha = .87$.

*Message acceptance* measured the extent participants agreed or disagreed with the information provided within the bowel cancer screening leaflet, rated on a 9–point Likert scale (ranging from strongly disagree– 0 to strongly agree – 9). For example, ‘Regular bowel cancer screening reduces the risk of dying from bowel cancer (by at least 25%)’. Participants were also asked ‘how important they think it is that people take part in bowel cancer screening to reduce their risk of bowel cancer’, again rated on a 9-point Likert scale (ranging from strongly disagree (0) to strongly agree (9)). Item phrasing and scales were informed by Sherman and colleagues (2000). An overall mean message acceptance score was computed. The Cronbach’s alpha for this scale in the current sample was $\alpha = .75$.

*Behavioural intention* to take part in bowel cancer screening tests was measured using a 4-point Likert scale (Definitely not (0); Probably not (1); Yes, probably (2); Yes, definitely (3)) in response to the question ‘will you do the test? (the FIT kit)’. The phrasing and scale for this item was taken from Kotzur et al. (2022).

*History of friends or family with bowel cancer* were recorded, asking participants ‘Do you have a family history of bowel cancer? i.e., has anyone in your family ever been diagnosed with bowel cancer?’ and ‘have any of your friends ever been diagnosed with bowel cancer?’ Options of response were Yes (1) or No (0).

*Self-esteem* was assessed using the Rosenberg self-esteem scale (RSES) 10-item assessment of global feelings of self-worth (Rosenberg, 1965). Participants rated how strongly they agreed with statements dealing with general feelings on a 4-point Likert scale (strongly disagree (1), disagree (2), agree (3), strongly agree (4)). For example, ‘I feel that I have a number of good qualities.’ Scores were summed, with higher scores indicating higher self-esteem. The Cronbach’s alpha for this scale in the current sample was $\alpha = .93$.
The Spontaneous self-affirmation Measure used a 16-item assessment of tendency to respond to threats with affirming self-related cognitions (Harris et al., 2019), rated on a 7-point Likert scale (ranging from disagree completely (1) to agree completely (7)). For example, ‘When I feel threatened or anxious by people or events, I find myself... Thinking about the things I like about myself’. Three items describing the tendency to think negative thoughts about self-items acted as controls for response bias and were not calculated in the mean score computed. The Cronbach’s alpha for this scale in the current sample was α = .94

Participant demographics were also asked to collate details of participant gender, ethnicity, and level of education. See Table 1 for participant characteristics.

5.3.5 Data analysis

The hypotheses were tested using two blocks of analyses, first a one-way between-participants analysis of variance (ANOVA) was carried out to test the main effect of experimental condition: values affirmation, health affirmation, non-active control, and active control. Planned contrasts were then used to specifically compare the effectiveness of values versus health affirmation. Second, a two-way (2x2) between-participants ANOVA was carried out to see whether having a history of friends or family with bowel cancer condition (history, no history) moderated the relationship between the affirmation interventions (values and health conditions-collapsed) on message acceptance, anxiety, and behavioural intention, compared to the control conditions (non-active control and active control conditions-collapsed). These analyses deviated from that preregistered on Aspredicted (#122350) on the 20th of February 2023 (https://aspredicted.org/2G2_LTV). Note that the preregistered 4 (condition) x 2 (history) way ANOVA was replaced with the analyses outlined above in response to reviewer feedback.

In exploratory analyses, the PROCESS Macro for SPSS, using model 1 (Hayes, 2012), was used to test the moderating effect of trait self-esteem and spontaneous self-affirmation on anxiety, intention, and message acceptance. Linear regression tested the
associations between levels of self-esteem and spontaneous self-affirmation with levels of anxiety, message acceptance and behavioural intention. Finally, education was controlled for in all the analyses because we wanted to ensure that any observed intervention effects held after accounting for differences in education. Moreover, we followed the recommendations put forward by Simmons et al. (2011) in terms of transparency regarding the treatment of covariates by running the analyses without any covariates and then with the covariates.

5.3.6 Treatment of data

Histograms and box plots of outcome variables were run to check for data normality and identify potential outliers. Outliers were replaced with a score equal to the mean plus three standard deviations. Data remained heavily skewed after removing outliers and Log10 transformation was applied to behavioural intention and message acceptance. We ran the analyses in datasets with and without transformations and the results were substantively the same. Therefore, we elected to report the results based on these data with the outliers removed. Data met the assumptions of linear regression, in that linearity, residuals and multicollinearity were not violated, Cooks Distance = .000, and the sample size was deemed sufficient.

The questionnaire included two attention checks. The attention checks identified participants who are not engaged with the questions and allowed the researchers to screen out those participants prior to conducting analyses (Maniaci & Rogge, 2014). The attention checks had to be completed by the participant for the data to be included. One participant was removed from the data because they did not complete the attention checks. Twenty-five participants exited the survey early and were therefore removed from the data set as non-completers. Three of the twenty-five non-completers had been assigned to the health condition, 8 had been assigned to the values condition, 6 assigned to the active control condition, and 1 to the non-active control condition. Seven of twenty-five non-completers participants exited at 5% progress; at that point they had not been assigned an experimental condition within the
survey. A further thirteen participants were removed because they had previous bowel cancer screening experience and therefore did not meet the eligibility criteria. 242 participants remained for analysis.
5.4 Results

5.4.1 Participant characteristics

See Table 1 for participant characteristics, n (%), overall and broken down by self-affirmation condition.

*Table 1. Participant characteristics for each study.*

<table>
<thead>
<tr>
<th>Participants Characteristics</th>
<th>Total Sample (N = 242)</th>
<th>Condition 1 Health affirmation (N = 63)</th>
<th>Condition 2 Values affirmation (N = 57)</th>
<th>Condition 3 Active Control (N = 59)</th>
<th>Condition 4 Non-active Control (N = 63)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>134 (55.4)</td>
<td>32 (50.8)</td>
<td>34 (59.6)</td>
<td>34 (57.6)</td>
<td>34 (54.0)</td>
</tr>
<tr>
<td>Male</td>
<td>108 (44.6)</td>
<td>31 (49.2)</td>
<td>23 (40.4)</td>
<td>25 (42.4)</td>
<td>29 (46.0)</td>
</tr>
<tr>
<td><strong>History of friends and family with bowel cancer</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>History of friend(s) with bowel cancer</td>
<td>26 (10.7)</td>
<td>7 (11.1)</td>
<td>4 (7.0)</td>
<td>9 (15.3)</td>
<td>6 (9.5)</td>
</tr>
<tr>
<td>History of family with bowel cancer</td>
<td>29 (12)</td>
<td>11 (17.5)</td>
<td>4 (7.0)</td>
<td>7 (11.9)</td>
<td>7 (11.1)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British or White other</td>
<td>230 (95.0)</td>
<td>60 (95.2)</td>
<td>56 (98.2)</td>
<td>53 (89.8)</td>
<td>61 (96.8)</td>
</tr>
<tr>
<td>Black or mixed Black or Black other</td>
<td>3 (1.2)</td>
<td>1 (1.6)</td>
<td>0 (0)</td>
<td>2 (3.4)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Asian or mixed Asian or Asian other</td>
<td>5 (2.1)</td>
<td>1 (1.6)</td>
<td>1 (1.8)</td>
<td>1 (1.7)</td>
<td>2 (3.2)</td>
</tr>
<tr>
<td>Mixed or multiple ethnic groups</td>
<td>4 (1.7)</td>
<td>1 (1.6)</td>
<td>0 (0)</td>
<td>3 (5.1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5.4.2 Descriptive statistics

The means, standard deviations and correlations between variables are shown in Table 2. The means and standard deviations for main study variables by each condition are shown in Table 3.

Table 2. Bivariate correlations of study variables.

<table>
<thead>
<tr>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Anxiety</td>
<td>.83</td>
<td>.67</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Behavioural Intention</td>
<td>2.66</td>
<td>.61</td>
<td>-.22**</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Message Acceptance</td>
<td>8.11</td>
<td>.94</td>
<td>-.0.12</td>
<td>.53**</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>4. Self esteem</td>
<td>29.18</td>
<td>6.29</td>
<td>-.46**</td>
<td>.15*</td>
<td>.14*</td>
<td>-</td>
</tr>
<tr>
<td>5. Spontaneous affirmation measure</td>
<td>4.33</td>
<td>1.22</td>
<td>-.17**</td>
<td>.18**</td>
<td>.17**</td>
<td>.42**</td>
</tr>
</tbody>
</table>

*p < .05  **p < .01
Table 3. Means and standard deviations for state anxiety, behavioural intention, and message acceptance measures by self-affirmation condition and history of friends or family with bowel cancer.

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>Condition 1</th>
<th></th>
<th>Condition 2</th>
<th></th>
<th>Condition 3</th>
<th></th>
<th>Condition 4</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Health affirmation</td>
<td></td>
<td>Values affirmation</td>
<td></td>
<td>Active Control</td>
<td></td>
<td>Non-active control</td>
<td></td>
</tr>
<tr>
<td>Overall sample</td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
<td>n</td>
<td>Mean</td>
</tr>
<tr>
<td>State anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous sample of friends or family with bowel cancer</td>
<td>63</td>
<td>0.69</td>
<td>0.63</td>
<td>57</td>
<td>0.74</td>
<td>0.67</td>
<td>59</td>
<td>0.94</td>
</tr>
<tr>
<td>No previous sample of friends or family with bowel cancer</td>
<td>14</td>
<td>1.02</td>
<td>0.65</td>
<td>8</td>
<td>0.94</td>
<td>0.42</td>
<td>16</td>
<td>1.07</td>
</tr>
<tr>
<td>No history of friends or family with bowel cancer</td>
<td>49</td>
<td>0.59</td>
<td>0.60</td>
<td>49</td>
<td>0.71</td>
<td>0.70</td>
<td>43</td>
<td>0.88</td>
</tr>
<tr>
<td>Behavioural intention</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall sample</td>
<td>63</td>
<td>2.75</td>
<td>0.54</td>
<td>57</td>
<td>2.72</td>
<td>0.62</td>
<td>59</td>
<td>2.58</td>
</tr>
<tr>
<td>Previous sample of friends or family with bowel cancer</td>
<td>14</td>
<td>3.00</td>
<td>0.00</td>
<td>8</td>
<td>2.75</td>
<td>0.71</td>
<td>16</td>
<td>2.81</td>
</tr>
<tr>
<td>No previous sample of friends or family with bowel cancer</td>
<td>49</td>
<td>2.67</td>
<td>0.59</td>
<td>49</td>
<td>2.73</td>
<td>0.53</td>
<td>43</td>
<td>2.53</td>
</tr>
<tr>
<td>Message Acceptance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall sample</td>
<td>63</td>
<td>8.08</td>
<td>1.10</td>
<td>57</td>
<td>8.11</td>
<td>0.93</td>
<td>59</td>
<td>8.25</td>
</tr>
<tr>
<td>Previous history of friends or family with bowel cancer</td>
<td>14</td>
<td>8.46</td>
<td>0.55</td>
<td>8</td>
<td>7.84</td>
<td>1.24</td>
<td>16</td>
<td>8.36</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
<td>----</td>
<td>------</td>
<td>------</td>
<td>---</td>
<td>------</td>
<td>------</td>
<td>---</td>
<td>------</td>
</tr>
<tr>
<td>No history of friends or family with bowel cancer</td>
<td>49</td>
<td>8.00</td>
<td>1.03</td>
<td>49</td>
<td>8.16</td>
<td>0.87</td>
<td>43</td>
<td>8.22</td>
</tr>
</tbody>
</table>
5.4.3 Main effects of experimental condition

A one-way (values affirmation, health affirmation, non-active control, and active control) ANOVA found no main effect of experimental condition on state anxiety levels, $F(3, 238) = 2.58, p = .054, \eta^2_p = .03$ (values affirmation: $M = .74, SE = .09$; health affirmation: $M = .69, SE = .08$; non-active control: $M = .96, SE = .09$; active control: $M = .94, SE = .08$), behavioural intention levels, $F(3, 238) = 1.36, p = .256, \eta^2_p = .02$ (values affirmation: $M = 2.72, SE = .08$; health affirmation: $M = 2.75, SE = .07$; non-active control: $M = 2.56, SE = .09$; active control: $M = 2.58, SE = .10$), or message acceptance levels, $F(3, 238) = 1.11, p = .347, \eta^2_p = .05$ (values affirmation: $M = 8.11, SE = .12$; health affirmation: $M = 8.08, SE = .13$; non-active control: $M = 7.93, SE = .15$; active control: $M = 8.25, SE = .10$). When controlling for education there continued to be no effect of experimental condition on state anxiety, $F(3, 237) = 2.53, p = .058, \eta^2_p = .03$, levels of behavioural intention, $F(3, 237) = 1.49, p = .217, \eta^2_p = .02$, or message acceptance, $F(3, 237) = 1.04, p = .376, \eta^2_p = .01$.

Planned contrasts showed participants who self-affirmed about their health or values (conditions-collapsed) were significantly less anxious, $t(238) = -2.72, p = .007$, reported significantly higher behavioural intentions, $t(238) = 2.02, p = .045$, and similar levels of message acceptance, $t(238) = .013, p = .990$, compared to participants in the active control or the non-active conditions (conditions-collapsed).

Planned contrasts showed participants who self-affirmed about their health were significantly less anxious, $t(238) = -2.51, p = .013$, yet reported similar levels of intention, $t(238) = 1.72, p = .086$, and message acceptance, $t(238) = -.02, p = .984$, compared to participants who did not self-affirm (receiving either the active control or the non-active conditions).

Planned contrasts also showed participants who self-affirmed about their values were no lower or higher in anxiety, $t(238) = -1.94, p = .054$, intention, $t(238) = 1.57, p = .117$, or message acceptance, $t(238) = .041, p = .968$, compared to participants who did not self-affirm (receiving the active control or the non-active conditions).
5.4.4 The effects of friends or family history with bowel cancer

A significant main effect of history of friends or family with bowel cancer was found only on state anxiety levels, $F(1, 238) = 5.77 \ p = .017 \ \eta_p^2 = .02$, with anxiety significantly higher in those with a history of friends or family with bowel cancer than those with no history. There were no significant main or interaction effects on any other dependent measures, without or with covariates. The inferential statistics are provided in Supplementary File 2.

5.4.5 Exploratory Analyses: Trait self-esteem and the spontaneous self-affirmation measure.

The effectiveness of the self-affirmation interventions was not moderated by trait self-esteem, with no significant effects for levels of anxiety, message acceptance or behavioural intention. See Supplementary file 2. When controlling for spontaneous self-affirmation there continued to be no significant effects for levels of anxiety, message acceptance or behavioural intention.

The effectiveness of the self-affirmation interventions was not moderated by spontaneous self-affirmation, with no significant effects for levels of anxiety, message acceptance or behavioural intention. See Supplementary file 2. When controlling for trait self-esteem there continued to be no significant effects for levels of anxiety, message acceptance or behavioural intention.

Irrespective of the experimental intervention, correlational analyses found that self-esteem and spontaneous self-affirmation were significantly associated with lower anxiety, higher behaviour intention and message acceptance (see Table 2). However, when self-esteem and SSAM were entered together in regression analyses, only self-esteem was significantly associated with lower anxiety ($\beta = .47$, $p < .001$), and only spontaneous self-affirmation was significantly associated with higher behavioural intention ($\beta = .16$, $p = .027$). Self-esteem and SSAM were no longer significantly
associated with message acceptance. When controlling for education all findings remained the same.

5.5 Discussion

This is the first study to investigate whether self- affirming about health and values before reading health threatening information, in the format of bowel cancer screening information, reduces participant state anxiety and increases message acceptance and behavioural intention to screen for bowel cancer. It is also the first study to investigate moderating effects of history of friends and family with bowel cancer, self-esteem, and SSA on participants levels of state anxiety, message acceptance and behavioural intention.

5.5.1 Summary of findings

The current study provided partial support for the first hypothesis. The main analyses found no effects of experimental condition on levels of state anxiety, message acceptance and behavioural intention. However, planned contrasts compared self-affirmation manipulations (conditions-collapsed) with the controls (conditions-collapsed) and showed intervention participants who self- affirmed to be significantly less anxious, have higher intentions to screen compared to control participants, yet similar in levels of message acceptance, after reading the leaflet. When comparing the self-affirmation conditions individually with controls (conditions-collapsed), participants who self-affirmed about their health were significantly less anxious, yet similar in levels of intention and message acceptance compared to those who did not self-affirm, having received non-active or active control conditions. Participants who self-affirmed about their values however reported similar levels of anxiety, intention and message acceptance compared to those who did not self-affirm, having received non-active or active control conditions. There was therefore some evidence of the effect of health-based self-affirmation on lower anxiety, future research is needed to further explore the effectiveness of different self-affirmation interventions in larger samples.
The second hypothesis was not supported: the effectiveness of the self-affirmation interventions was not found to be moderated by history of friends or family with bowel cancer. Intervention effects were not significantly different for participants with a history of friends or family with bowel cancer. The third hypothesis was partially supported: irrespective of the self-affirmation intervention, the current study found participants with a history of friends or family with bowel cancer to report higher levels of anxiety, yet similar levels of intention and message acceptance, compared to those with no history. In secondary analyses, the effectiveness of the self-affirmation interventions was not found to be moderated by self-esteem or spontaneous self-affirmation. Predictions were however supported in that irrespective of condition, higher levels of spontaneous self-affirmation were found to be associated with lower anxiety, message acceptance and higher screening intentions. Higher levels of trait self-esteem were also found to be associated with lower anxiety, and higher screening intentions. However, when self-esteem and SSAM were tested simultaneously, only self-esteem was found to be associated with lower anxiety and only spontaneous self-affirmation was associated with higher behavioural intention. Self-esteem and SSAM were no longer found to be associated with message acceptance.

5.5.2 Comparison with the literature

Several authors have argued that self-affirming in a domain related to the threat (e.g., health) is less effective, due to a potential increase in defensive processing and enhanced dissonance (Cohen & Sherman, 2014; Sivanathan et al., 2008). Klein et al. (2010) however found unrealistically optimistic participants who self-affirmed about their health before reading about bowel cancer risks, to have higher levels of bowel cancer screening interest, relative to controls. Future work should replicate and explore whether levels of unrealistic optimism and other (un)realistic beliefs moderate the effects for self-affirmation manipulations in bowel cancer screening patients. Furthermore, Iles and colleagues (2022) found similar levels of message acceptance and behavioural intention in response to a health threat, when comparing values and
health affirmation inductions. The current study builds on the existing literature (Good & Abraham, 2007; Epton et al., 2015; Ills et al., 2022), with no main effect of experimental condition on levels of state anxiety, message acceptance and behavioural intention. However, planned contrasts do provide some evidence towards the potential effectiveness of self-affirmation manipulations which are focussed on health-related affirmations, found in this study to lower anxiety. Future research should replicate with a larger sample, to compare the effect of different types of self-affirmation induction, inside and outside the domain of health on measures including patient reported anxiety within a cancer screening setting. This is of particular importance given the use and completion of a self-affirmation by people within the domain of health is imagined to be more natural, when received with a health information leaflet (Arpan et al., 2017; Epton et al., 2015).

A review by Vrinten and colleagues (2017) found people who have never experienced cancer in someone close to them to be less afraid of cancer, providing a false sense of security and lowering motivation levels to attend screening. Whilst those who have witnessed the consequences of cancer in a loved one, reported seeing them suffer from the side effects of chemotherapy or surgery or had experienced the loss of family and friends who have died from cancer thought to have shaped their fear of cancer (Vrinten et al., 2017).

In contrast to previous work, trait self-esteem and spontaneous self-affirmation did not moderate the effectiveness of the self-affirmation interventions, in the current study (Creswell et al., 2005; Ferrer et al., 2015). The results are however consistent with S. E. Taylor and colleagues (2003b) who found lower stress response in those with higher dispositional self-resources (self-esteem). Likewise, findings are consistent with previous work by Harris and colleagues (2019) who showed participants who tended to make spontaneous self-affirmations to have lower levels of depression, anxiety, and higher levels of wellbeing and message acceptance. Spontaneous self-affirmation may therefore act as a resource to reduce negative responses to health threatening
Further work is needed to test interventions which target self-esteem and spontaneous self-affirmation within a bowel cancer screening setting.

5.5.3 Strengths and limitations

The presence of a psychological threat, resources to foster change, and timeliness of self-affirmation in respect to a health threat and resources are known to facilitate the effectiveness of self-affirmation inductions (Ferrer & Cohen, 2019). These conditions were fully considered in the context of the current study to enable and maximise the self-affirmation effects for this behaviour change. A key strength of the current study was that the data was collected from an equal representation of male and female participants, with varying levels of education attainment (see Table 1). Validation of whether the current study findings are replicated in a larger sample of screening patients upon their first invitation to screen for bowel cancer is recommended. The information leaflet was the standard NHS England leaflet in current use, being of personal relevance to all participants, allowing for a real-world setting. At 49 years of age many participants are soon to be receiving their bowel cancer screening invitation for the first time when 50 years old. For some participants however this could be somewhat later than 50, due to the eligible screening age of 50-year-olds in England currently being in the process of being rolled out over the next 4 years. It could therefore be argued for these participants who receive their invitation after the age of 50 that the measure captured is one of willingness rather than intention to screen.

The current study has several limitations. First, participants were mostly White (95%). Despite 81% of the current population in England identifying as White (Office for National Statistics, 2022), participation in bowel cancer screening is lower within ethnic minority groups and deprived areas of England (Moss et al., 2017). Recruitment was conducted solely via a crowdsourcing platform, Prolific. To partake in the study, participants needed to have access to an online device and have a certain level of literacy. The extent of which current findings are generalisable is therefore limited.
Future research needs to target responses to self-affirmation inductions from underrepresented groups to fully test and propose improvements which will improve screening intention and uptake that address ethnic and socioeconomic disparities. Second, the number of participants with a history of friends or family with bowel cancer was relatively small, meaning that in some conditions, the cell sizes were small (e.g., in the values affirmation condition the number of participants with previous history was only eight). The test of the interaction between affirmation condition and family history is therefore underpowered. It is advised not to draw strong conclusions from the study analysis regarding history of the effect of friends and family with bowel cancer, and a larger sample in future work is therefore required. Third, similar to recent online work which tested modifications to bowel cancer screening invitation materials, levels of anxiety reported were low, and intentions to screen high, even within the control groups (Travis et al., 2023). Therefore, in contrast to qualitative work that reported patient anxiety to be a key barrier from the moment the patient receives the invitation letter (Travis et al., 2022), findings from the current study limit the practical importance of finding an affirmation intervention to reduce anxiety and increase intentions, within the participant group. It may be that other variables are more prominent predictors of the uptake of screening. This should be explored further when designing future experimental studies. Fourth, we recognise that the observed effects are relatively small and there is a need to replicate these findings and for further research using these interventions and measures before any firm conclusions can be drawn. Finally, item question wording for the current study questionnaire inductions used were taken and adapted from the previous inductions tested by Iles et al. (2022); however, we do not know whether any of the experimental conditions in fact lowered participants’ sense of self-worth or competence. For example, for participants in the health affirmation condition the questions may have reminded them of ways in which they struggle to maintain their health, engage in exercise, or resist unhealthy food. Future work is required to understand people’s reactions to the affirmation questions.
and to measure self-worth and competence responses. Additional manipulation checks are a way of measuring the extent to which each of the experimental conditions affirms the self and should be considered (Napper et al., 2009).

5.6 Conclusion

The current study findings showed no effects of experimental condition on levels of state anxiety, message acceptance and behavioural intention. However, planned contrasts provided some evidence towards the potential effectiveness of self-affirmation manipulations on lowering anxiety and increasing behavioural intentions. Specifically, planned contrasts provided some evidence towards the potential effectiveness of self-affirmation manipulations which are focussed on health-related affirmations, found in this study to lower anxiety. Future research is needed replicate with a larger sample, to compare the effect of different types of self-affirmation induction, inside and outside the domain of health on measures including patient reported anxiety within a cancer screening setting. Intervention effects did not differ by participant history of friends or family with bowel cancer, or by self-esteem or spontaneous self-affirmation. Predictions were however supported in that irrespective of condition, higher levels of spontaneous self-affirmation and trait self-esteem were found to be associated with lower anxiety, and higher screening intentions. Spontaneous self-affirmation may facilitate the reduction in negative responses to health threatening information. Further work is needed to test interventions which target self-esteem and spontaneous self-affirmation within a bowel cancer screening setting.
Chapter 6 General discussion

6.1 Summary of thesis findings.

The key findings in relation to the four thesis aims outlined in Chapter 1 (see Figure 1.7) have been summarised in Figure 6.1 below.

![Diagram of key thesis findings]

Figure 6.7. Key thesis findings.

6.1.1 Aim 1: a systematic review and thematic synthesis of qualitative evidence (Chapter 2).

The first aim of this thesis was to synthesise existing qualitative evidence to understand key barriers and facilitators to intention and uptake of flexible sigmoidoscopy screening (FSS) for CRC prevention and detection, and to identify those barriers to FSS intention and uptake amongst lower uptake groups. Considering
reports of low uptake of bowel scope screening (43.1%) in England (McGregor et al., 2016) an understanding of the existing literature regarding patient barriers and facilitators to flexible sigmoidoscopy was required. The novel findings from this systematic review and thematic synthesis are outlined in Chapter 2. Ten qualitative studies met the inclusion criteria and highlighted procedural anxieties as a key barrier to intention and uptake of FSS, particularly in the low uptake groups of women and UK Asian communities. For women, including UK Asian women, shame and embarrassment, perforation anxiety and test preparation difficulties were cited as reasons for not taking part. Religious and cultural-influenced health beliefs were also cited by UK Asian communities and competing priorities were cited as barriers to participation. Competing priorities such as caring commitments particularly impeded women’s ability to attend certain screening appointments. The review also 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.

6.1.2 Aim 2: semi-structured interviews with patients and SSPs (Chapter 3).

The second aim of this thesis was to understand barriers and facilitators to attending colonoscopy examination, following a routinely offered positive FIT result in England, and to provide key procedural recommendations that focussed on reducing patient barriers. Evidence of barriers to colonoscopy examination for primary CRC detection and prevention have been reported in many previous reviews (Green et al., 2008; Kerrison et al., 2021a; McLachlan et al., 2012). Few studies, however, have investigated patient and practitioner barriers as a follow-up test to a positive stool-based test (Bertels et al., 2020, 2022), and no studies have investigated barriers to follow-up colonoscopy examination, specifically in England, as part of the BCSP. Thirty-two qualitative semi-structured interviews with 20 patients, who had all previously attended screening as part of the BCSP, and 12 Specialist Screening Practitioners
(SSPs) were conducted. Important findings as shown in Chapter 3, focussed on a key barrier of patient anxiety experienced throughout the patient's screening pathway, commonly cited in examples of the fear of pain and discomfort and test invasiveness. Patients and SSPs provided novel practical-orientated suggestions intended to address patient barriers, improve the access and inclusion of all patients to be able to attend screening appointments, and increase follow-up colonoscopy uptake. Examples of suggestions included the earlier patient notification of the option to: (1) have sedation to address any fear of pain and discomfort, (2) request a same gender endoscopist should this be of concern due to religious beliefs or previous abuse, and (3) request financial support with transport costs to attend the nurse appointment and procedure.

6.1.3 Aim 3: modifications to written invitation for positive FIT colonoscopy examination (Chapter 4).

To test and measure for the first time the effects of these modifications to follow-up colonoscopy examination, the third aim of this thesis was to explore whether providing modified written invitation information to attending positive FIT colonoscopy examination, in England reduced participant reported barriers, and improved intention levels to attend a nurse appointment to discuss further medical tests. The novel recommendations provided by patients and SSPs interviewed, as detailed in Chapter 3, were used to develop a modified version of the BCSP invitation letter for positive FIT follow-up colonoscopy examination, for the first time, which provided patients with more procedural information about having a colonoscopy and included fewer uses of the term cancer. Prior to the study commencing, patient and public engagement work was carried out with 15 adults of eligible screening age (between 56-74), to gain further feedback on both the current NHS and the modified invitation letter with minor changes made to the modified letter. This aim was then addressed through an online written-based intervention with 538 adults of bowel cancer eligible screening age (56-74 years old). Findings outlined in Chapter 4 revealed modifications to the invitation letter to not be beneficial to levels of expected screening behavioural intention or state anxiety.
Interpretations of the novel findings were explored, and possible effects of risk perception and associated theories (Ferrer et al., 2016) were considered. Findings recommend a need to consider different ways to target risk perception in future health behaviour change interventions and communications (Ferrer et al., 2016), given modifications included fewer uses of the term cancer, which could have potentially reduced people's perceived need to attend and their susceptibility to the threat of bowel cancer. Interpretations also consider whether the modified letter provided those participants who had never been invited to colonoscopy before with too much additional procedural and risk information about the colonoscopy, which may be best to remain delivered in-person, through initial patient consultation with the SSP.

6.1.4 Aim 4: the use of self-affirmation on responses to bowel cancer screening information (Chapter 5).

The fourth aim of this thesis was to examine the effects of a self-affirmation intervention on responses to bowel cancer screening information provided to adults in England, measured through levels of message acceptance, intention to screen, and expected state anxiety. (Chapter 5). To extend existing research conducted on the use of theory-based frameworks and interventions to further understand and improve CRC screening behaviours, the effects of self-affirmation on people's reactions to reading CRC screening information were for the first time examined. The act of self-affirming is a novel intervention, only tested to our knowledge in one previous study, in its effects on screening intention (Klein et al., 2010). This aim was addressed in Chapter 5, conducted with 242 adults aged 49 years, randomised to one of two self-affirmation online written-based interventions (health or values) or one of two control conditions. The findings from this novel study are outlined in Chapter 5 and show no effects of experimental condition on levels of state anxiety, message acceptance and behavioural intention. Planned contrasts however provided some evidence of the potential effectiveness of health-based self-affirmation manipulations on lowering anxiety and increasing behavioural intentions. A particular important finding found however was that
irrespective of condition, higher levels of spontaneous self-affirmation and trait self-esteem were found to be associated with lower anxiety, and higher screening intentions. It is possible therefore that spontaneous self-affirmation may facilitate the reduction in negative responses to health threatening information.

6.2 Key findings in consideration of the existing literature.

6.2.1 Understanding and improving CRC screening intention and uptake: barriers and facilitators.

The findings presented in the systematic review and thematic synthesis of literature, detailed in Chapter 2 (Travis et al., 2020) corroborate and extend previous and ongoing research, with procedural related anxieties a key barrier cited by patients. Recent work by Le Bonniec and colleagues (2023) explored non-participation in CRC screening (all modalities). In their review of 13 qualitative studies these authors showed aversion to CRC screening expressed by patient fear, discomfort, disgust or not wanting to know. Von Wagner and colleagues (2019b) reported anticipated pain and embarrassment as common barriers to FSS uptake in 1478 individuals taking part in an online survey across 28 general practices in England, involving screeners (83.2%), non-responders (7.7%) active decliners (6.8%) and non-attenders (2.3%). Moreover, based on a rapid review of 42 quantitative studies, Kerrison et al. (2019) identified FSS factors associated with FSS intention and uptake, separated into 25 sociodemographic factors, 50 health and lifestyle factors and 48 psychosocial factors. Kerrison and colleagues (2019) included 7 studies about patient perceived psychosocial barriers, that cited barriers of; fear of screening, a worry of cancer, fatalism about screening (Power et al., 2008), and concerns of embarrassment and discomfort (Whitaker et al., 2011). Informed by Kerrison et al. (2019) of the sociodemographic factors negatively associated with FSS uptake, the review in this thesis provided qualitative insights into the specific reasons and narratives why women and UK Asian groups chose not to, or were unable to, due to barriers faced partake in FSS. Examples included competing
priorities of childcare commitments impeding some women’s ability to attend FSS (McCaffery et al., 2001; Robb et al., 2008b; Rawl et al., 2000; Gray & Snadden, 1999), and religious and cultural influenced health beliefs cited by UK Asian groups not feeling comfortable to request a same gender endoscopist (Austin et al., 2009; Robb et al., 2008b). Our review also identified facilitators, specific to women and UK Asian groups, examples included the presence of symptoms as a cue cited by UK Asian groups (Austin et al., 2009) and the importance of doctor/physician screening recommendation to promote screening; Pakistani men were disinclined to attend unless they had been advised to by their GP (Austin et al., 2009).

Interview findings presented in Chapter 3 (Travis et al., 2022) by patients and SSPs of follow-up colonoscopy invitation and their experiences with having a colonoscopy were similar to previous reviews highlighting patient anxieties, both in terms of procedural-related anxieties and of a fear of cancer, as a key barrier to attending FSS (Travis et al., 2020) and colonoscopy screening (Kerrison et al., 2021a). For instance, Kerrison et al. (2021a) reported psychosocial barriers of a fear of pain and discomfort and concerns with doing bowel preparation from 57 studies reviewed, mostly from the USA (84.2%). Initial insights into the patient barriers and facilitators, by SSPs, of follow-up colonoscopy examination in England were also examined by Kerrison and colleagues (2021b), with citations from SSPs of patient fear of pain and discomfort, and family and work commitments. The findings from Kerrison et al. (2021b) were consistent with the subsequent interview findings in Chapter 3 (Travis et al., 2022) of SSPs (12) and patient (20) perspectives, with sub themes centred upon the fear of pain and discomfort and test invasiveness. A recent review, by Kayal and colleagues (2023) of 6 studies on patient experiences of colonoscopy screening after a positive FOBt/FIT, highlighted a need for health-care providers to consider ways to make bowel preparation more acceptable, and colonoscopy and post-colonoscopy abdominal pain less painful. Interview findings also presented in Chapter 3 (Travis et al., 2023) provide novel practically orientated strategies suggested by patients and
SSPs to address barriers to positive FIT follow-up colonoscopy that now warrant future consideration by key health-care professionals in NHS England.

6.2.2 Understanding and improving CRC screening intention and uptake: the use of novel interventions.

A review by Tsipa and colleagues (2021) included 102 RCTs aimed at improving uptake in CRC screening, showing significant benefit of all interventions combined. The modifications made to the invitation letter for follow-up colonoscopy examination, as detailed in Chapter 4 (Travis et al., 2023), were however not beneficial to levels of screening intention or anxiety. Similarly other interventions which have varied or provided supplementary written materials have also produced null or adverse effects on CRC screening intention and uptake (Smith et al., 2015b; Watson et al., 2013). Findings from this thesis also showed those participants never invited for a colonoscopy to be significantly more concerned about embarrassment and test invasiveness, consistent with Shafer et al. (2018) who reported 1316 patients in Canada with no previous history of a colonoscopy to have higher levels of procedural-related anxiety. In comparison, other studies have shown lower patient self-reported pain, procedural-related anxiety, higher screening intentions and improvements in adherence to colonoscopy screening, when providing additional procedure-related information (Denberg et al., 2006; Hsueh et al., 2016; McGregor et al., 2015; Shaikh et al., 2010). To our knowledge, the effects of including fewer uses of the term cancer within written CRC screening invitation materials on levels of screening intention and expected anxiety have not been tested in previous studies. Simon and colleagues (2010) however highlighted differences in patient and provider views of the effects of using the word cancer in an invitation letter to women with an abnormal Papanicolaou (Pap) result to follow up. Providers cited concerns of using the word cancer thought to instigate fatalism and inhibit timely follow-up, while patients in contrast reported a need to include risk information about cancer to prompt timely follow-up (Simon et al., 2010). These findings support our interpretations of findings provided in Chapter 4; in that
including fewer uses of the term cancer could have reduced the perceived need for, and importance placed by some participants in attending the appointment.

The use of self-affirmation as a theory-based intervention in Chapter 5 (Travis et al., 2024) extends the existing literature (Good & Abraham, 2007; Epton et al., 2015; Illes et al., 2022), finding no main effect of experimental condition on levels of state anxiety, message acceptance and behavioural intention to take part in FIT screening for CRC detection. Null findings and low levels of expected anxiety and high levels of behavioural intention, even in the control groups as reported in Chapter 5 (Travis et al., 2024), could be because participants were not yet of CRC screening eligible age, and due to utilising a hypothetical scenario, resulting in participation in bowel cancer screening not being sufficiently relevant or central to the lives of this participant group.

A gist-based theory informed information leaflet, developed and tested on 4,452 participants aged 45 to 49 in the North of England by Smith et al. (2015b) similarly led to no effects on screening intention. The authors suggested the null effects on screening intention may have been due to the (pre-screening) age of participants and the hypothetical scenario presented (Smith et al., 2015b). Other predictors of uptake of CRC screening should now be considered in self-affirmation experimental work. For example, future work could aim to replicate findings by Klein et al. (2010) exploring further whether levels of optimism and (un)realistic beliefs moderate the effects for self-affirmation manipulations in bowel cancer screening patients. Significant findings reported in Chapter 5 (Travis et al., 2024) of associations between trait self-esteem and spontaneous self-affirmation and levels of anxiety and intention, are supported by similar findings from previous work (Harris et al., 2019; S. E. Taylor et al., 2003b). Further investigation on interventions which target these constructs, to test the effects specifically on CRC screening intention and uptake is therefore advised.

6.3 **Strengths of this thesis.**

The research conducted in this thesis has several key strengths.
6.3.1 Methodological rigor.

To conduct the systematic review and thematic synthesis in Chapter 2, the existing literature on FSS was searched and synthesized rigorously, in compliance with the PRISMA checklist (Moher et al., 2010). To avoid reviewer bias and for full inclusion of relevant articles, a second reviewer duplicate screened all abstracts and full texts during the screening process (Higgins et al., 2011).

The qualitative research conducted in Chapter 4 was guided by four fundamental dimensions of rigor for qualitative work, according to the Trust, Auditability, Credibility and Transferability (TACT) framework (Daniel, 2019). For instance, for credibility duplicate coding of an initial set of transcripts and the joint development of an analytical coding framework were completed, in accordance with the framework method (Gale et al., 2013).

Data quality and validity of online research have recently been considered by Douglas et al. (2023), given concerns of inattentive survey participants and non-human respondents (bots) (Chmielewski & Kucker, 2020). As Douglas and colleagues (2023) recommend, to ensure data quality, the use of attention checks were included in both online surveys conducted in this thesis, to identify and remove inattentive participants from the data. Explicit instructions and questions were also included to reduce the level of dishonest reporting (Douglas et al., 2023). The decision to use Prolific for the recruitment of participants in both online interventions conducted in this thesis, is supported by Douglas et al. (2023) who showed participants on Prolific to be more likely than participants on other online crowdsourcing platforms, such as Amazon Mechanical Turk (MTurk), to pass attention checks, follow instructions, work steadily through all items, and provide meaningful answers.

6.3.2 Open science.

All articles published in this thesis are fully available to all to download with open access rights. To separate hypothesis-generating (exploratory) from hypothesis-testing
(confirmatory) research, the quantitative research conducted in this thesis, as shown Chapter 4 and 5 was preregistered on AsPredicted (AsPredicted, 2023) in advance of data collection commencing. This prevented any specific analysis decisions being made based on the sample data collected, ensuring the research questions and methods of analyses were clearly defined, in advance of data collection.

6.3.3 Successful publication of studies.

Taken together this research collectively provides important and unique contributions to the current knowledge of barriers and facilitators to CRC screening intention and uptake and has developed and measured the effects of novel interventions to improve these. Real world issues, such as equality of access to screening, language barriers and patient anxiety have been identified and the implications associated with. Practical-orientated recommendations to address these have been investigated and tested in this thesis. All four studies in this thesis have been reviewed by experts in the field of cancer screening behaviours, and as a result the work conducted has been critiqued and developed further leading to the successful acceptance for publication in three leading worldwide health psychology journals.

Importantly, the first review article published in Psycho-Oncology, in June 2020, is now attracting a good citation rate with 13 citations to date, 79 downloads, and has a high attention score in the 82\textsuperscript{nd} percentile compared to outputs of the same age (Altmetric, 2023), reflecting the importance of these findings and their significance for the field.

6.4 Limitations of this thesis.

As with any research, there are key limitations to this thesis that must be acknowledged.

6.4.1 A population representative sample.

6.4.1.1 Low uptake groups and decliners.

There was a lack of sufficient participation by under-represented groups, in the three empirical research studies conducted in this thesis. Participants who took part in
the studies were mostly white, and although the current UK population aged 50+ in Great Britain identifying as White is 92.57% (Office for National Statistics, 2022), those choosing or unable to access cancer screening services are known to be largely from ethnic minority groups and reside in deprived areas of England (Moss et al., 2017). Although active recruitment was undertaken to target under-represented groups, of those individuals who had recently been invited but who were unable to attend positive FIT follow-up colonoscopy as part of the BCSP, no decliners were successfully recruited. Findings presented in this thesis therefore may not fully capture the reasons for non-attendance and barriers faced by under-represented groups and of decliners to CRC screening. SSPs have regular contact with patients, however, and were able to share their insights into their experiences and awareness of reasons patients had not attended. The effects of a modified letter to follow-up colonoscopy study, as detailed in Chapter 4, also included 24 participants (4.5%) who had previously been invited for a colonoscopy but did NOT attend, providing some degree of input from non-attenders. The participant samples for all empirical work in this thesis were however collected from an equal representation of female and male participants and with varying levels of education attainment. Eligibility criteria ensured that only members of the public at the screening appropriate age were included for relevance. For instance, only those people who had previously been invited to positive FIT follow-up colonoscopy screening were interviewed (see Chapter 3) and only people who were aged 49, therefore, soon to receive CRC screening invitation were approached and eligible to take part in the online written-based intervention, screened via the Prolific crowdsourcing platform (see Chapter 5).

6.4.1.2 Access to online research

The disparities in participant access to online research is a limitation for consideration in this thesis, given technology access disproportionately effects under-represented groups (Mehra et al., 2004). The two online research studies conducted, in Chapter 4 and 5, involved the recruitment of participants solely online, using the Prolific
crowdsourcing platform. Participants who took part in the research in this thesis were required to be aged 49 and over, have access to an online device, and have a certain level of literacy to take part in the surveys. A lower level of digital literacy and the use of the internet has been found to be associated with being older, those with long term illness, and those with no education qualifications, based on an online survey of 3,804 adults who lived in 15 deprived communities in Glasgow (Kearns & Whitley, 2019). Therefore, the extent of which the survey data and preliminary findings in this thesis are generalisable may be a limitation (Newman et al., 2021).

6.4.1.3 Sample size

Findings from this thesis are preliminary, given they are based on small samples of the general screening population in the UK and SSPs. Although qualitative research principles do not intend to be generalisable, but specific to a certain context, time and set of participants (Thomas & Harden, 2008), the validation, acceptability and feasibility of practical-orientated suggestions made by those patients and SSPs interviewed in Chapter 3 (Travis et al., 2020), now require wider involvement of members of the general screening population and of health-care professionals. A-priori sample size calculations were carried out using G*Power to determine the number of participants to take part in the online surveys of this thesis. To do so, the effect sizes reported from previous similar work were used, with 80% power and at alpha = 0.05. Nevertheless, for some of the analyses, the cell sizes were found to be small, meaning some of the data analysis may have been underpowered (Dziak et al., 2020). Therefore, future research ought to attempt to replicate the current findings using larger, more representative samples.

6.4.2 Validity

6.4.2.1 Ecological validity

This use of hypothetical scenarios presented in the two online written-based interventions conducted in this thesis is a limitation. Participants were asked to read
and imagine they had received the BCSP invitation letter to follow-up colonoscopy examination (Chapter 4; Travis et al., 2023) or the BCSP bowel cancer screening information leaflet (Chapter 5; Travis et al., 2024) in the post. They were asked to then rate and comment on their expected level of anxiety, intention to screen and expected concerns they would envisage having. These responses may not necessarily be experienced in the same way as in real life, with the surveys measuring intended rather than actual behaviour. Findings from the online surveys in this thesis may therefore lack ecological validity, and further tests with patients in real life, upon receiving CRC invitation materials is vital before any conclusions or consideration for change can be considered. Hypothetical scenario designs, however, are a useful methodological tool that allow for the manipulation of conditions, and a design used recently by other researchers in the UK to elicit expected responses from participants regarding CRC screening and patient symptom attribution was shown to be useful (Digby et al., 2020; Kaushal et al., 2020; Smith et al., 2023).

6.4.2.2 Criterion validity

State Anxiety was assessed in this thesis using the Spielberger six-item short form state anxiety inventory (STAI-6) scale (Marteau & Bekker, 1992). The STAI-6 measure was chosen given it is the most widely used measure of state anxiety (Marteau & Bekker, 1992). This scale measures state anxiety levels “right now” on a 4-point Likert scale (not at all (0), somewhat (1), moderately (2) and very much (3)). Participants in the two intervention studies (Chapter 4 and 5) were asked to rate and comment on their expected level of anxiety, based on hypothetical scenarios. The STAI-6 scale is primarily a measure of general state and trait anxiety, used in clinical settings to diagnose anxiety, and therefore it can be challenged as to whether this is an accurate indicator of the bowel screening specific cognitions sought to be investigated in this thesis, such as the level of fear of bowel cancer, and the level of procedural related anxieties related to attending bowel cancer screening tests. Although concerns relating to being at risk of bowel cancer and surrounding the positive FIT colonoscopy
procedure itself were measured in Chapter 4, further consideration as to how anxiety in
the context of bowel cancer screening is most accurately measured is needed.

6.5 Future avenues for research.

6.5.1 Replication of research

Research with larger samples is recommended to further explore the
effectiveness of the written-based interventions tested for the first time in this thesis,
involving the modification of invitation materials and the inclusion of self-affirmation
inductions. Recent theory: the I-SAM (K.A. Robb, 2021) demonstrates how individuals
at the same screening stage can face common barriers to one another, advising
interventions to be targeted per screening stage. Testing the impact of these novel
written-based interventions on other population-based screening programmes in
England (cervical and breast screening) could therefore have the potential to help
address common barriers to cancer screening uptake at invitation to screen stage.

6.5.2 A population representative sample.

To improve bowel cancer screening uptake, it is imperative that future research
focuses on measuring and addressing the effects of screening invitation materials on
individuals from under-represented groups and of those with low levels of literacy, for
example as previously explored by Smith et al. (2012b). This is important to fully
examine and suggest feasible interventions which will improve CRC screening uptake
for all, and to address ethnic and socioeconomic disparities. Focussing samples on
these groups is now recommended, as recently carried out by Kerrison et al. (2023)
who examined the differences in barriers to colonoscopy of people living in the UK,
from different ethnic minority backgrounds (e.g., interviewing participants from Black-
African, Black-Caribbean, South Asian and White British groups). Quantitative work
should also look to consider under-represented groups as a moderator in future
analyses. Community-based participatory research has been recognised as an
effective approach to consider when conducting intervention research aimed at
improving screening attitudes, knowledge, and behaviour (Bellhouse et al., 2018). Further research and action should look to find ways to build stronger connections with local ethnic minority and deprived communities, in order to effectively design and tailor interventions that address unique barriers faced by under-represented groups.

Not being able to read and speak English is a barrier to CRC screening, identified and discussed in Chapter 3 (Travis et al., 2022), reported as a key issue to people not being able to attend positive FIT follow-up colonoscopy. Cultural and language barriers to positive FIT colonoscopy examination now require further exploration, with an ecological sample in real-life with people whose first language is not English, and who have recently been invited to positive FIT follow-up colonoscopy. Further to the recommendation for changes to invitation materials, suggested by SSPs in Chapter 3 (Travis et al., 2022), it is crucial to continue to emphasise the need to update national systems to enable cancer screening invitations to be sent out to members of the public in their first language spoken.

6.5.3 Field-based research

Given the gap between intention and behaviour in cancer screening (Conner & Norman, 2022), where feasible further research should focus on investigating and measuring CRC screening behaviour as opposed to intention. Research that seeks to capture real-life in the moment feedback and responses to CRC screening invitation, and people’s lived experiences of screening would improve the ecological validity of preliminary research findings and recommendations made in this thesis. Future embedded research that co-locates the researcher within the NHS BCSP team would provide greater insight into the real-time communications, including patient queries raised, their issues, and lived experiences. It would also provide a deeper understanding of how the current NHS processes and communication channels influence patient behaviour to attend a positive FIT colonoscopy examination. For example, field-based research could involve in-person, audio, or video ethnography of real-time patient practitioner conversations had in the waiting room/reception, in the
SSP consultation meeting, or via the BCSP helpline, allowing for the capture of in the moment patient and staff issues, patient feedback and potential health inequalities requiring further attention.

6.6 General conclusions

This thesis aimed to expand the evidence base through identifying barriers and facilitators to CRC intention and uptake and by testing practical-orientated recommendations to address these, suggested by patients and health-care professionals. Specifically in this thesis, the understudied areas of CRC screening barriers and facilitators, flexible sigmoidoscopy and positive FIT colonoscopy screening examination in England were investigated through qualitative research methods. Patient anxiety was cited as a major barrier to participation in FSS and follow-up colonoscopy, experienced by patients throughout the screening pathway. Recommendations made by patients and SSPs to reduce patient anxiety included suggestions such as the earlier notification of the option for sedation to reduce any patient concerns of pain and discomfort. The test of these suggested modifications to the BCSP invitation letter were however found to not be beneficial to patient reported expected levels of anxiety or behavioural intentions to screen. It is possible that reducing the use of the term cancer in the modified invitation letter may have reduced the perceived need for and importance some participants placed on attending the appointment. Further research is required to understand whether procedural information about colonoscopy and risks for first-time invitees, may be best handled through in-person consultation as opposed to written forms of communication. Future research ought to also seek feedback on tailored invitation materials based on people’s past screening experiences and do so among under-represented groups. The research undertaken in this thesis also experimented with the use of self-affirmation inductions as a novel theory-based intervention to improve responses to bowel cancer screening information materials, yet findings showed no effects on participant expected levels of
anxiety, message acceptance or behavioural intentions to screen. There was some evidence of the effect of health-based self-affirmation on lowering anxiety, however future research is needed to explore the effectiveness of different self-affirmation interventions in larger samples. Cumulatively, the research findings from this thesis improve understanding of the effectiveness or otherwise of different novel interventions aimed at addressing key patient barriers to different modalities of CRC screening in order to improve uptake. The findings are promising and highlight the need for future research to endeavour to replicate the current results in larger and more representative samples.
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### Appendix 1.1 – Chapter 2 Supplementary material

**SUPPLEMENTARY FIGURE 1**   Critical Appraisal Skills Program (CASP) tool results

<table>
<thead>
<tr>
<th>CASP Tool Criteria</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Was there a clear statement of the aims of the research?</td>
<td>100%</td>
</tr>
<tr>
<td>2. Is a qualitative methodology appropriate?</td>
<td>100%</td>
</tr>
<tr>
<td>3. Was the research design appropriate to address the aims of the research?</td>
<td>100%</td>
</tr>
<tr>
<td>4. Was the recruitment strategy appropriate to the aims of the research?</td>
<td>80%</td>
</tr>
<tr>
<td>5. Was the data collected in a way that addressed the research issue?</td>
<td>50%</td>
</tr>
<tr>
<td>6. Has the relationship between researcher and participants been adequately considered?</td>
<td>10%</td>
</tr>
<tr>
<td>7. Have ethical issues been taken into consideration?</td>
<td>40%</td>
</tr>
<tr>
<td>8. Was the data analysis sufficiently rigorous?</td>
<td>80%</td>
</tr>
<tr>
<td>9. Is there a clear statement of finding?</td>
<td>100%</td>
</tr>
<tr>
<td>10. How valuable is the research?</td>
<td>100%</td>
</tr>
</tbody>
</table>
**SUPPLEMENTARY TABLE 1  Search terms used for OVID Databases**

<table>
<thead>
<tr>
<th>Barriers, facilitators and socio demographic factors</th>
<th>(Barrier$ or Facilitator$ or Factor$ or Obstacle$ or Difficult* or Issue$ or Restrict* or Limit* or Dilemma$ or Worr* or Catalyst* or Enable* or Initiat* or Mediat* or Expedite* or View* or Opinion$ or Perce* or Feeling$).mp. or Attitude to Health/ or Challenge$.mp. or Concern$.mp. or Consideration$.mp. or Circumstan$.mp. or Influen$.mp. or Aid$.mp. or Adhere*.mp. or exp Decision making/ or Choice Behavio?ri/ or Uncertainty/ or Volition/ or Judgement.mp. or predict*.mp. or demography/ or demographic$.mp. or socioeconomic/ or age.mp. or sex.mp. or gender.mp. or education*.mp. or Income.mp. or Marital status.mp. or occupation*.mp. or religio*.mp. or family size.mp. or Rac*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of cancer</td>
<td>(Colorectal Cancer or Bowel Cancer or Colon Cancer).mp. or Colorectal Neoplasms/ or Rect* Cancer.mp. or Rectal Neoplasms/ or CRC.mp.</td>
</tr>
<tr>
<td>Flexible sigmoidoscopy screening</td>
<td>(Flexi* Sig* or Bowel Scope or Endoscop* Screening or Sigmoidoscopy or Rectum screening).mp. or Colonic polyps/[mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]</td>
</tr>
<tr>
<td>Reference</td>
<td>Research Question/ Study Aims</td>
</tr>
<tr>
<td>-----------------</td>
<td>-----------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Austin et al. (2009)</td>
<td>To explore perceived barriers to Flexible sigmoidoscopy screening among UK ethnic minority groups using a qualitative methodology. To examine, using the Health Belief Model as a framework, lay recommendations to increase Flexible sigmoidoscopy screening participation.</td>
</tr>
<tr>
<td></td>
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<tr>
<td>Study</td>
<td>Objective</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Ritvo et al. (2013)</td>
<td>To elicit key gender differences in attitudinal obstructions towards colorectal cancer screening with the aim of deriving informative differences useful in planning promotions of screening uptake.</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Holt et al. (1991)</td>
<td>To elucidate factors that influence patients to complete screening sigmoidoscopy.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Objective</td>
</tr>
<tr>
<td>-------</td>
<td>-----------</td>
</tr>
<tr>
<td>Frew et al. (2005)</td>
<td>To understand more fully the personal motivating factors that contributed to individual behaviours.</td>
</tr>
<tr>
<td>Study</td>
<td>Purpose</td>
</tr>
<tr>
<td>-----------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Hall et al. (2016)</td>
<td>To investigate responses to the screening invitation to inform understanding of decision-making, particularly in relation to nonparticipation in screening. To explore similarities and differences in beliefs and decision-making processes.</td>
</tr>
<tr>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Gray et al. (1999)</td>
<td>To explore patients’ perceptions of the process of screening sigmoidoscopy.</td>
</tr>
<tr>
<td></td>
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</tr>
</tbody>
</table>
McCaffery et al. (2001)

To provide richer, more detailed, information about the decision-making process to complement quantitative data on predictors of participation, collected as part of the Flexible Sigmoidoscopy trial.

To explore respondents’ explanations of non-participation in their own terms rather than those imposed by the researchers.

Social Science and Medicine

England – Leicester General practices

n = 60
55-64 years

Women = 30
Men = 30

Not provided, however the study was nested within a randomised control trial of FSS among an asymptomatic general population sample in the UK.

Telephone open ended Interviews.

Thematic analysis

Screening intention and behaviour

Range = 50 – 60

however, no participant socio-demographic descriptive statistics were provided.
Weitzman et al. (2004) identified what adult men and women knew about colorectal cancer. To illustrate how sets of beliefs may contribute to low perceived risk and to screening noncompliance. To learn more about how respondents perceived their risk for colorectal cancer and what factors they considered in assessing risk. To identify factors that impeded or facilitated colorectal cancer screening using faecal occult blood testing or flexible sigmoidoscopy.

<table>
<thead>
<tr>
<th>Public Health Massachussets (USA)</th>
<th>n and Age</th>
<th>Women</th>
<th>Asian Ethnicity</th>
<th>Lower SES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 39</td>
<td>Women = 22</td>
<td>None</td>
<td>Not directly stated but participants were recruited from worksites and a YMCA.</td>
</tr>
<tr>
<td></td>
<td>Women:</td>
<td></td>
<td>All white with the exception of 1 African American male.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11 aged 50 – 64,</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>11 aged 65 +</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Men:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>8 aged 50 – 64, and</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>9 aged 65 +</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Screening intention and behaviour.

n = 39
Women: 11 aged 50 – 64,
11 aged 65 +
Men: 8 aged 50 – 64, and 9 aged 65 +

Women = 22
Men = 17

Unclear - the article contains examples of transcribed verbatim under each of the categories presented.
<table>
<thead>
<tr>
<th>Study</th>
<th>Research Question</th>
<th>Methodology</th>
<th>Sample Size</th>
<th>Age Distribution</th>
<th>Ethnicity Comparison</th>
<th>SES Distribution</th>
<th>Data Analysis</th>
<th>Analysis Type</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Robb et al. (2008b)</td>
<td>To understand beliefs about, and interest in, bowel cancer screening among ethnic minorities in the UK.</td>
<td>n and Age Content analysis Screening intention and behaviour</td>
<td>n = 875</td>
<td>Age: 16-24 = 201</td>
<td>Women = 446 Asian Ethnicity 750 from Ethnic groups: Indian = 234 Pakistani = 166 Bangladeshi = 63 Chinese = 53 Caribbean = 126 African = 108 White-British = 125 for comparison</td>
<td>Unemployed = 280 Semi-skilled/unskilled manual workers = 143</td>
<td>Face to face interviews</td>
<td>Content analysis</td>
<td></td>
</tr>
<tr>
<td>Rawl et al. (2000)</td>
<td>To enhance understanding of the perceived benefits and barriers to colorectal cancer screening in the Midwest.</td>
<td>Age</td>
<td>n = 22</td>
<td>Women = 13</td>
<td>None</td>
<td>Focus groups-discussion</td>
<td>Thematic analysis</td>
<td>Screening intention and behaviour</td>
<td></td>
</tr>
</tbody>
</table>


cancer screening reported by first-degree relatives of colorectal cancer patients. To assess health belief model perceptions among first degree relatives of colorectal cancer patients.

| Cancer practice | rn United States | Mean age = 44 years | Men= 9 | White= all | Income < $40,000 = 4 (18.1%) | s guided by semi structured questionaire. Groups segregate d by gender. |
### Barriers and facilitators of screening intention

**SUPPLEMENTARY TABLE 3a: General Quotes**

<table>
<thead>
<tr>
<th>Procedural anxieties</th>
<th>Quote</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety regarding test invasiveness</td>
<td>“Well it is a bit of a private area I suppose that is the thing and having people invading that would make me think twice about it”. (Austin et al., 2009) - White British man</td>
<td></td>
</tr>
<tr>
<td>Shame and embarrassment</td>
<td>“Flexible sigmoidoscopy would find things quickly, so what’s a few moments’ embarrassment?.” (Frew et al., 2005)</td>
<td></td>
</tr>
<tr>
<td>Procedural pain and discomfort</td>
<td>“I’ve heard people say flexible sigmoidoscopy was very painful for them.” (Rawl et al., 2000) - White participant</td>
<td></td>
</tr>
<tr>
<td>Perforation anxiety</td>
<td>“If your person’s not that accurate with the camera you can do more damage”; “I feel that any mucking about or whatever the case maybe, will disturb something that you’ve no need to disturb.’ (McCaffery et al., 2001)</td>
<td></td>
</tr>
<tr>
<td>Reassurance of doctor narrative received during the test</td>
<td>&quot;Someone else is in charge, there is a reassurance that a professional is present, and the FS test is a more sophisticated test as it is done by a professional.&quot; (Frew et al., 2005)</td>
<td></td>
</tr>
<tr>
<td>Avoidant decision-making about the test</td>
<td>“You really know that you ought to have it done, but ... I don’t know. I’m not sure.”; “I kept thinking I must send that back and I just didn’t. I just kept pushing it to the back of my mind.” (McCaffery et al., 2001)</td>
<td></td>
</tr>
<tr>
<td>Medical Fear</td>
<td>“It’s a fear of anything, any test, or any medical even going down to the doctor.” (McCaffery et al., 2001)</td>
<td></td>
</tr>
</tbody>
</table>

**The influence of family, friends and medical professionals**

<table>
<thead>
<tr>
<th>Family and peer pressure/s support</th>
<th>Quote</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“I think I discussed it with my wife ... it was sort of in passing while we were busy doing what we were doing.” (McCaffery et al., 2001) - Married man</td>
<td></td>
</tr>
</tbody>
</table>
Doctor/physician screening recommendation and trust

"If my doctor told me to go, I’d go." (Rawl et al., 2000) - White participant

The power of social role and identity

Masculinity-associated procrastination

"...an attack on your armour...men don't have to go and do that." (Austin et al., 2009) – African-Caribbean man

"They say they are all man…. you are not pushing anything up there." (Austin et al., 2009) - African-Caribbean woman

Being responsible for your own health

"I mean, if it’s something that you’ve got to have done then have it done, but if you’ve got the choice, then no.” (McCaffery et al., 2001)

The fear of the unknown

Fatalistic beliefs about colorectal cancer

"...the first thing that goes through your mind is what’s wrong with bits of your bowel...you’re thinking cancer." (Gray & Snadden, 1999)

Anxiety surrounding test results

"...I don’t want to have to worry if they find anything." (Frew et al., 2005)

"Positive results from flexible sigmoidoscopy would mean more anxiety, panic." (Rawl et al., 2000) - White participant

Avoidance due to underlying fatalism

"I’m healthy enough and I feel that any mucking about will disturb something that you’ve no need to disturb.” (McCaffery et al., 2001)

Peace of mind in knowing

Peace of mind - important cannot ignore

“Clean bill of health.” (Weitzman et al., 2001)

Technical sophistication of screening

“...there is a ‘high tech’ appeal.” (Gray & Snadden, 1999)

Understanding the value of early detection
Media exposure of colorectal cancer and screening

“The short news bits on TV go in one ear and out the other.” Holt, 1991)

The presence of symptoms

“I don’t need it. I feel alright…why do things like that when you feel well?” McCaffery et al., 2001)

Likelihood of colorectal cancer based on family & own history

“If I’ve got any hints of family history anywhere down the line, I’d seriously consider it. But at this moment in time I don’t honestly think there’s much real point.” (McCaffery et al., 2001)

“Once it’s been in your family you always think at the back of your mind that you’re going to get it eventually. It’s something you don’t want to know about.” (McCaffery et al., 2001)

Un)necessary healthcare

Value placed on own health

‘I’m not a believer in these things.” (Frew et al., 2005; McCaffery et al., 2001)

Competing priorities and the accessibility

Competing priorities

“You’ve got so many things on your mind and if you’re working and you’ve got kids, you’re not going to think about having a flexible sigmoidoscopy unless something gets your attention.” (Rawl et al., 2000) - White participant

No access to care insurance

“I’m sorry to say that I think a lot of people won’t do a flexible sigmoidoscopy because…most insurance won’t pay for that on a regular basis.” (Rawl et al., 2000) - White participant

SUPPLEMENTARY TABLE 3b: Quotes from Women

Procedural anxieties

Anxiety regarding test invasiveness

“…more personal…it’s a more intimate procedure than breast screening…I don’t particularly fancy it, a foreign body being…in that part of my body.” (McCaffery et al., 2001)
<table>
<thead>
<tr>
<th>Shame and embarrassment</th>
<th>“I can see a lot of people ...shying away .... because it's such a personal thing. Once you have a baby though, I mean ‘hello’ (embarrassment is no longer the obstacle).” (Ritvo et al., 2013)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“…I’ll just wear a mask, or paper bag over my head so he doesn’t recognize me…” (Ritvo et al., 2013)</td>
</tr>
<tr>
<td></td>
<td>“I’ll go to the dentist and have him look down your throat...the other end… that’s very private…” (Ritvo et al., 2013)</td>
</tr>
<tr>
<td></td>
<td>“Like my daughter said, they’re going to have their bum up in the air...you’re going to stick your fanny in somebody’s face.” (Weitzman et al., 2001) - Older woman 65</td>
</tr>
<tr>
<td></td>
<td>&quot;Older people will feel violated by this humiliation.&quot; (Robb et al., 2008b) - African-Caribbean woman</td>
</tr>
<tr>
<td></td>
<td>&quot;Probably be quite dramatic about the enema.&quot; (Austin et al., 2009) - White British woman</td>
</tr>
<tr>
<td></td>
<td>&quot;I just have never done anything like that so I would be frightened of it getting lost up there or something.&quot; (Austin et al., 2009) - African-Caribbean Woman</td>
</tr>
<tr>
<td>Test preparation difficulties</td>
<td></td>
</tr>
<tr>
<td>The influence of family, friends and medical professionals</td>
<td></td>
</tr>
<tr>
<td>Family and peer pressure/support</td>
<td>“Well I did talk to a few people about the test at the tennis club and my embroidery class and the opinion was that you should leave well alone.” (McCaffery et al., 2001)</td>
</tr>
<tr>
<td>The fear of the unknown</td>
<td>“…fear of the unknown...would rather not want to know about it.” (Austin et al., 2009) - African-Caribbean woman</td>
</tr>
<tr>
<td>Anxiety surrounding test results</td>
<td></td>
</tr>
<tr>
<td>Understanding the value of early detection</td>
<td>“It brought back memories of when I had a mastectomy”; “I think the word cancer frightens most people ...I lost my mother with it”” (McCaffery et al., 2001)</td>
</tr>
</tbody>
</table>
The presence of symptoms

“As far as that [risk for colorectal cancer and screening] I really don’t even think about it, because everything works fine for me…” (Weitzman et al., 2001) Older woman aged 65+

**Competing priorities and the accessibility to**

**Competing priorities**

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

**SUPPLEMENTARY TABLE 3c: Quotes from Asian Men and Women**

<table>
<thead>
<tr>
<th>Procedural anxieties</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Shame and embarrassment</strong></td>
</tr>
<tr>
<td>“too embarrassed talking about it with you, never mind the test.” (Robb et al., 2008b) - Indian woman</td>
</tr>
<tr>
<td>“I tend to say yes and then not turn up because of shame.” (Robb et al., 2008b) - Young Bangladeshi woman</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The influence of family, friends and medical professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Religious and cultural influenced health beliefs</strong></td>
</tr>
<tr>
<td>“Not my cultural way.” (Austin et al., 2009) - Pakistani man</td>
</tr>
<tr>
<td>“In our culture we don’t do these kinds of tests unless vital.” (Robb et al., 2008b) - Pakistani woman</td>
</tr>
<tr>
<td><strong>Doctor/physician screening recommendation and trust</strong></td>
</tr>
<tr>
<td>“It is up to the medical profession what they do, it is not up to the public to tell them what to do, it is the medical profession who suggests it…” (Austin et al., 2009) Pakistani Man</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The fear of the unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Avoidance due to underlying fatalism</strong></td>
</tr>
<tr>
<td>&quot;So, they believe that it was better without treatment and once you start treatment it gets worse.&quot; (Austin et al., 2009) - Pakistani woman</td>
</tr>
<tr>
<td><strong>Perceived susceptibility to colorectal cancer</strong></td>
</tr>
<tr>
<td>&quot;We are different because our diet is predominantly fibre-based…so maybe there isn't a lot in our community“ (Austin et al., 2009) - Gujarati Indian man</td>
</tr>
</tbody>
</table>
"I'm still a little bit not aware that it is prevalent, especially in these ethnic groups, Asians." (Austin et al., 2009) - Gujarati Indian man

<table>
<thead>
<tr>
<th>Peace of mind in knowing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reassurance from early detection and prevention</td>
</tr>
<tr>
<td>&quot;If you can pick this [bowel cancer] up at a much earlier stage and prevent something nasty, a killer disease basically at a later date, then surely it would make sense to go through a bit of discomfort.&quot; (Austin et al., 2009) - Gujarati Indian man</td>
</tr>
</tbody>
</table>

| The value of early detection and prevention |
| "Obviously if things are picked up earlier, they are much easier to handle…" (Austin et al., 2009) - Pakistani woman |

| Understanding the value of early detection |
| Knowledge and awareness of colorectal cancer |
| "If you don’t have much knowledge people may not attend." (Austin et al., 2009) - Pakistani woman |
| "Without little knowledge on what is going to happen, if no one explained then I do not want to go for the test, there is a little bit of fear and whether it is safe, but after explanation you might consider having it done." (Austin et al., 2009) - Gujarati Indian man |

| The presence of symptoms |
| "Why should I get something put in my body if there is nothing wrong with me?." (Austin et al., 2009) - Gujarati Indian woman |
Barriers and facilitators of screening behaviour

SUPPLEMENTARY TABLE 4a: General Quotes

<table>
<thead>
<tr>
<th>Category</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Procedural anxieties</td>
<td>“...I found the after-effects of it very painful, as I was so constipated.” (Holt, 1991)</td>
</tr>
<tr>
<td>Procedural pain and discomfort</td>
<td>“It’s the sensations when they go around corners.” (Weitzman et al., 2001) Older white man aged 65+</td>
</tr>
<tr>
<td>Test preparation difficulties</td>
<td>&quot;I had grave difficulty with the enema.&quot; (Gray &amp; Snadden, 1999)</td>
</tr>
<tr>
<td>Reassurance of doctor narrative received during the test</td>
<td>“Interesting, helpful and reassuring…he told me what he was doing…very fast. I wouldn’t mind doing it again.” (Weitzman et al., 2001) - Younger male screener</td>
</tr>
<tr>
<td>Avoidant decision-making about the test</td>
<td>“You really know that you ought to have it done, but ... I don’t know. I’m not sure.”; “I kept thinking I must send that back and I just didn’t. I just kept pushing it to the back of my mind.” (McCaffery et al., 2001)</td>
</tr>
<tr>
<td>The fear of the unknown</td>
<td></td>
</tr>
<tr>
<td>Perceived susceptibility to colorectal cancer</td>
<td>“I know that I dinnae (don’t) have cancer...so I dinnae (don’t) see the reason why anybody should put pressure on me to go.” (Gray &amp; Snadden, 1999)</td>
</tr>
<tr>
<td>Peace of mind in knowing</td>
<td></td>
</tr>
<tr>
<td>Peace of mind - important cannot ignore</td>
<td>“It was well worth the discomfort for the peace of mind.” (Holt, 1991) “Panic. I didn’t fancy this thing in my bum, but you’ve got to do it…I’ve got to do this for my peace of mind.” (Hall et al., 2016) - Male screener</td>
</tr>
</tbody>
</table>
Ease of procedure

“I will definitely have another sigmoidoscopy.” (Holt, 1991)

Competing priorities and the accessibility to attend screening

Competing priorities

“my wife was just about coming out of hospital and I couldn’t cope.” (McCaffery et al., 2001) - Married male respondent

SUPPLEMENTARY TABLE 4b: Quotes from Women

Procedural anxieties

Perforation anxiety

“I read the bit which stuck in my head that it could puncture your bowel…and thought oh right I’m not doing that…I was just too scared to have it done.” (Hall et al., 2016) - Non screener

“The main thing that struck me was the statistics, you know one in 300 might have cancer, I thought well I’m not having that shoved up my arse frankly for the sake of that, you know they might perforate my bowel.” (Hall et al., 2016) - Non screener

Test preparation difficulties

“...The only reason I cancelled my appointment was because after speaking to an assistant I realised I had to apply the enema an hour before attendance… I could not do this at work. I would also feel worried about driving to the hospital after applying an enema!” (Hall et al., 2016) - Non screener

The influence of family, friends, and medical professionals

Family and peer pressure/ support

“...If my husband had gone I would have probably gone along with him and had the test, both of us.” (McCaffery et al., 2001)

The fear of the unknown

Fatalistic beliefs about colorectal cancer

“Sometimes all these treatments and nothing works, so I think I would just give in at the first hurdle… they (friends with bowel cancer) went through all that battle and nothing worked.” (Hall et al., 2016) - Non screener
**Peace of mind in knowing**

The value of early detection and prevention  
"If they found something, how would I react to that? Well I might be better off not knowing. But in the back of my mind that's saying yeah but it's better to know early." (Hall et al., 2016) - Non screener

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**Un)necessary healthcare**

Viewed as an (in)effective use of NHS resources  
"I won't have treatment for cancer… So, you know, I just think I'm not wasting people's, the NHS's money or whatever, you know, I'm just not." (Hall et al., 2016) - Non screener

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**Competing priorities and the accessibility**

Competing priorities  
"I can only go on these certain dates and they said well we can't give you them dates because we can only go up to a fortnight or so many days. I says well I can't do it then and I was a bit annoyed about that… I rang back and they were filled up again, so I didn't bother." (Hall et al., 2016) - Non screener

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**SUPPLEMENTARY TABLE 4c: Quotes from Asian Men and Women**

**Procedural anxieties**

Shame and embarrassment  
"I tend to say yes and then not turn up because of shame." (Robb et al., 2008b) - Young Bangladeshi woman

---

**The influence of family, friends, and medical professionals**

Religious and cultural influenced health beliefs  
"They just make you feel uncomfortable [for requesting a female nurse]. So that is why I don't go, if I got the test I would say no I don't want to go because of this thing." (Austin et al., 2009) - Pakistani woman
Appendix 1.2 – Chapter 3 Supplementary material

Interview guides and additional SSP Questions/prompts

Patient interview schedule

Note - The alignment and mapping of the below patient interview questions to the Theoretical Domains Framework (Atkins et al., 2017) can be found in brackets after each question.

The researcher first introduces themselves and explains in layman terms what the research is about. The researcher checks for understanding by the participant, and attempts to gage from the participant’s response, what their bowel cancer screening experience is, i.e., the stage of screening they have undertaken.

Researcher checks they have receipt of the Demographics and background pre-filled form (e.g., living arrangements, location, age and ethnicity), completed ahead of the interview by the participant.

If screening experience is not known from the above introductions, the researcher asks directly. Please could you first tell me whether you:

1. Declined further screening, on receiving your letter invitation.
2. Attended further screening tests (known as a colonoscopy).
3. Initially accepted to attend further tests, but then later changed your mind and didn’t attend?

If 3, can you explain at what point exactly you decided not to attend?

Depending on the participant’s answer, the researcher continues to the relevant section…
1. Declinners

Event 1 – Invitation letter to screen

Please take a look at the letter shown on the screen, this sheet of paper or email I have sent you. You may recall seeing something similar when you were invited to attend further tests for bowel cancer screening.

Primary question:

What were your immediate thoughts when you read this letter? [all]

Prompts if needed:

- Was there anything particular written within this letter which concerned you? [all]
  - What other concerns or worries did you have? [all]
  - Did you do anything about these concerns? If so, what did you do? [Intentions, Skills, Knowledge]

- What were your reasons behind deciding not to attend further screening tests (a colonoscopy)? [All]
  - How does the thought of having a colonoscopy screening and the preparation required make you feel? [Emotion]
  - Did you speak to anyone else about your screening decision, a friend or family member say? [Social Influences]

- How do you think your views, about screening, compare to your friends and family? Does this matter to you? [Social Influences, Social role and identity, Beliefs about consequences]

If the participant still does not wish to take part, is there anything that could be done to change your mind? [all] For e.g., knowing more about the bowel preparation procedures or the test itself? [Knowledge] Or would being given additional support from a nurse with bowel prep or to speak to about your concerns with the test change your mind? [Skills, Knowledge, Beliefs about capabilities, Optimism] Or help with your travel arrangements to get to the screening centre, or the ease of changing the time of your appointment to suit you better [Environmental context and resources]?

Is there anything we haven’t discussed that you would like to share? [all]

2 & 3. Non-attenders and Screeners – for non-attenders continue up to the point of drop out

Event 1 – Invitation letter to screen

Please take a look at the letter shown on the screen. You may recall seeing something similar when you invited to attend further tests for bowel cancer screening.

Primary question:

What were your immediate thoughts when you read this letter? [all]

Prompts if needed:

- Was there anything particular written within this letter which concerned you? [all]
- What other concerns or worries did you have? [all]
- Did you do anything about these concerns? If so, what did you do? [Intentions, Skills, Knowledge]
- What were your reasons behind deciding to attend further screening tests (a colonoscopy)? [All]
• Why do you think some people might decide not to go see the nurse for this appointment? [All]
• How did the thought of having a colonoscopy screening and the preparation required make you feel? [Emotion]
• Did you speak to anyone else about your screening decision, a friend or family member say? [Social Influences]
• How do you think your views, about screening, compare to your friends and family? Does this matter to you? [Social Influences, Social role and identity, Beliefs about consequences]
• How do you feel today about bowel cancer screening? Is colonoscopy screening something you would or would not wish to take part in, in the future? Why? [Intentions, Goals, Emotion. Knowledge, Skills]
• If the participant does not wish to take part in the future, is there anything that could be done to change your mind? [all] For e.g., knowing more about the bowel preparation procedures or the test itself? [Knowledge] Or would being given additional support from a nurse with bowel prep or to speak to about your concerns with the test change your mind? [Emotion, Skills, Knowledge, Beliefs about capabilities, Optimism] Or help with your travel arrangements to get to the screening centre, or the ease of changing the time of your appointment to suit you better [Environmental context and resources]?

Event 2 – SSP appointment

You attended a meeting, face to face or via the telephone, with a nurse, called a specialist screening practitioner.

Primary question:

Can you tell me what the nurse talked to you about? [Knowledge, Skills, Emotion]
Prompts if needed:

- How helpful was the nurse? [Skills, Knowledge, Beliefs about capabilities, Optimism]
- Did you understand and feel confident about everything that the nurse told you? For e.g., what you needed to do next, before your screening test, and what the test actually involved? [Emotion, Skills, Knowledge, Beliefs about capabilities, Optimism]
- Did you ask the nurse any questions? If so, can you remember what you asked them? [Emotion, Skills, Knowledge, Beliefs about capabilities, Optimism, Intentions]
- Can you recall how you felt straight after your meeting with the nurse? [Emotion]
- Did you have any concerns or worries at this point? If so, what were they? (Probe barriers) [all]
- Did you raise any concerns and if so, in what way did the nurse help you overcome them? [Emotion, Skills, Knowledge, Beliefs about capabilities, Optimism]

*Event 3 – Bowel preparation procedure (BPP) materials*

We are now going to move on to talk about the BPP materials. The BPP might be a difficult or embarrassing thing for you to talk about, if you’d rather not talk about it please just let me know and we’ll skip this part. If ok to continue, please take a brief look at some bowel preparation instructions shown on the screen (online) or in the email sent (via telephone).

Primary question:

Did the nurse give you something similar to take home and read? [all]

Prompts if needed:
- Did you find your instructions easy or difficult to read and understand? If
difficult, what did you do to make sure you understood them? [Knowledge, Skills, Goals,
Intentions]
- How did you feel straight after reading these instructions? [Emotion]
- How confident did you feel about carrying out the bowel preparation
yourself? [Emotion, Beliefs about capabilities]
- Did you have any concerns or worries whilst reading these
instructions? [Emotion, Beliefs about capabilities, Knowledge, Skills,]
  - If so, how were you able to overcome these concerns? For e.g., Were you able
to phone the screening centre or nurse for more advice, if so, did this help? [Emotion,
Skills, Knowledge, Beliefs about capabilities, Optimism] Or did you seek help from a
family member to share your concerns with, or to potentially help you with the
procedure or associated circumstances? [Emotion, Skills, Social influences,
Environmental context and resources]

Event 4 – The bowel preparation procedure (BPP)
Again, check if the participant is happy to continue discussing the BPP, or if they’d
rather move past/ skip this part.

Primary question
How did you find your experience of the BPP? [all]

Prompts if needed:
  - Were you worried at all about being able to complete the BPP or did you feel
confident in what you needed to do? [Emotion, Beliefs about capabilities, Knowledge,
Skills]
  - Did you experience any problems? [Emotion, Beliefs about capabilities,
Knowledge, Skills]
• Did you seek help with problems with BPP? If so, who helped you? (Such as spouse, nurse etc) [Emotion, Skills, Social influences, Environmental context and resources]
  • How did the BPP make you feel? [Emotion]
  • Did this BPP put you off in any way from attending your screening test the next day? [Intentions, Optimism]

*Event 5 – Patient has a colonoscopy*

Primary question

Can you tell me about your colonoscopy screening test experience? [all]

Prompts if needed:

• How did you feel on the morning of your test? [Emotion]
• Did you experience any problems? If so, did you seek help to overcome these problems? Say from a spouse, friend or nurse at the screening centre? [Emotion, Skills, Social influences, Environmental context and resources]
• Did the experience of having another colonoscopy test put you off future screening in any way? Why was that exactly? [Intentions, Beliefs about consequences]

*Event 7 and 8 – patient waits and then receives their results.*

• How long did you have to wait for your test results?
• How did you feel during this wait period? [Emotion]
• When you got your results, were they clear to understand? [Knowledge, Beliefs about consequences, Goals]
• Was any support offered to help you understand your results? From the screening centre or from family and friends? [Knowledge, Skills, Social influences, Environmental context and resources]

Finally, is there anything we haven’t discussed that you would like to share?

_N.B. The interviews will take a conversational approach to allow participants to lead the discussion, and the topic guides will continue to evolve as the interview and observational data collection progresses and in response to suggestions from our PPI group. Therefore, it is likely that additional areas of interest will be identified and explored alongside the topics described above. For interview participants who have also been observed, additional questions may be asked about the events that have been observed._

**Specialist Screening Practitioner Interview Schedule**

The researcher first introduces themselves and explains briefly what the research is about.

The researcher presents the below timeline, either via sharing this image on screen, in paper or email copy to the SSP.
This timeline shows events that the patient may experience, following a positive/abnormal FIT result. Please read each of these boxes, and based on your understanding of the patient's experience confirm if these events still happen, and in the order as shown?

Please tell me if any events have changed or if any key events have been missed off. Or perhaps there are other reasons for deviations from this flow?

Based on your own understanding of the patient's experience, would you prefer to draw or explain verbally (if on the telephone) your own version of this timeline, to explain in your own words what happens to the patient? If not, are you happy to continue, based on this pre-defined timeline of patient events? If the SSP chooses to draw, they can use the whiteboard on the screen or sketch down on a piece of paper,

The same questions are asked at each of the 8 timeline points.

Primary question:

1. Can you explain to me exactly what happens here (during event X)?
Prompts if needed:

- In your opinion, what works well here (during event X)? *(Positives)*
- What issues, concerns and problems do patients and yourself as an SSP, experience (during event X) - probe for both behavioural, procedural and practical barriers here.
- The issue X appears to be a key challenge or problem from what you have said. Which patients struggle the most with this? *(groups)* Why do you think X group/patients struggle more than X group/patients?
- How do you think the challenge/problem/issue X could be overcome/addressed? *(Suggested Improvements and ideas).*

Now, I would like you to use the whiteboard here on the screen (if online) / verbally explain (via telephone) and map out the relationships between yourself, as an SSP and your key contacts during work. I have started this off by drawing a line (online only) between yourself the SSP and your patients. Who else can you think of that you work closely with? Can you draw and map them on your diagram?

Primary question:

Can you explain your connection with X contact here?

Prompts if needed:

- What are the specific tasks you do/dealings you have?
- What works well between yourself and this contact/group/ team?
- What doesn't work so well between yourself and this this contact/group/ team?
- Why do you think that is the case?
- How do you think the working relationship here, between yourself and X could be improved?
• To do so, what would those changes involve?
• And could these changes be realistically applied?

N.B. The interviews will take a conversational approach to allow participants to lead the discussion, and the topic guides will continue to evolve as the interview and observational data collection progresses and in response to suggestions from our PPI group. Therefore, it is likely that additional areas of interest will be identified and explored alongside the topics described above. For interview participants who have also been observed, additional questions may be asked about the events that have been observed.

Additional SSP questions/prompts:
• What sort of reasons do you hear/ know of why people don't show up for your appointments?
• What about, do you call it DNA's- those people who 'do not attend' - no shows on the day. What other reasons are there for a patient DNA? What do they tell you or you find out are the reasons for patient's not turning up?
• In your opinion, what do you think works well about that this letter for patients?
• What else do you think patient's worry about at XXX stage, what do you think is going through their minds?
• So, there is the <issue/barrier>, what else have you experienced or you're aware from your job?
• What about the colonoscopy test itself. What feedback do you get about the procedure, do you hear anything from patients about the actual colonoscopy and the bowel prep?
• How much do you think people are influenced by their friends and family, before they come in to see you?
• Are there any particular groups that you've come across, so demographic groups, gender, or religious groups, which have a particular issue with this invitation?
  Probe - Why do you think that is?
• What about religion. Do you get any particular issues from different ethnic minority groups, or religions?
• Language - do you arrange/who do you use for interpretation? And how often do you need an interpreter in your job?
• If we just go move on to the second timepoint. The patient is sat with you, they're at their appointment, those sorts of issues that you just talked about, how do you now address these?
• How many patients choose to take sedation versus how many just go with - do you offer gas and air?
• What other issues do patients come to you with at their appointment, how do you try and reduce or address these in some way?
• How many patients bring a family member with them?
• Are there any other issues that arise?
• What about people's health in general and co-morbidities, how much is this a challenge for you?
• What sort of medical complications would result in patients not being fit for a colonoscopy?
• A CT Colonography (CTC) - Is that the consultants/endoscopists decision to make?
• ...and do you get many patients' asking for CTCs, wanting a CTC? If so, do they give you a reason why?
• How many patients come into you, saying 'I've got this letter, but actually, I want a CTC'?
• I've been speaking to some patients. Do patients ever have a preference and request that they want a morning or an afternoon appointment?
• Are patients ever worried about accidents enroute to the procedure given the bowel preparation laxative taken?
• Do you ever get anybody reaching out to you or the helpline on the day before with any issues? If so, what are these?
• Bowel Preparation- How many patients fail/aren’t successful with bowel prep?
• And what happens if the patient is there for their morning appointment and it’s not good, the bowel is not ready. What do you do?
• Do you ever get them to come back later in the day or and or is it a new appointment? What happens?
• What other issues do patients come to you with and what other problems do they have on the morning of the procedure?
• If people are delayed, can you still fit them in or is that a rescheduled appointment?
• So, on number six (timepoint). The patient rests and recovery, the day after. Can you just talk to me about that courtesy call and what you talk to them about?
• Do they ever ask you any questions on that courtesy phone call?
• And what sort of reactions do you get from patients, does it vary?
SUPPLEMENTARY TABLE 1: Barriers and facilitator codes and factors – frequency of quotes recorded by SSPs and patients.

<table>
<thead>
<tr>
<th>Barriers and facilitator code</th>
<th>Factors based on Kerrison et al. (2021b) framework</th>
<th>Barrier/ Facilitator or Both</th>
<th>Patient quotes (N)</th>
<th>SSP quotes (N)</th>
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<td>Sexual Abuse</td>
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<td>To get diagnosis/ treatment</td>
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<td>Indirect costs</td>
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</tr>
<tr>
<td>Transport / Travel (Covid)</td>
<td>COVID-Related</td>
<td>B</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Anger</td>
<td>Psychological</td>
<td>B</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Relaxation techniques</td>
<td>Psychological</td>
<td>F</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Option to stop the procedure at anytime</td>
<td>Sociocultural</td>
<td>F</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Unable to leave the house due to shielding</td>
<td>COVID-Related</td>
<td>B</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Covid immunity- Either by vaccine or prior infection</td>
<td>COVID-Related</td>
<td>F</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Clinically ineligible or inappropriate</td>
<td>Health-related</td>
<td>F</td>
<td>0</td>
<td>13</td>
</tr>
<tr>
<td>Pre-determined time and date for SSP appointment (on letter)</td>
<td>Practical</td>
<td>Both</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Letter phrasing</td>
<td>Sociocultural</td>
<td>Both</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Low health literacy</td>
<td>Psychological</td>
<td>B</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Patient given time to reconsider having a colonoscopy</td>
<td>Sociocultural</td>
<td>F</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Bodily exposure culturally taboo</td>
<td>Sociocultural</td>
<td>B</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Gender difficulties experienced with pain and discomfort</td>
<td>Health-related</td>
<td>B</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Transport provision</td>
<td>Practical</td>
<td>F</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Language barriers - Covid</td>
<td>COVID-Related</td>
<td>B</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Unable to get in contact with patients</td>
<td>Practical</td>
<td>B</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Reason</td>
<td>Category</td>
<td>B</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------</td>
<td>------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Letter contains too much information to read</td>
<td>Psychological</td>
<td>B</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Initial invitation not received</td>
<td>Practical</td>
<td>B</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Lack of information about duration of SSP Appointment</td>
<td>Practical</td>
<td>B</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>GP Recommendation</td>
<td>Sociocultural</td>
<td>F</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Follow-up letters to patients</td>
<td>Sociocultural</td>
<td>F</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Recent Colonoscopy</td>
<td>Health-related</td>
<td>B</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Unable to accept blood products for religious reasons</td>
<td>Sociocultural</td>
<td>B</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Existing health condition interfering with ability to do the bowel preparation</td>
<td>Health-related</td>
<td>B</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Forgotten about colonoscopy appointment</td>
<td>Practical</td>
<td>B</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Concerns about perforation and procedural risks</td>
<td>Psychological</td>
<td>B</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Travelling/ on holiday</td>
<td>Practical</td>
<td>B</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Stigma</td>
<td>Sociocultural</td>
<td>B</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>
SUPPLEMENTARY TABLE 1: A description of the Trust, Auditability, Credibility and Transferability (TACT) framework dimensions (Daniel, 2019) and how the current study applied these.

<table>
<thead>
<tr>
<th>TACT Dimension</th>
<th>Description of dimension.</th>
<th>How the dimensions were applied within the study.</th>
</tr>
</thead>
</table>
| Trustworthiness | * Rigour in the research process and the relevance, and confidence in the research.  
  * A systematic process in organising and analysing data.  
  * The degree of trust or confidence readers have in research findings.                                                                                                           | * The researchers demonstrated a systematic approach in the analysis of data. Charting ensured the primary researcher engaged systematically with every participant in relation to every code and facilitated all team members to engage in theme development.  
  * For reflexivity purposes a description of the research teams experience has been provided.                                                                                                                                                                                                                     |
| Auditability    | * The process of undertaking the research is fully documented and described.                                                                                                                                               | * Reporting of the study adhered to the COnsolidated criteria for REporting Qualitative (COREQ) guidelines (Tong et al., 2007). See supplementary file.                                                                                                                                                                                                                             |
| Credibility     | * Description of the researchers approach to the data analysis.  
  * The use of direct quotations.                                                                                                                                                                                      | * Two researchers initially independently developed ideas for codes using the same sample of 6 transcripts, and then through discussion agreed upon the working list of codes to use.  
  * Direct quotes were included throughout the results to illustrate findings and provide meaning.                                                                                                                                                                                                                |
| Transferability | * Ensuring that the content of the interviews, the behaviours, and observed events are typical or atypical of the lives of the participants                                                                                                                                      | * The study included data collection from patients and SSPs across multiple screening centres and geographical locations with varying levels of deprivation in England and had a good representation of male and female patients with varying levels of education attainment (see Table 1).                                                                                                                                              |
A.3 Appendix 1.3 – Chapter 4 Supplementary material

As predicted submission (#97222) on the 16th of May 2022.

1) Have any data been collected for this study already?
No, no data have been collected for this study yet.

2) What’s the main question being asked or hypothesis being tested in this study?
Research question:
Does providing additional and modified information to a current NHS Bowel Cancer Screening Programme (BCSP) letter inviting patients for follow-up colonoscopy, reduce participant self-reported state anxiety and increase behavioural intention levels to attend further medical tests?

Hypotheses:
1. Participants who receive the modified NHS BCSP invitation letter will self-report significantly lower levels of state anxiety compared to those participants who receive the existing NHS BCSP invitation letter.
2. Participants who receive the modified NHS BCSP invitation letter will self-report significantly higher levels of behavioural intention to attend further medical tests compared to those participants who receive the existing NHS BCSP invitation letter.
3. Participants who receive the modified NHS BCSP invitation letter will self-report significantly lower levels of concern regarding types of concern, such as pain and discomfort, the gender of the NHS staff performing the colonoscopy, and test invasiveness compared to those participants who receive the existing NHS BCSP invitation letter.

3) Describe the key dependent variable(s) specifying how they will be measured.
1. The Spielberger six-item short form state anxiety inventory (STAI-A:6) scale (Spielberger, 1992) will measure self-reported state anxiety levels rated on a 4-point Likert scale: Not at all, Somewhat, Moderately and Very much.
2. Self-reported levels of behavioural intention to attend further medical tests will be measured by 4 item statements rated on a 10-point Likert scale, ranging from strongly agree - 1 to strongly disagree - 10.
3. Eight types of concerns including pain and discomfort, test invasiveness, and being at risk of bowel cancer will be measured on a 7-point Likert scale ranging from 1- not at all to 7 - very much will be used.

4) How many and which conditions will participants be assigned to?
This study will use a between-subjects cross-sectional online survey design. Participants will be randomised (using the Qualtrics randomizer function) to receive and read one of two conditions:

The current NHS BCSP letter.
A modified version of the NHS BCSP letter.

5) Specify exactly which analyses you will conduct to examine the main question/hypothesis.
To examine whether significant differences in the dependent variables will be self-reported by participants who receive the modified NHS BCSP invitation letter compared to those participants who receive the existing NHS BCSP invitation letter, the following analysis will be undertaken.

1. A one-way analysis of variance (ANOVA) test will be carried out with level of state anxiety as the dependent variable and condition (current letter vs modified letter) as the between-participants factor.
2. A one-way ANOVA test will be carried out with level of behavioural intention as the dependent variable and condition (current letter vs modified letter) as the between-participants factor.
3. A multivariate analysis of variance (MANOVA) test will be carried out on eight dependent variables regarding the types of concern reported, with the condition (current letter vs modified letter) as the between-participants factor. A significant main effect will be followed up with univariate tests.

All analyses will be run with and without controlling for covariates (as appropriate), using analysis of covariance (ANCOVA) and multivariate analysis of covariance (MANCOVA) respectively.

6) Describe exactly how outliers will be defined and handled, and your precise rule(s) for excluding outliers.
Box plots will be used to identify potential outliers and any outliers will then be replaced with a score equal to the mean plus three SDs. The survey will include an attention check to identify respondents who are not engaged with the survey questions and allow researchers to screen them out prior to conducting analyses (Manioci & Rüger, 2014; Schmitt & Stoll, 1985). Therefore, the attention check must be completed by the participant for
the data to be included. 
To take part in the study participants must be 56-74 years old.
Little’s Missing Completely at Random (MCAR) test will be used to explore if data are missing at random.

7) How many observations will be collected or what will determine sample size? No need to justify decision, but be precise about exactly how the number will be determined.

Given there are no previous studies, the sample size calculation was informed by a related study that measured the effect social norm messages on screening intention for bowel scope (flexible sigmoidoscopy) (von Wagner et al., 2019). This study reported odds ratios of 2.383 and 5.343 for two messages compared to the control condition (Table 2). This translates into a Cohen’s $d$ of 0.239 and 0.462 respectively. Based upon the smaller effect size, the study was powered for ANCOVA and MANOVA using G*Power. The highest sample size has been taken, to ensure the study is powered for all outcomes. The analyses suggested a total sample size = 230. Then adding on 20 per condition (2 groups) to account for missing data and technical difficulties; the target sample size is $n = 270$.

8) Anything else you would like to pre-register? (e.g., secondary analyses, variables collected for exploratory purposes, unusual analyses planned?)

No.
The current NHS invitation letter for follow-up colonoscopy examination for bowel cancer detection.

22 October 2022
A Smith
Hembury House
Shobrooke
YY1 7TY
A183# 278/7/26
Dear A Smith

Thank you for returning your bowel cancer screening test kit. Your kit result shows that further tests are needed. Usually this result is not caused by cancer.

To get a diagnosis you may need an investigation called a colonoscopy. This is currently the best way of detecting bowel cancers. Of those people who have a screening colonoscopy, 9 out of 10 will not have bowel cancer. Colonoscopy does not just look for bowel cancer. It can also find polyps (clumps of cells). Polyps are not cancers but can sometimes develop into them. We can remove polyps during colonoscopy before they turn into cancer.

Before arranging a colonoscopy, we are inviting you to an appointment with a screening practitioner. You are welcome to bring a partner, family member or friend with you. The practitioner will explain colonoscopy and answer any questions you have. If you wish to go ahead and are fit to do so, we will then arrange an appointment for a colonoscopy examination at your local bowel cancer screening centre.

Your screening practitioner appointment (see enclosed map) has been booked for:
Date: Friday 9 December 2022 Time: 12:00
Location: Shobrooke Hospital

Please note, this appointment is for a consultation, not for a colonoscopy. Please bring all medication you are currently taking to this appointment.

This is the first available appointment date at the screening centre nearest to your home address. If this appointment is not convenient, please call the free helpline number at the top of this letter. Also call if you need additional help such as an interpreter (some NHS trusts require an NHS interpreter to be used). Please read the enclosed leaflet before your appointment.

We have told your GP that we have offered you a screening practitioner appointment.

Yours sincerely

Preview Signatory
The modified invitation letter for follow-up colonoscopy examination for bowel cancer detection.

NHS No: 999 000 5451

22 October 2022

A Smith

Hembury House
Shobrooke
YY1 7TY
A183# 278/7/26

Dear A Smith

Thank you for returning your bowel screening test kit. Your kit result shows that further investigations are needed.

What to do next:

To get a diagnosis you may need a colonoscopy. This is currently the best way to examine your bowel to detect abnormalities, irregularities, and bowel cancer. Of those people who have a colonoscopy, 9 out of 10 will not have bowel cancer.

Before arranging a colonoscopy, we are inviting you to an appointment with a screening practitioner. You are welcome to bring a partner, family member or friend with you. The practitioner will explain colonoscopy and answer any questions you have*.

Your Appointment:

Date: Friday 9 December 2022          Time: 12:00
Location: Shobrooke Hospital (See enclosed map)

Please note, this appointment is for a consultation, not for a colonoscopy. Please bring all medication you are currently taking to this appointment.

What to do if you cannot attend:

If this appointment is not convenient, please call the free helpline number at the top of this letter. Also call if you need additional help such as an interpreter (some NHS trusts require an NHS interpreter to be used).

Please read the enclosed leaflet before your appointment. We have told your GP that we have offered you a screening practitioner appointment.

Yours sincerely,

Preview Signatory

*Did you know?

1. A same-gender medical team can be arranged for your colonoscopy.

2. For those who are concerned about pain and discomfort, pain relief (known as sedation) can be given during your colonoscopy.

3. If you are uncomfortable for whatever reason in having a colonoscopy, alternative procedures can be discussed.

Your screening practitioner will be happy to discuss any needs or concerns you have during your appointment.
Questionnaire measures and scales

Q) Have you ever been invited for a colonoscopy? (For any medical reason)

- I have never been invited for a colonoscopy.
- I have previously been invited for a colonoscopy but did NOT attend.
- I have previously been invited for and have attended a colonoscopy.

Q) Imagine that you have just received this letter inviting you to attend a nurse appointment, to talk about having a colonoscopy. How do you feel right now, at this moment? There are no right or wrong answers. Give the answer which seems to describe your present feelings best.

<table>
<thead>
<tr>
<th></th>
<th>Not at all (1)</th>
<th>Somewhat (2)</th>
<th>Moderately (3)</th>
<th>Very much (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel calm (1)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I am tense (2)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel upset (3)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I am relaxed (4)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel content (5)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I am worried (6)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

Q) Continue to imagine that you have just received this letter inviting you to attend a nurse appointment, to talk about having a colonoscopy. To what degree would you be concerned about:

- Not at all
- Very much
<table>
<thead>
<tr>
<th>Concern</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain and discomfort ()</td>
<td></td>
</tr>
<tr>
<td>Embarrassment ()</td>
<td></td>
</tr>
<tr>
<td>Test Invasiveness ()</td>
<td></td>
</tr>
<tr>
<td>Being at a risk of bowel cancer ()</td>
<td></td>
</tr>
<tr>
<td>The bowel preparation (involves taking a laxative drink the day before to clear your bowel) ()</td>
<td></td>
</tr>
<tr>
<td>The gender of the NHS staff (Doctors/Nurses) performing the colonoscopy ()</td>
<td></td>
</tr>
<tr>
<td>Travel costs to get to and from the hospital ()</td>
<td></td>
</tr>
<tr>
<td>Getting time off work or time out from other commitments, such as childcare or carer duties to attend the appointment and colonoscopy. ()</td>
<td></td>
</tr>
</tbody>
</table>

Q) Would you have any other concerns? Please provide detail of any other concerns in the below box

______________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

Q) Imagine that you have just received this letter inviting you to attend a nurse appointment, to talk about having a colonoscopy. How will you respond?

Strongly DISAGREE   Strongly AGREE
<table>
<thead>
<tr>
<th>Statement</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>I will go to the nurse appointment ()</td>
<td></td>
</tr>
<tr>
<td>I want to go to the nurse appointment ()</td>
<td></td>
</tr>
<tr>
<td>I expect to go to the nurse appointment ()</td>
<td></td>
</tr>
<tr>
<td>I plan to go to the nurse appointment ()</td>
<td></td>
</tr>
</tbody>
</table>

Q) Please explain the reason for your answers provided to the previous question "How would you respond"?

________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________
As predicted submission (#122350) on the 20th of February 2023

Appendix 1.4 – Chapter 5 Supplementary material

This is an anonymised copy (without author names) of the pre-registration. It was created by the author(s) to use during peer-review. A non-anonymised version (containing author names) should be made available by the authors when the work it supports is made public.

1) Have any data been collected for this study already?
No, no data have been collected for this study yet.

2) What’s the main question being asked or hypothesis being tested in this study?
Research question: Does completing a health or values-based self-affirmation task before reading an information leaflet about bowel cancer screening reduce participant self-reported state anxiety, and increase message acceptance and behavioural intention levels to attend screening?

Primary Hypotheses:
(1) Participants who complete a health or values-based self-affirmation task before reading an information leaflet about bowel cancer screening will report lower levels of state anxiety and higher levels of message acceptance and behavioural intention, compared to those participants who do not complete a self-affirmation induction task (provided with usual care or an active control condition).
(2) The effectiveness of the self-affirmation interventions will be moderated by history of friends or family with bowel cancer, such that participants who have a history of friends or family with bowel cancer and who have affirmed health or values before reading an information leaflet about bowel cancer screening will report lower levels of anxiety, and higher levels of message acceptance and behavioural intention, compared to those with no history of friends or family with bowel cancer.

Secondary Hypotheses:
(3) Irrespective of the self-affirmation intervention, participants who have a history of friends or family with bowel cancer will report higher levels of anxiety, message acceptance and behavioural intention, compared to those with no history of friends or family with bowel cancer.

3) Describe the key dependent variable(s) specifying how they will be measured.
(1) State anxiety will be assessed using the Spielberger six-item short-form state anxiety inventory (STAI-6) scale (Spielberger, 1992). This scale measures state anxiety levels “right now, at this moment” on a 4-point Likert scale (not at all [0], somewhat [1], moderately [2], and very much [3]). A mean state anxiety score will be computed.
(2) Behavioural intention to take part in bowel cancer screening tests will be measured using a 4-point Likert scale (Definitely not; probably not; yes, probably; yes, definitely) in response to the question “...Will you do the test?” The phrasing and scale for this item has been taken from Kotur et al. (2022).

4) How many and which conditions will participants be assigned to?
This study will use a between-subjects cross-sectional online questionnaire design. Participants will be randomised (using the Qualtrics randomiser function) to receive and read one of four conditions:
1. Usual care control - no information/questions.
2. Active control questionnaire.
3. Values affirmation questionnaire.
4. Health affirmation questionnaire.

5) Specify exactly which analyses you will conduct to examine the main question/hypothesis.
A 2-way (4 x 3) Analysis of Variance (ANOVA) test will be carried out with self-affirmation condition (usual care control, active control, values affirmation, and health affirmation), and history of friends or family with bowel cancer condition (history, no history).
Analyses will be run to see whether a history of family and friends with bowel cancer moderates the relationship between the affirmation interventions (health and values) and message acceptance, anxiety, and behavioural intention.

All analyses will be run with and without controlling for covariates (as appropriate), using analysis of covariance (ANCOVA) respectively.

Several planned contrasts will group and compare the four conditions with one another individually and in combination, to consider the effects of the controls (usual care and active control) with the self-affirmation inductions individually and collectively (health and values-based questionnaire tasks).

Analysis of variance and regression tests will also be carried out to explore the moderating effect of self-esteem and spontaneous affirmation.

6) Describe exactly how outliers will be defined and handled, and your precise rule(s) for excluding observations.

Box plots will be used to identify potential outliers and any outliers will then be replaced with a score equal to the mean plus three SDs.

The questionnaire will include two attention checks to identify respondents who are not engaged with the questions and allow researchers to screen them out prior to conducting analyses (Maniaci & Ragge, 2014; Schmitt & Stuhls, 1985). Therefore, the attention checks must be completed by the participant for the data to be included.

To take part in the study participants must be 49 years old and have never been invited to take part in bowel cancer screening before. This participant age range may be increased to 45 – 49 years should uptake be an issue.

7) How many observations will be collected or what will determine sample size? No need to justify decision, but be precise about exactly how the number will be determined.

We referred to two meta-analyses, Good and Abraham (2007) a review of 46 tests measuring defensive responses, and Epton et al. (2014), a review of the impact of self-affirmation on health behaviour change. Based on effect sizes reported in these reviews ($f = .38$ and $f = .085$ retrospectively) we calculated a mean effect size of $f = .23$. A power analysis using G*Power determined 111 participants to provide power $>.80$. We then added 20 participants per condition to the total sample size to allow for failed attention checks or previous bowel cancer screening experience (both exclusion criteria), providing a target sample size of 291 participants.

8) Anything else you would like to pre-register? (e.g., secondary analyses, variables collected for exploratory purposes, unusual analyses planned?)

No.
NHS bowel cancer screening

Helping you decide

It is your choice whether to take part in bowel cancer screening. This leaflet aims to help you decide.

Why we offer bowel cancer screening

We offer screening to detect bowel cancer when it is at an early stage in people with no symptoms. This is when treatment is more likely to be effective. Screening can also find polyps. These are abnormal clumps of cells in the bowel. Polyps are not cancers but may develop into cancers over time. Polyps can be easily removed, which reduces the risk of bowel cancer developing.

Regular bowel cancer screening reduces the risk of dying from bowel cancer.

Who we invite

We offer bowel cancer screening using a home testing kit to everyone in England from the age of 60. Your GP practice gives us your contact details so please make sure they always have your correct name, date of birth and address. Many GPs also like to have your mobile number and email address.

We offer screening every 2 years between the ages of 60 and 74. We are gradually extending this age range, and people aged 56 are now being invited as part of this process. If you are over 74, you can ask for a kit every 2 years by calling our free helpline on 0800 707 60 60.

You may be asked to take part in a research project. Research helps the NHS improve bowel cancer prevention and treatment. You can choose whether to take part or not. Your choice will not affect your bowel cancer screening.

How the bowel works
The bowel is part of your digestive system. It takes nutrients and water from food and turns what is left into poo (also known as faeces, stools or bowel motions).

The colon and rectum make up the large bowel, and are part of the digestive system.

**Bowel cancer**

Bowel cancer is also known as colon, rectal or colorectal cancer. Sometimes the cells that make up the bowel grow too quickly and form a clump of cells known as a bowel polyp (some types of polyp are called an ‘adenoma’). Polyps are not bowel cancers, but they can sometimes change into a cancer over a number of years.

**Risks of developing bowel cancer**

Everyone, whatever your sex, is at risk of developing bowel cancer. Things that can increase your risk include:

- getting older (8 out of 10 people diagnosed with bowel cancer are over 60)
- not being active enough
- being overweight
- a diet high in red and processed meat and low in fibre, vegetables and fruits
- smoking
- drinking too much alcohol
- having type 2 diabetes
- having inflammatory bowel disease (ulcerative colitis or Crohn’s disease)
- a family history of bowel cancer

**How bowel cancer screening works**

We send you an invitation letter with information about bowel cancer screening. The information is to help you decide whether to take part. Then we send you a faecal immunochemical test, or ‘FIT kit’ for short. It detects blood in your poo (blood you would not notice by eye). We look for blood because polyps and bowel cancers
sometimes bleed. Finding blood doesn’t diagnose bowel cancer but it means you need further tests (usually a bowel examination).

Most people’s screening result shows they do not need any further tests.

Some people will need further tests. If this is the case for you, we will offer you an appointment to talk about having a colonoscopy. Colonoscopy looks at the inside of your bowel (see page 5). We use colonoscopy to find the source of the blood.

Reduce your risk of bowel cancer

Having bowel cancer screening reduces your risk of dying from bowel cancer by at least 25%.*

You can also reduce your risk of bowel cancer by:

- keeping physically active
- keeping a healthy weight
- eating plenty of fibre, for example choose wholegrain and wholemeal foods
- eating plenty of vegetables and fruit
- eating less red meat and especially less processed meat
- drinking less alcohol
- not smoking


Using the FIT kit

You use the FIT kit in the privacy of your home. It is a simple way to collect a tiny sample of poo. The kit is a small plastic bottle with a stick attached inside the lid. You use the stick to collect the sample, which you seal into the bottle. There are instructions with each kit. Once used, you post the kit in its prepaid packaging to a laboratory for processing. Using the kit takes just a few minutes and it is an easy and effective way to screen for early bowel cancer.

If you’re not sure whether you should use the kit, please call our free helpline on 0800 707 60 60 for advice. For example, if you have had surgery and have an artificial opening that allows poo from the bowel to pass into a bag (a stoma) then you might want to call us.
The FIT kit. Instructions for using the kit are inside the lid of the packaging. You can use a clean disposable container to collect your sample.

Bowel cancer screening results

You should receive a results letter within 2 weeks of sending in your sample. There are 2 possible results.

No further tests needed at this time

Most people (about 98 out of 100) have this result. It means that we did not find any blood in your sample, or only a tiny amount which is within the screening range.

This result does not guarantee that you do not have bowel cancer, or that it will never develop in the future. Being aware of the symptoms of bowel cancer is very important (see page 6). We will offer you bowel cancer screening again in 2 years’ time if you are under the age of 75.

Further tests needed

About 2 in every 100 people have this result. It means we found an amount of blood in your poo above the screening range.

This does not mean that you have cancer, but it does mean we will offer you an appointment to discuss having a colonoscopy. Several things can cause blood in poo, such as:

- haemorrhoids (piles)
- bowel polyps
- bowel cancer

Having further tests means we can look for the cause of the blood.
For 100 people getting their FIT kit results:

- 98 do not need further tests
- 2 will need further tests

What happens to samples after testing

Once we have analysed the FIT sample, we record the result onto a database and then destroy the test kit and contents.

We keep the database information so we can check you are treated correctly. We also use it to monitor the performance of the bowel cancer screening programme.

If you need further tests

1. We will offer you an appointment at a local screening centre (usually in a hospital). This is to discuss having a more detailed examination of your bowel (colonoscopy). The colonoscopy is to see if there is a problem that needs treatment.

   A specialist screening practitioner (SSP) will talk with you about your screening result and answer any questions you have. He or she will discuss colonoscopy with you, and check if you are fit enough for the procedure.

2. If you are fit for colonoscopy and want to go ahead with the examination, we will arrange an appointment for you. If we do not think you are fit enough for colonoscopy, we may offer you a different investigation such as a computerised tomography (CT) scan (sometimes called a ‘virtual colonoscopy’).

Colonoscopy

Only around 2 in 100 people who complete the FIT kit need a colonoscopy.

Colonoscopy looks at the lining of your large bowel. A colonoscopy specialist (usually a doctor or nurse) passes a thin flexible tube with a tiny camera attached (a colonoscope) into your back passage (rectum). They guide the colonoscope around your large bowel. If they find any polyps, they can usually remove them painlessly using a wire loop passed down the colonoscopy tube. They will check any removed polyps for cancer cells.

Colonoscopy is the best way to diagnose bowel cancer. For most people, colonoscopy is straightforward. But as with most medical procedures, complications
can happen. Data from the NHS Bowel Cancer Screening Programme shows that these complications include:

- a hole (perforation) in the bowel caused by the colonoscope (around 1 person in 1,700); around half of people with a perforation will need surgery to repair it
- heavy bleeding needing a transfusion (around 1 person in 2,400)

In rare cases, people have died following colonoscopy complications. However, the most recent published national colonoscopy audit recorded no deaths. The audit looked at 20,085 colonoscopies carried out for both screening and symptom investigations.*


For more information, you can read our leaflet about colonoscopy (see page 8).

Remember, most people who complete the FIT kit will **not** need a colonoscopy.

### Possible benefits and risks of bowel cancer screening

Being aware of the possible risks and benefits will help you decide whether or not to take part in bowel cancer screening.

#### Benefits

Bowel cancer screening:

- reduces your risk of dying from bowel cancer by at least 25%
- allows us to remove any polyps found during colonoscopy, which reduces your risk of developing bowel cancer
- can be completed at home in private

#### Risks

Bowel cancer screening might:

- cause complications, for example, during or after colonoscopy (see page 5)
- miss a cancer if it was not bleeding when you used the FIT kit

It is important to be aware of the symptoms of bowel cancer even if you have screening. If you do not need further tests after using the FIT kit this does not guarantee that you do not have bowel cancer, or that it will never develop in the future.

No screening test is completely effective. In bowel cancer screening this is because:

- a polyp or cancer can sometimes be missed if it was not bleeding when the screening test was taken (a ‘false negative’ result)
• bowel cancer may develop in between screening tests

**Bowel cancer symptoms**

Symptoms of bowel cancer include:

• blood in your poo (faeces)
• looser poo, pooing more often and/or constipation
• a pain or lump in your abdomen (tummy)
• feeling more tired than usual for some time
• losing weight for no obvious reason

Please remember that these symptoms do not necessarily mean that you have bowel cancer. But if you have any of these symptoms for 3 weeks or more, please speak with your GP. It is important to do this even if you have recently had bowel cancer screening and/or a colonoscopy.

Bowel cancer screening is not a test for symptoms.

**Treatment for bowel cancer**

A diagnosis of bowel cancer is unlikely. But if it does happen, we will refer you to a team of specialists who will look after you.

If the cancer is in a polyp removed during colonoscopy, regular check-ups may be all you need.

The main treatment for bowel cancer is surgery. In some cases, the specialists may offer you chemotherapy or radiotherapy.

Not all bowel cancers found at screening are curable. But for people who have bowel cancer found at its earliest stage, over 90% are still alive 5 years later.*


**Further support**

For more information about bowel cancer screening call our free helpline on 0800 707 60 60.
If you have hearing or speech difficulties, you can use the Relay UK service to contact us. Dial 18001 then 0800 707 60 60 from your textphone or the Relay UK app.

You can also:

• talk to your GP
• visit www.nhs.uk/bowel
• visit www.gov.uk and search for ‘bowel cancer screening’

If you are 75 or over and would like a FIT kit, please call our free helpline on 0800 707 60 60. You can ask for a kit every 2 years.

To read our leaflet about colonoscopy, visit:

Information for transgender and non-binary people about NHS population screening programmes is available at: www.gov.uk/government/publications/nhs-population-screening-information-for-transgender-people

Except where indicated, all statistics are from Public Health England (PHE).

An HTML version of this leaflet is available. You can view and download it in large print and use a screen reader for an audio version. Visit: www.gov.uk/phe/bowel-screening-leaflet

We can provide a braille version. Email: phe.screeninghelpdesk@nhs.net

More information

The NHS Screening Programmes use personal information from your NHS records to invite you for screening at the right time. NHS England also uses your information to ensure you receive high quality care and to improve the screening programmes. Find out more about how your information is used and protected, and your options, at www.gov.uk/phe/screening-data.

Find out how to opt out of screening at www.gov.uk/phe/screening-opt-out.

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SUPPLEMENTARY FILE 2:

Inferential statistics results

The effects of friends or family history with bowel cancer

A 2 (self-affirmations, controls) x 2 (history, no history of friends or family with bowel cancer) factorial ANOVA found no main effect of experimental condition, $F(1, 238) = 2.90, p = .090$, $\eta_p^2 = .01$, on state anxiety levels (self-affirmations: $M = 2.78$, $SE = .08$; controls: $M = 2.61$, $SE = .07$). However, there was no interaction effect between experimental condition and history of friends or family with bowel cancer, $F(1, 238) = 2.44, p = .120$, $\eta_p^2 = .01$, on state anxiety. There continued to be no main effect of experimental condition, $F(1, 237) = 2.90, p = .090$, $\eta_p^2 = .01$, on state anxiety. There continued to be no interaction effect between experimental condition and history of friends or family with bowel cancer and experimental condition, $F(1, 237) = .85, p = .357$, $\eta_p^2 = .00$, on state anxiety.

A 2 (self-affirmations, controls) x 2 (history, no history of friends or family with bowel cancer) factorial ANOVA found no main effect of experimental condition, $F(1, 238) = 2.54, p = .113$, $\eta_p^2 = .01$, on state anxiety levels (self-affirmations: $M = .82$, $SE = .08$; controls: $M = .99$, $SE = .07$). However, a main effect of history of friends or family with bowel cancer, $F(1, 238) = 5.77, p = .017$, $\eta_p^2 = .02$, was found on state anxiety, with anxiety significantly higher in those with a history of friends or family with bowel cancer ($M = 1.03$, $SE = .09$) than those with no history ($M = .78$, $SE = .05$). There was no interaction effect between experimental condition and history of friends and family with bowel cancer, $F(1, 238) = .83, p = .37$, $\eta_p^2 = .00$. When controlling for education there continued to be no main effect of experimental condition, $F(1, 237) = 2.45, p = .119$, $\eta_p^2 = .01$, on state anxiety. There continued to be a main effect of history of friends or family with bowel cancer, $F(1, 237) = 5.60, p = .019$, $\eta_p^2 = .02$, and no interaction effect between history of friends or family with bowel cancer and experimental condition, $F(1, 237) = .85, p = .357$, $\eta_p^2 = .00$, on state anxiety.
controlling for education there continued to be no main effect of experimental condition, $F(1, 237) = 3.01\ p = .084\ \eta_p^2 = .01$, and no main effect of history of friends or family with bowel cancer, $F(1, 237) = 2.32\ p = .129\ \eta_p^2 = .01$, and no interaction effect between history of friends or family with bowel cancer and experimental condition, $F(1, 237) = .00\ p = .998\ \eta_p^2 = .00$, on levels of behavioural intention.

A 2 (self-affirmations, controls) x 2 (history, no history of friends or family with bowel cancer) factorial ANOVA found no main effect of experimental condition, $F(1, 238) = .08\ p = .780\ \eta_p^2 = .00$, (self-affirmations: $M = 8.15\ SE = .12$; controls: $M = 8.11\ SE = .11$) and no main effect of history of friends or family with bowel cancer $F(1, 238) = .64\ p = .423\ \eta_p^2 = .00$ (history: $M = 8.19, SE = .14$; no history: $M = 8.07, SE = .07$) on message acceptance levels. There was also no interaction effect between experimental condition and history of friends and family with bowel cancer, $F(1, 238) = .09\ p = .763\ \eta_p^2 = .00$, on message acceptance. When controlling for education there continued to be no main effect of experimental condition, $F(1, 237) = .06\ p = .800\ \eta_p^2 = .00$, and no main effect of history of friends or family with bowel cancer, $F(1, 237) = .70\ p = .405\ \eta_p^2 = .00$, and no interaction effect between history of friends or family with bowel cancer and experimental condition, $F(3, 237) = .09\ p = .771\ \eta_p^2 = .00$, on levels of message acceptance.
Moderation Analysis - Spontaneous self-affirmation and trait self-esteem.

Moderator: SSA
Outcome variable: Anxiety

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Moderator: Spontaneous self-affirmation
Outcome variable: Behavioural Intention

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### Model Estimates

**Active control**

-0.69 0.43 -1.6 0.111 -1.53 0.16

**Values affirmation**

-0.58 0.43 -1.34 0.181 -1.52 0.13

**Non-active control**

-0.69 0.42 -1.66 0.098 -1.52 0.13

**Spontaneous self-affirmation**

-0.01 0.07 -0.11 0.911 -0.15 0.13

**Interaction: Active control X SSA**

0.13 0.09 1.35 0.179 -0.06 0.31

**Interaction: Values affirmation X SSA**

0.13 0.09 1.39 0.164 -0.05 0.32

**Interaction: Non-active control X SSA**

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**Moderator: SSA**

**Outcome variable: Message acceptance**

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Moderator: Self-esteem  
Outcome variable: Anxiety

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Moderator: Self-esteem  
Outcome variable: Behavioural Intention

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