Title Page

Title of the article: Patients' experience of using colonoscopy as a diagnostic test after a positive FOBT/FIT: a systematic review of the quantitative literature**.**

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Abstract

Objectives: Faecal occult blood testing (FOBT) and faecal immunochemical testing (FIT) are among the most used screening modalities for colorectal cancer (CRC). Colonoscopy is also widely used as a screening and diagnostic test for adults with a positive FOBT/FIT. Patient experience of colonoscopy is an important component for most CRC screening programmes. Individuals with negative experiences are less likely to engage with colonoscopy in the future and can deter others from attending colonoscopy when invited. This review synthesised data on patient experience with colonoscopy, following a positive result, to provide insights into how to improve patient experience within the English Bowel Cancer Screening Programme.

Methods: MEDLINE, EMBASE and PsychInfo were searched for quantitative questionnaire studies evaluating patient-reported experience with colonoscopy, following a positive screening FOB/FIT result. The search was limited to studies published between 2000-2021 (i.e. when the first FOBT/FIT screening programmes for CRC were introduced). Data-driven and narrative summary techniques were used to summarise the literature.

Results: In total, six studies from the United Kingdom (n=4), Spain (n=1) and the Netherlands (n=1) were included in the review (total participants: 152,329; response rate: 68.0-79.3%). Patient experiences were categorised into three 'stages': 'pre-colonoscopy', 'during the test', and 'post-colonoscopy'. Overall, patients reported a positive experience in all six studies. Bowel preparation was the most frequently endorsed issue experienced pre-test (experienced by 10.0% to 41.0% of individuals, across all studies), pain and discomfort for during the test (experienced by 10.0% to 21.0% of participants) and abdominal pain and discomfort after the test (these were experienced by 14.8%-22% of patients).

Conclusion: This review highlighted that patient-reported experiences associated with colonoscopy were generally positive. To improve the colonoscopy experience, bowel screening centres should investigate means to: make bowel preparation more acceptable, make colonoscopy less painful, and reduce post-colonoscopy symptoms.

Strengths and limitations of the study:

- This review focused on patients' experience with colonoscopy as a diagnostic test for those with a positive primary screening test, making the results highly specific and generalisable to the population in the context of organised screening.
- Multiple reviewers screened the papers for eligibility.
- The measures used across studies were heterogeneous, so conducting a metanalysis to synthesise the results was not possible.

Introduction:

The global incidence rate of colorectal cancer (CRC) is predicted to grow by 60%, with more than 2.2 million new cases and 1.1 million additional deaths by 2030 (1). Screening aims to discover signs of cancer early, before the appearance of any symptoms, when treatment is less invasive and more effective. Screening can also decrease CRC mortality by preventing cancer progression by removing precancerous polys (2).

There is significant evidence to support the implementation of organised CRC screening programmes (3). As a result, CRC screening is offered in many countries throughout Europe, Asia, America and Australia (4–6). Most offer eligible adults a home-based self-sampling kit (called a 'faecal occult blood test' [FOBT] or a 'faecal immunochemical test' [FIT]), which tests for the presence of blood in the stool. Patients who receive a positive result are then invited for a colonoscopy to determine the source of the bleeding (which is cancer in about 10% of cases – considerably higher than those referred via symptomatic pathways [about 8%]) (7,8).

The global target of CRC screening participation rate is 65% which is met in most European countries, and up to 74% in the United States (US) (9,10). However, participation in CRC screening is considerably lower compared with other cancer screening programmes, such as breast and cervical, both of which routinely achieve rates of over 70% (11). The efficacy of CRC screening is further reduced by non-attendance at colonoscopy, with between 10.0% to 30.0% of individuals, with an abnormal FIT/FOBT result, not attending (12). Some of the main reasons for not attending colonoscopy include previous negative experiences with colonoscopy, and hearing negative stories about the experiences of others (12,13)

As with many health services, patient experience is a primary quality indicator for colonoscopy, and the European Society of Gastrointestinal Endoscopy (ESGE) recommend that it should be consistently measured before, during and after the procedure (14). Doing so has been shown to confer several benefits, including sustaining quality assurance (QA) in healthcare service delivery and improved patient-reported outcomes (15). The latter is particularly important, given that positive experiences foster trust in health services more broadly, and patients with positive

experiences are more likely to return for colonoscopy if needed (13), and those with negative experiences often deter others from attending colonoscopy when invited (12).

In addition to hindering attendance, several studies have indicated that patients who undertake CRC screening experience anxiety, particularly those in which the colonoscopy is requested after an abnormal primary test, such as FOBT or FIT (13,16). Furthermore, invasive screening modalities, such as colonoscopy and computed tomographic Colonography (CTC) are considered painful, uncomfortable, and embarrassing. This perception hinders patient participation in screening programmes. Patient-reported experience measures have been developed from qualitative research, which identified the most pertinent elements of patient experience, including anxiety; irrational expectations regarding the procedure; information provision and communication; comfort; embarrassment & dignity (17–19).

Patient-reported experience covers not only the test itself, but the pre-test experience (e.g., satisfaction with the invitation letter, the stool test kit instruction, and transportation), the day of the test experience (e.g., pain and discomfort from colonoscopy), after the test experience (e.g., side-effects after colonoscopy).

Several reviews of patient-reported experiences of colonoscopy have been conducted; however, they often combine the perspectives of patients with those of healthcare professionals, making it difficult to determine the extent to which the results reflect the experiences of patients themselves (16,20). Others, meanwhile, have not been specific to the screening context, and have included patients' experiences from surveillance programmes, making it difficult to establish what factors are associated with experiences among adults undergoing colonoscopy as a diagnostic investigation following a positive screening result, specifically (21). Further, several reviews combined more than one test procedure (e.g. CT colonography) and did not focus on colonoscopy itself, or focused on colonoscopy as a primary screening test (22,23) / focused on patients' experience with the stool test and not the diagnostic test (5,24).

Previous research (e.g. Gupta at al., and Sarkar et al.), exploring patient experience with colonoscopy in the symptomatic and screening pathway suggests there are important differences in colonoscopy experience, according to the purpose and context. For example, Sarkar et al. (2012) found that bowel preparation outcomes between adults in the bowel cancer screening pathway were different to the

symptomatic pathway, with poorer experience reported in the symptomatic pathway. To date, however, no review has synthesised the data for colonoscopy as a follow-up test, independently.

The purpose of this review was to synthesise data on the experiences of patients undergoing colonoscopy following an abnormal primary test, independently of those available for health professionals / other contexts. The findings of the review will be used to inform policy recommendations for the delivery of colonoscopy, within FOBT / FIT-based screening programmes.

Methods:

Search strategy and type of studies:

This review included retrospective, prospective, and cross-sectional survey studies exploring the patient-reported experience of colonoscopy among asymptomatic FIT or FOBT positive patients.

To maximise the total literature retrieved, a comprehensive search strategy, which included subheadings, Mesh terms, and free text searching, was established and registered with PROSPERO (ref: CRD42022304598). The key terms used for this review were developed around the three key elements; Bowel cancer and colorectal neoplasms, early detection of cancer and screening (colonoscopy, FIT, FOBT) and patients experience (PROMS, PREMS, acceptability and satisfaction). Full details of the string and strategy are available in the Supplementary Table 1. The search was conducted in June 2020 and updated in June 2021. The search results were assessed and screened by title and abstract, then full-article assessment. Duplicates were removed during the title review process.

The search strategy was intended to detect published research. As per Cochrane guidelines, advice about which databases, and whether or not to include grey literature, was sought from a librarian (25). Grey literature was subsequently excluded, so as to decrease resource burden and, importantly, ensure the inclusion of accurate data. Three databases were searched (all in the OVID platform): Medline, PsycInfo

and Embase. In addition, hand searching of reference lists was performed for eligible papers.

Data collection and analysis:

Eligible studies were assessed using the Critical Appraisal Skills Programme (CASP) (26) tools for cross-sectional and cohort studies (see Supplementary Material). Each study was rated 'high', 'moderate' or 'low' quality according to eight assessment criteria. The scoring was performed by GK, followed by discussion with the research team to secure consensus.

Eligibility criteria:

Papers were eligible for inclusion if they: 1) measured at least one patient-reported outcome (defined as "direct reports from patients about how they function or feel regarding a health condition or its treatment"); (27), 2) were published from 2000 onwards (i.e. when FOBT and FIT-based CRC screening programmes first began to be implemented) and 3) were available in English. Papers were excluded if they: 1) were not patient-centred (e.g., reported alongside practitioners' views), 2) focused on colonoscopy for surgery or treatment (i.e. as opposed to follow-up for an abnormal bowel cancer screening result) and / or 3) evaluated cost-effectiveness. All studies identified by the search strategy were assessed for eligibility by GK, CVW and RK.

Data Synthesis and reporting:

Relevant data on patient experience were extracted and categorised as being related to either: pre-test aspects of the procedure, post-test aspects of the procedure, or related directly to the colonoscopy itself. Data synthesis and review extraction was written in line with PRISMA guidelines (see Supplementary Material). A narrative summary technique was used to assist the interpretation of the extracted study results. This approach allows conclusions to be taken, based on common factors across studies (28). The majority of the studies included Likert-type scales (ranging from Strongly Agree [SA], to Strongly Disagree [SD]) to measure the three stages of the experience. Their results are as proportions of those stating 'definitely yes' and 'probably yes'.

Patient and public involvement:

This study is a review of secondary analysis which involve patients' experience. Therefore, these patients cannot be identified, and no personal information is included in the review.

Results:

Description of studies:

165 studies were assessed for eligibility (Figure 1). Among those, 20 were identified as potentially relevant, based on title and abstract review. After considering the full text of these studies, six were determined to meet the eligibility criteria and were included in the review. All studies, originating from Europe, used prospective or cross-sectional designs and employed questionnaires to assess patient-reported outcomes in the context of FOBT or FIT-based CRC screening. Assessments were made up to 30 days after the initial test (29–31), the day after colonoscopy (32), and two weeks after the procedure (33)

<Figure 1 here>

Only one study from the included papers used FIT as a primary screening test (n=1,16.67%) (33); the remainder used FOBT (n=5, 83.33%) as a primary test. Most of the studies (n=4, 66.67%) were conducted in the United Kingdom, one was completed in Spain (n=1,16.67%) and one in the Netherlands (n=1,16.67%). Table 1 demonstrate an overview of the included studies. A summary of the included studies is available in the online Supplementary Table 2.

Table 1. An overview of the included studies							
Study	**Country**	**Age range**	**Gender ratio**	**Sample size**	**Screening test**	**Response rate**	**Study design (prospective, retrospective)**
Plumb, 2019	UK	60-74 years, mean 66.3 years	41.4% female	52,805 out of 67,114 returned a questionnaire	FOBT (first line) + CTC or Colonoscopy	79%	Retrospective analysis of patient experience postal questionnaires after 30 days
Buron, 2017	Spain	50-69 years	53.5%, female 46.5%, male	912 out of 1189 were included in the study	FOBT (First line test) + Colonoscopy	76.7%	Cross-sectional study of Telephone survey questionnaire)
Ghanouni, 2015	UK	60-74 years, mean 66.3	58.6 % male	50858 out of 64152 returned a questionnaire and were included in the study	FOBT (First line test) + Colonoscopy	79.3 %	questionnaires send to FOBT positive patients who undergo a colonoscopy after 30 days
Denters, 2012	The Netherlands	50–75 years, mean age was 63 years	53% were men.	373 FIT-positive persons underwent colonoscopy,and of these, 273 returned the questionnaire.	FIT (First line test) + Colonoscopy	73 %	Cohort study of data collected in the second round of the Dutch FIT-based CRC screening pilot from the population database. Patients were sent a postal questionnaire two weeks after colonoscopy
Gupta, 2012	UK	60–75 years, mean 60 years	57.5% men screening patients, (58%) men symptomatic patients	100 patients (50 routine diagnostic and 50 screening colonoscopies),	FOBT (First line test) + Colonoscopy	76% (42 in the BCSP group, and 34 in the diagnostic group).	data were collected prospectively and entered a national screening database. Positive FOBT Patients after their procedure at St mark hospital were given a questionnaire to complete at home
Sarkar, 2012	UK	18-69 years, screening mean, 65 years, Non-screening 65 years	Male from screening 63%, and 51% from the surveillance.	488/720 patients completed the study.	FOBT (First line test) + Colonoscopy screening and surveillance	68%	Retrospective study & telephone interview survey patient survey 30 days following their procedure

Half of the studies (n=3) were assigned a high score based on CASP quality ssessment criteria, and thus considered of high scientific quality (34–36).The remainder (n=3) were scored as being of moderate quality, based on the follow up for longitudinal studies and confounding factors criteria (29,30,33).

Purpose of studies:

The purpose of the included studies were to assess the psychological and physical experience of colonoscopy, from receiving the invitation letter, to preparing for the test, and from undergoing the procedure, to the post-test experience of symptoms, side effects and overall satisfaction with participating in the programme. Figure 2 summarises the range of patient reported outcomes measured in the papers included. Some specifics to note: Plumb et al. (2017) evaluated patient-reported outcomes for colonoscopy compared with Computed Tomography Colonography (CTC) (a less invasive procedure than colonoscopy), while Sarkar et al. (2012) and Gupta et al. (2011) compared outcomes between patients from the English Bowel Cancer Screening Programme (BCSP), with those referred via the symptomatic pathway (non-BCSP). Having this, Sarkar et al. included a wider age group of participants who performed a colonoscopy, whether from the screening programme or diagnosed participants. Table 2 presents all the outcome measures reported in the studies included.

Table 2. Outcomes measured across the included studies						
	Plumb, 2019	**Buron, 2017**	**Ghanouni, 2015**	**Denters, 2012**	**Gupta, 2012**	**Sarkar, 2012**
Pre-colonoscopy experience						
Satisfaction with information material (The invitation letter)	NT	✓	TNR	NT	✓	NT
Satisfaction with test kit instructions/ usage	ü	✓	TNR	NT	NT	NT
Satisfaction with communication of the risks of the diagnostic test	ü	NT	✓	TNR	✓	NT
Satisfaction with communication of the benefits of the diagnostic test	ü	NT	✓	NT	NT	NT
Satisfaction with helpline service	NT	✓	TNR	NT	NT	NT
Anxiety and disturbance in daily activities and sleep	NT	NT	NT	✓	✓	NT
Most important contributor to satisfaction	NT	NT	NT	✓	NT	NT
Demographic factors (Measured across the extracted outcomes)	✓ Gender, Age, Socioeconomic deprivation	✓ Gender, Age,	✓ Gender, Age, Socioeconomic deprivation	✓ Gender, Age,	NT	NT
Test experience						
Satisfaction with bowel preparation procedure /instructions	✓	✓	✓	✓	NT	✓
Pain/Discomfort	✓	✓	✓	✓	✓	✓
Use of sedation	✓	NT	✓	✓	✓	✓
Test stopped/paused	✓	NT	✓	NT	✓	NT
Privacy/ Respect maintained	✓	NT	✓	NT	✓	NT
Comprehension of results on the day of the appointment	Available in post-test	✓	TNR	✓	✓	NT
Satisfaction with results feedback and follow up	Available in post-test	✓	TNR	NT	✓	NT
Post-test experience						
Pain/Discomfort	✓	NT	✓	✓	NT	NT
Patient overall satisfaction experience/Expectation	NT	✓	NT	✓	NT	✓
Complications, adverse effects, and Daily restrictions	✓	NT	✓	✓	✓	✓
Comprehension of the results letter	✓	NT	NT	NT	✓	NT
Satisfaction With the result letter and follow-ups instructions	✓	NT	NT	✓	✓	NT
The total number of outcomes measure n=21						
proportion measured	12/20	8/20	9/20	10/20	12/20	5/20

✓ Outcome measured in the paper
NT Not Tested
TNR Tested Not Reported

<Figure 2 here>

Response rates:

The proportion of participants completing the patient reported experience assessment questionnaires ranged from 68.0% to 79.3%, as follows: 68.0% (29), 73.0% (33), 76.0%(30), 76.7 (31), 79.0% (32), and 79.3% (34).

The proportion of responders who were men and women varied between the studies. In general, the proportion of responders who were men was greater than women, except in one study, in which more women (54.5%) responded than men (35).

Demographic characteristics:

Out of six studies, four (66.67%) compared patient-reported experiences by gender, as identified by the participant, as well as age (31–34). Studies had more male participants than females (the range was from minimum to maximum of 53%- 63% of male participants). The participants' age ranged from 50-75 years old. The mean age of participants was 64.8 years old. Only three studies (50.0%), two conducted in the UK (32,34), and one in The Netherlands (33), considered participants' level of socioeconomic deprivation. None of the included studies compared patients' reported experiences between ethnic groups.

Outcome 1: pre-test experience

The pre-test experience included receiving the invitation letter to attending the colonoscopy procedure. As a result, the primary outcomes of this stage included: 'satisfaction with the information material' (n= 2, 33%) (30,35), 'satisfaction with the test kit' (instructions/ usage) (n=2,33%) (35,36), 'satisfaction with communication of the risks and benefits of colonoscopy' (n=3,50%) (30,34,36), and 'anxiety and disturbance in daily activities and sleep' (n=2, 33%)(30,33) (Table 2). The Supplementary Table 3 provide a summary of the patient-reported experience pre-colonoscopy procedure.

Satisfaction with the information material:

The studies by Buron et al. (2017) and Gupta et al. (2012), which examined participant satisfaction with the information about screening tests, found that people who participated in the programme were highly satisfied with the information material (a scale of 8.9 out of 10 and 98% were satisfied, respectively). A subgroup analysis, reported in Buron's study, revealed that people who did not attend their appointment were significantly more likely to report an incomplete understanding of the invitation letter than those who participated (38.9% vs 28%, p=0.001) (Supplementary Table 3).

Satisfaction with communication of the risks of colonoscopy:

The studies by Plumb et al., Ghanouni et al. and Gupta et al. also measured risk and benefit communication (Table 2). Both Plumb et al and Ghanouni et al. reported high satisfaction (95.7%). Plumb et al. (2019), found that patients receiving colonoscopy were significantly more likely to be satisfied with the communication of risks and benefits compared with those receiving CTC (95% of colonoscopy patients were satisfied compared with 86% of CTC patients; p<0.0001). In another study by Ghanouni et al. (2016), male participants were significantly more likely to report being satisfied with the communication of risks and benefits, than females (96% vs.95%; p<0.01). Gupta et al. which compared participants from the BCSP and non-BCSP pathway report the latter group not having an adequate explanation of the risk: 13% compared to 0% of participants in the non-BCSP, P=0.03 (30) (Supplementary Table 3).

Anxiety and disturbance in daily activities and sleep:

Finally, a study by Denters et al. (2012) reported disturbance in sleep and daily activities before colonoscopy (Table 2). They found that 125 of 273 (48%) participants did not experience any disturbance in daily activities, while 21% of participants (n=75) reported disturbance for half a day, 20% (n=75) for the entire day, and 13% (n=34) for more than a day before the procedure. Regarding sleep disturbance, the authors also reported that 33% of respondents reported sleep disturbance for one night before the procedure (Supplementary Table 3).

Outcome 2: Test experience

The second stage comprised the colonoscopy experience, from taking the bowel preparation, until being in the recovery room (Table 2). The Supplementary Table 4 includes a summary of the patient-reported experiences during the colonoscopy procedure.

The reported outcomes measured comprised ‘satisfaction with bowel preparation and instructions’ (n=5, 85.71%) (29,31–34), ‘discomfort’ (n=6,100%), and ‘comprehension of the results on the day of the appointment’ (n=6, 85.71%) (29–34).

Satisfaction with bowel preparation procedure /instructions:

The bowel preparation procedure was a common concern across all studies and was frequently reported as the worst aspect of the experience. For example, Denters et al. (2012) observed that most responders (82%) cited that the drinking of the bowel preparation was burdensome. The items ranged from 1-5 (1 = not at all, 5 = very, Mean: 2.87, Standard deviation: 1.28).

A slightly higher proportion of men (98%) and older responders (aged > 68-93 years) reported being satisfied with the bowel preparation, compared with women (97.7%) and younger individuals (aged 59-64 years old) (p=0.04). (34). Buron et al. found that younger women, aged 50-59, years were less likely to be satisfied and reported greater discomfort completing the bowel preparation than males the same age (60.7% of women aged 50-59 reported some or a lot of discomfort during preparation, compared with 39.4% of men the same age; p<0.001) (Burón *et al.*, 2017). Similarly, Denters et al. (2012) found that women were more likely to report discomfort from the effects of bowel preparation than men (mean discomfort scores were 1.73 and 1.39, respectively; p= 0.01). Denters et al., also measured the most burdensome experience of participating in the screening programme and found that the burden of drinking the

bowel preparation solution was endorsed most frequently? (n=148, 56%) followed by burden of abdominal complaints (n=53, 20%).

Sarkar et al. (2012) compared bowel preparation outcomes between adults in the BCSP pathway and symptomatic non-BCSP pathways and found that poor experience was reported more in non-BCSP patients than in BCSP patients (BCSP 5% vs. non-BCSP 17%; P <0.001). They suggested that the reason for this was the superior Quality standards within the BCSP, such as 'The Caecal intubation rate' (CIR) (99% vs. 91% respectively; p>0.001), which conceivably supports the notion of an 'elite tier' of endoscopists created for the programme.

Pain/Discomfort from colonoscopy:

Denters et al found that patients reported pain or discomfort from the colonoscopy procedure as the second most burdensome aspect of participating in the screening programme (20%, n=53) (33).

In Plumb et al's study, significantly more people undergoing CTC considered the test to be more uncomfortable than expected (n= 506/1,970, 25.7%); compared with colonoscopy users (10,705/50,975= 21.0%)(P<0.0001) (32).

Of the three studies that investigated pain and discomfort experience by gender (31,33,34), Ghanouni et al. found that women (25.1%) were more likely than men (18.0 %) to report unexpected discomfort (p<0.01). Buran et al., and Denters et al. found no significant differences between gender. Two studies found that adequate bowel preparation was associated with reduced odds of painful colonoscopy (29,33).

Ghanouni et al measured participants' level of deprivation, by using their postcode, and explored whether socioeconomic status was associated with test experience. They found that individuals in the most deprived group of postcodes were more likely to report unexpected discomfort than those in the more affluent groups of postcodes (low deprivation: n= 3880 (19.5%), medium deprivation: n=3878 (21.2%), high deprivation: n=2909 (23.0%; p<0.01). They also found that individuals in the most deprived group of postcodes were less likely to report sedation administration than

those in the least deprived groups of postcodes (Low deprivation: 81.2%, Medium deprivation: 79.0%, High deprivation: 75.8%, P<0.01) (34).

Satisfaction with results, feedback and follow up:

Four studies (66.67%) measured patients' assessment of the communication of the test result (30,33–35). Studies reported that 83.4-97% of patients understood what their results meant. When comparing BCSP participants and symptomatic patients, Gupta et al. (2015) found that BCSP participants were significantly more likely to report comprehension of the communication of the results than symptomatic patients (BCSP 97% vs symptomatic patients 64%, P<0.001) (Supplementary Table 4).

Outcome 3: Post-test experience:

The final stage focused on the post-procedure experience, which spanned the day after the test, until at least two weeks after, and examined pain and discomfort post-procedure (n=3, 50%) (33,34,36), as well as overall satisfaction (n=3, 50%) (29,33,35) and complications, side-effects and daily restrictions (n=5, 83.3%) (29,30,33,34,36) (Table 1). A summary of the data from each study is included in the Supplementary Table 5.

Pain and Discomfort post-procedure

Three studies (50%) reported patients' experience of pain and / or discomfort post-procedure. Abdominal complaints were the most frequently reported type of discomfort after colonoscopy. Two of the studies found that only a small proportion individuals (14.8%) experienced some pain and discomfort after the test (32,34). However, in one of the studies, 85% of participants reported at least some degree of pain, and 22% experienced a high level of pain (33).

Plumb et al. (2015) reported those who underwent a colonoscopy were more likely to report feeling more uncomfortable than expected compared with CTC (57% vs 26%, p= 0.001).

In one study, women were more likely to report higher pain and discomfort after going home than men (34). Ghanouni et al stated the proportion reporting post-procedure pain was 18.2% in women and 12.3% in men, and the odds for painful colonoscopy were increased in women (OR 1.70, 95%CI 1.62 to 1.80, p<0.01). Another study found

no difference between men and women (23), and the remaining studies did not measure gender differences.

Individuals in the most deprived group of postcodes also reported experiencing pain and discomfort after going home more frequently than individuals from the least deprived population. (16.1% vs. 13.6%, p=0.01 respectively) (34) .

Complications, adverse effects, and daily restrictions:

Perforation and post polypectomy bleeding were the two most frequently reported complications and side effects for the five studies that investigated them, even though they were proportionally rated very low by patients (29,30,33,34,36). Plumb et al. stated that, of 64,312 individuals, 683 had complications, and colonoscopy complications were more often recorded (compared with CTC), including 34 perforations, ten cardiac arrhythmias, and two respiratory arrests.

Ghanouni et al. reported that 7.6% of responders reported rectal bleeding after going home; women reported it significantly more often than men (6.8% vs 8.2%, p= 0.03). Furthermore, older patients were less likely to report rectal bleeding (65-68 years, 7.3%, and 69-93 years, 7.4%) than younger responders (59-64 years old, 8.0%, p= 0.01).

Denters et al. (2012) measured participants' daily restrictions and found that most responders (71%) could resume their normal activities after the procedure without any restrictions. However, 13% took half a day to return to their normal activities, 9% took them the entire day, and 7% took more than a day.

Finally, Gupta et al. (2015) compared complications between participants in the BCSP and diagnostic patients observed that none were reported in the BCSP participants, and ten complications were reported in diagnostic patients (eight post-polypectomy bleeding, one post-polypectomy syndrome, and one colonic perforation).

Patients' overall satisfaction: Experience/ Expectation

Half of the studies reported patients' overall experience and satisfaction with the screening programme (29,33,35) (Table 1). Denters et al. found that overall satisfaction was high (the mean score was 7.9 out of 10). In their study, Buron et al. asked participants to list the most satisfying aspect of the programme and the most where improvement is needed. 'Early cancer detection' was the most mentioned

positive aspect (n=478, 52.4%), followed by ‘the ease, convenience (n= 94, 10.3%), and speed of the screening process’ (n= 85, 9.3%). The least positive aspect for improvement was ‘colonoscopy preparation’ (n=33, 3.6%) and the ‘waiting time receiving results letter’ (n=22, 2.4%).

Discussion:

Summary of main findings

This review found that the most burdensome aspect of colonoscopy, offered to adults with a positive FOBT / FIT CRC screening result, is the bowel preparation. Importantly, this review also found that adequate bowel preparation is a pertinent and modifiable predictor for a less painful colonoscopy.

This review also found that pain and discomfort were frequently reported during and after the procedure, and that, women reported a higher degree of abdominal pain, more complications, and greater difficulty sleeping / longer day disturbance in the days before and after the procedure. This could be due to previously suggested reasons, such as the full colonic length being larger in women (37). Interestingly, this review found that more men responded to the questionnaires than women across the studies. This may be due to the fact that more men are invited for colonoscopy as more likely to have an abnormal result. Similarly, this review found that younger participants (less than the average age) reported more discomfort during and after the procedure, experienced more side effects, and had more difficulty getting back to their daily activities, compared with older participants.

One interesting finding by Ghanouni et al., was inadequate sedation among the socioeconomically disadvantaged population which might explain that highly deprived participants report experiencing greater pain and discomfort with colonoscopy. We think that potential reason may be related to work, travel, and finance. People who are more deprived might not have adequate support commuting to the hospital and back home, less likely to have salaried jobs, and therefore lose pay when taking time off. So, they need to go back to work and therefore, can’t be sedated.

More research is required to assess why less deprived participants experienced more discomfort and received less sedation in the screening programme.

Comparisons with the previous literature

When comparing our findings with previous reviews, there was similarity on many fundamental elements of patient reported experience of colonoscopy in CRC screening. For example, our findings on discomfort associated with bowel preparation support the results of previous reviews investigating patient experience with colonoscopy in other contexts (e.g. symptomatic setting) (12,22,38). Similarly, our review is consistent with other reviews, which have reported pain from colonoscopy to be a major issue of patient satisfaction (39–41). These findings are also aligned with the qualitative studies' exploring patient experience (19,42).

Importantly, our review is the first to show this to be the case in the context of colonoscopy as a follow-up test for positive FOBT / FIT-based CRC screening, and that women in particular are more likely to report discomfort and pain during and after colonoscopy, in this context. This is consistent with previous literature where women reported a higher level of pain and discomfort in other contexts (23,43–45). Our review is also the first to find that older participants are less likely to report pain and discomfort than younger participants, in the context of follow-up colonoscopy. This appears to contradict previous studies, where pain was reported to be more intense in older patients with previous colonoscopy experience (23). One possible explanation for this, is that, in contradictory studies, such as Bugajski's study, patricipants were offered three types of sedation: no sedation, benzodiazepine-opioid sedation (administered by endoscopist), or propofol sedation (administered by anaesthesiologist). The latter type was significantly associated with less painful colonoscopy; however, propofol cannot be offered to everyone since it is associated with complications, such as cardiovascular events, or pneumonia, which could put older participants at additional risk (23).

Implications for policy and future research:

There is a dearth of literature assessing patients' experience among seldom heard groups, such as ethnic minority groups, those with learning disabilities, and those experiencing homelessness. This will not allow us to conclude if health delivery inequalities were addressed among these populations. As a potential result, the data

may be skewed and cannot be used to reduce inequalities in patient experience for these groups. Further, advanced colonoscopy instruments are in the market now and, based on evidence, they have been linked with improved colonoscopy experience (46–48). Future research of these advanced instruments should be conducted to both enhance the quality of screening services and patients' experience of colonoscopy.

Pain from the procedure was reported quite often. Therefore, it is recommended for all bowel screening centres to focus on improved bowel preparation techniques and encourage participants to take bowel cancer preparation seriously and carefully to have more effective results with less painful experience of colonoscopy.

Women and younger adults were less satisfied with the experience than men and older participants in general. Research is now needed, therefore, to understand why younger adults and females experience more pain during / after colonoscopy, compared with their counterparts.

Strengths and limitations

This review has several limitations in the review itself on in the included studies. Over half of studies originated from UK, limiting the generalisability of findings to other settings. This may be because our search strategy was in line with the English National Bowel Screening Programme. We were interested in patients-reported experience of colonoscopy after a positive stool test, which excludes many other screening programmes. We chose this strategy as the experience of first line colonoscopy for an asymptomatic population at average risk is different to that for people whose CRC risk after an abnormal FOBT/FIT averages around 10%.

None of the papers reviewed reported differences by patient ethnicity, which would have provided better insight into any ethnic inequalities in screening experience; Another general shortcoming of the literature is that none of the studies assessed the extent to which pre-test experience was affected by potential access issues, relating to availability or affordability of private/public transport.

Half of the studies were of moderate quality, reducing the reliability of the results (Supplementary Table 6 for the CASP quality assessment tool). We did not include studies not available in English (meaning some relevant literature may have been excluded). Finally, it was not possible to conduct meta-analysis, due to the

heterogenicity of the reported outcomes, time assessment of the data, and the different design of the studies.

This review also has several strengths: 1) titles, abstracts and full papers were reviewed by two reviewers, minimising the likelihood that relevant peer-reviewed articles were excluded; 2) multiple databases were searched, again, minimising the likelihood that relevant peer-reviewed articles were excluded; 3) only peer-reviewed articles were reviewed, improving the reliability of data that were included.

Conclusion:

This systematic review of the literature highlighted patient-reported experiences, which were generally positive for the key outcomes of the review. Anxiety and sleep disturbance were often reported before the colonoscopy experience. Bowel preparation and discomfort during and after the test, with particular vulnerability in women and younger patients, were the most reported unsatisfactory colonoscopy experience. Bowel screening centres should encourage participants, particularly women, to adhere to bowel preparation guidelines for a better colonoscopy experience. Meaningful motivations were also reported from the literature, including a positive attitude to screening, and early detection of bowel cancer.

Figure 1. Search strategy and inclusion criteria

Figure 2: Patients'-reported experience outcome

Author's contribution:

GK**:** Conceptualization, Methodology, Writing - Original Draft, Writing - Review and Editing

RK: Supervision, Writing - Original Draft, Writing - Review and Editing and Visualisation

CW: Conceptualization, Methodology, Supervision, Writing- Review and Editing

YH: Supervision, Writing- Review and Editing

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N/A- This study is a systematic review. All data extracted are presented in tables.

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