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Clinician-reported Gloucester Comfort Scale scores underestimate patient discomfort and pain during colonoscopy: insights from comparison with a patient-reported experience measure

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Abstract:

Background

Patient experience is a fundamental element of colonoscopy. The Gloucester Comfort Scale (GCS) is used by clinicians to report patient comfort. However, insights regarding the extent to which clinician-reported GCS scores represent the patient‘s experience are lacking. We assessed the level of agreement between clinician-reported GCS scores and patient-reported discomfort and pain.

Methods

Consecutive patients undergoing colonoscopy at two Dutch endoscopy clinics were included. Patient comfort during colonoscopy was reported using the GCS (1-5 scale). Patients’ colonoscopy experience was assessed using the Newcastle ENDOPREM, a validated endoscopy patient-reported experience measure (PREM). Patients reported both discomfort and pain levels experienced during colonoscopy on a 1-5 scale. Levels of agreement were assessed using Cohen‘s kappa statistic.

Results

For 243 included patients, the GCS score was higher than the discomfort score in 52 (21%) patients, and lower in 72 (30%). GCS score was higher than the pain score in 39 (16%) patients, and lower in 71 (29%). Moderate to severe discomfort and pain (scores <u>></u>3) were reported by 53 (22%) patients for discomfort and 60 (25%) patients for pain. For these patients, the GCS underestimated discomfort and pain levels in almost all cases (discomfort: 49/53 [92%], pain: 54/60 [90%]). The levels of agreement between GCS scores and discomfort and pain scores were minimal (Cohen’s κ: 0.34) and weak (Cohen’s κ: 0.47), respectively.

Conclusions

Clinician-reported GCS scores frequently underestimate the level of discomfort and pain as reported by patients. For accurate monitoring of patients’ colonoscopy experience, the use of PREMs should be considered.

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Clinician-reported Gloucester Comfort Scale scores underestimate patient discomfort and pain during colonoscopy: insights from comparison with a patient-reported experience measure

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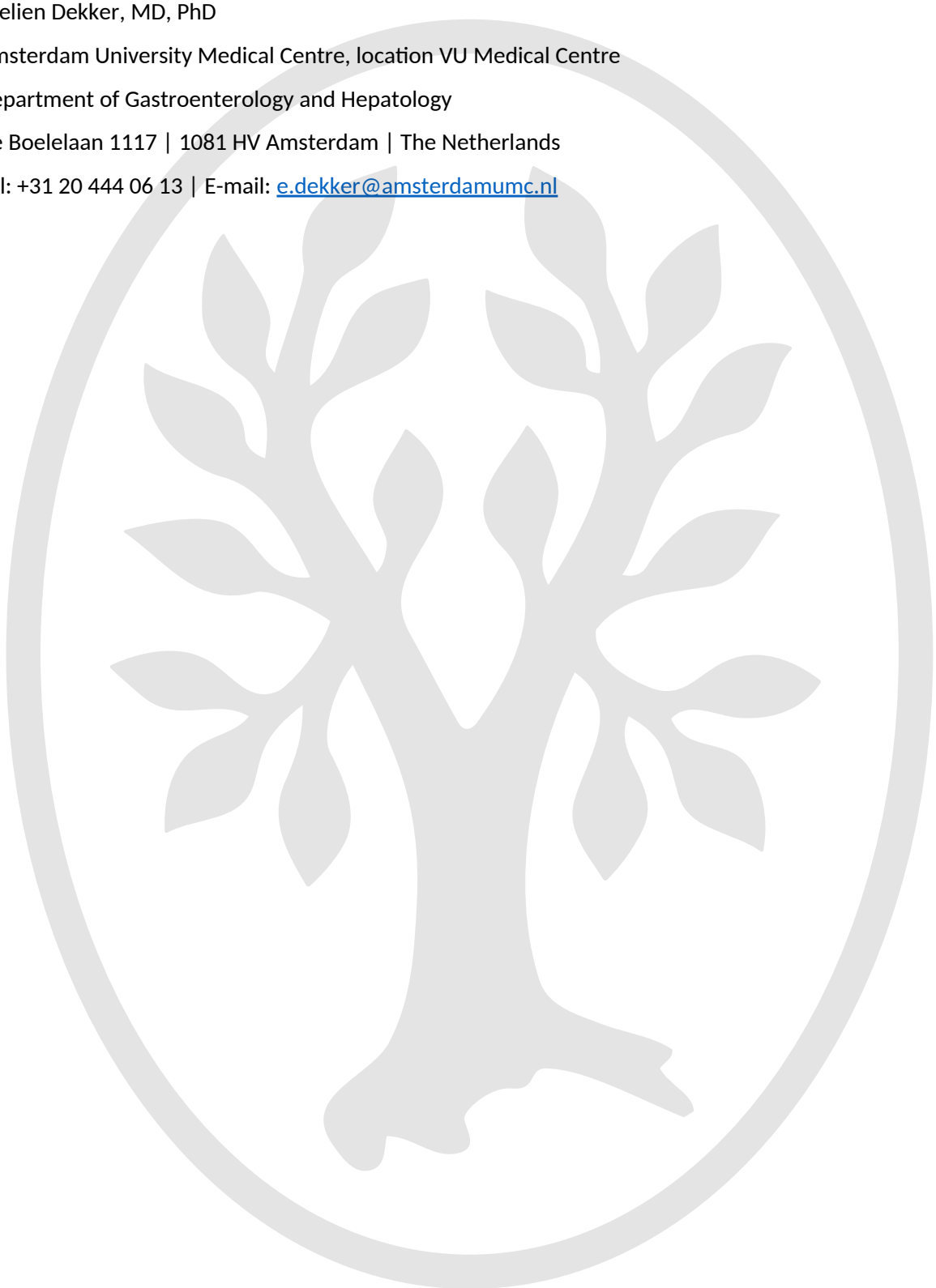

INTRODUCTION

Colonoscopy is the preferred method for diagnosing colorectal diseases. However, patients may perceive colonoscopy as an uncomfortable, painful and embarrassing procedure. A previous negative colonoscopy experience can lead to decreased patient satisfaction and a negative attitude towards colonoscopy, potentially hampering participation in future screening activities, adherence to surveillance recommendations and diagnostic workup of colorectal symptoms [1-4].

Current quality guidelines for colonoscopy include patient experience as one of the key performance measures and recommend routine measurement of patient experience. However, these guidelines also acknowledge the lack of a standardized approach for this purpose [5-7]. Consequently, patient experience is currently mostly derived and measured by clinicians (nurses and endoscopists) using rating scales such as the Gloucester Comfort Scale (GCS) [8]. The GCS is designed to measure and report patient experience in terms of patient comfort during colonoscopy. Despite widespread use of the GCS, preliminary studies have suggested that clinician-reported GCS scores may not provide accurate representations of the colonoscopy experience from the patient's perspective [9, 10]. However, specific insights regarding the extent of discrepancy between clinician-reported GCS scores and patient-reported experience in terms of colonoscopy-related discomfort and pain are lacking.

Recently, a new patient-reported experience measure (PREM) for gastrointestinal endoscopy was developed and validated: the Newcastle ENDOPREM [11, 12]. This questionnaire is designed to provide a comprehensive insight into the patient's endoscopy experience, covering all aspects of the endoscopy procedure from referral up until communication of test results and follow-up arrangements. The PREM also assesses patient experience in terms of the level of discomfort and pain during colonoscopy.

The comprehensive information provided by the Newcastle ENDOPREM can aid in comparing colonoscopy experience from both the clinicians' and patients' perspectives. In this study, we aimed to use this information to evaluate the extent of discrepancy between clinician-reported GCS scores and patient-reported levels of colonoscopy-related discomfort and pain. Moreover, we aimed to identify physical, procedural and emotional factors associated with moderate to severe levels of discomfort and pain and identify patients in whom clinicians were more likely to over- or underestimate discomfort and pain using the GCS.

METHODS

Study design

Consecutive patients undergoing colonoscopy at Bergman Clinics, Amsterdam (centre A) and Amsterdam University Medical Centres, Amsterdam (centre B) were invited to complete the Newcastle ENDOPREM [11, 12]. Agreement between clinician- and patient-reported colonoscopy experience was assessed using clinician-reported GCS scores and patient-reported levels of discomfort and pain. In addition, patient-specific and procedural characteristics, as well as patient-reported experiences regarding various aspects of the colonoscopy procedure, were used to identify factors that may be associated with greater colonoscopy-related discomfort and pain.

The Institutional Review Board of the Amsterdam University Medical Centre, Amsterdam (2023.0266) decided that formal revision according to the Medical Research Involving Human Subjects Act (WMO) was not required.

Patient recruitment and selection

Patients were recruited between July 2023 and February 2024. All adult patients (≥18 years) scheduled for outpatient colonoscopy for any indication and able to complete a questionnaire in Dutch (alone or with assistance) were considered eligible. Eligible patients were provided with a study pack, consisting of an invitation letter, participant information sheets (including a consent form) and questionnaire. Study packs were distributed by front office personnel at the endoscopy clinic on the day of the procedure, before the start of the colonoscopy. As such, endoscopists and nurses were unaware of the ongoing study. The questionnaire and signed consent form could be returned using a prepaid envelope.

To enable monitoring of the response rate all questionnaires were numbered. Patients were identified based on returned questionnaires with the completed consent form. Patients were retrospectively excluded if their endoscopy report did not include a GCS score, if they underwent a colonoscopy under propofol sedation (i.e. unconscious or deep sedation [13]), if they had a medical history of extensive colorectal surgery (e.g. subtotal colectomy), if they underwent a procedure other than intended complete colonoscopy (e.g. sigmoidoscopy) or if they did not report both a discomfort and pain score within the questionnaire.

To minimise the effect of recall bias, patients were requested to complete the questionnaire at home within two days (48 hours) of the colonoscopy. However, patients were permitted to complete the questionnaire within a 30-day period following their colonoscopy. Questionnaires completed beyond the

30-day window were excluded, as patients' perceptions of their colonoscopy experience may change over a longer period after the procedure [14].

Colonoscopies

Colonoscopies were performed by both gastroenterologists and supervised gastroenterologists in training (0-4 years of endoscopy experience). While participating centres are affiliated, endoscopies at both centres were performed by the same rotating group of endoscopists. Both centres use the same sedation protocol. Prior to the procedure, all patients were enquired whether they wished to receive a sedative (midazolam), an analgesic (fentanyl), or both. For patients willing to receive medication, a dosage of 2.5 mg midazolam and 0.05 mg fentanyl was considered standard. Administration of additional medication was based on the discretion of the endoscopist considering the patient's previous colonoscopy experience and per-procedural comfort. The level of sedation was reported by the endoscopist using the Leeds Scale (**Table 1**).

Patient comfort during colonoscopy was assessed using the GCS (**Table 1**) [8]. As part of routine practice, at centre A the GCS scores were reported by the attending endoscopy nurse, while at centre B the GCS scores were reported by the endoscopist. In this study, clinician-reported GCS scores refer to the combined scores recorded by both nurses and endoscopists. Scores reported solely by nurses or endoscopists will be referred to as nurse-reported and endoscopist-reported scores, respectively. Considering the 'textbook process' composite quality measure for colonoscopy, high GCS scores were defined as scores $\geq$3 [15]. Overestimation was defined as a GCS score higher than the patient-reported score, while underestimation was defined as a GCS score lower than the patient-reported score.

Questionnaire

The Newcastle ENDOPREM is a comprehensive patient-reported experience measure for gastrointestinal endoscopy. Development and validation of this PREM has been described elsewhere [11, 12]. The questionnaire comprises seven sections (labelled A to G) and is structured to follow the temporal phases of endoscopic procedures. Section A enquires general patient and procedure information. Subsequent sections (B to F) enquire the patient's experience before coming to the hospital (e.g., referral and patient's expectations), when preparing for the procedure at home (i.e., bowel preparation), when arriving at the hospital (e.g., privacy while waiting for the procedure), during the procedure and after the procedure, respectively. Section G enquires the patient's overall experience. More detailed insights into the composition and aims of each section have been previously described elsewhere [11, 12, 16].

Most questions ask patients to indicate the extent to which they agree with specific statements on a five-point Likert scale ranging from 'strongly agree' to 'strongly disagree'. The questionnaire enquires the levels of discomfort and pain as experienced during the procedure using a 0-10 numeric rating scale, with a score of 0 representing no discomfort or pain and 10 representing the worst discomfort or pain imaginable. To compare patient-reported scores to GCS scores using similar scales, the scores as reported on the eleven-point numeric scale were converted to a five-point scale (**Table 1**). Moderate to severe patient-reported discomfort and pain were defined as scores $\geq$3 on the five-point scales.

For the purposes of this study, the original Newcastle ENDOPREM questionnaire was modified for colonoscopy, translated to Dutch and contextualised for the Dutch population (**Appendix S1**). The process of development and validation of this adapted version of the PREM will be described elsewhere.

Statistical analysis

Patient and procedure characteristics were described using descriptive statistics. Normality of data were checked using stem-and-leaf and QQ-plots. Levels of agreement between clinician-reported GCS scores and converted patient-reported discomfort and pain scores were assessed using the Cohen's kappa statistic with squared weights [17]. Exploratory post-hoc analyses were performed to compare levels of agreement for different types of assessors (nurses and endoscopists), endoscopists with different levels of endoscopy experience and for patients with different degrees of sedation. The strength and direction of the association between patient-reported discomfort and pain scores were examined using the Goodman and Kruskal's gamma statistic [18]. The 95% confidence intervals (CIs) around the reported Cohen's kappa and Goodman and Kruskal's gamma values were calculated using bootstrapping with a 1000 iterations.

Logistic regressions were used to assess the putative association between moderate to severe patient-reported discomfort and pain (dependent variables) and various patient- and procedure-related factors (independent variables). We adjusted for age (dichotomised at 55 years) and gender as these factors are already well-known to increase the likelihood of moderate to severe discomfort and pain during colonoscopy [19-22]. We adjusted for endoscopy centre to account for potential variations across locations. Additional univariable regression analyses were performed using over- and underestimation of discomfort and pain as dependent variables, as well as analyses using experience-related predictor variables as independent variables (an overview of questions corresponding to each of the experience-

related and emotional domains is shown in **Table S1**). Results of the regression analyses were reported as odds ratios (ORs) with 95% CIs.

All analyses were performed using R version 4.2.1 (R Foundation for Statistical Computing, Vienna, Austria). Two-sided p-values <0.05 were considered statistically significant.

Sample size

We based our sample size on the study aim to identify patient- and procedure-related factors associated with moderate to severe patient-reported discomfort and pain. We aimed our data to allow for multivariable regression analyses with five degrees of freedom. In order not to cross the '10 events per variable' criterion [23], this required inclusion of at least 50 patients with both moderate to high discomfort and pain scores. Presuming an incidence of moderate to high pain scores around 21% [24], an estimated number of 238 participants was required. Accounting for an estimated questionnaire response rate of 48% [12] and a 10% exclusion rate, we estimated that distribution of approximately 545 questionnaires was needed.

RESULTS

A total of 579 patients were invited, of whom 312 (54%) returned the questionnaire. Due to the staggered return of questionnaires, the number of invitees slightly surpassed the estimated required number. Sixty-four (21%) respondents were excluded, resulting in a total of 243 included patients. Reasons for exclusions are reported within **Figure 1**. Most questionnaires were completed within the first 48 hours (198/243, 81%) or the first week (225/243, 93%) after colonoscopy.

Patient and procedure characteristics are shown in **Table 2**. The majority of patients were female (51%) and the median age was 65 (IQR 58-71) years. Patients underwent colonoscopy for a surveillance indication (after previously detected polyps or colorectal cancer or due to an increased familial risk of colorectal cancer) (40%), after a positive faecal immunochemical test within the context of the national colorectal cancer screening programme (CRCSP) (34%), for symptoms (24%) or for other indications (2%) (**Table S2**). Colonoscopies were performed under conscious sedation with midazolam and/or fentanyl in 215 (88%) patients, while 28 (12%) patients received no medication.

Level of agreement between clinician-reported GCS scores and patient-reported scores

GCS and patient-reported discomfort scores matched in 119 (49%) patients, while GCS score was lower in 72 (30%) patients and higher in 52 (21%) (**Figure 2A**). The GCS and patient-reported pain score

matched in 133 (55%) patients, while GCS score was lower in 71 (29%) patients and higher in 39 (16%) (**Figure 2B**). A GCS score ≥3 was reported in 18 (7%) patients. Moderate to severe discomfort and pain were reported by 53 (22%) and 60 (25%) patients, respectively. For these patients the GCS score was lower than reported discomfort score for 49/53 (92%) and lower than reported pain score for 54/60 (90%).

The level of agreement between the GCS and patient-reported discomfort scores was minimal (Cohen's κ: 0.34 [95% CI: 0.19-0.47]), agreement between GCS scores and patient-reported pain scores was weak (Cohen's κ: 0.47 [95% CI: 0.34-0.57]) [17]. The Goodman and Kruskal's gamma statistic showed a strong positive association between patient-reported discomfort and pain scores (Goodman and Kruskal's γ: 0.78 [95% CI: 0.69-0.86]) (**Figure S1**) [18]. Exploratory analyses revealed Cohen's κ values of 0.34 (95% CI: 0.15-0.49) and 0.52 (95% CI: 0.38-0.65) for the level of agreement between nurse-reported scores and patient-reported discomfort and pain scores, respectively. The corresponding Cohen's κ values for endoscopist-reported scores were 0.32 (95% CI: 0.10-0.54) and 0.33 (95% CI: 0.15-0.52). Analyses only involving gastroenterologists in training showed Cohen κ values of 0.47 (95% CI: 0.26-0.69) for discomfort and 0.61 (95% CI: 0.39-0.82) for pain, with corresponding values of 0.27 (95% CI: 0.11-0.44) and 0.40 (95% CI: 0.26-0.53) for analyses only involving certified gastroenterologists (**Table S3**) [17]. Rates of moderate to severe discomfort and pain were comparable for patients completing the questionnaire either within or outside the allotted two-days time frame (discomfort: 44/198 [22%] vs. 9/45 [20%], pain: 48/198 [24%] vs. 12/45 [27%]).

Sedation and discomfort and pain scores

An overview of reported GCS and discomfort and pain scores in relation to the (dosage of) administered medication is shown in **Table S4**. All patients with a GCS ≥3 (n = 18) had received medication, out of which 15/18 (83%) had received higher than standard dosages. Of patients that reported moderate to severe discomfort or pain, respective numbers of 48/53 (91%) and 55/60 (92%) patients received medication. This concerned a higher than standard dosage for 19/53 (36%) patients reporting moderate to severe discomfort and 26/60 (43%) patients reporting moderate to severe pain.

For patients with a Leeds score of 1 (n = 116), the Cohen's κ values for the level of agreement between GCS-scores and discomfort and pain scores were 0.20 (95% CI: 0.01-0.37) and 0.38 (95% CI: 0.21-0.55), respectively. The corresponding Cohen's κ values for patients with a Leeds score of ≥2 (n = 125) were 0.33 (95% CI: 0.15-0.50) and 0.45 (95% CI: 0.28-0.59) (**Table S3**)[17]. The strength of the

association between discomfort and pain scores was similar in both groups (Goodman and Kruskal's γ values of 0.74 [95% CI: 0.55-0.87] and 0.79 [95% CI: 0.67-0.88]) [18].

Factors associated with moderate to severe patient-reported scores

Multivariable regression analyses revealed a significant association between female gender and both moderate to severe discomfort and pain. Age <55 years was associated with moderate to severe discomfort, while diverticulosis of the sigmoid showed a significant association with moderate to severe pain. Lastly, likelihood for moderate to severe discomfort and pain was significantly lower for CRCSP colonoscopies compared to colonoscopies for other indications (**Table 3**, **Table S5-S6**).

Univariable regression analyses between experience-related and emotional factors and patient-reported discomfort and pain levels showed that pre-procedural anxiety for both the procedure itself and procedure-related discomfort or pain, a bad experience with bowel preparation, a low sense of general comfort or support (from the medical staff), feelings of embarrassment and a procedure duration longer than expected were significantly associated with both moderate to severe discomfort and pain. Additionally, unsatisfactory waiting times were associated with moderate to severe discomfort, while anxiety for the procedure results was associated with moderate to severe pain (**Table 4**).

Factors associated with over- and underestimation of patient discomfort and pain using the GCS

We identified no factors significantly associated with overestimation of discomfort using the GCS. Female gender, age <55 years, a previous colonoscopy and a colonoscopy with an indication other than for the CRCSP were significantly associated with underestimation of patient discomfort (**Table S7**). Regarding pain, a significant association with both over- and underestimation was found for female gender, age <55 years and a colonoscopy indication other than colonoscopy for the CRCSP (**Table S8**).

DISCUSSION

This prospective questionnaire study is the first study to compare clinician-reported GCS scores with both patient-reported colonoscopy-related discomfort and pain. We demonstrated that clinician-reported GCS scores poorly reflect the colonoscopy experience of the patient. Especially for patients reporting moderate to severe levels of discomfort and pain, nurse- or endoscopist-reported GCS scores underestimate patient discomfort and pain in almost all cases.

The results of this study add to the existing evidence that clinician-derived assessments often do not match the patient-reported level of procedural pain, discomfort or procedure tolerability [9, 10, 24-

27]. Moreover, our study findings align with results of earlier studies demonstrating a moderate correlation between GCS scores and patient-reported pain scores, as well as significant underestimation of patient-reported procedure tolerability using the GCS [9, 10]. The poor level of agreement between clinicians' and patients' perspectives, as reflected in Cohen's κ values of 0.34 (95% CI: 0.19-0.47) and 0.47 (95% CI: 0.34-0.57), pertains to both the overestimation (up to 21%) and underestimation (up to 30%) of patient-reported discomfort and pain. However, from the clinical standpoint, underestimation seems of greater concern as it is more prevalent and associated with potentially preventable negative colonoscopy experiences.

Underestimation of patient discomfort and pain might relate to several factors. Primarily, clinicians may tend to base their judgement of patient comfort on procedural difficulty, rather than on patient feedback [28]. The fact that endoscopists are likely to be primarily focused on (successful completion of) the procedure rather than the patient's comfort might also explain why, similar to preliminary studies [24, 25, 27], nurse-derived assessments more frequently aligned with patients' experiences in our study. Moreover, there may be differences in the understanding of what constitutes tolerable discomfort and pain between clinicians and patients, while clinicians may also be less cautious in detecting signals of discomfort and pain in patients who lack classical risk factors (e.g. younger age) for an uncomfortable colonoscopy [27]. Our study also shows that discomfort and pain are often perceived as separate aspects of the colonoscopy: the discomfort and pain scores of 82/243 (34%) patients did not match. Colonoscopy-related pain seems mainly a physical phenomenon that is generally caused by bowel insufflation and traction by, and looping of, the endoscope during insertion. We identified younger age and sigmoid diverticulosis as factors associated with an increased likelihood of painful colonoscopy, which corroborates earlier studies [19-22]. Optimizing medication regimens, choosing the endoscope that best suits the patient's situation and using add-on techniques such as magnetic endoscopic imaging might aid in reducing colonoscopy-related pain [29, 30].

In contrast to pain, discomfort may be more multifactorial and related to both the physical and emotional burden of the colonoscopy. This study illustrates that patients may be more likely to experience higher levels of discomfort when they experience anxiety, a low sense of general comfort or support (by the medical staff) or feelings of embarrassment. Moreover, factors such as a negative experience with bowel preparation, unsatisfactory waiting times and a longer procedure duration than expected seem more likely to influence the level of discomfort than the level of pain. However, as aforementioned factors were mostly not only significantly associated with discomfort but also with pain, this implies that discomfort and pain are often intertwined. This is in line with findings of preliminary

studies that illustrated that emotional burdens may lead to decreased acceptability of colonoscopy procedures and a higher incidence of painful colonoscopies [19, 31, 32]. Therefore, inquiring and addressing emotional burdens of a colonoscopy might be of equal importance compared to the colonoscopy's technical aspects when it comes to optimizing patients' colonoscopy comfort. In doing so, clinicians should also be aware that emotional burdens regarding colonoscopy may be more prevalent in females [16, 33, 34]. This is emphasised by the significant association between female gender and moderate to severe discomfort in this study.

Adequate estimation of the patient's level of discomfort and pain during colonoscopy is an essential step to initiate measures to improve patient comfort. In our study, 83% of patients with a GCS score $\geq$3 received more than the standard dosage of sedative and/or analgesic medication. For patients reporting moderate to severe discomfort and pain, these percentages were considerably lower (36% and 43%, respectively). These numbers illustrate that recognition of moderate to severe patient discomfort or pain by clinicians generally leads to administration of additional medication. Therefore, the notably low percentage of patients that received additional medication while reporting moderate to severe discomfort or pain appears to primarily be a result of clinicians' underestimation of patients' level of discomfort and pain. If patients' discomfort and pain were more adequately appraised, these patients likely could have benefitted of additional medication. Notwithstanding, as a preliminary study showed that an individual endoscopist's medication practice and the comfort of their patients are not always directly related [35], enhancing the endoscopist's overall colonoscopy practice (e.g. insertion technique, addressing emotional factors) might be at least of equal importance compared to the endoscopist's medication practice to optimise patients' experience.

While accurate assessment of the level of discomfort and pain has proven to be difficult, awareness of factors that increase the likelihood of an uncomfortable or painful colonoscopy might aid clinicians in taking appropriate measures to improve patient's colonoscopy experience. As shown in this study, clinicians should be aware that for females, younger patients (i.e. <55 years) and patients undergoing colonoscopy outside the context of the CRCSP, underestimation of pain and discomfort is more common. In addition, previous colonoscopy was identified as a risk factor for underestimation of moderate to severe pain. Lastly, factors such as anxiety, embarrassment and a low sense of general comfort and support (by the medical staff) should be appropriately addressed.

Clinicians should also be aware that patient experience may be influenced by the patient's pre-procedural expectations. For instance, patients anticipating a completely pain-free procedure might be more likely to report higher levels of discomfort and pain, while experienced discomfort and pain will be

unexpected. If patients are aware that procedure-related discomfort or pain is sometimes inevitable to establish a high-quality and complete colonoscopy, this might assure better (emotional) patient preparation and acceptation. The same applies for procedure duration: patients should know that procedure duration is dependent on the technical procedural difficulty and procedural findings, and can therefore be longer than expected. The beneficial effects of adequate patient information on patient's colonoscopy experience have been previously illustrated [14, 32]. This study supports these results, as the likelihood to experience moderate to severe discomfort and pain was lower for CRCSP colonoscopies compared to other indications. For CRCSP colonoscopies the pre-procedural consultation concerns a 30-minute face-to-face consultation, while for other indications the pre-procedural consultations are generally considerably shorter and conducted via telephone.

Towards the future, use of PREMs in daily practice could aid in reducing the considerable underestimation of patient discomfort and pain as is currently observed using the GCS. Moreover, PREMs could aid clinicians in identification of factors that increase the likelihood of an uncomfortable or painful colonoscopy. One of the main issues with incorporating a PREM in daily practice is that the distribution and processing of comprehensive PREMs can be time consuming and logistically challenging. Nevertheless, PREMs comprising only a few key questions could already provide useful information for improving (future) colonoscopy procedures for individual patients. Development and validation of a shortened PREM which still encompasses the full breadth of patient experience, and its implementation in routine practice, should therefore be considered a focus for future research. Facilitating completion of PREMs via online healthcare platforms may facilitate distribution and completion of PREMs without significant increases in workload for healthcare professionals [36].

This study has several strengths. Primarily, this is the first study to specifically address discrepancies between clinician-reported GCS scores and both patient-reported levels of colonoscopy-related discomfort and pain. Moreover, a validated PREM was used to enquire patient experience, patients undergoing colonoscopy for a wide variety of indications were included and clinicians were unaware of the ongoing study (i.e., distribution of the PREM). Therefore, this study provides realistic insights into daily practice. Furthermore, while patients were asked to complete the PREM after discharge from the endoscopy ward, effects of sedation had likely mostly worn off.

One of the study's limitations concerns the study's sample size: our study was not primarily powered for multivariable regression analyses regarding over- and underestimation of discomfort and pain, as well as analyses involving the questionnaire-derived experience-related and emotional factors. As such, reported findings warrant further exploration on a larger scale to allow for adequate adjustment

for potential confounding factors. Moreover, described exploratory post-hoc analyses were performed within smaller subgroups of our study population. Therefore, results of these analyses should be interpreted with some caution. Notwithstanding, as these analyses suggest that levels of agreement may differ between nurses and endoscopists, endoscopists with different levels of experience and patients with different levels of sedation, these findings might serve as a valuable starting point for future studies.

Another issue to consider, concerns the response bias that is inherent to questionnaire research: patients with certain demographic characteristics or a specific colonoscopy experience (e.g. predominantly positive or negative) may be under- or overrepresented [37]. Comparison of both the responding and non-responding patients would provide useful insights into the extent of the response bias. However, due to privacy regulations and the retrospective identification of patients through returned consent forms, identification of non-responders was not possible in this study. For future studies, a prospective patient counselling and consent procedure should be considered to (partially) address this issue.

As we adhered to a 30-days inclusion cut-off, this may have induced some degree of recall bias. However, the impact of recall bias appears limited as the rates of moderate to severe discomfort and pain were comparable between patients completing the questionnaire within or outside the requested two-days time frame. For future studies, a cut-off shorter than 30 days seems feasible given the high questionnaire completion rates within shorter time frames in our study (two days: 81%, one week: 93%). Furthermore, all questionnaires were completed after the colonoscopy procedure. As some of the questionnaire sections cover the pre-procedural experience and patient's expectations, patient responses could have been biased by the actual colonoscopy experience. Therefore, testing the questionnaire in two phases (before and after the procedure) would be useful for future studies. Partly completion of PREMs before the procedure may also facilitate useful insights for the patients' current colonoscopies, rather than future colonoscopies only. Lastly, as this study only involved two Dutch centres, the generalizability of our results may be compromised by factors such as standard sedation practices, patient population and experience of the involved medical staff.

In conclusion, clinician-reported GCS scores, used to indicate patient comfort during colonoscopy, frequently underestimate the level of discomfort and pain as reported by patients themselves. A validated PREM, such as the Newcastle ENDOPREM, allows enquiring the patients' experience and the definition of patient factors that may be associated with greater patient-reported discomfort and pain during colonoscopy. For these reasons, the use of validated PREMs could allow for

more accurate monitoring of patients' colonoscopy experience compared to using the GCS as a standard measure for reporting patient comfort during colonoscopy.

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TABLES

Table 1. Gloucester Comfort Scale for reporting patient comfort and Leeds Scale for reporting degree of sedation during colonoscopy

Gloucester Comfort Scale		
Score	**Degree of discomfort**	**Corresponding numeric rating scale scores***
1	None to very mild – No discomfort, resting comfortably throughout	0-2
2	Mild - One or two episodes of mild discomfort, well tolerated	3-4
3	Moderate - More than two episodes of mild discomfort, adequately tolerated	5-6
4	Severe - Significant discomfort, experienced several times during the procedure	7-8
5	Very severe - Extreme discomfort, experienced frequently during the test	9-10
Leeds Scale		
Score	**Degree of sedation**	
1	Fully awake	
2	Sleepy / drowsy	
3	Sleeps, response to voice	
4	Sleeps, response to touch	
5	Unresponsive	

*To allow for study analyses, patient-reported pain and discomfort scores as reported on a 0-10 numeric rating scale within the Newcastle ENDOPREM questionnaire were converted to scores on a 1-5 scale.

Table 2. Characteristics of included patients and performed colonoscopies

		Centre A (n = 182)	Centre B (n = 61)	All (n = 243)
Patient characteristics, n (%)				
Gender	Male	88 (48)	30 (49)	118 (49)
	Female	94 (52)	31 (51)	125 (51)
Age, median (IQR)		65 (59, 72)	61 (48, 66)	65 (58, 71)
Body mass index, median (IQR)		25 (23, 28)	25 (23, 29)	25 (23, 29)
Educational level*	Low	43 (24)	9 (15)	52 (21)
	Intermediate or high	129 (71)	51 (84)	180 (74)
	Not available	10 (5.5)	1 (1.6)	11 (4.5)
ASA score	ASA I	73 (40)	15 (25)	88 (36)
	ASA II	108 (59)	46 (75)	154 (64)
	ASA III	1 (0.5)	0 (0)	1 (0.4)
Previous colonoscopy	No	104 (57)	8 (13)	112 (46)
	Yes	78 (43)	53 (87)	131 (54)
Previous abdominal surgery†	No	138 (76)	46 (75)	184 (76)
	Yes	44 (24)	15 (25)	59 (24)
Diverticulosis‡	No	82 (45)	50 (82)	132 (54)
	Yes	100 (55)	11 (18)	111 (46)
Colonoscopy characteristics				
Indication¶	CRCSP	82 (45)	0 (0)	82 (34)
	Surveillance**	48 (26)	50 (82)	98 (40)
	Symptoms and other	52 (29)	11 (18)	63 (26)
Quality of bowel preparation††	Excellent	159 (89)	48 (79)	207 (85)
	Sufficient	19 (10)	6 (9.8)	25 (10)
	Not available	4 (2)	7 (12)	11 (4.5)
Caecal intubation	No	6 (3.3)	2 (3.3)	8 (3.3)
	Yes	176 (97)	59 (97)	235 (97)
Endoscopist	Gastroenterologist (CRCSP accredited)‡‡	124 (68)	24 (39)	148 (61)
	Gastroenterologist (not CRCSP accredited)‡‡	26 (14)	8 (13)	34 (14)
	Gastroenterologist in training	32 (18)	29 (48)	61 (25)
Analgesic and sedative medication	Midazolam and fentanyl	149 (82)	56 (92)	205 (84)
	Midazolam only	2 (1.1)	0 (0)	2 (0.8)
	Fentanyl only	6 (3.3)	2 (3.3)	8 (3.3)
	None	25 (14)	3 (4.9)	28 (12)
Leeds score	1	95 (52)	21 (34)	116 (48)
	2	68 (37)	32 (52)	100 (41)
	≥3	17 (9.3)	8 (13)	25 (10)
	Not reported	2 (1.1)	0 (0)	2 (0.8)

ASA, American Association of Anaesthesiologists; CRCSP, Colorectal Cancer Screening Programme; IQR, inter quartile range. *Education level according to ISCED-11. Patients were considered to have an intermediate or high educational level if they had at least an upper secondary or university degree. †Defined as any (laparoscopic) surgical procedure in which the abdominal cavity was entered, excluding diagnostic laparoscopies and caesarean sections; ‡Of all patients with diverticulosis, 103/111 (93%) had diverticulosis within the sigmoid colon. Ten patients had a medical history reporting at least one episode of diverticulitis. Ten patients had diverticulosis with stricture(s). Out of these ten patients, six patients had passage problems; ¶An overview of colonoscopy indications belonging to each category is shown in Table S1; **Surveillance colonoscopies after previously detected polyps or colorectal cancer and surveillance colonoscopies in individuals with an increased familial risk for colorectal cancer; ††Based on Boston Bowel Preparation Scale (BBPS) score: poor (<6 points), sufficient (6-8 points), excellent (9 points); ‡‡To assure colonoscopy quality for colonoscopies performed within the context of the Dutch CRCSP, all endoscopists performing these procedures have to be accredited. The endoscopist accreditation programme consists of three modules: (1)

colonoscopy registration module, (2) theoretical e-learning module combined with online assessment of the acquired knowledge and (3) a practical evaluation of colonoscopy and polypectomy skills.

Table 3. Univariable and multivariable regression analyses assessing the association between different patient- and procedural factors and moderate to severe patient-reported discomfort and pain

		Discomfort				Pain			
		Univariable analysis		Multivariable analysis*		Univariable analysis		Multivariable analysis*	
		OR (95% CI)	P-value	OR (95% CI)	P-value	OR (95% CI)	P-value	OR (95% CI)	P-value
Gender	Male	Reference		Reference		Reference			
	Female	2.68 (1.40-5.15)	0.003	2.46 (1.25-4.86)	0.009	2.81 (1.51-5.23)	<0.001	2.68 (1.41-5.09)	0.003
Age	≥55	Reference		Reference		Reference			
	<55	4.14 (2.00-8.56)	<0.001	2.91 (1.33-6.36)	0.007	2.89 (1.41-5.92)	0.004	2.01 (0.92-4.36)	0.078
Educational level†	Low	Reference		Reference		Reference			
	Medium or high	1.45 (0.66-3.23)	0.357	1.12 (0.48-2.59)	0.797	1.18 (0.57-2.43)	0.656	0.99 (0.46-2.12)	0.972
Body mass index‡	18.5-25.0	Reference		Reference		Reference			
	>25.0	0.74 (0.40-1.36)	0.327	0.98 (0.51-1.90)	0.959	0.71 (0.40-1.27)	0.250	0.86 (0.46-1.60)	0.628
Previous abdominal surgery	No	Reference		Reference		Reference			
	Yes	1.48 (0.75-2.91)	0.258	1.40 (0.68-2.89)	0.357	1.48 (0.77-2.85)	0.241	1.37 (0.69-2.72)	0.369
Previous colonoscopy	No	Reference		Reference		Reference			
	Yes	1.55 (0.83-2.89)	0.169	1.16 (0.57-2.37)	0.681	1.16 (0.64-2.09)	0.621	0.85 (0.43-1.67)	0.636
Diverticulosis sigmoid	No	Reference		Reference		Reference			
	Yes	0.86 (0.46-1.61)	0.644	1.64 (0.79-3.41)	0.187	1.38 (0.77-2.48)	0.248	2.26 (1.11-4.58)	0.024
Colonoscopy indication	CRCSP	Reference		Reference		Reference			
	Surveillance and familial risk	5.07 (1.98-12.97)	<0.001	3.22 (1.13-9.21)	0.029	1.92 (0.31-4.03)	0.086	1.06 (0.43-2.61)	0.893
	Symptoms and other	5.47 (2.03-14.72)	<0.001	3.77 (1.33-10.70)	0.013	2.65 (1.20-5.85)	0.016	1.82 (0.78-4.29)	0.169
Endoscopist experience	Gastroenterologist	Reference		Reference		Reference			
	Gastroenterologist in training	1.97 (1.02-3.80)	0.043	1.60 (0.77-3.32)	0.158	1.40 (0.73-2.67)	0.320	1.10 (0.54-2.26)	0.787
Endoscopist type¶	CRCSP accredited	Reference		Reference		Reference			
	Not CRCSP accredited	0.52 (0.17-1.60)	0.258	0.41 (0.12-1.40)	0.156	1.15 (0.64-2.09)	0.639	0.81 (0.31-2.11)	0.664

OR, odds ratio; CI, confidence interval; CRCSP, Colorectal Cancer Screening Programme. *Adjusted for gender, age (dichotomised at 55 years) and endoscopy centre. †Education level according to ISCED-11. Patients were considered to have an intermediate or high educational level if they had at least an upper secondary or university degree; ‡One patient with BMI <18.5 was excluded from the analyses; ¶To assure colonoscopy quality for colonoscopies performed within the context of the Dutch CRCSP, all endoscopists performing these procedures have to be accredited. The endoscopist accreditation programme consists of three modules: (1) colonoscopy registration module, (2) theoretic al e-learning module combined with online assessment of the acquired knowledge and (3) a practical evaluation of colonoscopy and polypectomy skills.

Table 4. Univariable regression analyses assessing the association between specific experience-related and emotional factors and moderate to severe patient-reported discomfort and pain

	Discomfort						Pain					
	Disagree*		Agree*				Disagree*		Agree*			
Domain	No to mild, n (%)	Moderate to severe, n (%)	No to mild, n (%)	Moderate to severe, n (%)	OR (95% CI)	P-value	No to mild, n (%)	Moderate to severe, n (%)	No to mild, n (%)	Moderate to severe, n (%)	OR (95% CI)	P-value
Inadequate information	179 (80)	46 (20)	11 (61)	7 (39)	2.48 (0.91-6.74)	0.087	170 (76)	55 (24)	13 (72)	5 (28)	1.19 (0.41-3.48)	0.755
Anxiety: procedure in general	151 (79)	41 (21)	33 (73)	12 (27)	1.34 (0.64-2.82)	0.449	147 (77)	45 (23)	30 (67)	15 (33)	1.63 (0.81-3.30)	0.179
Anxiety: procedure results	157 (80)	39 (20)	27 (66)	14 (34)	1.65 (0.89-3.06)	0.109	111 (80)	28 (20)	66 (67)	32 (33)	1.92 (1.06-3.47)	0.030
Anxiety: procedure-related discomfort	111 (90)	13 (10)	73 (65)	40 (35)	4.68 (2.34-9.35)	<0.001	105 (85)	19 (15)	72 (64)	41 (36)	3.15 (1.69-5.86)	<0.001
Anxiety: procedure-related pain	112 (91)	11 (9)	73 (63)	42 (37)	5.86 (2.83-12.11)	<0.001	108 (88)	15 (12)	70 (61)	45 (39)	4.63 (2.40-8.93)	<0.001
Bad experience bowel preparation	73 (89)	9 (11)	115 (72)	44 (28)	3.10 (1.43-6.73)	0.002	71 (87)	11 (13)	111 (70)	48 (30)	2.79 (1.36-5.73)	0.003
Unsatisfactory waiting times	181 (80)	46 (20)	9 (56)	7 (44)	3.06 (1.08-8.65)	0.035	173 (76)	54 (24)	10 (63)	6 (37)	1.92 (0.67-5.53)	0.226
Insufficient privacy or unrespected dignity	179 (78)	50 (22)	11 (72)	3 (28)	0.98 (0.26-3.64)	0.972	172 (75)	57 (25)	11 (79)	3 (21)	0.82 (0.22-3.05)	0.771
Endoscopist with unpreferred gender†	185 (79)	50 (21)	4 (57)	3 (43)	2.77 (0.60-12.81)	0.208	179 (76)	56 (24)	3 (43)	4 (57)	4.26 (0.93-19.62)	0.064
Low sense of comfort and support (by the medical staff)	188 (81)	44 (19)	2 (18)	9 (82)	19.23 (4.01-92.14)	<0.001	179 (77)	53 (23)	4 (36)	7 (64)	5.91 (1.67-20.96)	0.005
Feelings of embarrassment	186 (80)	46 (20)	4 (36)	7 (64)	7.08 (1.99-25.20)	0.002	178 (77)	54 (23)	5 (45)	6 (55)	3.96 (1.16-13.47)	0.030
Longer procedure duration than expected	182 (80)	45 (20)	8 (50)	8 (50)	4.04 (1.44-11.36)	0.010	178 (78)	49 (22)	5 (31)	11 (69)	7.99 (2.65-24.09)	<0.001

OR, odds ratio; CI, confidence interval. *Questions and criteria used for assigning patients to either the 'disagree' or 'agree' group are displayed in Table S1. Patients that completed none of the questions related to each domain were excluded from the analyses; †Patients were assigned to the 'disagree' group in case the patient preferred endoscopist gender of the patient matched the gender of the endoscopist that performed the procedure, or patients indicated not to have a preference regarding the endoscopist's gender. Patients were assigned to the 'agree' group in case the patient's preferred endoscopist gender did not match the gender of the endoscopist that performed the procedure.

FIGURE LEGEND

Figure 1. Study flowchart: patient invitation and inclusion process.

Figure 2. Plots illustrating the agreement between clinician-reported Gloucester Comfort Scale (GCS) scores and (A) patient-reported discomfort scores and (B) patient-reported pain scores. The number of patients that is represented by each data point within the plots is indicated by the size of each data point and the number within each data point. The Cohen's kappa statistic reports the level of agreement between clinician- and patient-reported scores and indicates that the level of agreement between GCS scores and patient-reported discomfort scores is minimal (Cohen's κ: 0.34 [95% CI: 0.19-0.47]) and the level of agreement between GCS scores and patient-reported pain scores is weak (Cohen's κ: 0.47 [95% CI: 0.34-0.57]).

Figure S1. Plot illustrating the agreement between patient-reported discomfort and pain scores. The number of patients that is represented by each data point within the plot is indicated by the size of each datapoint and the number within each datapoint. The Goodman and Kruskal's gamma reports the strength and direction of the association between patient-reported scores and indicates a strong positive association between discomfort and pain scores (Goodman and Kruskal's γ: 0.78 [95% CI: 0.69-0.86]).

SUPPLEMENTARY MATERIALS

Table S1. Overview of questions used to determine patient experience regarding specific domains of the colonoscopy and criteria for inclusion within the 'agree' group as described in Table 4

Experience domain	Question(s)	Inclusion to 'agree' group in Table 4 in case one of the questions is answered as underneath*
Inadequate information	B5: Before coming for the test, I was given enough information about what te test would involve	Disagree
	B6: After reading the information, I did not have any questions about the test	Disagree
	B8: I had enough time to discuss the test with the person who referred me	Disagree
	D3: I felt able to ask the staff any questions before the test	Disagree
	D4: I had no unanswered questions before the test	Disagree
Anxiety: procedure in general	B9: I felt anxious about what the test would involve	Agree
	B10: I was made anxious by talking to other people who had previously had the test	Agree
Anxiety: procedure results	B11: I felt anxious about the results of the test	Agree
Anxiety: procedure-related discomfort	B12: I expected to experience discomfort during the test	Agree
Anxiety: procedure-related pain	B13: I expected to experience pain during the test	Agree
	B14: I was worried that inserting the tube / camera would cause discomfort	Agree
Bad experience bowel preparation	C1: The preparation had an unpleasant taste	Agree
	C2: The preparation tasted better than I had expected	Disagree
	AND	
	C3: The volume (*amount*) of the bowel preparation was more than I had expected	Agree
	C4: The amount of bowel preparation I had to drink was manageable	Disagree
Unsatisfactory waiting times	B2: The time from first being referred to having the test done was satisfactory	Disagree
	D1: The length of time I waited in the department was acceptable	Disagree
Insufficient privacy or unrespected dignity	C6: I had enough privacy when getting ready for the test (*e.g. when changing clothes*)	Disagree
	D5: I had enough privacy when waiting for the test	Disagree
	D6: I had enough privacy when moving from the waiting area to the procedure room	Disagree
	E1: During the test my dignity was maintained at all times	Disagree
Endoscopist with unpreferred gender	E4: I would have preferred the person doing the test (*inserting the tube or camera*) to be:	N/A†
	E5: The person doing the test was:	N/A†
Low sense of comfort and support (from the medical staff)	D2: I was comfortable while sitting in the waiting area	Disagree
	E6: I felt confident that the person doing the test knew what they were doing	Disagree
	E7: The person doing the test did their best to put me at ease	Disagree
	E8: The other staff in the test room did their best to put me at ease	Disagree
	E9: I was satisfied with the explanation given to my about the test	Disagree
	E10: The person doing the test addressed any concerns I had	Disagree
	E11: I felt I could stop the test if it became too uncomfortable	Disagree
Feelings of embarrassment	E12: I felt embarrassed during the test	Agree
Longer procedure duration than expected	E13: The test took longer than expected	Agree

N/A, not available. *A patient was considered to 'disagree' in case the corresponding question was answered with either 'disagree' or 'strongly disagree', while patients were considered to 'agree' if the corresponding question was answered with 'agree' or 'strongly agree'; †Patients were assigned to the 'disagree' group in case the patient's preferred endoscopist gender matched the gender of the endoscopist that performed the procedure, or if patients indicated not to have a preference regarding the endoscopist's gender. Patients were assigned to the 'agree' group in case the patient's preferred endoscopist gender did not match the gender of the endoscopist that performed the procedure.

Table S2. Definition of different colonoscopy indication categories and number of included patients per indication

CRCSP (n = 82)	Surveillance (n = 68)	Familial risk (n = 30)	Symptoms (n = 59)	Other (n = 4)
Initial colonoscopy after positive FIT within the context of the Dutch CRCSP (n = 82)	Surveillance – after adenoma(s) (n = 34)	Familial risk – polyposis coli (n = 4)	Changed stool patterns (n = 13)	Abnormality found at imaging or peri-anal examination (n = 1)
	Surveillance – after CRC (n = 10)	Familial risk – CRC (n = 12)	Rectal blood loss (n = 13)	Positive FIT outside context of the Dutch CRCSP (n = 1)
	Surveillance – IBD (n = 21)	Familial risk – HNPCC / Lynch syndrome (n = 12)	Analysis iron deficiency anemia (n = 9)	Therapeutic colonoscopy (n = 1)
	Surveillance – after excision colorectal lesion (n = 3)	Familial risk – other (n = 2)	Chronic diarrhea (n = 5)	Evaluation of (endoscopic) treatment possibilities of colorectal lesions (n = 1)
			Abdominal pain (n = 12)	
			Suspicion of IBD (n = 3)	
			Evaluation of disease activity of IBD (n = 4)	

CRCSP, colorectal cancer screening programme; FIT, faecal immunochemical test; CRC, colorectal cancer; IBD, inflammatory bowel disease; HNPCC, hereditary non-polyposis colorectal cancer.

Table S3. Matching percentages and levels of agreement between clinician- and patient-reported scores for specific subgroups

		Discomfort				Pain			
		Match, n (%)	GCS lower, n (%)	GCS higher, n (%)	Cohen's κ (95% CI)*	Match, n (%)	GCS lower, n (%)	GCS higher, n (%)	Cohen's κ (95% CI)*
Type of assessor	Nurse (n = 182)	98 (54)	42 (23)	42 (23)	0.34 (0.15-0.49)	105 (58)	44 (24)	33 (18)	0.52 (0.38-0.65)
	Endoscopist (n = 61)	21 (34)	30 (49)	10 (16)	0.32 (0.10-0.54)	28 (46)	27 (44)	6 (9.8)	0.33 (0.15-0.52)
Experience level of endoscopist	Gastroenterologist (n = 182)	91 (50)	48 (26)	43 (24)	0.27 (0.11-0.44)	98 (54)	50 (27)	34 (19)	0.40 (0.26-0.53)
	Gastroenterologist in training (n = 61)	28 (46)	24 (39)	9 (15)	0.47 (0.25-0.64)	35 (57)	21 (34)	5 (8.2)	0.61 (0.43-0.75)
Degree of sedation†	Leeds score 1 (n = 116)	68 (59)	30 (26)	18 (16)	0.20 (0.01-0.37)	74 (64)	29 (25)	13 (11)	0.38 (0.21-0.55)
	Leeds score ≥2 (n = 125)	50 (40)	41 (33)	34 (27)	0.33 (0.15-0.50)	57 (46)	42 (34)	26 (21)	0.45 (0.28-0.59)

*The Cohen's κ statistic represents the level of agreement between the clinician reported GCS-scores and patient-reported scores. Reported Cohen's κ values can be interpreted according to the recommendations by McHugh (2012): 0-0.20: none, 0.21-0.39: minimal, 0.40-0.59: weak, 0.60-0.79: moderate, 0.80-0.90: strong, >0.90: almost perfect.; †Two patients for whom no Leeds score was reported were excluded from the analyses.

Table S4. Frequency of specific score counts for clinician-reported GCS scores and patient-reported discomfort and pain scores in relation to (dosage of) administered medication

Medication type	Medication		Number of patients, n (%)	Score	Score count, n				
	Dosage midazolam (mg)	Dosage fentanyl (mg)			1	2	3	4	5
None	None	None	**28 (12)**	GCS	22	6	0	0	0
				Discomfort	15	8	3	2	0
				Pain	16	7	4	1	0
Midazolam only	<2.5	None	**0**	GCS	0	0	0	0	0
				Discomfort	0	0	0	0	0
				Pain	0	0	0	0	0
	2.5	None	**1 (0.4)**	GCS	1	0	0	0	0
				Discomfort	1	0	0	0	0
				Pain	1	0	0	0	0
	>2.5	None	**1 (0.4)**	GCS	1	0	0	0	0
				Discomfort	0	1	0	0	0
				Pain	0	1	0	0	0
Fentanyl only	None	<0.05	**0**	GCS	0	0	0	0	0
				Discomfort	0	0	0	0	0
				Pain	0	0	0	0	0
	None	0.05	**4 (1.6)**	GCS	4	0	0	0	0
				Discomfort	2	2	0	0	0
				Pain	2	1	1	0	0
	None	>0.05	**4 (1.6)**	GCS	3	1	0	0	0
				Discomfort	3	1	0	0	0
				Pain	3	1	0	0	0
Midazolam and fentanyl	<2.5	<0.05	**1 (0.4)**	GCS	1	0	0	0	0
				Discomfort	1	0	0	0	0
				Pain	1	0	0	0	0
	<2.5	0.05	**3 (1.2)**	GCS	2	0	1	0	0
				Discomfort	1	0	0	2	0
				Pain	1	1	1	0	0
	<2.5	>0.05	**1 (0.4)**	GCS	1	0	0	0	0
				Discomfort	1	0	0	0	0
				Pain	1	0	0	0	0
	2.5	<0.05	**4 (1.6)**	GCS	2	2	0	0	0
				Discomfort	2	1	1	0	0
				Pain	1	3	0	0	0
	2.5	0.05	**142 (58)**	GCS	91	49	2	0	0
				Discomfort	93	23	15	10	1
				Pain	98	18	13	12	1
	2.5	>0.05	**20 (8.2)**	GCS	0	13	7	0	0
				Discomfort	9	4	1	5	1
				Pain	4	2	4	9	1
	>2.5	<0.05	**0**	GCS	0	0	0	0	0
				Discomfort	0	0	0	0	0
				Pain	0	0	0	0	0
	>2.5	0.05	**22 (9.1)**	GCS	8	12	1	1	0
				Discomfort	14	2	3	3	0
				Pain	12	4	3	3	0
	>2.5	>0.05	**12 (4.9)**	GCS	1	5	3	2	1
				Discomfort	4	2	0	4	2
				Pain	2	3	1	4	2

GCS, Gloucester Comfort Scale. Notes: all patients with a GCS ≥3 (n = 18) received medication. Compared to standard dosages of fentanyl and midazolam, 15/18 (83%) of these patients received either extra fentanyl (n = 7), midazolam (n = 2) or both (n = 6). Of patients that reported a discomfort score ≥3, 48/53 (91%) received medication. The majority of these patients (n = 45) received at least a standard dosage of both fentanyl and midazolam, while 19/53 (36%) patients received a higher than standard dosage of fentanyl (n = 7), midazolam (n = 6) or both (n = 6). Of patients that reported a pain score ≥3, 55/60 (92%) received medication. A higher than standard dosage of fentanyl (n = 14), midazolam (n = 6) or both (n = 6) was administered to 26/60 (43%) patients.

Table S5. Univariable and multivariable regression analyses assessing the association between different patient- and procedural factors and moderate to severe patient-reported discomfort (extended table)

				Univariable analysis		Multivariable analysis*	
	Variable	**No to mild discomfort, n (%)**	**Moderate to severe discomfort, n (%)**	**OR (95% CI)**	**P-value**	**OR (95% CI)**	**P-value**
Gender	Male	102 (86)	16 (14)	Reference		Reference	
	Female	88 (70)	37 (30)	2.68 (1.40-5.15)	0.003	2.46 (1.25-4.86)	0.009
Age	≥55	169 (83)	35 (17)	Reference		Reference	
	<55	21 (54)	18 (46)	4.14 (2.00-8.56)	<0.001	2.91 (1.33-6.36)	0.007
Educational level†	Low	43 (83)	9 (17)	Reference		Reference	
	Medium or high	138 (77)	42 (23)	1.45 (0.66-3.23)	0.357	1.12 (0.48-2.59)	0.797
Body mass index‡	18.5-25.0	89 (75)	29 (25)	Reference		Reference	
	>25.0	100 (81)	24 (19)	0.74 (0.40-1.36)	0.327	0.98 (0.51-1.90)	0.959
Previous abdominal surgery	No	147 (80)	37 (20)	Reference		Reference	
	Yes	43 (73)	16 (27)	1.48 (0.75-2.91)	0.258	1.40 (0.68-2.89)	0.357
Previous colonoscopy	No	92 (82)	20 (18)	Reference		Reference	
	Yes	98 (75)	33 (25)	1.55 (0.83-2.89)	0.169	1.16 (0.57-2.37)	0.681
Diverticulosis sigmoid	No	108 (77)	32 (23)	Reference		Reference	
	Yes	82 (80)	21 (20)	0.86 (0.46-1.61)	0.644	1.64 (0.79-3.41)	0.187
Colonoscopy indication	CRCSP	76 (93)	6 (7)	Reference		Reference	
	Surveillance and familial risk	70 (71)	28 (29)	5.07 (1.98-12.97)	<0.001	3.22 (1.13-9.21)	0.029
	Symptoms and other	44 (70)	19 (30)	5.47 (2.03-14.72)	<0.001	3.77 (1.33-10.70)	0.013
Endoscopist experience	Gastroenterologist	148 (81)	34 (19)	Reference		Reference	
	Gastroenterologist in training	42 (69)	19 (31)	1.97 (1.02-3.80)	0.043	1.60 (0.77-3.32)	0.158
Endoscopist type¶	CRCSP accredited	118 (80)	30 (20)	Reference		Reference	
	Not CRCSP accredited	30 (88)	4 (12)	0.52 (0.17-1.60)	0.258	0.41 (0.12-1.40)	0.156

OR, odds ratio; CI, confidence interval; CRCSP, Colorectal Cancer Screening Programme. *Adjusted for gender, age (dichotomised at 55 years) and endoscopy centre; †Education level according to ISCED-11. Patients were considered to have an intermediate or high educational level if they had at least an upper secondary or university degree; ‡One patient with BMI <18.5 was excluded from the analyses; ¶To assure colonoscopy quality for colonoscopies performed within the context of the Dutch CRCSP, all endoscopists performing these procedures have to be accredited. The endoscopist accreditation programme consists of three modules: (1) colonoscopy registration module, (2) theoretical e-learning module combined with online assessment of the acquired knowledge and (3) a practical evaluation of colonoscopy and polypectomy skills.

Table S6. Univariable and multivariable regression analyses assessing the association between different patient- and procedural factors and moderate to severe patient-reported pain (extended table)

				Univariable analysis		Multivariable analysis*	
	Variable	**No to mild discomfort, n (%)**	**Moderate to severe discomfort, n (%)**	OR (95% CI)	P-value	OR (95% CI)	P-value
Gender	Male	100 (85)	18 (15)	Reference			
	Female	83 (66)	42 (34)	2.81 (1.51, 5.23)	<0.001	2.68 (1.41-5.09)	0.003
Age	≥55	161 (79)	43 (21)	Reference			
	<55	22 (56)	17 (44)	2.89 (1.41, 5.92)	0.004	2.01 (0.92-4.36)	0.078
Educational level†	Low	40 (77)	12 (23)	Reference			
	Medium or high	133 (74)	47 (26)	1.18 (0.57, 2.43)	0.656	0.99 (0.46-2.12)	0.972
Body mass index‡	18.5-25.0	85 (72)	33 (28)	Reference			
	<18.5 or >25.0	98 (78)	27 (22)	0.71 (0.40, 1.27)	0.250	0.86 (0.46-1.60)	0.628
Previous abdominal surgery	No	142 (77)	42 (23)	Reference			
	Yes	41 (69)	18 (31)	1.48 (0.77, 2.85)	0.241	1.37 (0.69-2.72)	0.369
Previous colonoscopy	No	86 (77)	26 (23)	Reference			
	Yes	97 (74)	34 (26)	1.16 (0.64, 2.09)	0.621	0.85 (0.43-1.67)	0.636
Diverticulosis sigmoid	No	109 (78)	31 (22)	Reference			
	Yes	74 (72)	29 (28)	1.38 (0.77, 2.48)	0.248	2.26 (1.11-4.58)	0.024
Colonoscopy indication	CRCSP	69 (84)	13 (16)	Reference			
	Surveillance and familial risk	72 (73)	26 (27)	1.92 (0.31, 4.03)	0.086	1.06 (0.43-2.61)	0.893
	Symptoms and other	42 (67)	21 (33)	2.65 (1.20, 5.85)	0.016	1.82 (0.78-4.29)	0.169
Endoscopist experience	Gastroenterologist	140 (77)	42 (23)	Reference			
	Gastroenterologist in training	43 (70)	18 (30)	1.40 (0.73, 2.67)	0.320	1.10 (0.54-2.26)	0.787
Endoscopist type¶	CRCSP accredited	113 (76)	35 (24)	Reference			
	Not CRCSP accredited	70 (74)	25 (26)	1.15 (0.64, 2.09)	0.639	0.81 (0.31-2.11)	0.664

OR, odds ratio; CI, confidence interval; CRCSP, Colorectal Cancer Screening Programme. *Adjusted for gender, age (dichotomised at 55 years) and endoscopy centre; †Education level according to ISCED-11. Patients were considered to have an intermediate or high educational level if they had at least an upper secondary or university degree; ‡One patient with BMI <18.5 was excluded from the analyses; ¶To assure colonoscopy quality for colonoscopies performed within the context of the Dutch CRCSP, all endoscopists performing these procedures have to be accredited. The endoscopist accreditation programme consists of three modules: (1) colonoscopy registration module, (2) theoretical e-learning module combined with online assessment of the acquired knowledge and (3) a practical evaluation of colonoscopy and polypectomy skills.

Table S7. Univariable regression analyses assessing the association between various patient- and procedure-related factors and over- and underestimation of patient-reported discomfort using the GCS

		Overestimation				Underestimation			
	Variable	**Match, n (%)**	**GCS score higher, n (%)**	**OR (95% CI)**	**P-value**	**Match, n (%)**	**GCS score lower, n (%)**	**OR (95% CI)**	**P-value**
Gender	Male	67 (74)	23 (26)	Reference		67 (71)	28 (29)	Reference	
	Female	52 (64)	29 (36)	1.62 (0.84, 3.13)	0.147	52 (54)	44 (46)	2.02 (1.12, 3.68)	0.020
Age	≥55	103 (68)	48 (32)	Reference		103 (66)	53 (34)	Reference	
	<55	16 (80)	4 (20)	0.54 (0.17, 1.69)	0.288	16 (46)	19 (54)	2.31 (1.10, 4.85)	0.027
Educational level*	Low	28 (65)	15 (35)	Reference		28 (76)	9 (24)	Reference	
	Medium or high	86 (72)	34 (28)	0.74 (0.35, 1.55)	0.422	86 (59)	60 (41)	2.17 (0.96, 4.93)	0.064
Body mass index†	18.5-25.0	54 (68)	25 (32)	Reference		54 (58)	39 (42)	Reference	
	>25.0	65 (71)	26 (29)	0.86 (0.45, 1.67)	0.663	65 (66)	33 (34)	0.70 (0.39, 1.26)	0.240
Previous abdominal surgery	No	89 (70)	38 (30)	Reference		89 (61)	57 (39)	Reference	
	Yes	30 (68)	14 (32)	1.09 (0.52, 2.29)	0.814	30 (67)	15 (33)	0.78 (0.39, 1.58)	0.490
Previous colonoscopy	No	61 (70)	26 (30)	Reference		61 (71)	25 (29)	Reference	
	Yes	58 (69)	26 (31)	1.05 (0.55, 2.02)	0.879	58 (55)	47 (45)	1.98 (1.08, 3.62)	0.027
Diverticulosis sigmoid	No	69 (73)	25 (27)	Reference		69 (60)	46 (40)	Reference	
	Yes	50 (65)	27 (35)	1.49 (0.77, 2.87)	0.232	50 (66)	26 (34)	0.78 (0.43, 1.43)	0.419
Colonoscopy indication	CRCSP	50 (72)	19 (28)	Reference		50 (79)	13 (21)	Reference	
	Surveillance and familial risk	40 (69)	18 (31)	1.18 (0.55, 2.55)	0.666	40 (50)	40 (50)	3.85 (1.81, 8.15)	<0.001
	Symptoms and other	29 (66)	15 (34)	1.36 (0.60, 3.08)	0.460	29 (60)	19 (40)	2.52 (1.09, 5.84)	0.031
Endoscopist experience	Gastroenterologist	91 (68)	43 (32)	Reference		91 (65)	48 (35)	Reference	
	Gastroenterologist in training	28 (76)	9 (24)	0.68 (0.30, 1.57)	0.365	28 (54)	24 (46)	1.62 (0.85, 3.11)	0.142
Endoscopist type‡	CRCSP accredited	72 (69)	33 (31)	Reference		72 (63)	43 (37)	Reference	
	Not CRCSP accredited	19 (66)	10 (34)	1.15 (0.48, 2.74)	0.755	19 (79)	5 (21)	0.44 (0.15, 1.27)	0.108

GCS, Gloucester Comfort Scale; OR, odds ratio; CI, confidence interval; CRCSP, Colorectal Cancer Screening Programme. *Education level according to ISCED-11. Patients were considered to have an intermediate or high educational level if they had at least an upper secondary or university degree; †One patient with BMI <18.5 was excluded from the analyses; ‡To assure colonoscopy quality for colonoscopies performed within the context of the Dutch CRCSP, all endoscopists performing these procedures have to be accredited. The endoscopist accreditation programme consisting of three modules: (1) colonoscopy registration module, (2) theoretical e-learning module combined with online assessment of the acquired knowledge and (3) a practical evaluation of colonoscopy and polypectomy skills.

Table S8. Univariable regression for assessment of the association between various patient- and procedure-related factors and over- and underestimation of patient-reported pain using the GCS

		Overestimation				Underestimation			
	Variable	**Match, n (%)**	**GCS score higher, n (%)**	**OR (95% CI)**	**P-value**	**Match, n (%)**	**GCS score lower, n (%)**	**OR (95% CI)**	**P-value**
Gender	Male	100 (85)	18 (15)	Reference		77 (75)	26 (25)	Reference	
	Female	83 (66)	42 (34)	2.81 (1.51, 5.25)	0.001	56 (55)	45 (45)	2.38 (1.32, 4.31)	0.004
Age	≥55	161 (79)	43 (21)	Reference		116 (69)	52 (31)	Reference	
	<55	22 (56)	17 (44)	2.89 (1.41, 5.92)	0.004	17 (47)	19 (53)	2.49 (1.20, 5.18)	0.014
Educational level*	Low	40 (77)	12 (23)	Reference		28 (72)	11 (28)	Reference	
	Medium or high	133 (74)	47 (26)	1.18 (0.57, 2.43)	0.656	98 (63)	57 (37)	1.48 (0.69, 3.20)	0.318
Body mass index†	18.5-25.0	85 (72)	33 (28)	Reference		61 (60)	40 (40)	Reference	
	>25.0	98 (79)	26 (21)	0.68 (0.38, 1.23)	0.206	72 (71)	30 (29)	0.64 (0.35, 1.14)	0.128
Previous abdominal surgery	No	142 (77)	42 (23)	Reference		104 (66)	53 (34)	Reference	
	Yes	41 (69)	18 (31)	1.48 (0.77, 2.85)	0.235	29 (62)	18 (38)	1.22 (0.62, 2.39)	0.567
Previous colonoscopy	No	86 (77)	26 (23)	Reference		65 (71)	27 (29)	Reference	
	Yes	97 (74)	34 (26)	1.16 (0.64, 2.09)	0.622	68 (61)	44 (39)	1.56 (0.87, 2.80)	0.137
Diverticulosis sigmoid	No	82 (81)	19 (19)	Reference		82 (68)	39 (32)	Reference	
	Yes	71 (72)	20 (28)	1.69 (0.82, 3.47)	0.151	51 (61)	32 (39)	1.32 (0.74, 2.36)	0.352
Colonoscopy indication	CRCSP	76 (93)	6 (7)	Reference		55 (80)	14 (20)	Reference	
	Surveillance and familial risk	70 (71)	28 (29)	5.07 (1.98, 12.97)	<0.001	51 (59)	35 (41)	2.70 (1.30, 5.58)	0.008
	Symptoms and other	44 (70)	19 (30)	5.47 (2.03, 14.72)	<0.001	27 (55)	22 (45)	3.20 (1.42, 7.22)	0.005
Endoscopist experience	Gastroenterologist	140 (77)	42 (23)	Reference		98 (66)	50 (34)	Reference	
	Gastroenterologist in training	43 (70)	18 (30)	1.40 (0.73, 2.67)	0.320	35 (63)	21 (38)	1.18 (0.62, 2.23)	0.620
CRCSP certification	CRCSP certified	113 (76)	35 (24)	Reference		83 (67)	41 (33)	Reference	
	Not CRCSP certified	27 (79)	7 (21)	0.84 (0.34, 2.09)	0.703	15 (63)	9 (38)	1.21 (0.49, 3.01)	0.676

GCS, Gloucester Comfort Scale; OR, odds ratio; CI, confidence interval; CRCSP, Colorectal Cancer Screening Programme. *Education level according to ISCED-11. Patients were considered to have an intermediate or high educational level if they had at least an upper secondary or university degree; †One patient with BMI <18.5 was excluded from the analyses; ‡To assure colonoscopy quality for colonoscopies performed within the context of the Dutch CRCSP, all endoscopists performing these procedures have to be accredited. The endoscopist accreditation programme consisting of three modules: (1) colonoscopy registration module, (2) theoretical e-learning module combined with online assessment of the acquired knowledge and (3) a practical evaluation of colonoscopy and polypectomy skills.

Appendix S1. Overview of questions included within the Newcastle ENDOPREM colonoscopy questionnaire, adapted for the Dutch population (English version)

Note: development and validation of this questionnaire will be described elsewhere.

SECTION A: Completing this survey

A1. Please fill in today's date
d: _____ m: _____ y: _____

A2. How long ago was your most recent test?
Weeks: _____ Days: _____

A3. Please fill in your age (in years)
_____

A4. Are you?
❍ Male ❍ Female ❍ Other ❍ Prefer not to tell

A5. How many years of full time education have you completed (*starting from age 5*)?
_____

A6. To which of these ethnic groups would you say you belong?
❍ West-European (*including the Netherlands, Germany or any other West-European country*)
❍ East-European (*including Poland, Russia or any other East-European country)*
❍ Asian (*including Indonesia, India or any other Asian country*)
❍ Middle East (*including Syria, Iraq, Afghanistan or any other country within the Middle East*)
❍ Mediterranean (*including Turkey, Morocco or any other mediterranean country)*
❍ Caribbean and Surinam (*including (former) Netherlands Antilles and Surinam)*

A7. Please tell us if someone is helping you complete this survey
❍ I am completing this survey by myself
❍ Someone is helping me complete the survey

A8. Have you ever had another camera test (endoscopy) of the stomach or large bowel or a CT scan (CT colonography) of the large bowel?
❍ Yes ❍ No

Excluding your most recent rest, please indicate which test and how many you have had
❍ Colonoscopy (*camera or tube inserted though the back passage*) Number: _____
❍ Gastroscopy (*camera or tube inserted though the mouth into the stomach*) Number: _____
❍ Transnasal gastroscopy (*camera or tube inserted through the nose into the stomach*) Number: _____
❍ CT colonography (*CT scan where a short tube is inserted into the back passage – done in the X-ray department)* Number: _____
❍ Flexible sigmoidoscopy (*camera inserted through the back passage into the last part of the bowel only – usually only requires an enema*) Number: _____

A9. How were you referred for your most recent test?
❍ I was referred directly by my general practitioner (without seeing a hospital doctor)
❍ The test was organised by a hospital doctor
❍ I have regular test to monitor a medical condition / because of my family history
❍ I was referred through the national bowel cancer screening programme
❍ I was referred another way (please tell us more below)

_____

SECTION B: Before coming to the hospital for your test

B1. I was happy with the way I was referred for the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B2. The time from first being referred to having the test done was satisfactory

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B3. I felt able to change the appointment if it didn't suit me

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B4. My appointment was cancelled or changed by the hospital

❍ Yes ❍ No ❍ Not sure / cannot remember

B5. Before coming for the test, I was given enough information about what the test would involve

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B6. After reading the information, I did not have any questions about the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B7. The instructions on what I needed to do before the test were easy to follow

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B8. I had enough time to discuss the test with the person who referred me

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B9. I felt anxious about what the test would involve

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B10. I was made anxious by talking to other people who had previously had the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B11. I felt anxious about the results of the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B12. I expected to experience discomfort during the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B13. I expected to experience pain during the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

B14. I was worried that inserting the tube/camera would cause discomfort

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

SECTION C: Preparing for you test

C1. The bowel preparation had an unpleasant taste
❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

C2. The bowel preparation tasted better than I had expected
❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

C3. The volume (*amount*) of the bowel preparation was more than I had expected
❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

C4. The amount of bowel preparation I had to drink was manageable
❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

C5. I was worried that the bowel preparation would not clear my bowel properly
❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

C6. I had enough privacy when getting ready for the test (*e.g., when changing clothes)*
❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

SECTION D: At the hospital, before the test

D1. The length of time I waited in the department was acceptable
❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

D2. I was comfortable while sitting in the waiting area
❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

D3. I felt able to ask the staff any questions before the test
❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

D4. I had no unanswered questions before the test
❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

D5. I had enough privacy when waiting for the test
❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

D6. I had enough privacy when moving from the waiting area to the procedure room

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

SECTION E: During the test

E1. During the test my dignity was maintained at all times

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

E2. I felt free to choose what medication to take (*e.g., sedative, no medication*)

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

E3. The medication worked as well as I had expected

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

❍ I didn't have any medication

E4. I would have preferred the person doing the test (*inserting the tube or camera*) to be:

❍ Male ❍ Female ❍ I have no preference

E5. The person doing the test was:

❍ Male ❍ Female

E6. I felt confident that the person doing the test knew what they were doing

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

E7. The person doing the test did their best to put me at ease

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

E8. The other staff in the test room did their best to put me at ease

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

E9. I was satisfied with the explanation given to me about the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

E10. The person doing the test addressed any concerns I had

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

E11. I felt I could stop the test if it became too uncomfortable

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

❍ *I slept during the procedure*

E12. I felt embarrassed during the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

❍ *I slept during the procedure*

E13. The test took long than I expected

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

❍ *I slept during the procedure*

E14. How would you rate the level of discomfort you experienced during the test? Please circle a number below:

No discomfort | 0 | 1 2 3 | 4 | 5 6 | 7 8 | 9 10 | Worst discomfort imaginable

❍ *I slept during the procedure*

E15. How long did the discomfort last during the test?

❍ I didn't have discomfort ❍ A short time ❍ A moderate time ❍ A long time

❍ *I slept during the procedure*

E16. How many times did you experience discomfort during the test?

❍ None ❍ 1 or 2 times ❍ 3 or 4 times ❍ More than 4 times ❍ Constantly

❍ *I slept during the procedure*

E17. How would you rate the level of pain you experienced during the test? Please circle a number below:

No pain | 0 | 1 2 3 | 4 | 5 6 | 7 8 | 9 10 | Worst pain imaginable

❍ *I slept during the procedure*

E18. How long did the pain last during the test?

❍ I didn't have pain ❍ A short time ❍ A moderate time ❍ A long time

❍ *I slept during the procedure*

E19. How many times did you experience pain during the test?

❍ None ❍ 1 or 2 times ❍ 3 or 4 times ❍ More than 4 times ❍ Constantly

❍ *I slept during the procedure*

E20. Overall, I experienced more discomfort than I expected during the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

❍ *I slept during the procedure*

E21. Overall, I experience more pain than I expected during the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

❍ *I slept during the procedure*

E22. I felt embarrassed by the discomfort I experienced

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

❍ *I slept during the procedure*

E23. I felt embarrassed by the pain I experience

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

❍ *I slept during the procedure*

SECTION F: After the test

F1. I was satisfied by the explanation given to me by the person doing the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

F2. I had discomfort after the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

F3. It took longer than I expected to recover from the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

F4. I was worried about the test results

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

F5. Have you received the results of your test (*please tick all that apply*)

❍ Yes, I have received all of my test results
❍ Yes, I have received some of my test results
❍ No

F6. When I left the hospital, I was clear about what the next steps would be

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

F7. I was happy with the way I received the results of my test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

❍ *I do not have my results*

F8. I received the results of my test sooner than I had expected

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

❍ *I do not have my results*

SECTION G: Overall experience

G1. Overall I was satisfied with my experience of the test

❍ Strongly agree ❍ Agree ❍ Neither agree or disagree ❍ Disagree ❍ Strongly disagree

G2. If there is something else you would like to tell us about your test, please use the space below

_____