BMJ Open

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

Ghalia Kayal [1], Robert Kerrison,[2] Yasemin Hirst,[3] Christian von Wagner [4]

To cite: Kayal G, Kerrison R, Hirst Y, *et al*. Patients' experience of using colonoscopy as a diagnostic test after a positive FOBT/FIT: a systematic review of the quantitative literature. *BMJ Open* 2023;**13**:e071391. doi:10.1136/bmjopen-2022-071391

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2022-071391).

Received 20 January 2023
Accepted 23 August 2023

[1]Department of Behavioural Science and Health, University College London, London, UK
[2]School of Health Science, University of Surrey, Guildford, UK
[3]Health Technology Assessment, University of Central Lancashire, Preston, UK
[4]Department of Epidemiology and Public Health, UCL, London, UK

Correspondence to
Ghalia Kayal;
ghalia.kayal.19@ucl.ac.uk

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 PsycINFO 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 and 2021 (ie, 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 UK (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 10.0–41.0% of individuals, across all studies), pain and discomfort for during the test (experienced by 10.0–21.0% 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 THIS 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 meta-analysis 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 polyps.[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 USA.[9 10] However, participation in CRC screening is considerably lower compared with other cancer screening programmes, such as breast cancer and cervical cancer, 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% and 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 recommends 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 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 CT 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 and dignity.[17–19]

Patient-reported experience covers not only the test itself, but the pre-test experience (eg, satisfaction with the invitation letter, the stool test kit instruction and transportation), the day of the test experience (eg, pain and discomfort from colonoscopy), after the test experience (eg, 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 (eg, CTC) 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 (eg, Gupta *et 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, Medical Subject Headings 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 (Patient Reported Outcome Measures (PROMs), Patient Reported Experience Measure (PREMs), acceptability and satisfaction). Full details of the string and strategy are available in the online supplemental 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 online supplemental 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 (ie, 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 (eg, reported alongside practitioners' views), (2) focused on colonoscopy for surgery or treatment (ie, 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 Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (see online supplemental 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, to strongly disagree) 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 involves patients' experience. Therefore, these patients cannot be identified, and no personal information is included in the review.

RESULTS

Description of studies

One hundred and sixty-five 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 30–32] the day after colonoscopy and 2 weeks after the procedure[33]

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 UK, one was completed in Spain (n=1, 16.67%) and one in the Netherlands (n=1, 16.67%). Table 1 demonstrates an overview of the included studies. A summary of the included studies is available in the online supplemental table 2.

Half of the studies (n=3) were assigned a high score based on CASP quality assessment criteria, and thus considered of high scientific quality.[29 34 35] The remainder (n=3) were scored as being of moderate quality, based on the follow-up for longitudinal studies and confounding factors criteria.[30 31 33]

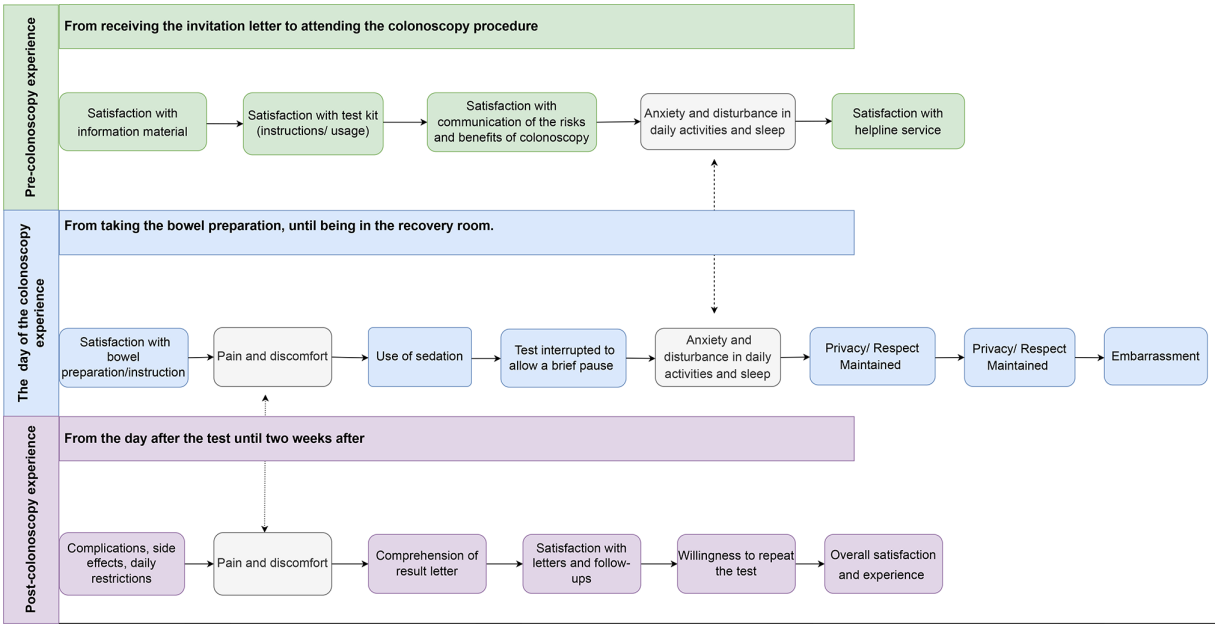


Figure 1 Search strategy and inclusion criteria.

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, 2017	UK	60–74 years, mean 66.3 years.	41.4% female.	52 805 out of 67 114 returned a questionnaire.	FOBT (first-line test) + CTC or colonoscopy.	79%	Retrospective analysis of patient experience postal questionnaires after 30 days.
Burón, 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 years.	58.6% male.	50,858 out of 64,152 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 63 years.	53% were male.	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 2 weeks after colonoscopy.
Gupta, 2012	UK	60–75 years, mean 60 years.	57.5% male screening patients, (58%) male 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 and telephone interview survey patient survey 30 days following their procedure.

BCSP, bowel cancer screening programme; CTC, CT colonography; FIT, faecal immunochemical test; FOBT, faecal occult blood test.

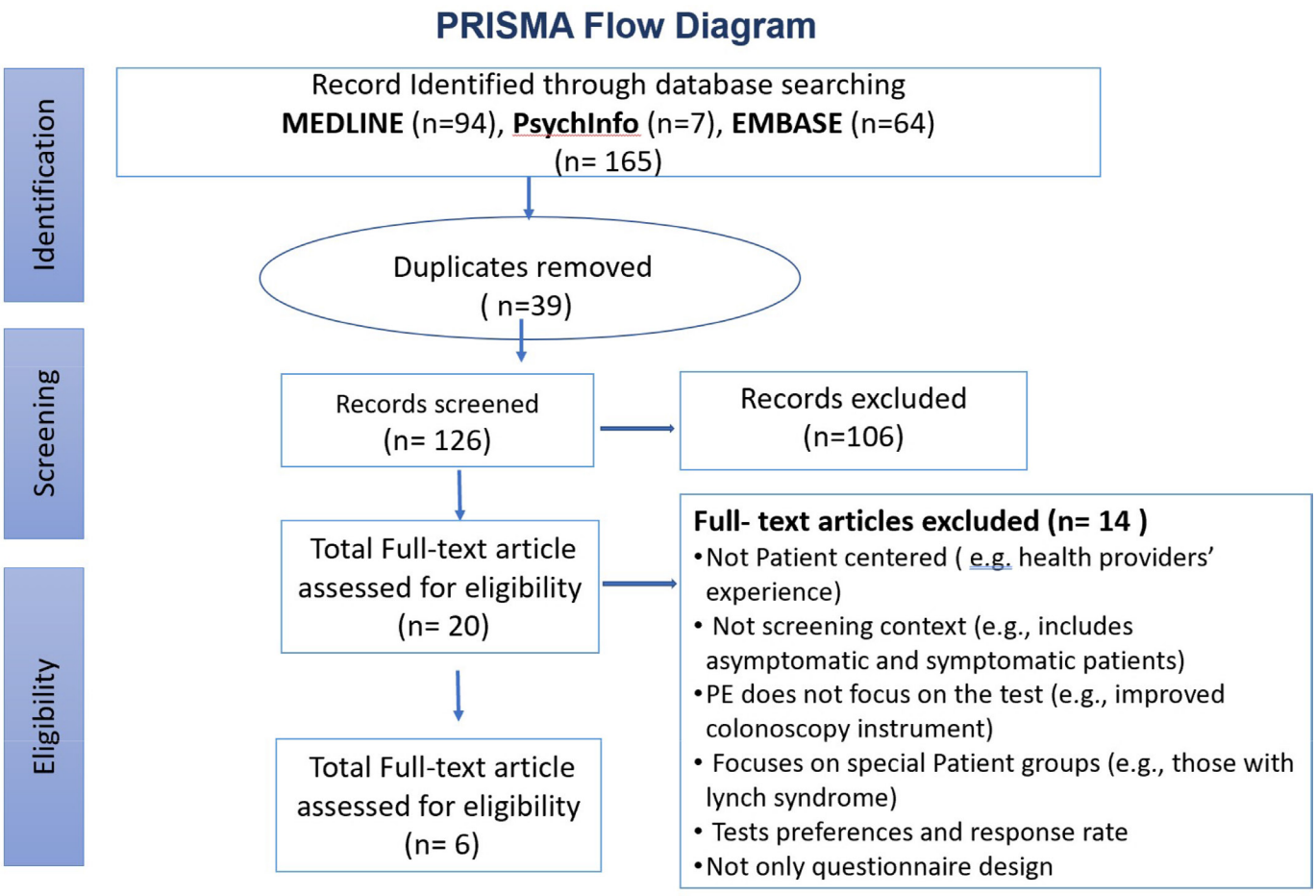


Figure 2 Patients' reported experience outcome. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses. PE, Patient Experience.

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)[29] evaluated patient-reported outcomes for colonoscopy compared with CTC (a less invasive procedure than colonoscopy), while Sarkar *et al*[30] and Gupta *et al* (2011)[31] 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.

Response rates

The proportion of participants completing the patient-reported experience assessment questionnaires ranged from 68.0% to 79.3%, as follows: 68.0%,[30] 73.0%,[33] 76.0%,[31] 76.7,[32] 79.0%[29] 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 studies (66.67%) compared patient-reported experiences by gender, as identified by the participant, as well as age. [29 32–34] Studies had more male participants than females (the range was from minimum to maximum of 53% to 63% of male participants). The participants' age ranged from 50 to 75 years old. The mean age of participants was 64.8 years old. Only three studies (50.0%), two conducted in the UK,[2934] 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 attend the colonoscopy procedure. As a

Table 2 Outcomes measured across the included studies

	Plumb, 2017	Burón, 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.

result, the primary outcomes of this stage included: 'satisfaction with the information material' (n=2, 33%),[31 35] 'satisfaction with the test kit' (instructions/usage) (n=2, 33%),[29 35] 'satisfaction with communication of the risks and benefits of colonoscopy' (n=3, 50%)[29 31 34] and 'anxiety and disturbance in daily activities and sleep' (n=2, 33%)[31 33] (table 2). The online supplemental table 3 provides a summary of the patient-reported experience pre-colonoscopy procedure.

Satisfaction with the information material

The studies by Burón *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 Burón'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) (online supplemental 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* (2017), 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 with 0% of participants in the non-BCSP, p=0.03[31] (online supplemental 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 (online supplemental 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 online supplemental 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 30 32–34] 'discomfort' (n=6, 100%) and 'comprehension of the results on the day of the appointment' (n=6, 85.71%).[29 30–34]

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 to 5 (1=not at all, 5=very, mean: 2.87, SD: 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]. Burón *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 men 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)[32] . 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 the burden of abdominal reports (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' (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=506/1970, 25.7%); compared with colonoscopy users (10 705/50 975=21.0%) (p<0.0001).[29 32]

Of the three studies that investigated pain and discomfort experience by gender,[32–34] 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.[30 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.[31 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) (online supplemental 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 2 weeks after and examined pain and discomfort post-procedure (n=3, 50%),[29 33 34] as well as overall satisfaction (n=3, 50%)[30 33 35] and complications, side effects and daily restrictions (n=5, 83.3%)[29–31 33 34] (table 1). A summary of the data from each study is included in the online supplemental table 5.

Pain and discomfort post-procedure

Three studies (50%) reported patients' experience of pain and/or discomfort post-procedure. Abdominal problems were the most frequently reported type of discomfort after colonoscopy. Two of the studies found that only a small proportion of individuals (14.8%) experienced some pain and discomfort after the test.[2934] 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* (2017) 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.[29–31 33 34] 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, 10 cardiac arrhythmias and 2 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 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 10 complications were reported in diagnostic patients (8 post-polypectomy bleeding, 1 post-polypectomy syndrome and 1 colonic perforation).

Patients' overall satisfaction: experience/expectation

Half of the studies reported patients' overall experience and satisfaction with the screening programme[30 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, Burón *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.[36] 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 they are 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 reasons 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, cannot 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 (eg, symptomatic setting).[12 22 37] Similarly, our review is consistent with other reviews, which have reported pain from colonoscopy to be a major issue of patient satisfaction.[38–40] These findings are also aligned with the qualitative studies' exploring patient experience.[19 41]

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 42–44] 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, participants 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.[45–47] 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 women experience more pain during/after colonoscopy, compared with their counterparts.

Strengths and limitations

This review has several limitations in the review itself and in the included studies. Over half of studies originated from the 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 (online supplemental 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.

Twitter Robert Kerrison @RobertSKerrison and Yasemin Hirst @maryyasemin

Contributors GK: Conceptualisation, Methodology, Writing—Original Draft, Writing—Review and Editing, and Guarantor . RK: Supervision, Writing—Original Draft, Writing—Review and Editing and Visualisation. CvW: Conceptualisation, Methodology, Supervision, Writing—Review and Editing. YH: Supervision, Writing—Review and Editing.

Funding This work was supported by Princes Nora University, which is under the government of Saudi Arabia's educational sponsorship scheme. Robert S Kerrison is supported by a Cancer Research UK Population Research Fellowship (C68512/A28209).

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data sharing not applicable as no data sets generated and/or analysed for this study. All data relevant to the study are included in the article or uploaded as supplementary information. Not applicable. This is a review study. So we used secondary data, and all the articles included are publicly available.

ORCID iDs
Ghalia Kayal http://orcid.org/0000-0002-6803-5416
Christian von Wagner http://orcid.org/0000-0002-7971-0691

REFERENCES

1 Arnold M, Sierra MS, Laversanne M, *et al*. Global patterns and trends in colorectal cancer incidence and mortality. *Gut* 2017;66:683–91.
2 Power E, Miles A, von Wagner C, *et al*. Uptake of colorectal cancer screening: system, provider and individual factors and strategies to improve participation. *Future Oncol 5(9)* 2009.
3 Hewitson P, Glasziou P, Watson E, *et al*. Cochrane systematic review of colorectal cancer screening using the fecal occult blood test (Hemoccult): an update. *Am J Gastroenterol* 2008;103:1541–9.
4 Săftoiu A, Hassan C, Areia M, *et al*. Role of gastrointestinal endoscopy in the screening of digestive tract cancers in Europe: european society of gastrointestinal endoscopy (ESGE) position statement. *Endoscopy* 2020;52:293–304.
5 Pham R, Cross S, Fernandez B, *et al*. Finding the right FIT": rural patient preferences for fecal Immunochemical test (FIT) characteristics. *J Am Board Fam Med* 2017;30:632–44.
6 Brown LJ, Roeger SL, Reed RL. Patient perspectives on colorectal cancer screening and the role of general practice. *BMC Fam Pract* 2019;20:109.
7 West NJ, Poullis AP, Leicester RJ. The NHS bowel cancer screening programme - A realistic approach with additional benefits. *Colorectal Dis* 2008;10:708–14.
8 Wardle J, Robb K, Vernon S, *et al*. Screening for prevention and early diagnosis of cancer. *Am Psychol* 2015;70:119–33.
9 Europe DC. Colorectal screening in Europe saving lives and saving money. 2019. Available: https://www.jnjmedicaldevices.com/sites/default/files/user_uploaded_assets/pdf_assets/2019-09/118262-190709 EMEA DiCE White Paper Colorectal Screening in Europe %281%29.pdf
10 CDC. Use of colorectal cancer screening tests, Available: https://www.cdc.gov/cancer/colorectal/statistics/use-screening-tests-BRFSS.htm [Accessed 21 Jun 2023].
11 Wardle J, Williamson S, McCaffery K, *et al*. Increasing attendance at colorectal cancer screening: testing the efficacy of a mailed, psychoeducational intervention in a community sample of older adults. *Health Psychology* 2003;22:99–105.
12 Kerrison RS, Sheik-Mohamud D, McBride E, *et al*. Patient barriers and facilitators of colonoscopy use: a rapid systematic review and thematic synthesis of the qualitative literature. *Prev Med* 2021;145:106413.
13 Kerrison RS, Travis E, Dobson C, *et al*. Barriers and facilitators to colonoscopy following fecal immunochemical test screening for colorectal cancer: a key informant interview study. *Patient Educ Couns* 2022;105:1652–62.
14 Kaminski MF, Thomas-Gibson S, Bugajski M, *et al*. Performance measures for lower gastrointestinal endoscopy: a European society of gastrointestinal endoscopy (ESGE) quality improvement initiative. *UEG Journal* 2017;5:309–34.
15 Valori R, Sint Nicolaas J, de Jonge V. Quality assurance of endoscopy in colorectal cancer screening. *Best Pract Res Clin Gastroenterol* 2010;24:451–64.
16 Brotons A, Guilabert M, Lacueva FJ, *et al*. The colonoscopy satisfaction and safety questionnaire (CSSQP) for colorectal cancer screening: a development and validation study. *Int J Environ Res Public Health* 2019;16:392.
17 Neilson LJ, Sharp L, Patterson JM, *et al*. The Newcastle ENDOPREM: a validated patient reported experience measure for gastrointestinal endoscopy. *BMJ Open Gastroenterol* 2021;8:e000653.
18 Mikocka-Walus AA, Moulds LG, Rollbusch N, *et al*. It's a tube up your bottom; it makes people nervous": the experience of anxiety in initial colonoscopy patients. *Gastroenterol Nurs* 2012;35:392–401.
19 Von Wagner C, Knight K, Halligan S, *et al*. Patient experiences of colonoscopy, barium enema and CT colonography: a qualitative study. *Br J Radiol* 2009;82:13–9.
20 Lim KT, Ng CH, Decruz GM, *et al*. Barriers and facilitators towards colonoscopy: a qualitative systematic review. *Eur J Cancer Prev* 2021;30:232–8.
21 Rosvall A, Annersten Gershater M, Kumlien C, *et al*. Patient-reported experience measures for colonoscopy: a systematic review and meta-ethnography. *Diagnostics (Basel)* 2022;12:242.

22 McLachlan SA, Clements A, Austoker J. Patients' experiences and reported barriers to colonoscopy in the screening context-A systematic review of the literature. *Patient Educ Couns* 2012;86:137–46.
23 Bugajski M, Wieszczy P, Hoff G, *et al*. Modifiable factors associated with patient-reported pain during and after screening colonoscopy. *Gut* 2018;67:1958–64.
24 Clarke N, Sharp L, Osborne A, *et al*. Comparison of uptake of colorectal cancer screening based on fecal Immunochemical testing (FIT) in males and females: A systematic review and meta-analysis. *Cancer Epidemiol Biomarkers Prev* 2015;24:39–47.
25 Patrick DL, Guyatt GH. Outcomes. In: SG JPH, ed. *Cochrane Handbook for Systematic Reviews of Interventions: Cochrane Book Series. The Cochrane Collaboration*. 2008: 531–45.
26 Critical Appraisal Skills Programme. CASP checklist. cohort study [Internet] [1-7]. 2018. Available: http://www.casp-uk.net/casp-tools-checklists
27 Rees CJ, Trebble TM, Von Wagner C, *et al*. British society of gastroenterology position statement on patient experience of GI endoscopy. *Gut* 2020;69:1.
28 Jahan N, Naveed S, Zeshan M, *et al*. How to conduct a systematic review: a narrative literature review. *Cureus* 2016;8:e864.
29 Plumb AA, Ghanouni A, Rees CJ, *et al*. Patient experience of CT colonography and colonoscopy after fecal occult blood test in a national screening programme. *Eur Radiol* 2017;27:1052–63.
30 Sarkar S, Athwal V, Sturgess RP, *et al*. The effect of high quality assurance measures in bowel cancer screening on patient satisfaction of colonoscopy. *J Gastrointest Liver Dis* 2012;21:251–8.
31 Gupta S, Saunders BP, Fraser C, *et al*. The first 3 years of national bowel cancer screening at a single UK tertiary centre. *Colorectal Disease* 2012;14:166–73.
32 Burón A, Grau J, Andreu M, *et al*. Colorectal cancer early screening program of Barcelona, Spain: indicators of the first round of a program with participation of community pharmacies. *Medicina Clínica (English Edition)* 2015;145:141–6.
33 Denters MJ, Deutekom M, Bossuyt PM, *et al*. Patient burden of colonoscopy after positive fecal immunochemical testing for colorectal cancer screening. *Endoscopy* 2013;45:342–9.
34 Ghanouni A, Plumb A, Hewitson P, *et al*. Patients' experience of colonoscopy in the English bowel cancer screening programme. *Endoscopy* 2016;48:232–40.
35 Burón A, Posso M, Sivilla J, *et al*. Analysis of participant satisfaction in the Barcelona colorectal cancer screening programme: positive evaluation of the community pharmacy. *Gastroenterología y Hepatología (English Edition)* 2017;40:265–75.
36 Saunders BP, Williams CB. Premedication with intravenous antispasmodic speeds colonoscope insertion. *Gastrointest Endosc* 1996;43:209–11.
37 Dyer KE, Shires DA, Flocke SA, *et al*. Patient-reported needs following a referral for colorectal cancer screening. *Am J Prev Med* 2019;56:271–80.
38 Goel V, Gray R, Chart P, *et al*. Perspectives on colorectal cancer screening: a focus group study. *Health Expect* 2004;7:51–60.
39 de Wijkerslooth TR, de Haan MC, Stoop EM, *et al*. Burden of colonoscopy compared to non-cathartic CT-colonography in a colorectal cancer screening programme: randomised controlled trial. *Gut* 2012;61:1552–9.
40 Niv Y, Bogolavski I, Ilani S, *et al*. Impact of colonoscopy on quality of life. *Eur J Gastroenterol Hepatol* 2012;24:781–6.
41 Neilson LJ, Patterson J, von Wagner C, *et al*. Patient experience of gastrointestinal endoscopy: informing the development of the newcastle ENDOPREM™ . *Frontline Gastroenterol* 2020;11:209–17.
42 Murphy G, Devesa SS, Cross AJ, *et al*. Sex disparities in colorectal cancer incidence by anatomic Subsite, race and age. *Int J Cancer* 2011;128:1668–75.
43 von Wagner C, Baio G, Raine R, *et al*. Inequalities in participation in an organized national colorectal cancer screening programme: results from the first 2.6 million invitations in England. *Int J Epidemiol* 2011;40:712–8.
44 Ogedegbe G, Cassells AN, Robinson CM, *et al*. Perceptions of barriers and facilitators of cancer early detection among low-income minority women in community health centers. *J Natl Med Assoc* 2005;97:162–70.
45 Bevan R, Ngu WS, Saunders BP, *et al*. The ADENOMA study. Accuracy of detection using endocuff vision™ optimization of mucosal abnormalities: study protocol for randomized controlled trial. *Endosc Int Open* 2016;4:E205–12.
46 Ngu WS, Bevan R, Tsiamoulos ZP, *et al*. Improved ADENOMA detection with endocuff vision: the ADENOMA randomised controlled trial. *Gut* 2019;68:280–8.
47 Groth S, Rex DK, Rösch T, *et al*. High cecal intubation rates with a new computer-assisted colonoscope: a feasibility study. *Am J Gastroenterol* 2011;106:1075–80.

Appendices for systematic review study

1.1 Supplementary Table 1 A: Search Strategy for systematic review study: Database(s): Ovid MEDLINE(R) 2000 to June, 2021

#	Searches	Results
1	Colorectal Neoplasms/	110010
2	bowel cancer.mp.	2377
3	1 or 2	111517
4	bowel cancer screening.mp.	562
5	"Early Detection of Cancer"/	37516
6	4 or 5	37775
7	Colonoscopy/	31298
8	FIT.mp.	157988
9	f?ecal immunochemical test*.mp.	1855
10	FOBT.mp.	1482
11	7 or 8 or 9 or 10	189625
12	Patient* experience*.mp.	77706
13	Patient reported outcome measures.mp.	20030
14	PROMs.mp.	4844
15	PREMs.mp.	234
16	Acceptability.mp.	52747
17	Patient Satisfaction/	89442
18	12 or 13 or 14 or 15 or 16 or 17	230496
19	3 and 6 and 11 and 18	94

1.2 Supplementary Table 1B: Search Strategy for systematic review study: Database(s): APA PsycInfo 2000 to June 2021

#	Searches	Results
1	colorectal cancer.mp.	3060
2	bowel cancer.mp.	123
3	1 or 2	3131
4	bowel cancer screening.mp.	56
5	early detection of cancer.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	1773
6	4 or 5	1808
7	colonoscopy.mp.	789
8	FIT.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	67975
9	f?ecal immunochemical test*.mp.	99
10	FOBT.mp.	212
11	7 or 8 or 9 or 10	68821
12	Patient* experience*.mp.	10786
13	Patient reported outcome measures.mp.	1622
14	PREMs.mp.	38
15	PROMs.mp.	425
16	Acceptability.mp.	18688
17	Patient* Satisfaction*.mp.	14896
18	12 or 13 or 14 or 15 or 16 or 17	44163
19	3 and 6 and 11 and 18	7

1.3 Supplementary Table 1C: Search Strategy for systematic review study: Database(s): Embase 2000 to June 2021

#	Searches	Results
1	colorectal neoplasms/	16540
2	bowel cancer.mp.	4253
3	1 or 2	20609
4	colorectal cancer/ or bowel cancer screening.mp.	191149
5	early cancer diagnosis/	13274
6	4 or 5	203544
7	colonoscopy/	102840
8	FIT.mp.	203861
9	f?ecal immunochemical test.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]	2545
10	FOBT.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]	2930
11	7 or 8 or 9 or 10	305143
12	patient* experience*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]	133719
13	patient reported outcome measures.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]	13671
14	PROMs.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]	7499
15	PREMS.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]	418

16	acceptability.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]	68172
17	patient satisfaction/	168996
18	12 or 13 or 14 or 15 or 16 or 17	372880
19	3 and 6 and 11 and 18	64

Results Tables

Supplementary Table 2: Overview of studies

Author/ country	Sample characteristics	Type of screening	Timing of patient-reported assessment	Outcome 1 Pre-test experience	Outcome 2 Test experience	Outcome 3 Post-test experience	Demographic factors & additional information
Plumb et al, 2019, UK	-Sample size: 52,805. -Response rate: 79%. -Gender ratio: female 41.4%. -Age (min max, average) 60-74, mean 66.3. -Ethnicity: Not given. -Deprivation: median deprivation = 42nd percentile.	-FOBt first line. -CTC (Second line test) + colonoscopy -CTC was performed when colonoscopy was incomplete or unsuitable.	-Screened tested between January 1st, 2011, and December 31st, 2012, (the first two full calendar years after programme roll-out). -All participants undergoing a colonic test are sent a standard questionnaire 30 days after the process.	-Satisfaction with the communication of risks and benefits of CTC and colonoscopy. -Bowel preparation instructions. -A five-point Likert-type scale (Strongly agree to strongly disagree.	-Expected comfort -Expected pain SA-SD. -Test stopped/Paused binary yes/ no response. - Dignity and respect SA-SD -Variation across screening centre SA-SD	-Rectal/ abdominal pain binary yes/ no response. -understood their results SA-SD. -Complication (adverse reaction to bowel prep, pain, bleeding, perforation SA-SD	- Gender differences -Age differences -Ethnicity not reported -Socioeconomic Status (SES) Deprivation
Buron, 2017, Spain	-Sample size: 1189 people: 310 from the NoP (non-participants) profile, 553 from the PNeg (Negative test) and 326 from the PPo (positive test) -In total, 912 people agreed to participate in the survey -Response rate: 76.7% -Gender ratio: women 53.5, men 46.5 -Age (min max, average)	FOBT (First line test) + colonoscopy	Between December 2013 and February 2014	1-Informational material, understanding of the invitation letter, and role of the general Practitioner (grouping of ''not at all'', ''barely'' or ''fairly'' easy to understand) 2- Programme-based telephone service: a-Incomplete resolution of the reason for calling (not resolved at all, barely	1-FOBT collection Some difficulty understanding the instructions ''a lot of'', ''some'' and ''few'' difficulties –Some difficulty collecting the sample ''a lot of'', ''some'' and ''few'' difficulties 2-colonoscopy experience -discomfort during colonoscopy prep Some/a lot of discomfort during	-Waiting time to receive results was quite/very worried during the waiting time. -Some concern when the result was received ''a lot of'', ''some'' and ''a little'' concern -Incomplete understanding of the information about the test result ('some'',	-Age differences -Gender differences -Differences in uptake/ outcomes between the 3 groups, participant with positive FOBT, negative FOBT, and non-participants -Ethnicity: Not reported -Deprivation: Not given

Author/ country	Sample characteristics	Type of screening	Timing of patient-reported assessment	Outcome 1 Pre-test experience	Outcome 2 Test experience	Outcome 3 Post-test experience	Demographic factors & additional information
	50-69			resolved or somewhat resolved) b-Some difficulty making telephone contact (hardly/not at all simple c-Excessive waiting time to be seen (fairly/very).	the colonoscopy	''little'' and ''no''). -Overall assessment of program (positive aspect and improvement) (arranged in groups and number of times mentioned).	
Ghanouni, 2015, UK	-Sample size: 50858 -Response rate: 79.3 % -Gender ratio: men (58.6 %). -Age (min max, average) 60-74, mean 66.3 -Ethnicity: Not given -Deprivation: the median IMD score was 14.6 (IQR 8.6– 24.6).	Colonoscopy / screening Participants with positive FOBT in BCSP	Data were extracted between 1 Jan 2011 and 31 Dec 2012 (i.e. two full years after completion of the program's rollout in 2010).	(informed choice) -Satisfaction with the communication of risks and benefits of colonoscopy. -Bowel preparation instructions (SA-SD) -Satisfaction with SP (SA_SD) Contacting free helpline (binary yes/ no response). -Satisfaction with helpline (SA-SD)	(physical discomfort) -Expected discomfort during the test SA-SD -Test stopped or posed binary yes/ no/DR response. -use of sedation binary yes/ no/DR response. -Treated with respect and privacy was maintained (SA-SD)	Post-test abdominal pain (SA-SD) -Adverse effect, e.g. bleeding (binary yes/ no response). -Colonoscopy results clear (SA_SD)	Gender differences -Age group differences (ranged 60-74, mean 66.3). -Ethnicity not reported -SES deprivation
Denters, 2012, The Netherlands	-Sample size: of 373 FIT-positive persons underwent colonoscopy, and of these, 273 returned the questionnaire. -Response rate: (73 %) -Gender ratio: 53%were men. -Age (min max, average) 50–75 years, mean age was 63 years -Ethnicity: Dutch, 257 (96%) Other, 10 (4%) -SES: Education level, n (%) Low 73 (28) Intermediate: 128 (49) High: 63 (24)	Colonoscopy (Second line) / Screening with positive FIT	-A random sample of the population aged 50–75 years living in the screening pilot catchment area (selected from the population database based on date of birth and postal code) was sent an invitation package for the second screening round -The duration of the study not given. -Questionnaire to test positive participants 2 weeks after their colonoscopy.	- Good explanation of the colonoscopy procedure. -A short waiting time for the colonoscopy appointment. -Quality of preparation, n (%). -Complete dose or split dose (Good, Fair, Poor) - Burden of drinking of the bowel prep (quite/very, a little/somewhat, not at all). -Embarrassment: a-embarrassment with the effects of bowel prep (quite/very, a little/somewhat, not at	-Embarrassment/pain/ and burden. -Burden of bowel prep -Burden, pain, embarrassment of the effect of bowel prep. -Of the introduction to colonoscopy. -Of colonoscopy procedure itself. -Burden of recovery -Burden of abdominal complains after procedure. - Discussion of the preliminary results of colonoscopy on the day of the procedure. -Embarrassment with colonoscopy itself (quite/very, a little/somewhat, not at all). - Pain from colonoscopy itself (quite/very, a little/somewhat,	Disturbance of normal living - Restrictions of activity and sleep on the day after the procedure and level of sleep disturbance in the nights after the procedure. (n of participants,%) -Burden of waiting for results (quite/very, a little/somewhat, not at all). -Overall satisfaction with the procedure (Mean score which each of a list of 19 items was chosen as one of the three	-Gender differences -Age differences 50–75 years, mean age was 63 years -Test results differences within outcomes -Reported demographics but not measured across outcomes; a- Education level, n (%) b- SES: Low 73 (28) Intermediate: 128 (49) High: 63 (24) c- ethnicity

Author/ country	Sample characteristics	Type of screening	Timing of patient-reported assessment	Outcome 1 Pre-test experience	Outcome 2 Test experience	Outcome 3 Post-test experience	Demographic factors & additional information
				all). b-embarrassment with introduction of colonoscope (quite/very, a little/somewhat, not at all). -Pain from effects of bowel prep (quite/very, a little/somewhat, not at all). - Restrictions of activity and sleep on the day before the procedure and level of sleep disturbance in the nights before (n,%)	not at all). -Burden of colonoscopy itself (quite/very, a little/somewhat, not at all). -Burden of recovering from sedation (quite/very, a little/somewhat, not at all). - Restrictions of activity and sleep on the day of the procedure (n of participants, %).	most important contributors to a more satisfactory colonoscopy procedure). -Good explanation of the colonoscopy procedure, discussion of the preliminary results of colonoscopy on the day of the procedure, and a short waiting time for the colonoscopy appointment were selected most often.	Dutch, 257 (96) Other, 10 (4)
Gupta, 2012, UK	Sample size: Of the 1488 participants requiring further investigation, 1339 (90%), 1138 (85%) were considered suitable for a colonoscopy, attended the clinic. 1057 (79%) went on to have a first procedure colonoscopy (of the 1138 considered suitable for colonoscopy, 81 did not attend), 115 had a CTC and eight had a flexible Sigmoidoscopy -100 consecutive patients (50 routine diagnostic and 50 BCSP colonoscopies) were giving a questionnaire to complete at home. -Response rate: The	colonoscopy / screening + surveillance after +FOBT	-The screening and symptomatic populations in the St Mark's bowel cancer screening centre attending between October 2006 and September 2009. -Patients were given a questionnaire to complete at home following the procedure.	Differences in satisfaction between screened and symptomatic patients experience. -Clear information material (Yes/No). -Opportunity to ask questions (Yes/No). -Adequate explanation of risk (Yes/No). -Pre-procedure anxiety (relaxed, slight concern, worried-fearful).	-Differences in satisfaction between screened and symptomatic patients experience during procedure. -Privacy maintained during procedure (Always, most of time). -Adequate sedation (Yes, right amount, needed more). -Level of discomfort during procedure (minimal, slight discomfort, quite uncomfortable, extremely uncomfortable /painful). -Test stopped/paused (Yes, No) -Unexpected and overwhelming room (Yes, No) -Enough time to recover (Yes, No)	Differences in satisfaction between screened and symptomatic patients experience after procedure -Results adequately explained (Yes, Told to see GP/OPD, No). -Following steps instructions given (Yes, No) -Appointment given (Yes, No) -Treated with dignity (Yes, Less than all times)	-Reported demographics but not measured across outcomes; a- Gender 20.79% men b- Age (mean) 66.7 Others: -Colorectal cancer characteristic of patients diagnosed with CRC in screening program -Abdominal symptoms. -Bleeding. -Change in bowel frequency. -Rectal irritation -Weight loss -Complication Ten were related to colonoscopy

Author/ country	Sample characteristics	Type of screening	Timing of patient-reported assessment	Outcome 1 Pre-test experience	Outcome 2 Test experience	Outcome 3 Post-test experience	Demographic factors & additional information
	overall response rate was 76% (42 in the BCSP group and 34 in the diagnostic group. -Gender ratio: 46 (57.5%) men screening patients, 146 (58%) men symptomatic patents. -Age (min max, average):60-75 years, average screening patients 66.7, symptomatic 66.3						(eight post polypectomy bleeds, one post polypectomy syndrome and one colonic perforation).
Sarkar, 2012, UK	Sample size: 488/720 patients completed the study. -Response rate: 68% -Gender ratio: Male gender BCSP 63%, 51% NON-BCSP. -Age (min max, average): BCSP 65 years, Non-BCSP 65	Colonoscopy/ screening + surveillance after + FOBT	-Patient survey was performed between 1/1/07-01/10/08 on patients that underwent colonoscopy. -Telephone interview clinics 30 days following their procedure.	-Bowel prep Poor bowel preparation where bowel preparation was rated the worst by the NON-BCSP group	-Procedure expectation 0-10; 0 being the worst score and', 5 'as expected' and 10'much better than expected'. -Procedure experience 0-10; 0 was the worst score that denoted 'terrible', 5; average and 10 the best score denoting excellent'. -Pain 0-10; 0 being the best score denoting 'none', and 10; denoting the 'worst pain ever experienced -Comfort 1-5; 1 being the best score representing 'Comfortable throughout procedure', 2; 'Comfortable through majority of procedure'. 3; 'Some discomfort, but as expected'. 4: Uncomfortable in long periods of procedure and 5 the worst score representing Very uncomfortable throughout procedure'. -Sedation use (Frequency between the groups)	-Complication -Test repeatability (willingness to repeat) 1-5; 1 was the worst score denoting 'Never', 2; 'Only if no other option', 3; 'If necessary', 4; 'Yes, willingly' and 5 the best score denoting 'Yes & I will recommend the procedure to others'.	-The effect of colonoscopies experience to patient's satisfaction

Supplementary Table 3: Pre-colonoscopy experience

Author	Satisfaction with information material (The invitation letter)	Satisfaction with test kit instructions/ usage	Satisfaction with communication of the risks of the diagnostic test	Satisfaction with communication of the benefits of the diagnostic test	Satisfaction with waiting time appointment (SSP/ test)	Satisfaction with helpline service	Anxiety and disturbance in daily activities and sleep	Most important contributor to satisfaction
Plumb, 2019, UK	Not Tested (NT)	-CTC participant who found the test easy to use: 1752/1958 89% -Colonoscopy participants who found the test easy to use : 46,285/50,975 90.8% -The differences were not significant	Respondents agreed or strongly agreed they understood risks of tests. CTC : 1712/1970 (86.9%) Understanding was slightly higher for colonoscopy Colonoscopy: 48,783/50,975 (95.7 %) **P< 0.0001**	Respondents agreed or strongly agreed they understood benefits of tests. CTC: 1844/1970 (93.6 %) Understanding was slightly higher for colonoscopy Colonoscopy: 50,057/50,975 (98.2 %) **P< 0.0001**	NT	NT	NT	NT
Buron, 2017, Spain	-By participation Incomplete understanding of the invitation letter Overall: 37.6% Participants: 38.9% Non-participants: 28.0% **P<0.001.** -Incomplete understanding of the information brochure*:* Overall: 37.7% Participant and non-participants wasn't significant -Overall assessment of the Programme's written information *(scale 0-10) : 8.86* Mean participants: 8.89 Mean non-participant: 8.57 **P<0.008**	-By test results the participants with a pathological test result (Ppos) reported greater difficulties than the participants with a normal result (Pneg). -Some difficulty in understanding the instructions: Pneg: 1.5% Ppos: 7.0% **P<0.001** -Some difficulty in collecting the sample: Pneg: 1.3 Ppos: 10.5%, **P<0.001**	NT	NT	NT	By participation 5.6% of the respondents reported having made telephone contact with the Programme, of these: Some reported difficulty making contact (hardly/not at all simple): Overall: 27.1. Participant: 31.0% Non-part: 0.0% **P<0.013** -Some reported Incomplete resolution of the reason for calling (not resolved at all, barely resolved or somewhat resolved) overall:18.8%	NT	NT

Author	Satisfaction with information material (The invitation letter)	Satisfaction with test kit instructions/ usage	Satisfaction with communication of the risks of the diagnostic test	Satisfaction with communication of the benefits of the diagnostic test	Satisfaction with waiting time appointment (SSP/ test)	Satisfaction with helpline service	Anxiety and disturbance in daily activities and sleep	Most important contributor to satisfaction
						participants: 19.0 non-participant: 16.7 Comparison Participant and non-participants wasn't significant.		
Ghanouni, 2015, UK	Tested, not reported (TNR)	TNR	Patients (strongly) agreeing that they had an understanding of the risks: Overall, 95.7% -By Gender Female 20 073 (95.3) Male 28 593 (96.0) **P<0.01** -By age: 59-64 (95.7) >64-68 (95.9) >68-93 (95.5) The differences were not significant -By Index of Multiple Deprivation (IMD) high vs. Low, **p<0.01**	Patients (strongly) agreeing that they had an understanding of the benefits Overall, 98.2 %, -By Gender Female 20 652 (98.0) Male 29 301 (98.4) **P<0.01** -By age: 59-64 (98.2) >64-68 (98.3) >68-93 (98.1) The differences were not significant -By IMD low: (98.3) medium: (98.3) high: (97.9) The differences were not significant	TNR	TNR	NT	NT
Denters, 2012 The Netherlands	NT	NT	TNR	NT		NT	Disturbance in daily activities before colonoscopy -(125, 48%) participants had not experienced any disturbance in daily activity: -21% disturbed for half day -20% disturbed for one whole day. -13% indicated they	The most important contributors to a more satisfactory colonoscopy procedure: 93 selected "good explanation of the colonoscopy procedure",

Author	Satisfaction with information material (The invitation letter)	Satisfaction with test kit instructions/ usage	Satisfaction with communication of the risks of the diagnostic test	Satisfaction with communication of the benefits of the diagnostic test	Satisfaction with waiting time appointment (SSP/ test)	Satisfaction with helpline service	Anxiety and disturbance in daily activities and sleep	Most important contributor to satisfaction
							had had a disturbance of daily activities for more than 1 day before the procedure. -Sleep disturbance the night before -52% had not experienced any sleep disturbance. -33 % for one night -7 % for two nights -9 % for more than 2 nights Women and participants younger than 60 reported restrictions in daily activities more often than did men and participants over age 60, -By Gender women, 54% reported a complete day's disturbance, compared with 39% of men **(P=0.013).** - Men had sleep disturbances before the procedure less often than did women; 62% of men indicated no sleep disturbance at all, compared with	P value not given 71 selected " a short waiting time for the colonoscopy appointment P value not given

Author	Satisfaction with information material (The invitation letter)	Satisfaction with test kit instructions/ usage	Satisfaction with communication of the risks of the diagnostic test	Satisfaction with communication of the benefits of the diagnostic test	Satisfaction with waiting time appointment (SSP/ test)	Satisfaction with helpline service	Anxiety and disturbance in daily activities and sleep	Most important contributor to satisfaction
							40% of women **(P=0.001).** -By age Among participants under 60, 58% reported a complete day's disturbance, compared with 40% of participants over 60 **(P=0.001).** -Older participants experienced disturbances in their daily activities in the days before the procedure less often than did younger participants 51% of participants aged over 60 indicated not having experienced any disturbances, compared with 36% of participants aged under 60; **(P=0.027)**	
Gupta, 2012, UK	Participants are given Clear information material. By health status (BCSP/Diagnostic No: NON-BCSP 0 (0%), BCSP: 1 (2%) Yes: NON-BCSP: 34 (100%), BCSP: 41 (98%) **P=1.00**	NT	-Adequate explanation of risk By health status BCSP/Diagnostic 13%) patients who underwent diagnostic. colonoscopy reported not having been given adequate explanation of the risk, compared with no	NT	NT	NT	pre-procedure anxiety Relaxed: NON-BCSP: 11 (33%), BCSP: 13 (32%) Slight concern: NON-BCSP: 16 (48%), BCSP: 18 (44%) Worried-fearful:	NT

Author	Satisfaction with information material (The invitation letter)	Satisfaction with test kit instructions/ usage	Satisfaction with communication of the risks of the diagnostic test	Satisfaction with communication of the benefits of the diagnostic test	Satisfaction with waiting time appointment (SSP/ test)	Satisfaction with helpline service	Anxiety and disturbance in daily activities and sleep	Most important contributor to satisfaction
	-Opportunity to ask questions No: NON-BCSP= 0 (0%), BCSP: 0 (0%) Yes: NON-BCSP 24(100%), BCSP: 41(100%) P value missing		patients within the BCSP group **(P= 0.03).**				NON-BCSP: 6 (18%), BCSP: 10 (24%) The differences were not significant	
Sarkar, 2012	NT	NT	NT	NT	NT	NT	NT	NT

Supplementary Table 4: Test experience

Author	Satisfaction with bowel preparation procedure /instructions	Pain/Discomfort	Use of sedation	Test stopped/paused	Privacy/ Respect maintained	Comprehension of results on the day of the appointment	Satisfaction with results feedback and follow up
Plumb, 2019, UK	Respondents found bowel preparation instructions clear for tests. CTC users: 1875/1970 (95.2 %) agreement Colonoscopy users: 49,905/50,975 (97.9 % statistically significant difference in favour of colonoscopy **P< 0.0001**	The test more uncomfortable than expected CTC participants: 25.7% more uncomfortable than expected. This was a larger proportion than for colonoscopy. Colonoscopy participants: 21.0% more uncomfortable that expected. **P<0.0001**	Compares sedation with pain and discomfort, and with the item (test paused/stopped) e.g. There was no significant difference in asking for the test to be stopped/paused whether or not patients reported receiving sedation for their colonoscopy sedated: 1867/39,441 (4.7 %), unsedated: 587/9195 (6.4 %)	CTC participant: 114/1970 (5.8%) Colonoscopy users: 2600/50,975 (5.1%) There was no significant difference in asking for the test to be stopped/paused between the two groups	Almost all individuals agreed they had been treated with both privacy and respect for both tests. CTC participant: *Privacy* 95.4%, *respect* 96.2% Colonoscopy participant: *Privacy* 97.9%, *respect* 98.4% there were statistically significant differences in favour of colonoscopy **P<0.0001**	Available in Outcome 3	- Available in Outcome 3
Buron, 2017, Spain	Participants reported some or a lot of discomfort during preparation. overall: 41.6%	Some or a lot of discomfort during the colonoscopy Overall: 2.1% By Gender: Women: 2.1	NT	NT	NT	Assessment of the communication of the pathological test -Incomplete understanding of the	78.9% of participants with a pathological result reported experiencing some concern when receiving the call, -By Gender

Author	Satisfaction with bowel preparation procedure /instructions	Pain/Discomfort	Use of sedation	Test stopped/paused	Privacy/ Respect maintained	Comprehension of results on the day of the appointment	Satisfaction with results feedback and follow up
	-By Gender women: 51.8% men: 31.7% **p<0.001** -By age (greater among people aged 50-59): 60.7% vrs 45.9% (aged 60=69) **(P=0.001)**	Men: 2.1 No differences between gender or age.				information about the test result was reported by 16.6% -By Gender: Women: 13.7 Men: 19.4 No differences between gender	women: 78.7% men: 79.2 Not significant -Only 6.5% (19 people) stated ''a lot of concern''.
Ghanouni, 2015, UK	Overall, 97.8% of patients felt the bowel instructions was clear. -By Gender Female 20 579 (97.7) Male 29 185 (98.0) **P 0.04** -By age: Aged 59-64 (97.7) Aged 64-68 (98.0) Aged 68-93 (98.0) P=0.11 The differences not significant -By IMD low: 97.7 medium: 97.8 high: 97.9 P= 0.37 The differences not significant	Overall, 21.0% experienced more discomfort than expected. -By Gender Women: 25.1% were more likely than men to report unexpected discomfort 18.0 %) **P <0.01** -By age patients aged >64–68 years (20.8) and those aged >68–93 years (20.4%,) were slightly less likely to report pain after going home than those aged 59–64 years (21.6 %) P= 0.06 The differences not significant. -By IMD individuals in the most deprived tertile were slightly more likely to report unexpected discomfort than those in the least deprived tertile low: 3880 (19.5) medium: 3878 (21.2) high: 2909 (23.0) **P<0.01**	79.1% use of sedation -By Gender Women: 86.7% more to report receiving sedation Men: 73.6 % **P <0.01** -By age: Aged 59-64 (78.2) Aged 64-68 (79.0) Aged 68-93 (80.3) P=0.25 The differences not significant -By IMD Patients in the most deprived tertile were also less likely to report sedation administration than those in the least deprived tertile Low : 81.2% Medium: 79.0% High: 75.8% **P<0.01**	5.1% asked for the colonoscopy to be stopped -By Gender Women: 6.8% more asked for the test to be paused men: 3.9 % **P <0.01** -By age: Aged 59-64 (5.8) Aged 64-68 (5.0) Aged 68-93 (4.3) **P<0.01** -By IMD low: 5.1 medium: 5.1 high: 5.2 P= 0.40 The differences not significant.	Overall : 98.3% treated with respect. -By Gender Women: 20 694 (98.2) Men: 29 323 (98.4) P=0.12 Overall, 97.9% reported privacy was maintained. -By Gender Women: 20 663 (98.1) Men: 29 115 (97.7) P 0.01 -By age (respect) Ppl aged 68+ were treated with respect more than ppl in the age group of 59-68. Aged 59-64 (98.1) Aged 64-68 98.3) Aged 68-93 (98.8) **P<0.01** -By age (privacy maintained) Ppl aged 68+ privacy were maintained more than ppl in the age group of 59-68.	TNR	TNR

Author	Satisfaction with bowel preparation procedure /instructions	Pain/Discomfort	Use of sedation	Test stopped/paused	Privacy/ Respect maintained	Comprehension of results on the day of the appointment	Satisfaction with results feedback and follow up
					Aged 59-64 (97.4) Aged 64-68 97.9) Aged 68-93 (98.5) **P<0.01** -By IMD (respect) P= 0.36 The differences not significant -By IMD (privacy maintained) P= 0.39		
Denters, 2012, The Netherlands	Almost everyone (82 %) felt the drinking of the bowel preparation was burdensome (mean score 2.87, SD 1.28). -By Gender Women assigned higher average discomfort scores to the effects of the laxative -Burden of drinking the bowel prep Women: mean score 3.12 Men: mean sore 2.66 **P= 0.03** -Burden of effects of bowel prep Women: mean score 2.31 Men: mean score 1.94 **P 0.05** -Pain from effects of bowel prep Women: mean score 1.73	The colonoscopy procedure itself received the second highest pain scores, (mean score 1.96, SD 1.20), after post procedure pain complaints (mean 2.55, SD 1.03) -By Gender Women assigned higher average discomfort scores and more pain from colonoscopy but the differences were not significant. -Pain from colonoscopy itself Women: mean score 2.10, SD=1.25 Men: mean score 1.84, SD 1.45 P= 0.08 -Pain from abdominal complaints Women: mean score 2.62, SD 0.99 Men: mean score 2.46, SD 1.11 P= 0.56 Burden of colonoscopy itself Women: mean score 1.79, SD 1.18 Men: mean score 1.65, SD 1.02, P= 0.32	Burden of recovering from sedation -By Gender Women: mean score 1.22 , SD 0.59 Men: mean score 1.14, SD 0.46 The differences were not significant	NT	NT	The most important contributors to a more satisfactory colonoscopy procedure: 77 selected “discussion of the preliminary results of colonoscopy on the day of the procedure”.	

Author	Satisfaction with bowel preparation procedure /instructions	Pain/Discomfort	Use of sedation	Test stopped/paused	Privacy/ Respect maintained	Comprehension of results on the day of the appointment	Satisfaction with results feedback and follow up
	Men: mean score 1.39 **P= 0.01**						
Gupta, 2012 UK	NT	-By health status BCSP/Diagnostic Discomfort was reported higher in the diagnostic group than in the BCSP group, with 14 / 33 (42%) diagnostic patients reporting a 'quite or extremely uncomfortable procedure' compared with only four of 41 (10%) in the BCSP group the difference was significant **P=0.004**	Adequate sedation -By health status BCSP/Diagnostic patients in the routine colonoscopy group felt that they needed more sedation compared with none of 30 (0%) patients in the BCSP group **P=0.005**	Procedure to be stopped/paused -By health status BCSP/Diagnostic No: NON BCSP 32 (97%), BCSP 40 (100%) Yes: NON BCSP 1 (3%), BCSP 0 (0) The differences were not significant	Privacy maintained during the procedure -By health status BCSP/Diagnostic Always: non-BCSP 32 (97%), BCSP 41 (100%) Most of time: NON-BCSP 1 (3%), BCSP 0 (0) The differences were not significant	The findings adequately explained -By health status BCSP/Diagnostic Yes: NON BCSP 21 (64%), BCSP 39 (97) Told to see GP/ OPD: NON BCSP 9 (27), BCSP 1 (3%) **P<0.001**	Participants were given an adequate explanation of the findings -By health status BCSP/Diagnostic BCSP group: 39 of 40 (97%) patients felt that were given an adequate explanation of the findings compared with 21／32 (64%) of those having routine colonoscopy **(P < 0.001).** -Were given instructions on what to do next -By health status BCSP/Diagnostic No: NON-BCSP 1 (3%), BCSP 2 (5%) Yes: Non-BCSP 29 (97%), BCSP 40 (95%) P=1.00
Sarkar, 2012 UK	Adequate bowel prep -By health status BCSP/Diagnostic Poor bowel prep were reported more in non-BCSP than in BCSP BCSP 5% NON-BCSP 17% **P 0.001**	Level of Pain (0-10 medium score), By health status BCSP/Diagnostic BCSP 1 (0, 5), NON BCSP 2 (0, 5) P= 0.09 -Level of Comfort In BCSP group, comfort scores seemed better with trends to less pain. BCSP 1 (1, 3), Non-BCSP 2 (1, 3) P= 0.04 -Procedure time	By health status BCSP/Diagnostic BCSP 12% patients no sedation/analgesi was used for the procedures within BCSP and in the NON-BCSP group 7% (p=0.085). midazolam use was lower in the BCSP vs NON-BCSP **p<0.0001)** -At lower doses (1[0, 2], vs 2 [1, 3] mg; compared to the NON-BCSP	NT	NT	NT	

Author	Satisfaction with bowel preparation procedure /instructions	Pain/Discomfort	Use of sedation	Test stopped/paused	Privacy/ Respect maintained	Comprehension of results on the day of the appointment	Satisfaction with results feedback and follow up
		The procedure time was longer in the BCSP than in NON-BCSP (30 [23, 38] vs 25 [19, 40] minutes **(P=0.005)**	**(P=0.0001)**				

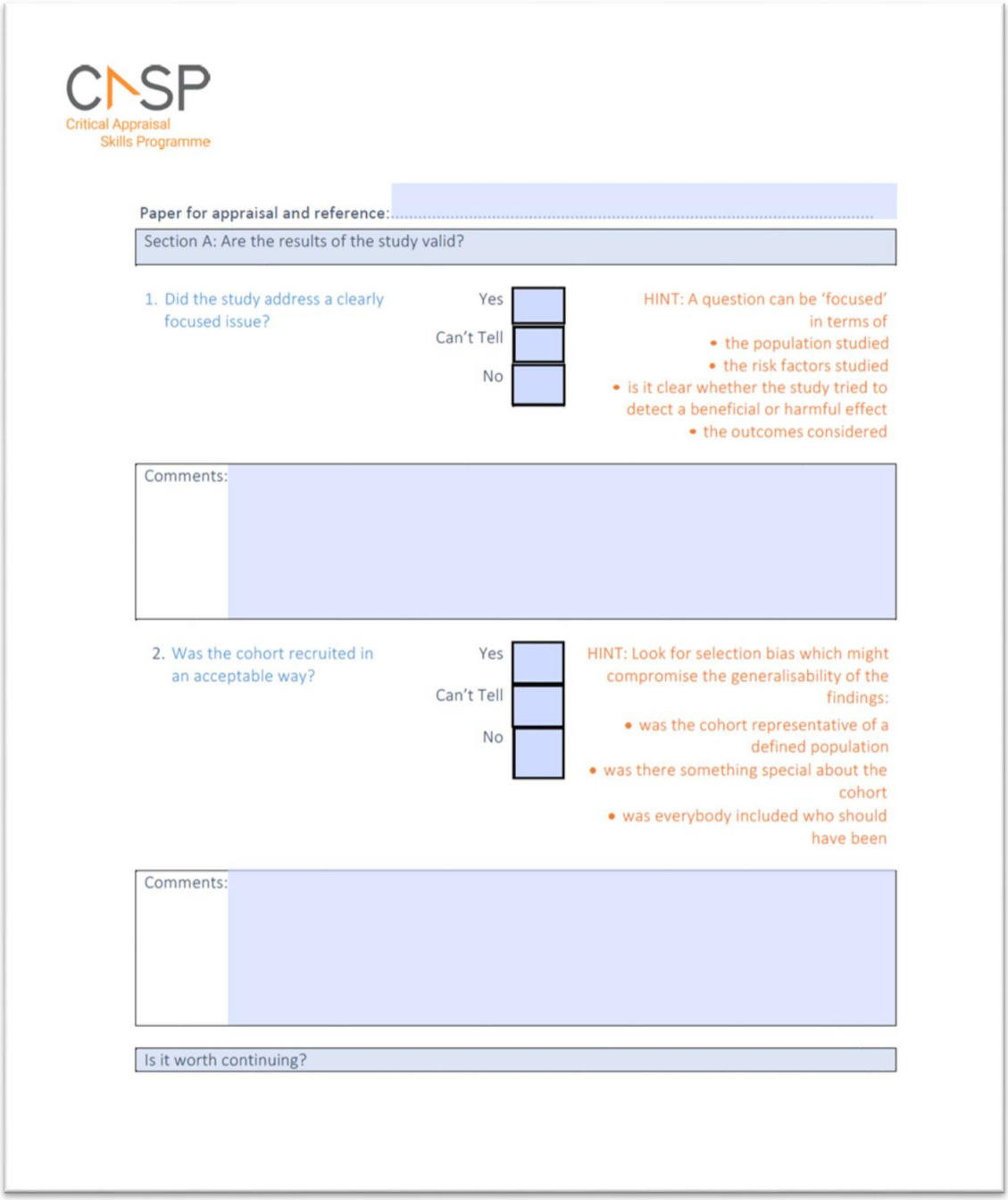
Supplementary Table 5: Post-test experience

Author	Pain/Discomfort	Patient overall satisfaction experience/Expectation	Complication, adverse effects, and Daily restrictions	Comprehension of the results letter	Satisfaction With result letter and follow-ups instructions
Plumb et al, 2019, UK	Participants rectal/abdominal pain following their diagnostic test. CTC users: 288/1970 (14.6 %), Colonoscopy users: 7544/50,975 (14.8 %) P = 0.55). - For CTC participants performed after incomplete colonoscopy. more abdominal pain after colonoscopy (187/779, 24.0 %) than after CTC (108/779, 13.9 %, **p < 0.001** -Colonoscopy was more uncomfortable than expected when compared with CTC (CTC: 205/779, 26.3 %; colonoscopy: 444/779, 57.0 %, **p < 0.001).**	NT	in 64,312 individuals, of whom 683 had complications, corresponding to a per-test rate of 1.0 % and a per patient rate of 1.1	Within 7 days of the test colonoscopy users agreed they understood their results (49,395/50,975 = 96.9 %) more than CTC users (1783/1970 = 90.5 %, **p < 0.0001**).	Within 7 days of the test Those who had CTC were less likely to have received their results within seven days (1564/1970 = 79.4 %) than for colonoscopy (42,105/50, 975 = 82.6 %, **p < 0.0001)**
Buron, 2017 , Spain	NT	-Positive aspects of the Programme: 1- Early cancer detection was the most cited positive aspect, 2- The ease, convenience and speed of the screening process. -The main aspects for improvement:	NT	NT	NT

Author	Pain/Discomfort	Patient overall satisfaction experience/Expectation	Complication, adverse effects, and Daily restrictions	Comprehension of the results letter	Satisfaction With result letter and follow-ups instructions
		Bowel preparation and the waiting times for receiving results letters			
Ghanouni, 2015, UK	Participant Reported pain after going home overall: (14.8 %) -By Gender: women: 18.2% report pain after going home more than men, 12.3 % **P <0.01** -By Age: patients aged >64–68 years (13.8%) and those aged >68–93 years (12.8 %) were slightly less likely to report pain after going home than those aged 59–64 years (16.9 %, **P<0.01)** -By IMD: The most deprived were more likely to report pain after going home low: 13.6% medium: 15.0 high: 16.1%, **P<0.01**	NT	Reported bleeding from bottom after going home Overall: (7.6 %). -By Gender**:** Women: 1432 (6.8%) reported bleeding from bottom more than Men: 2432 (8.2%), **P 0.03** -By age patients aged >64–68 years (7.3%) and those aged >68–93 years (7.4 %) were slightly less likely to report bleeding from bottom after going home than those aged 59–64 years (8.0 %), **P<0.01**) By IMD: The differences were not significant	NT	NT
Denters, 2012, The Netherlands	Abdominal complaints after the colonoscopy procedure received the highest pain scores; 85% of participants reported at least some degree of pain, and 22% abdominal complaints as quite or even very painful (mean score 2.55, SD 1,03)) -By Gender Pain from abdominal complaints Women mean score 2.62, SD 0.99 Men mean score 2.46, SD 1.11 P=0.56 -The burden of the abdominal complaints following the procedure was rated second highest: 75% rated these as burdensome (mean score 2.53, SD 1.23).	Overall satisfaction with the procedure was rated with a mean score of 7.9 (SD 1.8).	Burden of abdominal complaints -BY Gender Women mean score 2.75, SD 1.21 Men mean score 2.50, SD 1.20 -Recovering afterwards, (71 %) reported that they had been able to resume their normal activities after the colonoscopy without any restrictions. -13 % took half a day -25 (9%) took a whole day. -7 % were only able to resume their normal activities after more than 1 day - 87% of participants indicated not having slept any worse than normal on the nights following the procedure. -7% reported sleeping worse than normal for one night,	NT	Overall, 49 participants 19 % selected waiting on the results as the most burdensome Burden of waiting for the final results -By Gender Burden of waiting for the final results Women mean score 2.09, SD 1.26 Men mean sore 1.93, SD 1.11 , P= 0.27

Author	Pain/Discomfort	Patient overall satisfaction experience/Expectation	Complication, adverse effects, and Daily restrictions	Comprehension of the results letter	Satisfaction With result letter and follow-ups instructions
			-6 % slept worse for two nights or more. -By Gender Women 54% reported a complete day's disturbance, compared with 39% of men **(P=0.013).** -By Age Participants under 60, 58% reported a complete day's disturbance, compared with 40% of participants over 60 **(P=0.001)**		
Gupta, 2012, UK	NT	NT	Surveillance Complication, 10 related to colonoscopy (eight post polypectomy bleeds, one post polypectomy syndrome and one colonic perforation).	BCSP participants group: (97%) cited they were given an sufficient explanation of the results compared with (64%) of those having routine colonoscopy **(P < 0.001)**	NT
Sarkar, 2012, UK	NT	Patient Expectation, and Experience (0-10, best score10) -By health status BCSP/Diagnostic Median (IQR) Expectation and Patient Experience: Was insignificant between the two groups	Complication between the 2 groups. In the BCSP group One post-polypectomy syndrome recorded (0.002%) related to therapeutic procedure. NON-BCSP group None in this group		

2.1 Critical Appraisal Skills Programme (CASP): page 1



CASP
Critical Appraisal Skills Programme

Paper for appraisal and reference:.....

Section A: Are the results of the study valid?

1. Did the study address a clearly focused issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: A question can be 'focused' in terms of
- the population studied
- the risk factors studied
- is it clear whether the study tried to detect a beneficial or harmful effect
- the outcomes considered

Comments:

2. Was the cohort recruited in an acceptable way?

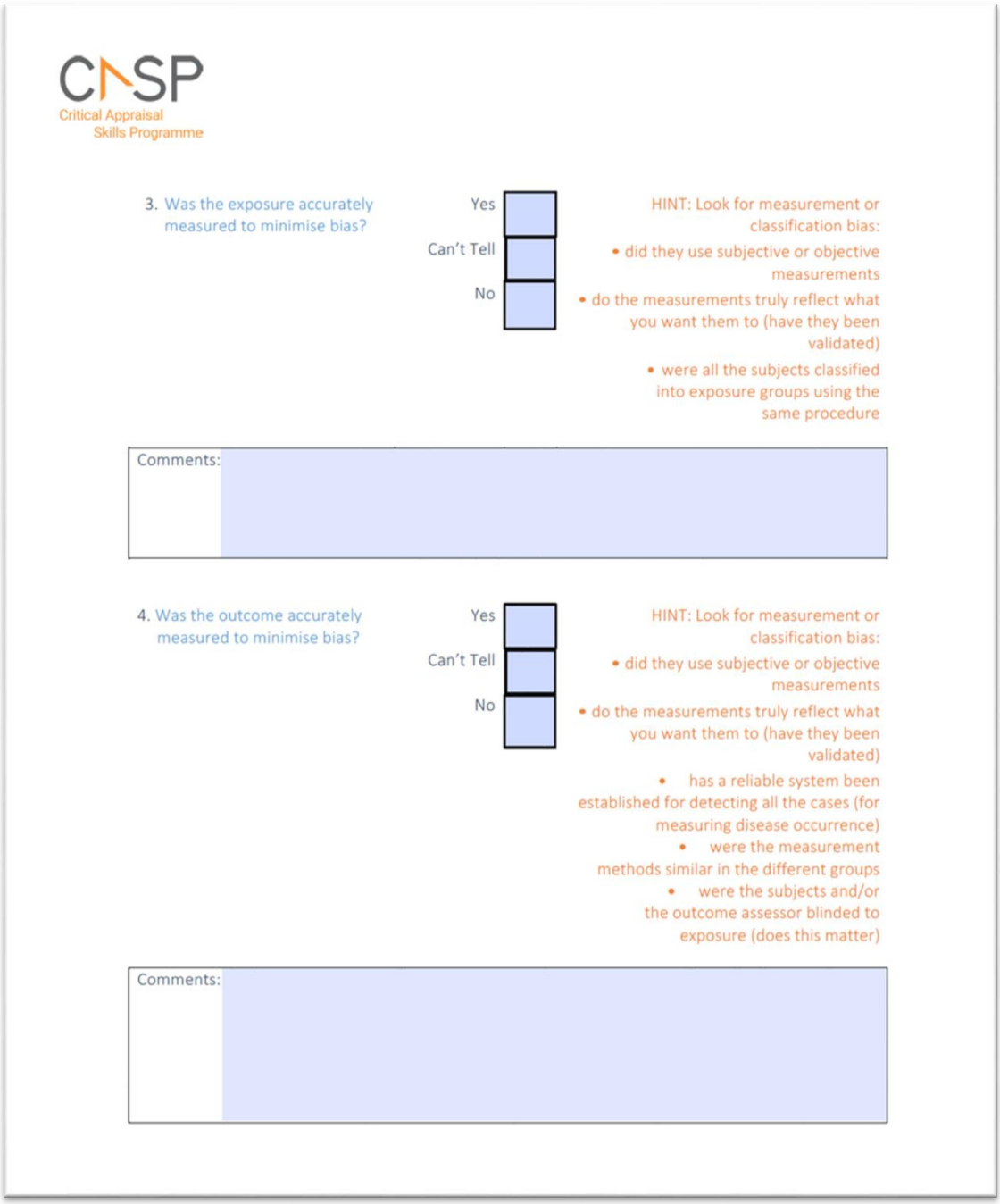
Yes ☐
Can't Tell ☐
No ☐

HINT: Look for selection bias which might compromise the generalisability of the findings:
- was the cohort representative of a defined population
- was there something special about the cohort
- was everybody included who should have been

Comments:

Is it worth continuing?

2.2 Critical Appraisal Skills Programme (CASP): page 2



CASP
Critical Appraisal Skills Programme

3. Was the exposure accurately measured to minimise bias?

Yes ☐
Can't Tell ☐
No ☐

HINT: Look for measurement or classification bias:
- did they use subjective or objective measurements
- do the measurements truly reflect what you want them to (have they been validated)
- were all the subjects classified into exposure groups using the same procedure

Comments:

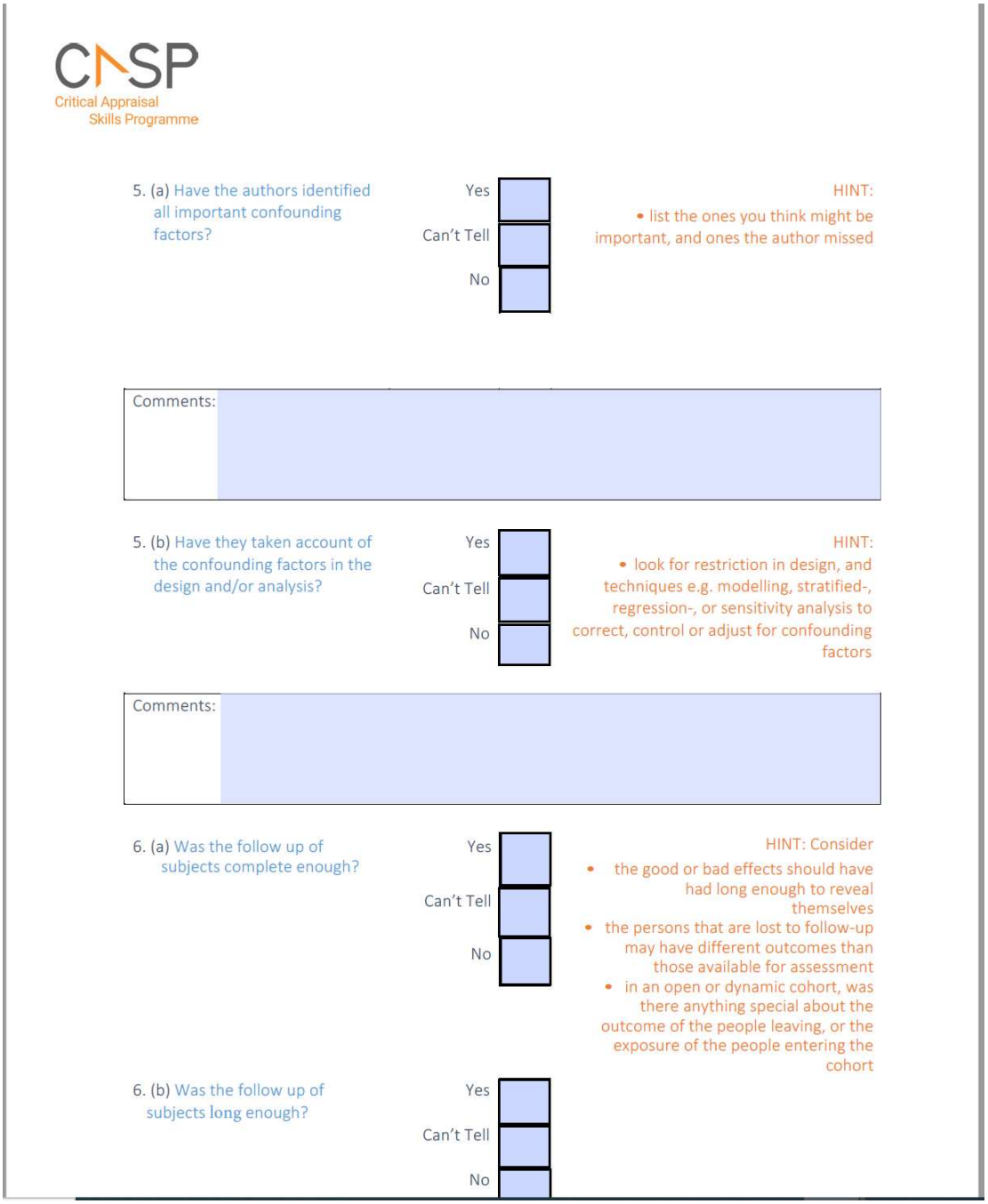
4. Was the outcome accurately measured to minimise bias?

Yes ☐
Can't Tell ☐
No ☐

HINT: Look for measurement or classification bias:
- did they use subjective or objective measurements
- do the measurements truly reflect what you want them to (have they been validated)
- has a reliable system been established for detecting all the cases (for measuring disease occurrence)
- were the measurement methods similar in the different groups
- were the subjects and/or the outcome assessor blinded to exposure (does this matter)

Comments:

2.3 Critical Appraisal Skills Programme (CASP): page 3



CASP
Critical Appraisal Skills Programme

5. (a) Have the authors identified all important confounding factors?

Yes ☐
Can't Tell ☐
No ☐

HINT:
- list the ones you think might be important, and ones the author missed

Comments:

5. (b) Have they taken account of the confounding factors in the design and/or analysis?

Yes ☐
Can't Tell ☐
No ☐

HINT:
- look for restriction in design, and techniques e.g. modelling, stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors

Comments:

6. (a) Was the follow up of subjects complete enough?

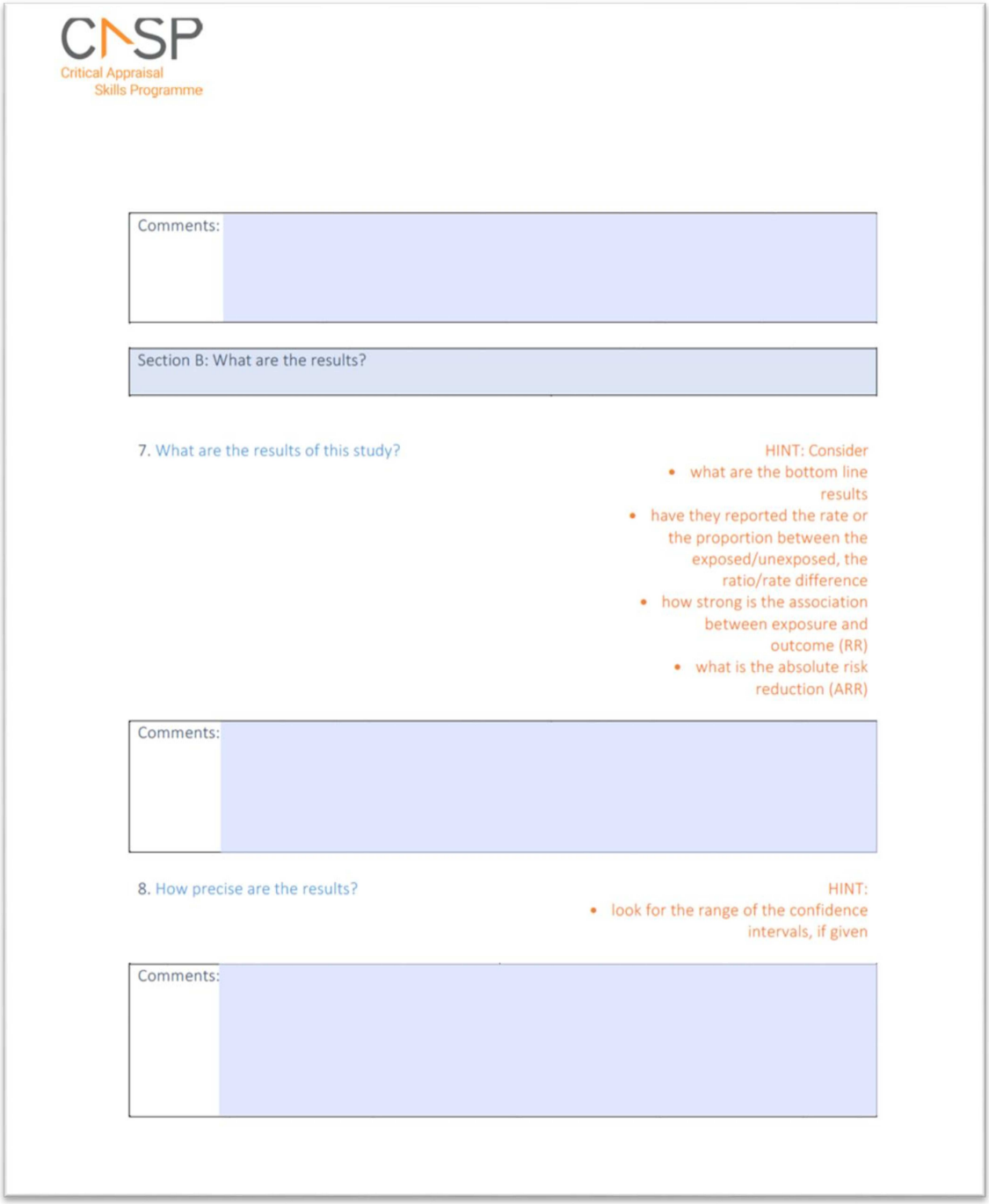
Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- the good or bad effects should have had long enough to reveal themselves
- the persons that are lost to follow-up may have different outcomes than those available for assessment
- in an open or dynamic cohort, was there anything special about the outcome of the people leaving, or the exposure of the people entering the cohort

6. (b) Was the follow up of subjects long enough?

Yes ☐
Can't Tell ☐
No ☐

2.4 Critical Appraisal Skills Programme (CASP): page 4



CASP
Critical Appraisal Skills Programme

Comments:

Section B: What are the results?

7. What are the results of this study?

HINT: Consider
- what are the bottom line results
- have they reported the rate or the proportion between the exposed/unexposed, the ratio/rate difference
- how strong is the association between exposure and outcome (RR)
- what is the absolute risk reduction (ARR)

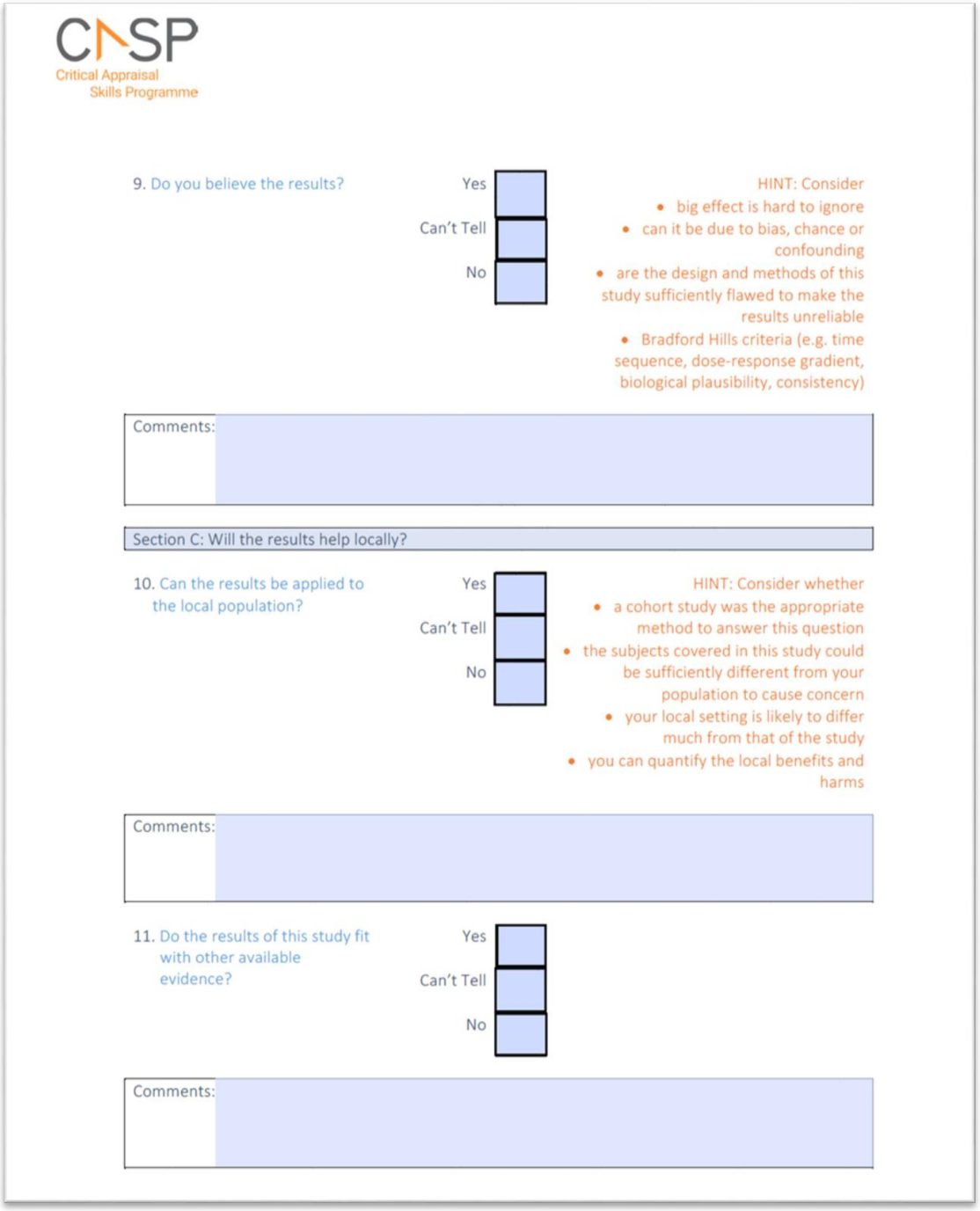
Comments:

8. How precise are the results?

HINT:
- look for the range of the confidence intervals, if given

Comments:

2.5 Critical Appraisal Skills Programme (CASP): page 5



CASP
Critical Appraisal Skills Programme

9. Do you believe the results?

Yes
Can't Tell
No

HINT: Consider
- big effect is hard to ignore
- can it be due to bias, chance or confounding
- are the design and methods of this study sufficiently flawed to make the results unreliable
- Bradford Hills criteria (e.g. time sequence, dose-response gradient, biological plausibility, consistency)

Comments:

Section C: Will the results help locally?

10. Can the results be applied to the local population?

Yes
Can't Tell
No

HINT: Consider whether
- a cohort study was the appropriate method to answer this question
- the subjects covered in this study could be sufficiently different from your population to cause concern
- your local setting is likely to differ much from that of the study
- you can quantify the local benefits and harms

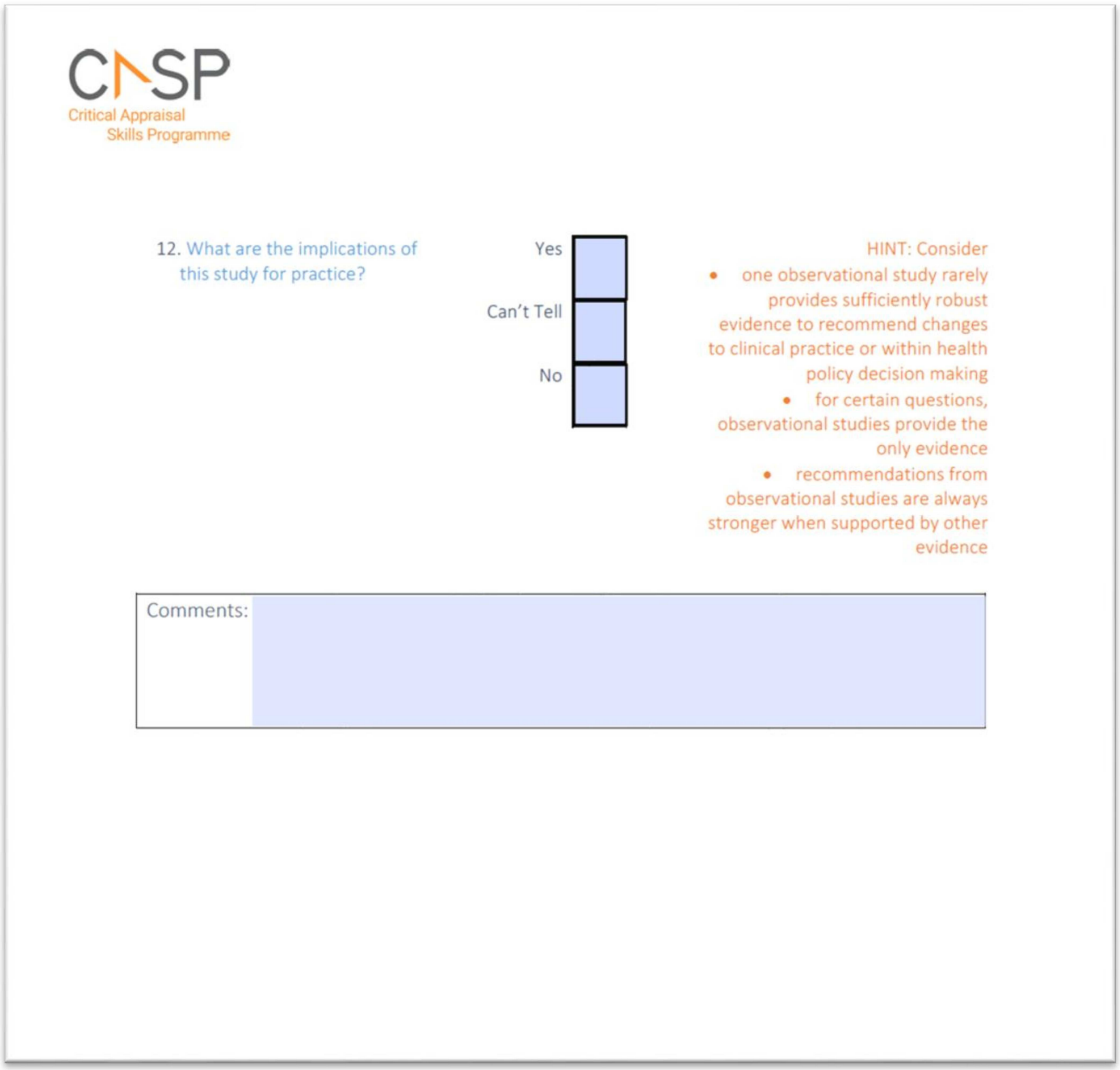
Comments:

11. Do the results of this study fit with other available evidence?

Yes
Can't Tell
No

Comments:

2.6 Critical Appraisal Skills Programme (CASP): page 6



3. Supplementary CASP Table 6, Quality assessment tools for the included studies in the systematic review.

Authors, date	The study addressed a clearly focused issue	Use of an appropriate method	Recruitment/ comparability of a study group at baseline	Exposure measurement	Outcome measurement	Follow up for longitudinal studies	Confounding factors	Applicability	Overall
Plumb et al, 2019	High	High	High	High	High	High	Medium	High	High
Buron, 2017	High	High	High	High	High	NA	low	High	High
Ghanouni, 2015	High	High	High	High	High	High	Medium	High	High
Denters, 2012	High	High	Medium	High	High	Low	Low	High	Medium
Gupta, 2012	Medium	High	Low	Medium	High	High	Low	High	Medium
Sarkar, 2012	Medium-low	High	Low	Medium	Medium	low	Low	low	Medium