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Patients' experience of colonoscopy in the English Bowel Cancer Screening Programme

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Abstract

Background and study aims: Understanding patients' experience of screening programmes is crucial for service improvement. The English Bowel Cancer Screening Programme (BCSP) aims to achieve this by sending out questionnaires to all patients who undergo a colonoscopy following an abnormal faecal occult blood test result. This study used the questionnaire data to report experiences of these patients.

Patients and methods: Data on patients who underwent colonoscopy between 2011 and 2012 were extracted from the BCSP database. Descriptive statistics summarised key questionnaire items related to informed choice, psychological wellbeing, physical experience, and after-effects. Multilevel logistic regression was used to test for associations with variables of interest: gender, age, socioeconomic status, colonoscopy results, and screening centre performance (adenoma detection rate, caecal intubation rate, proportion of colonoscopies involving sedation).

Results: Data from 50,858 patients (79.3% of those eligible) were analysed. The large majority reported a positive experience on items relating to informed choice (e.g. 95.7% felt they understood the risks) and psychological wellbeing (e.g. 98.3% felt treated with respect). However, an appreciable proportion experienced unexpected test discomfort (21.0%) or pain at home (14.8%). There were few notable demographic differences although women were more likely to experience unexpected discomfort (25.1% vs. 18.0%; $p<0.01$) and pain at home (18.2% vs 12.3%; $p<0.01$). No associations were apparent with centre-level variables.

Conclusions: Colonoscopy experience is generally positive, suggesting high satisfaction with the BCSP. Reported pain and unexpected discomfort are more negative than most other outcomes (particularly for women); measures to improve this should be considered.

Introduction

The National Health Service (NHS) Bowel Cancer Screening Programme (BCSP) in England was initiated in light of strong evidence that screening is effective in reducing colorectal cancer (CRC) mortality when individuals aged 60-74 years are offered a biennial guaiac Faecal Occult Blood test (gFOBt) and those who receive an abnormal result are offered a colonoscopy [1,2,3]. As a matter of routine, the BCSP posts a questionnaire to all individuals who undergo colonoscopy, asking about their experience. The national scale of the programme means that a large volume of patient experience data is collected.

The systematic assessment of patients' experience of healthcare is an increasingly important part of refining quality and effectiveness of service delivery [4]. Data on patients' experience can be used to identify aspects of a service that warrant improvement, that are poorer for particular subgroups of patients, or that are associated with markers of clinical performance, which allows for more effective allocation of resources. Measures of patients' experience have been used in a diverse range of contexts including general practice [5], elective surgery [6], and chronic heart failure [7], and have recently been incorporated into measures of quality in the NHS in England [8]. Screening programmes like the BCSP can use routinely collected data to highlight potential improvements and inform other screening programmes. For example, programme data has been used to understand how adjusting the threshold for categorising a gFOBt sample as 'abnormal' would affect cancer detection rates and colonoscopy activity [9]. Evaluating questionnaire data would help devise methods of improvement and strategic planning in the domain of patients' experience as well.

We describe patients' experience of colonoscopy over two years of the English BCSP using routinely recorded patient-reported data. Questionnaire items considered particularly important were those related to informed choice, psychological wellbeing, physical experience, and after-effects of the colonoscopy procedure. We also compare experience between demographic subgroups (gender, age, area-level socioeconomic deprivation),

screening results, and centre-level variables (adenoma detection rates, caecal intubation rates, proportion of colonoscopies involving any sedation use at investigating hospitals) in order to explore potentially important associations.

Method

Participants

The organisation and screening pathway used by the English BCSP is reported in detail elsewhere [2,3]. In brief, individuals in the eligible age range and registered at any General Practice are invited to undertake gFOBt at home and then return it by post to a laboratory at one of five "Screening Hubs" for analysis. Individuals older than 74 years are also able to participate by manually requesting a kit. Participants receiving an abnormal gFOBt result are invited to one of 62 "Screening Centres" (59 existed during the study period) for an appointment with a Specialist Screening Practitioner (SSP), who assesses suitability for colonoscopy, explains the procedure, and answers questions. Centres are also where colonoscopies ultimately take place. The BCSP began rollout in 2006 and the process was completed in 2010. As of December 2014, the BCSP had invited over 24 million people, received over 25.7 million test kits, which precipitated over 272,000 colonoscopies (Bowel Evaluation Group, February, 2015, personal communication).

The sampling population consisted of all patients who underwent colonoscopy following an abnormal gFOBt result in the English BCSP and were sent a questionnaire. Data were extracted for all such procedures between 1st January 2011 and December 31st 2012 (i.e. two full years after completion of the programme's rollout in 2010). Completion and return of the questionnaire indicated implied consent to participate in this service evaluation [10]. Ineligible patients were excluded based on the following criteria: i) tested outside the date range of interest; ii) undergoing surveillance rather than screening; iii) did not receive colonoscopy, iv) experienced an administrative error with their questionnaire; v) investigated at more than one centre or had no centre recorded; vi) did not have a screening result (i.e.

the most severe test result that a patient received during their screening episode, ranging from cancer to a normal result); vii) did not have postcode data (necessary for determining area-level socioeconomic deprivation; described below).

Based on guidance from the Health Research Authority, Research Ethics Committee approval was deemed unnecessary for this service evaluation [11]. Permission was granted to access anonymised data by the English Bowel Cancer Screening Research Committee.

Procedures

Colonoscopy is performed to nationally mandated standards; all colonoscopists are required to demonstrate experience, knowledge, and competence in order to achieve accreditation [3] [12]. Performance of colonoscopists within the BCSP is also monitored via several key metrics, such as adenoma detection rates and caecal intubation rates. Previous research has found high levels of both quality and safety [3]. All patients were provided with one of several forms of bowel preparation (per centre preference).

Measures

The precise number of questionnaire items varies depending on whether patients' episodes were for screening or surveillance (i.e. following previous removal of adenomas), and whether they had endoscopic or radiological testing, or both. The most commonly used questionnaire (for screening patients who underwent colonoscopy alone) consists of 35 items (Appendix 1). The alternative questionnaire applicable to this study (for screening patients who received both colonoscopy and radiological tests) consists of 52 items; most items relating to the radiological test are identical to those for the endoscopic test (Appendix 2). Most items are answered on either a 5-point Likert scale ranging from *"strongly agree"* to *"strongly disagree"* (e.g. *"I felt I had an understanding of the risks of having a colonoscopy"*) or via 2 or 3 response options (*"yes"*, *"no"*, *"don't remember"*; e.g. for *"During the colonoscopy, I asked for it to be stopped or paused"*).

The questionnaire assesses experience that is relevant to several key concerns regarding service delivery. Colonoscopy should cause as little pain and discomfort as possible and so two items measure unexpected discomfort during the test and whether it was stopped or paused. Data are also collected regarding bleeding and pain after going home. Since patients' experience is affected by more than the physical aspects of the investigation [13], measures of psychological wellbeing are included, such as whether patients felt they were treated with respect and given sufficient privacy at the hospital. Furthermore, the National Screening Committee has set a policy goal of ensuring that invitees make an informed choice before undergoing the test [14]. Consequently, the questionnaire also asks patients whether they felt they understood the risks and benefits, and whether they were given clear information regarding the bowel preparation. These ten questions (relating to the four topics of interest) were selected for analysis, following discussion between the authors regarding the items that were expected to be the most valid and important to patients' experience (Table 3).

In addition to questionnaire data, the Bowel Cancer Screening System (BCSS) records demographic information on patients' age, gender and postcode. The latter was used to derive an area-level measure of socioeconomic deprivation (Index of Multiple Deprivation; IMD) using an online tool (GeoConvert) [15]. IMD scores consist of a composite measure of education, income, housing, health and environment; higher scores represent greater deprivation [16]. The BCSS records details of previous screening participation, test results, and the centre at which patients were investigated. Centre-level data on the proportion of colonoscopies during which sedation was administered (either intravenously or nitrous oxide and oxygen), adenoma detection rates, and caecal intubation rates were also available. Questionnaires are prepared with patients' NHS Numbers (but no other identifying information) before they are disseminated, which allowed these fields were to be extracted from the BCSS for all patients investigated during the date range of interest and matched with questionnaire data.

Analysis

Data cleaning, recoding and analysis used SPSS 22 for Windows (IBM, Armonk, NY, USA) and R 3.0.1 for Mac OS X (R Foundation for Statistical Computing, Vienna, Austria). For patients responding to at least one item, missing data were addressed using 10 multiple imputations under the missing at random assumption [17] as part of a parallel study comparing patients' experience of colonoscopy and Computed Tomographic colonography (submitted). The imputation models used fully conditional specification, with predictive mean matching for continuous variables, ordered logistic regression for ordinal variables and multinomial logistic regression for categorical variables. Imputation models included patient age, gender, IMD, screening round type (i.e. whether a patient was participating in gFOBt screening for the first time or whether they had participated at least once before [18]), test type, screening result, and responses to questionnaire items [19]. Model fit was assessed by diagnostic plots and comparing imputed and non-imputed data via worm plots to estimate distributional discrepancy.

The analysis consisted of four components: i) testing whether patient-level variables were associated with (non-)response to the questionnaire; ii) summarising overall questionnaire outcomes; testing whether iii) patient-level and iv) centre-level variables were associated with questionnaire outcomes.

For i), iii), and iv), multilevel logistic regression was used; screening centre was included as a higher-level variable to account for possible clustering effects. Odds ratios and p-values (adjusted, based on all independent variables) are reported alongside crude overall proportions (e.g. the proportions of men and women responding to the questionnaire). For i) and iii), patient-level independent variables consisted of gender, age, IMD, and screening result. Screening round type was incorporated as a covariate. Participant-reported sedation use was also added as a covariate for iii) (except when this was an outcome variable). Age and IMD were divided into tertiles to facilitate interpretation.

For ii), descriptive statistics were used to summarise crude overall imputed proportions of participants (strongly) agreeing or stating *'yes'* for each of the 10 questionnaire items. These also comprised the outcomes for iii). For analyses of associations between questionnaire items and screening result (in iii) or centre-level variables (in iv), outcomes consisted of the four that were considered most likely to be related (Table 6).

For iv), available centre-level independent variables were first summarised using descriptive statistics. Models were then constructed for each of the four relevant questionnaire items, with and without each of the independent variables. A likelihood ratio test was used to test whether any improved model fit. In all analyses of imputed data (i.e. ii), iii), and iv), models were constructed for each imputation and pooled [20].

Results

Participant characteristics and variables associated with questionnaire response

Out of the original data extraction of 79,493 patients who were sent the questionnaire, 64,152 eligible patients remained after exclusions (Table 1), of whom 50,858 responded to the questionnaire and were included in the main analysis (79.3%). The final sample consisted of 29,792 (58.6%) males, had a median age of 66 years (interquartile range [IQR]: 63 to 69) and a median IMD score of 14.6 (IQR: 8.6 to 24.6). 22,091 (43.4%) were participating in gFOBt screening for the first time. Cancer was diagnosed in 8.3% of participants and adenomas were found in a further 43.9% of participants. Patients were marginally more likely to respond if they were in an older tertile, living in a less deprived tertile, or were diagnosed with adenomas rather than cancer (differences between categories were no more than 9.2%; $p<.01$). Full results for the analysis of associations with whether patients responded to the questionnaire are reported in Table 2.

Overall questionnaire outcomes

For the individuals who had responded to at least one questionnaire item, further missing data were minimal, ranging from 1.4% to 2.7% of participants for each variable (i.e. if participants responded to the questionnaire at all, they usually completed every item). Consequently, the imputed models were considered realistic and highly plausible.

Responses to items relating to informed choice were almost always positive for all three relevant items. The overall imputed percentages of participants (strongly) agreeing that they had an understanding of the risks and benefits were 95.7% and 98.2%, respectively. With respect to information about bowel preparation, 97.8% of participants felt it was clear. Responses were also nearly unanimous for items on psychological wellbeing. 98.3% of participants stated that they were treated with respect and 97.9% endorsed the item on whether their privacy was maintained. Experience was notably more mixed in terms of items on physical discomfort: 21.0% of participants experienced more discomfort than expected and 5.1% asked for the colonoscopy to be stopped/paused. Use of sedation was reported by 79.1% of participants. It was also not uncommon for participants to report pain after going home (14.8%), or bleeding after going home (7.6%).

Exploratory subgroup analyses – associations between experience and demographics or screening results

Demographic characteristics were statistically significantly associated with various aspects of participants' experience. In several cases, this corresponded with moderately large adjusted odds ratios (e.g. of agreeing or strongly agreeing with questionnaire items for males vs. females) and appreciable absolute differences between demographic characteristics. Specifically, in the case of gender, women were more likely to report unexpected discomfort (crude imputed proportions: 25.1% vs. 18.0%), to report receiving sedation (86.7% vs. 73.6%), to ask for the test to be stopped/paused (6.8% vs. 3.9%), and to report pain after going home (18.2% vs. 12.3%). Furthermore, in analyses of age, >64 to 68 year old participants and >68 to 93 year old participants were slightly less likely to report pain after

going home (13.8% and 12.8%, respectively) compared to 59 to 64 year old participants (16.9%). Finally, individuals in the most socioeconomically deprived tertile were slightly more likely to report unexpected discomfort (23.0%) than in the least deprived tertile (19.5%). This was also the case for pain after going home (16.1% vs. 13.6%). Participants in the most deprived tertile were also less likely to report sedation administration than those in the least deprived tertile (75.8% vs. 81.2%). There were few meaningful associations between screening results and the four outcomes of interest. Compared with the reference group of participants diagnosed with cancer, participants diagnosed with high-risk adenomas were more likely to report pain after going home (18.6% vs. 15.0%). In addition, participants with adenomas (low-, intermediate-, or high-risk) or normal results were less likely to report bleeding after going home compared to participants diagnosed with cancer (3.3 to 11.2% vs. 15.1%).

Crude imputed proportions of participants (strongly) agreeing or responding *"yes"* to the main outcomes of interest are reported by gender (Table 3), age tertiles (Table 4), IMD tertiles (Table 5), and screening results (Table 6) along with adjusted odds ratios, 95% confidence intervals (CIs) and p-values (also for imputed sample data).

Exploratory subgroup analyses – centre level associations with experience

The three centre-level variables included in this analysis were adenoma detection rate (median percentage across all centres: 47.8%; IQR: 44.4% to 50.1%), caecal intubation rate (median: 95.4%; IQR: 93.9% to 96.5%), and proportion of colonoscopies involving sedation (median: 92.5%; IQR: 81.8% to 97.9%). No associations were found between any of the centre-level variables and the four outcomes of interest. Given that missing data were minimal, results of analyses on non-imputed data are not reported since they did not differ meaningfully for any models.

Discussion

Patient experience is a fundamental element of healthcare delivery [21] and should be a priority in screening programmes. Previous comparable studies of patients' experience of colonoscopy using the Global Rating Scale have been relatively small, limited to a subset of national endoscopy departments, and not necessarily specific to a screening context [22,23]. In contrast, this study comprised a large sample of patients investigated with colonoscopy following an abnormal gFOBt result, making this one of the largest studies of patient experience in the context of cancer screening. The response rate was high and similar to comparable previous research [24], meaning that the results are likely to be highly representative and applicable to the target population. We found that experience was positive for most participants for most items assessed. With respect to items relating to feeling informed, the overwhelming majority of participants reported understanding the risks and benefits of colonoscopy, and agreed that information for bowel preparation was clear. This suggests that participants were satisfied with the information provided by leaflets and screening practitioners. It was also reassuring that there were no large social disparities (in terms of deprivation, gender or age) on these items. This provides some evidence that participants across all demographic groups felt well-informed about the test [25,26,27]. However, it is important to remain cautious about making any inferences about the extent to which these participants made an informed choice to undergo colonoscopy. By definition, objective understanding is a more relevant facet of *'informed'* choice than subjective understanding [28] and the available measures only assess the latter. Previous research has found that patients' overall knowledge of colonoscopy (as a first-line screening test in the US) is generally low, even after discussion with a clinician [29] and the very high proportion of participants who reported that they felt they had an understanding may be an indication that they had overestimated their knowledge.

The large majority of participants' also reported a positive experience in terms of their psychological wellbeing at the hospital, with most participants agreeing that they felt they were treated with respect and given enough privacy. In some respects, this corresponds with

previous findings that embarrassment during colonoscopy is generally minimal [24]. There were no meaningful differences observed between men and women; this is reassuring given previous research suggesting that feelings of vulnerability and embarrassment are more common in women [13].

In relation to the colonoscopy experience itself, results were more mixed. Although only a small proportion asked for the procedure to be stopped/paused (5.1%), approximately 1 in 5 participants reported experiencing more discomfort than they had expected. Furthermore, in terms of after-effects, 14.8% reported pain after going home. Women were more likely to report both unexpected discomfort and pain at home than men, which adds to previous research indicating that women report greater overall levels of pain and discomfort during the colonoscopy procedure itself [30,31]. Previously suggested reasons include colonoscopy being more technically difficult in women due to greater colonic length [32] and also lower pain thresholds in women [33]. In addition to pain, women were slightly more likely to report bleeding after going home, meaning they represent a group for whom there is likely to be greater scope to improve experience.

Pain after going home was also reported slightly more often in younger participants. As with women, greater overall discomfort and pain has previously been observed for younger patients during colonoscopy itself [30]. Possible reasons include decreasing perceptions of pain with age [34] but also greater stoicism or reluctance to rate healthcare negatively in older patients [35]. However, there is limited evidence to support these possibilities, which should also be interpreted in the context of the small absolute differences observed here.

Although it was unsurprising that participants diagnosed with cancer were more likely to report bleeding than participants with adenomas or normal results, the finding that participants diagnosed with high-risk adenomas were more likely to report pain after going home than participants diagnosed with cancer was somewhat more unexpected. This may reflect differences in therapeutic approaches: removal of a high-risk (i.e. relatively large)

adenoma entails a more protracted process involving insufflation with greater potential for pain in comparison to a biopsy, which is the more likely intervention when a cancer is observed.

The overall levels of unexpected discomfort suggest that the counselling patients receive from SSPs prior to the procedure could be improved and this may be particularly true for more deprived individuals and women. It also emphasises the need for endoscopists to attend to patients' physical well-being during the procedure in order to minimise discomfort and pain. Carbon dioxide insufflation is not mandated within the programme but widespread utilisation may reduce the prevalence of pain after going home, in addition to post-procedural advice on pain management.

We found no associations in terms of centre-level adenoma detection rates, caecal intubation rates, or proportion of colonoscopies involving sedation and potentially related outcomes. For some independent variables, this was not surprising since there was little variance (e.g. caecal intubation rates were high and IQR was narrow). However, only centre-level data were available, rather than endoscopist- or patient-level data, so these findings should be interpreted with appropriate caution.

A limitation related to the large sample was that absolute differences between comparator and reference groups in subgroup analyses were often marginal and unlikely to be of practical importance, despite small p-values and moderately large odds ratios. For example, after adjusting for possible confounding variables, the odds ratio for females vs. males (strongly) agreeing that they understood the risks of having a colonoscopy was 0.83 (95% CI: 0.76 to 0.91; p<.0005), which corresponds to an absolute difference of only 0.7% (95.3% vs. 96.0%). As a result, we focused our interpretation on the largest differences that we judged most likely to be clinically important. Further limitations relate primarily to shortcomings of the questionnaire. For example, although unexpected discomfort is measured, patients are not able to report the absolute degree of discomfort or pain

experienced during the procedure. Moreover, the item relating to whether the colonoscopy was stopped/paused does not allow patients to distinguish between the two, despite the substantially different implications (a diagnostic test with longer duration vs. an incomplete one).

In addition to the inability of the questionnaire to assess informed choice objectively, it does not assess patients' views on the decision-making process for colonoscopy. There is evidence that only a small proportion of patients would prefer to make a completely autonomous decision for first-line gFOBt screening, while the majority would prefer guidance or a recommendation from a clinical authority [36]. It is unclear to what extent patients felt they were encouraged to participate in a process of shared decision-making by the SSP and whether this matched their preferences.

More generally, the questionnaire is not validated and so items reported here were selected on the basis of our subjective judgements regarding which items had superior face validity and relevance to patients. Although this resulted in a pool of items that assessed a wide range of topics, the questionnaire is likely to omit important aspects of patients' experience (in addition to those already suggested). For example, the questionnaire does not assess experience of bowel preparation, which has been found to be the worst part of whole-colon testing [24] [37,38]. Another notable omission is the lack of items relating to the extent of any interruption to daily routine [24].

There are established methods of developing psychometrically sound measures of patients' experience. For example, interviews and discussion groups involving patients who have undergone the test can be used to compile a pool of potentially relevant items [39,40]. This provisional set can then be piloted as a questionnaire in order to determine a final measure that is both reliable and valid. However, it is unclear what the development process was for the current questionnaire and whether any patient input went into producing it. A previous review found that measures are often limited by a lack of patient involvement to determine

key determinants of their experience [41] and clinicians are often poor at judging what these determinants are [39] [42]. It is highly likely that these limitations also apply to the current questionnaires. Hence, a rigorously designed Patient-Reported Experience Measure (PREM) is likely to be able to make a greater contribution to service delivery than the existing ad-hoc measure.

In conclusion, the large majority of self-reported experience of colonoscopy is positive on key outcomes in the existing questionnaire. Although it would be beneficial to revise the questionnaire so that it more accurately and completely assesses patients' experience, data from the existing questionnaire highlights scope for improvement in several areas. It may be possible to more effectively assess and manage patients' expectations regarding possible levels of discomfort during colonoscopy, for endoscopists to further reduce discomfort during the procedure itself, and to provide more advice on managing pain after patients have gone home (including information regarding support available after the test). Such interventions may be particularly effective for women, younger patients and individuals that are more deprived.

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Tables

Table 1 - Numbers and percentages of patients excluded from the original extraction of 79,493 patients

Reason for exclusion	n (%)
Tested for the purpose of adenoma surveillance, not screening	12,316
Did not receive colonoscopy	1,876
Tested outside applicable date range	920
Did not have IMD data	106
Administrative error with the questionnaire	76
Investigated at more than one centre or had no centre record	46
Did not have most severe test result data	1
Total excluded	**15,341**

Table 2 – Analysis of variables potentially associated with whether patients responded to the questionnaire (p-values <0.01 are in bold)

Independent variable	Crude overall n (%) not responding / responding				Variable level vs. reference category	
	Non-responders (n=13,294)		Responders (n=50,858)		Adjusted OR (95% CI)	p-value
Gender						
Females	5,778	*21.5*	21,066	*78.5*	0.95 (0.91 to 0.99)	0.01
Males (reference category)	7,516	*20.1*	29,792	*79.9*		
Age						
>68-93 years	3,280	*18.0*	14,935	*82.0*	1.30 (1.24 to 1.37)	**<0.01**
>64 to 68 years	3,824	*19.5*	15,807	*80.5*	1.14 (1.08 to 1.20)	**<0.01**
59 to 64 years (reference category)	6,190	*23.5*	20,116	*76.5*		
IMD* tertiles						
High	4,441	*26.0*	12,667	*74.0*	0.64 (0.60 to 0.67)	**<0.01**
Medium	4,815	*20.9*	18,263	*79.1*	0.84 (0.79 to 0.88)	**<0.01**
Low (reference category)	4,038	*16.8*	19,928	*83.2*		
Screening result						
High-risk adenoma	1,133	*18.8*	4,905	*81.2*	1.30 (1.18 to 1.43)	**<0.01**
Intermediate-risk adenoma	1,658	*17.2*	7,990	*82.8*	1.41 (1.30 to 1.54)	**<0.01**
Low-risk adenoma	2,452	*20.6*	9,438	*79.4*	1.13 (1.04 to 1.23)	**<0.01**
Abnormal (no histology)	65	*27.2*	174	*72.8*	0.77 (0.57 to 1.04)	0.09
Abnormal	4,000	*20.6*	15,456	*79.4*	1.10 (1.02 to 1.19)	0.01
Normal (no abnormalities detected)	2,802	*24.4*	8,690	*75.6*	0.98 (0.91 to 1.07)	0.69
Cancer (reference category)	1,184	*22.0*	4,205	*78.0*		

IMD: Index of Multiple Deprivation; OR: Odds ratio; CI: Confidence interval
Covariates: Screening round type; Screening centre (as a higher-level variable)

Table 3 – Analysis of imputed questionnaire responses by gender (p-values <0.01 are in bold)

Item	Crude overall n (%) agreeing / strongly agreeing / stating yes				Females vs. males	
	Males (n=29,792)		Females (n=21,066)		Adjusted OR (95% CI)	p-value
Informed choice						
I felt I had an understanding of **the risks** of having a colonoscopy	28,593	*96.0*	20,073	*95.3*	0.83 (0.76 to 0.91)	**<0.01**
I felt I had an understanding of **the benefits** of having a colonoscopy	29,301	*98.4*	20,652	*98.0*	0.81 (0.70 to 0.93)	**<0.01**
I was given clear information on how to take the bowel prep medicine (laxative)	29,185	*98.0*	20,579	*97.7*	0.87 (0.76 to 0.99)	0.04
Psychological wellbeing						
I feel I was treated with respect during my visit to the hospital	29,323	*98.4*	20,694	*98.2*	0.89 (0.77 to 1.03)	0.12
I feel that my privacy was maintained as much as possible during my visit to the hospital	29,115	*97.7*	20,663	*98.1*	1.20 (1.05 to 1.37)	0.01
Physical aspects of colonoscopy						
The colonoscopy was more uncomfortable than I expected	5,376	*18.0*	5,290	*25.1*	1.62 (1.55 to 1.70)	**<0.01**
I was given sedation for my colonoscopy (sedation is a drug to make you feel relaxed)	21,940	*73.6*	18,272	*86.7*	2.49 (2.37 to 2.62)	**<0.01**
During the colonoscopy, I asked for it to be stopped or paused	1,159	*3.9*	1,441	*6.8*	1.97 (1.81 to 2.14)	**<0.01**
Colonoscopy after-effects						
After going home, I suffered from pain in my bottom and/or stomach	3,671	*12.3*	3,838	*18.2*	1.70 (1.62 to 1.80)	**<0.01**
After going home, I had bleeding from my bottom	2,432	*8.2*	1,432	*6.8*	0.92 (0.86 to 0.99)	0.03

Covariates: Screening round type; Sedation use (except where this was the outcome); Screening centre (as a higher-level variable)

Table 4 – Analysis of imputed questionnaire responses by age tertiles (p-values <0.01 are in bold)

Item	Crude overall n (%) agreeing / strongly agreeing / stating yes						>64-68 vs. 59-64		>68-93 vs. 59-64	
	59-64 (n=20,116)		>64-68 (n=15,807)		>68-93 (n=14,935)		Adjusted OR (95% CI)	p-value	Adjusted OR (95% CI)	p-value
Informed choice										
I felt I had an understanding of **the risks** of having a colonoscopy	19,252	*95.7*	15,154	*95.9*	14,261	*95.5*	0.99 (0.89 to 1.10)	0.39	0.92 (0.82 to 1.02)	0.12
I felt I had an understanding of **the benefits** of having a colonoscopy	19,751	*98.2*	15,544	*98.3*	14,658	*98.1*	1.03 (0.87 to 1.22)	0.38	0.92 (0.78 to 1.09)	0.24
I was given clear information on how to take the bowel prep medicine (laxative)	19,646	*97.7*	15,489	*98.0*	14,629	*98.0*	1.17 (1.01 to 1.37)	0.05	1.13 (0.97 to 1.32)	0.11
Psychological wellbeing										
I feel I was treated with respect during my visit to the hospital	19,731	*98.1*	15,537	*98.3*	14,750	*98.8*	1.09 (0.93 to 1.29)	0.22	1.50 (1.24 to 1.81)	**<0.01**
I feel that my privacy was maintained as much as possible during my visit to the hospital	19,594	*97.4*	15,474	*97.9*	14,710	*98.5*	1.21 (1.05 to 1.41)	0.01	1.69 (1.43 to 2.00)	**<0.01**
Physical aspects of colonoscopy										
The colonoscopy was more uncomfortable than I expected	4,337	*21.6*	3,288	*20.8*	3,042	*20.4*	0.96 (0.91 to 1.02)	0.16	0.95 (0.90 to 1.00)	0.06
I was given sedation for my colonoscopy (sedation is a drug to make you feel relaxed)	15,740	*78.2*	12,484	*79.0*	11,988	*80.3*	1.02 (0.96 to 1.08)	0.34	1.03 (0.97 to 1.09)	0.25
During the colonoscopy, I asked for it to be stopped or paused	1,166	*5.8*	788	*5.0*	646	*4.3*	0.88 (0.79 to 0.97)	0.01	0.77 (0.70 to 0.86)	**<0.01**
Colonoscopy after-effects										
After going home, I suffered from pain in my bottom and/or stomach	3,404	*16.9*	2,188	*13.8*	1,917	*12.8*	0.78 (0.73 to 0.83)	**<0.01**	0.72 (0.67 to 0.76)	**<0.01**
After going home, I had bleeding from my bottom	1,610	*8.0*	1,151	*7.3*	1,102	*7.4*	0.88 (0.81 to 0.95)	**<0.01**	0.84 (0.78 to 0.92)	**<0.01**

Covariates: Screening round type; Sedation use (except where this was the outcome); Screening centre (as a higher level variable)

Table 5 – Analysis of imputed questionnaire responses by IMD tertiles (p-values <0.01 are in bold)

Item	Crude overall n (%) agreeing / strongly agreeing / stating yes						Medium vs. Low		High vs. Low	
	Low (n=19,928)		Medium (n=18,263)		High (n=12,667)		Adjusted OR (95% CI)	p-value	Adjusted OR (95% CI)	p-value
Informed choice										
I felt I had an understanding of **the risks** of having a colonoscopy	19,167	*96.2*	17,476	*95.7*	12,023	*94.9*	0.88 (0.79 to 0.98)	0.03	0.77 (0.68 to 0.87)	**<0.01**
I felt I had an understanding of **the benefits** of having a colonoscopy	19,597	*98.3*	17,958	*98.3*	12,398	*97.9*	1.01 (0.86 to 1.18)	0.40	0.81 (0.69 to 0.96)	0.02
I was given clear information on how to take the bowel prep medicine (laxative)	19,503	*97.9*	17,863	*97.8*	12,398	*97.9*	0.98 (0.85 to 1.13)	0.38	1.04 (0.88 to 1.23)	0.37
Psychological wellbeing										
I feel I was treated with respect during my visit to the hospital	19,592	*98.3*	17,976	*98.4*	12,449	*98.3*	1.09 (0.93 to 1.29)	0.23	1.04 (0.87 to 1.25)	0.36
I feel that my privacy was maintained as much as possible during my visit to the hospital	19,479	*97.7*	17,918	*98.1*	12,381	*97.7*	1.18 (1.02 to 1.37)	0.04	1.02 (0.87 to 1.19)	0.39
Physical aspects of colonoscopy										
The colonoscopy was more uncomfortable than I expected	3,880	*19.5*	3,878	*21.2*	29,09	*23.0*	1.12 (1.06 to 1.18)	**<0.01**	1.24 (1.17 to 1.32)	**<0.01**
I was given sedation for my colonoscopy (sedation is a drug to make you feel relaxed)	16,190	*81.2*	14,423	*79.0*	9,599	*75.8*	0.93 (0.88 to 0.98)	0.01	0.88 (0.82 to 0.93)	**<0.01**
During the colonoscopy, I asked for it to be stopped or paused	1,007	*5.1*	929	*5.1*	664	*5.2*	0.99 (0.9 to 1.09)	0.39	1.00 (0.9 to 1.12)	0.40
Colonoscopy after-effects										
After going home, I suffered from pain in my bottom and/or stomach	2,720	*13.6*	2,748	*15.0*	2,041	*16.1*	1.12 (1.06 to 1.19)	**<0.01**	1.22 (1.14 to 1.31)	**<0.01**
After going home, I had bleeding from my bottom	1,494	*7.5*	1,413	*7.7*	957	*7.6*	1.04 (0.96 to 1.13)	0.23	1.02 (0.93 to 1.11)	0.37

Covariates: Screening round type; Sedation use (except where this was the outcome); Screening centre (as a higher-level variable)

Table 6 – Analysis of imputed questionnaire responses by screening results (p-values <0.01 are in bold)

	Item			
Screening result	The colonoscopy was more uncomfortable than I expected	During the colonoscopy, I asked for it to be stopped or paused	After going home, I suffered from pain in my bottom and/or stomach	After going home, I had bleeding from my bottom
Cancer detected (n=4,205)				
Reference category				
Crude overall n; %	887; *21.1*	167; 4.0	633; *15.0*	635; *15.1*
(Strongly) agreeing or stating yes				
High-risk adenoma (n=4,905)				
Crude overall n; %	1,091; *22.2*	276; *5.6*	912; 18.6	549; *11.2*
Adjusted OR (95% CI); p-value	1.15 (1.04 to 1.27); 0.01	1.62 (1.32 to 1.98); **<0.01**	1.36 (1.22 to 1.53); **<0.01**	0.70 (0.62 to 0.79); **<0.01**
Intermediate-risk adenoma (n=7,990)				
Crude overall n; %	1,776; *22.2*	434; *5.4*	1,265; *15.8*	674; *8.4*
Adjusted OR (95% CI); p-value	1.07 (0.98 to 1.17); 0.14	1.39 (1.15 to 1.67); **<0.01**	1.04 (0.93 to 1.15); 0.33	0.51 (0.45 to 0.57); **<0.01**
Low-risk adenoma (n=9,438)				
Crude overall n; %	1,887; *20.0*	455; *4.8*	1,364; *14.4*	657; *7.0*
Adjusted OR (95% CI); p-value	0.94 (0.85 to 1.02); 0.14	1.24 (1.03 to 1.50); 0.03	0.93 (0.84 to 1.03); 0.16	0.42 (0.37 to 0.47); **<0.01**
Abnormal, no histology (n=174)				
Crude overall n; %	73; *42.1*	30; *17.1*	35; *19.9*	19; *11.0*
Adjusted OR (95% CI); p-value	2.52 (1.84 to 3.46); **<0.01**	4.49 (2.90 to 6.95); **<0.01**	1.27 (0.86 to 1.88); 0.19	0.71 (0.43 to 1.16); 0.15
Abnormal (n=15,456)				
Crude overall n; %	3,142; *20.3*	777; *5.0*	2,171;*14.0*	1,039; *6.7*
Adjusted OR (95% CI); p-value	0.89 (0.82 to 0.97); 0.02	1.19 (1.00 to 1.42); 0.06	0.84 (0.76 to 0.93); **<0.01**	0.41 (0.37 to 0.45); **0.01**
Normal (n=8,690)				
Crude overall n; %	1,810; *20.8*	461; *5.3*	1,130; *13.0*	291; *3.3*
Adjusted OR (95% CI); p-value	0.89 (0.81 to 0.98); 0.02	1.19 (0.99 to 1.43); 0.08	0.72 (0.65 to 0.81); **<0.01**	0.19 (0.16 to 0.22); **<0.01**

Covariates: Screening round type; Sedation use; Screening centre (as a higher-level variable)