

Patient experience of gastrointestinal endoscopy: informing the development of the Newcastle ENDOPREM™

Neilson LJ, Patterson J, von Wagner C, Hewitson P, McGregor LM, Sharp L *, Rees CJ *

* Joint senior authors

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Corresponding Author

Dr Laura Jane Neilson
South Tyneside District Hospital
Harton Lane
South Shields, United Kingdom
NE34 0PL

l.neilson@nhs.net

07540459057

Affiliations

Neilson LJ - South Tyneside District Hospital & Population Health Sciences Institute, Newcastle University, United Kingdom

Patterson J – Sunderland Royal Hospital & Population Health Sciences Institute, Newcastle University, United Kingdom

von Wagner C – Research Department of Behavioural Science and Health, University College London, United Kingdom

Hewitson P - Nuffield Department of Population Health, University of Oxford, Oxford, United Kingdom

McGregor LM – Division of Psychology, Faculty of Natural Sciences, University of Stirling, United Kingdom

Sharp L –Population Health Sciences Institute & Newcastle University Centre for Cancer, Newcastle University, United Kingdom

Rees CJ –Population Health Sciences Institute & Newcastle University Centre for Cancer Newcastle University, & South Tyneside District Hospital, United Kingdom

Contributorship statement

CJR secured funding. CJR, LNJ, and LS conceived the study and reviewed the literature. CJR, LS and JP oversaw data collection, analysis and interpretation. LNJ undertook the semi-structured interviews and thematic analysis and drafted the paper. LM double coded a proportion of the interview transcripts. Other authors contributed to study design. All authors critically reviewed manuscript drafts and approved the final article for submission.

Abstract

Background

Measuring patient experience is important for evaluating the quality of patient care, identifying aspects requiring improvement and optimising patient outcomes. Patient Reported Experience Measures (PREMs) should, ideally, be patient derived, however no such PREMs for gastrointestinal (GI) endoscopy exist. This study explored the experiences of patients undergoing GI endoscopy and computerised tomography colonography (CTC) in order to: identify aspects of care important to them; determine whether the same themes are relevant across investigative modalities; develop the framework for a GI endoscopy PREM.

Methods

Patients aged ≥ 18 years who had undergone oesophagogastroduodenoscopy (OGD), colonoscopy or CTC for symptoms or surveillance (but not within the national bowel cancer screening programme) in one hospital were invited to participate in semi-structured interviews. Recruitment continued until data saturation. Inductive thematic analysis was undertaken.

Results

35 patients were interviewed (15 OGD, 10 colonoscopy, 10 CTC). Most patients described their experience chronologically, and five “procedural stages” were evident: before attending for the test; preparing for the test; at the hospital, before the test; during the test; after the test. Six themes were identified: anxiety; expectations; choice & control; communication & information; comfort; embarrassment & dignity. These were present for all three procedures but not all procedure stages. Some themes were inter-related (e.g. expectations and anxiety; communication and anxiety).

Conclusion

We identified six key themes encapsulating patient experience of GI procedures and these themes were evident for all procedures and across multiple procedure stages. These findings will be used to inform the development of the Newcastle ENDOPREM™.

Summary

What is already known about this subject?

Patient experience is an important aspect of quality of healthcare. It should be measured using an instrument (Patient Reported Experience Measure (PREM)) developed from experiences of patients themselves. No patient derived PREMs for GI endoscopy exist.

What are the new findings?

We conducted semi-structured interviews with GI endoscopy patients to understand the issues important to them. Identified themes were anxiety; expectations; choice & control; communication & information; comfort; embarrassment & dignity. These themes were present across GI procedures indicating that it would be possible to develop a common PREM for different GI investigations.

How might it impact on clinical practice in the foreseeable future?

Following validation both in the UK and internationally, the Newcastle ENDOPREM™ will be available to measure patient experience of GI endoscopy in both routine clinical care and research studies.

BACKGROUND

Gastrointestinal (GI) endoscopy is widely performed; the lifetime chance of requiring a GI endoscopy is around 35%[1]. Quality in healthcare is defined by three inter-linked dimensions: patient safety, clinical effectiveness and patient experience[2]. Variation in quality has been demonstrated for all GI endoscopy modalities and Computerised Tomographic Colonoscopy (CTC)[3–5]. This has led to improvement initiatives; to date these have largely concentrated on improving patient safety (e.g. reducing complications) or clinical effectiveness (e.g. increasing diagnostic rates)[6–8]. There has been relatively little focus on patient experience.

Patient experience encompasses the details of what occurs during a healthcare episode and to what degree a patient's needs have been met; it is therefore different from "patient satisfaction" which tends to measure how content a patient is with the care received during the episode as a whole[9]. A range of reasons for measuring patient experience of GI endoscopy are becoming apparent. Patient experience influences uptake of initial procedures, attendance for repeat procedures, and screening programme participation[10]. Positive experiences correlate with better patient outcomes[11–13]. Thus, measuring patient experience is important for evaluating overall quality of care provided, identifying specific aspects of care that may need improvement, and optimising patient outcomes.

Patient experience should, ideally, be measured using a Patient Reported Experience Measure (PREM) which: has been developed from a thorough understanding of patient experiences; incorporates events throughout the patient journey; captures aspects of care prioritised by patients; and has been validated[10,14,15]. Robust PREMs for GI endoscopy are lacking. Most tools assess satisfaction (not experience) asking broad questions about the entire clinical episode.[16,17] The internationally-used Global Rating Scale (GRS) patient experience domain was derived from literature review and expert opinion.[18] Similarly, the Gastrointestinal Endoscopy Satisfaction Questionnaire comprised the "most relevant" questions from existing questionnaires following literature review and review by patients and clinicians [19]. However, patients' and clinicians' priorities around endoscopy experience differ; clinicians tend to focus on in-room elements of GI endoscopy (e.g. comfort, pain) while broader issues (e.g. communication, pre-procedural preparation) may be important to patients.[20,21] Only one measure of patient comfort during endoscopy has been formally validated, but this was clinician and nurse developed.[22]

To inform development of the first patient-derived PREM for GI endoscopy, this study explored patient experiences with the aims of: identifying aspects of care considered important to patients; determining whether the same themes and issues are relevant across investigative modalities; and developing the framework for a PREM for GI endoscopy.

METHODS

We followed a systematic process to develop the Newcastle ENDOPREM™ (Figure 1); phase 1 is reported here and subsequent phases will be reported elsewhere in due course.

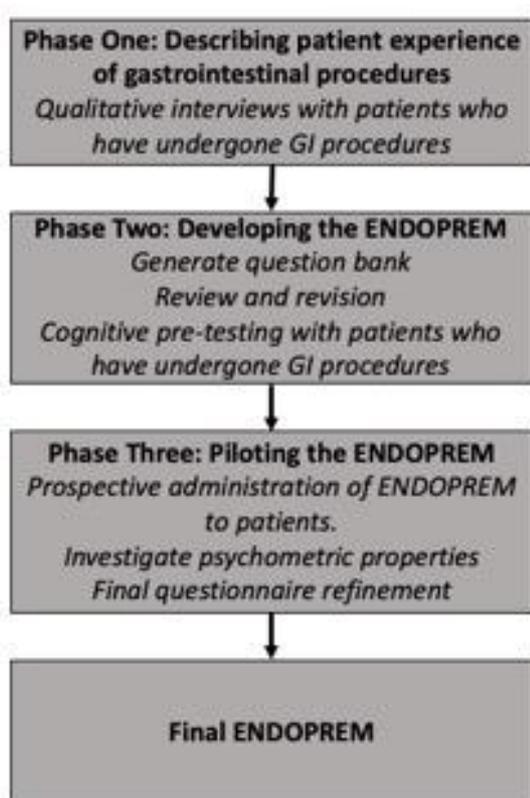


Figure 1: Development of the Newcastle ENDOPREM™ flow chart

Patients aged ≥ 18 years at a single NHS Trust who had undergone oesophagogastroduodenoscopy (OGD), colonoscopy or CTC for symptoms or surveillance were invited to participate in a 1:1 semi-structured interview, conducted by a clinical researcher trained in qualitative interviewing. CTC is increasingly used, especially as an alternative to colonoscopy in patients who are unfit to undergo an invasive procedure. Inclusion of CTC patients enabled us to assess whether it would be possible to develop a PREM which captured experiences of GI endoscopy and related procedures which might be used in the same patient group; such a tool could be valuable for future research or

service evaluation. Due to the very different patient pathway involved, individuals undergoing Bowel Cancer Screening Programme procedures were excluded. To maximise diversity of experience, purposive sampling by age and sex was undertaken, and variation sought in socioeconomic background, whether individuals had undergone previous endoscopy, procedural investigation type, endoscopist grade, completeness of procedure and endoscopic diagnosis.

Interviews took place during February 2016- April 2017 in a non-clinical building at the hospital (at a separate time from a clinical appointment). We sought to conduct the interviews face-to-face, and this occurred for all but one patient who was unable to return to the hospital so was interviewed by telephone. Interviews were guided by a topic guide developed from literature review and expert opinion. This was used flexibly to allow participants to talk about their experience in a way that was comfortable for them, while ensuring all aspects of the “process” were covered. Interviews were audio-recorded, transcribed verbatim and anonymised; they lasted between 20 and 60 minutes.

Recruitment and analysis were conducted in parallel so that new topics arising in earlier interviews could be explored further in later interviews. In particular, we paused after 10 interviews to review participant characteristics and conduct some preliminary analyses. Recruitment continued until data saturation, defined as no new issues arising in the last three interviews[23]. Thematic analysis was undertaken[24]. Transcripts were read and re-read for familiarisation, coded and codes combined into themes producing a detailed account of the data. A transcript from each procedure type was double-coded for rigour. This inductive process meant themes were derived solely from the dataset.[25] Most participants described their experience in chronological order and the final themes were subsequently organised into chronological procedure stages (before attending for test; preparing for test; at the hospital, before test; during test; after test). Illustrative quotes are provided to supplement narrative descriptions.

Ethical approval was obtained through the NRES Committee London-Stanmore (IRAS ID: 14689, National Institute for Health Research UKCRN ID 18749). Participants provided informed consent before interview.

RESULTS

Of 127 patients who agreed to be contacted about the study, semi-structured interviews were undertaken in 35 (15 OGD, 10 colonoscopy, 10 CTC). Interviews were conducted between five to 52 days following the procedure (mean 16.2). Participants' characteristics are shown in Table 1.

Characteristic	Strata	OGD	Colonoscopy	CT Colonography	Total
Number of participants	-	15 (3 transnasal endoscopy)	10	10	35
Sex	Male	8 (53.3%)	5 (50.0%)	6 (60.0%)	19 (54.3%)
	Female	7 (46.7%)	5 (50.0%)	4 (40.0%)	16 (45.7%)
Age	<50 years	5 (33.3%)	0 (0.0%)	1 (10.0%)	6 (17.1%)
	50 -59 years	4 (26.7%)	5 (50.0%)	1 (10.0%)	10 (28.6%)
	60 – 69 years	2 (13.3%)	2 (20.0%)	3 (30.0%)	7 (20.0%)
	70+ years	4 (26.7%)	3 (30.0%)	5 (50.0%)	12 (34.3%)
Previous test experience	None	4 (26.7%)	3 (30.0%)	4 (40.0%)	11 (31.4%)
	Same test previously	10 (66.7%)	4 (40.0%)	1 (10.0%)	15 (42.9%)
	Different test previously	1 (6.7%)	3 (30.0%)	5 (50.0%)	9 (25.7%)

Table 1: Participant Characteristics

Six themes were identified: anxiety; expectations; choice & control; communication & information; comfort; embarrassment & dignity. Table 2 shows examples of the themes with illustrative quotes. The themes were present for all test modalities but not all five procedure stages (Figure 2). Themes were sometimes inter-related.

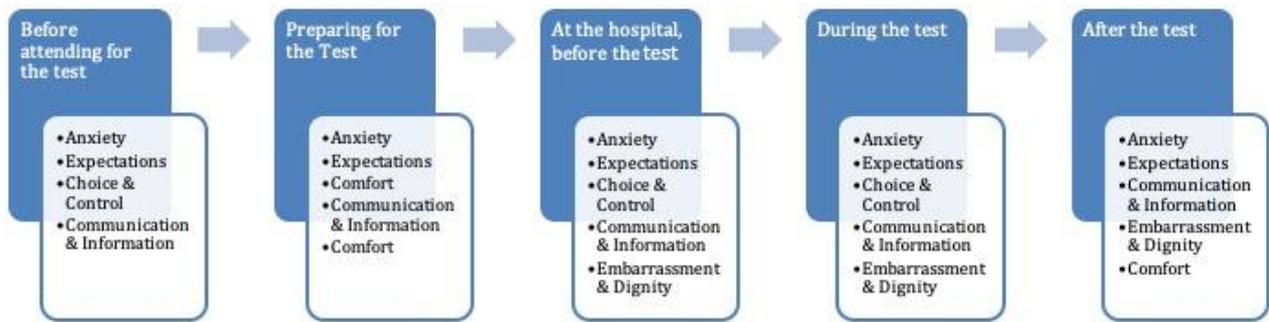


Figure 2: Themes according to procedure stage

Theme	Subtheme	Quote
Anxiety	Effect of previous experience	<i>"I was frantic, because I thought it would be no different...to what the first one was."</i> CT2
	Effect of waiting time for test	<i>"I didn't have much time to think about it, which makes the procedure a lot better. I think the longer you've got to wait for it I think the more anxious people become."</i> OG6
	Anxiety about whether bowel preparation worked	<i>"The first day when I took it, nothing really happened. And I was getting a bit concerned because obviously your interest is as far as the clinical side is to have a real clear view of the bowel like to make sense of the thing."</i> CT10
	Anxiety about results	Interviewer: <i>"How do you feel about that [waiting for the results]?"</i> Pt: <i>"Just a little bit worried: it could be something, it could be nothing. I think it's just understandable to feel a little bit apprehensive."</i> CT4
Expectations	Appointment quicker than expected	<i>"When you get it [the appointment] that quick you think oh does he think it's something serious."</i> OG6
	Expectation of test duration	<i>"She [radiographer] said the whole preparation will take about just under twenty minutes which it did. So I knew I just had to suffer for twenty minutes and that was it all done."</i> CT3
	Recovery longer than expected	<i>"I expected to have diarrhoea for at least a day, but not for about three or four or five days. I don't know if this might just have aggravated what problem I may have."</i> CT1
Choice & Control	Choice of endoscopist versus convenience	<i>"If there was another specialist that could have done it...rather than just relying on Mr X to do it. So I suppose that would be a good thing from a patient's point of view, if there's another specialist that can do the same thing on another day."</i> CO2
	Alternative procedures	<i>"I was quite reluctant to have another one unless it was absolutely necessary and that was when she explained that there was an alternative if I would prefer that."</i> CT8
	Perceived staff preferences of sedation	<i>"But obviously I know they don't like to give you it because obviously they've got to keep you in a bit longer and you've got to have somebody to look after you. I understand that, but if it makes my experience better I don't care personally."</i> OG6
Information & communication	Effect of insufficient information	Interviewer: <i>"Do you think you had enough information before the test?"</i> Pt: <i>"No. I thought, me being naïve, I was just gonna go and stand in front of an x-ray machine, but once she said you're taking your clothes off right down to</i>

		<i>your socks, and putting these two dressing gowns on, I knew I was in for something totally different!"</i> CT3
	Information can put patients off	<i>Pt: "I had all the information on the tests saying what was going to happen yes. To be honest with you I didn't particularly read through it." Interviewer: "Why not?" Pt: "I'm not going to read this to put myself off...if you read that you're going to put that down your throat. I would think I'm not going."</i> OG7
	Effect of staff talking through the procedure	<i>"They know the situation...They can foresee it before it happens so it's taking away the unknown from people and I just felt that that's what they did."</i> CT6
Comfort	Effect of tube insertion	<i>"It's just actually the penetration if that's the word I'm looking for... but once it's inside it's great. He waxes it [the colonoscope]"</i> CO4
	Discomfort due to air insufflation	<i>"I felt bloated. Oh when the air, yes I felt it was very painful, but it were like bad wind."</i> CT8
	Discomfort in days following test	<i>"It was like there was something lodged there and you got it free and it's a bit raw."</i> OG15
Embarrassment & Dignity	Dignity in shared gender waiting area	<i>Pt: "There are husbands and wives and you're sitting waiting with just your dressing gown on and this silly little Wee Willy Winky night gown on." Interviewer: "So what do you think about that?" Pt: "Well, I think I'm too old to be embarrassed, but the thing is I think other people can be embarrassed and so you have to be very careful for your dignity."</i> CT5
	Embarrassment about own reaction	<i>"The water that comes up and everything it's embarrassing for me. I think that's the worst of it all for me. But it's part and parcel of it isn't it? If that bit didn't happen it would be great."</i> OG10
	Embarrassment due to operator gender	<i>Male Pt: "A young girl having to put her fingers into my bottom, that's the only thing; it's very embarrassing."</i> CT4
	Effect of dignity shorts	<i>"I just had a gown on. You know, that was the first time I had it done. But the second time, they gave me these knickers with the slit up and I thought that's a lot of better. That's a lot more dignified."</i> CO7

Table 2: Illustrative Quotes. Key: OG= OGD, CT= CTC, CO= colonoscopy

Anxiety

Patients described anxiety at all procedural stages. Anxiety generally increased the longer patients waited for an appointment, however, a few patients equated a faster appointment with a more serious potential diagnosis and this also increased anxiety. Patients worried about the test itself and what it would involve, often because they did not know what to expect, or were concerned about discomfort. Those with previous bad experiences of endoscopy were more anxious. Several colonoscopy and CTC patients described anxiety that the laxative preparation might not work adequately, hindering test completion. Patients undergoing all modalities commonly described anxiety about what the test might show.

Waiting for the test in the department was described as *'like waiting for the firing squad.'* Longer waits increased anxiety. Waiting rooms were described as *'functional'* or *'pleasant,'* but patients reported that the atmosphere could have been made more relaxing.

Most patients (aside from those undergoing CTC) were told results verbally by a staff member before discharge; those who were not described feeling anxious about how they would receive the results and what they would show.

Expectations

A small number of patients had an outpatient consultation pre-procedure but had expected that this appointment would be for the procedure. These patients described feeling they were *'wasting the consultant's time'* and that the appointment delayed the procedure unnecessarily. Patients interpreted waiting times for appointments differently. Anxiety resulted when expectations and reality were mismatched.

A few patients undergoing OGD and colonoscopy waited longer in the department than they expected (up to two hours). Some accepted this but extended waits increased anxiety for others, particularly when no explanation was given.

OGD and colonoscopy patients who elected for sedation during the procedure described expecting they would *'float away,'* be *'knocked out'* or that the sedation would *'take the edge off.'* However, sedation effects varied significantly: a few patients did not remember the procedure; others felt no effect or that they had not been given enough: *'I don't think I was sedated at all...or very mildly.'* A

few patients who had previously had endoscopy noted that sedation experience varied between procedures. Most patients described not knowing how long the test would take. A few felt it was *'going on forever.'* Others, particularly in the CTC and OGD groups, said it was *'over quickly'*. Knowing approximately how long the procedure took might have made the experience more manageable.

Following the test, some patients described feeling back to normal almost immediately, some felt *'wobbly'* or *'fragile'* and a few described *'discomfort'* for several days afterwards. A few patients described unexpected ongoing altered bowel habit.

Choice & control

Patients reported that it was important to have choice and control over elements of the test. While some patients preferred the clinician who referred them to perform the test, others prioritised a quicker or more convenient appointment (even if this was with another clinician). Many patients preferred a morning appointment perceiving this would mean: easier parking; shorter fasting; and less waiting in the department (as the clinic would be less likely to be running late) and so less time to worry. No patients were given a choice of the sex of the endoscopist/radiographer but having choice or control over this was not considered important.

Where patients were offered the choice between CTC and colonoscopy, some patients valued that choice however others felt the doctor *'knows better than me'*.

When offered a choice of throat spray or sedation, patients undergoing OGD or colonoscopy considered perceived effectiveness or their own convenience (speed of recovery, ability to drive, need for post procedure supervision). Some patients felt that opting for sedation would inconvenience staff, but this did not influence their decision. One who chose sedation was also given throat spray without this being discussed and was unhappy that they had not been given the choice. Patients undergoing OGD and colonoscopy (but not those undergoing CTC) said they felt able to stop the test if needed. Patients undergoing OGD said that *'swallowing the camera'* was the hardest part. A few patients felt that it was their responsibility to *'get that [the camera] down'*.

Communication & Information

Communication and information were strongly inter-linked and therefore formed a single theme.

All patients described being given information – mainly in written form – pre-procedure; this included information about the test, pre-procedure preparation/diet and risks of the test. A few said they would have preferred if someone (ideally the health professional referring them) had conveyed the information verbally and that this would have reduced their anxiety and helped them prepare for the test. A small number of patients said they would have liked more specific written information (e.g. what would happen during the test, the effects of sedation, and how they might feel in the days afterwards). Others felt the information was contradictory, too lengthy or contained irrelevant detail. A minority of patients, most commonly those who had undergone tests previously, said they did not read information. One patient said they *'didn't want to know.'* Some patients spoke to peers who had undergone the procedure. Most wished *'they hadn't listened'* to others as they tended to tell *'horror stories,'* however one described feeling less nervous realising it was *'just routine.'* A few sought information online but most admitted this was often unhelpful.

Colonoscopy and CTC patients said the diet was restrictive and one patient felt they would have found meal plans helpful. These patients described laxative preparation as *'severe'* and a few felt the written information did not prepare them for what would happen after they took the preparation. A few CTC patients were surprised that the first dose of laxative had no effect, and one phoned the department for advice.

Patients repeatedly spoke about the importance of staff communication. They said that having the endoscopist/radiographer talk during the procedure put them at ease. They cited instances where they felt communication was poor, including: failure of staff to introduce themselves; no explanation of procedure; staff discussing unrelated topics in the room.

Nursing staff were described as *'fantastic,' 'friendly,' 'professional'*. Patients reported nurses *'took care'* of them during the test, reassuring, advising them how to cope, helping them change position and distracting them with jokes or conversation. A very small number of patients described instances where they felt staff had a negative attitude towards them (e.g. a patient who struggled to retain air during CTC felt they were being negatively judged).

Comfort

Comfort was discussed in relation to the test and immediate recovery period. Patients used the terms pain and discomfort; some used these to mean the same thing, whereas others spoke about pain as something more intensive than discomfort. In their accounts, patients spoke about three

aspects of comfort: the intensity of the discomfort/pain, how long the discomfort/pain lasted, and how many times discomfort/pain were experienced.

For OGD, mouth guard insertion was described as *'not very easy to deal with.'* Descriptions of endoscope insertion included *'gagging,' 'retching'* and *'choking.'* A few patients undergoing biopsies reported pain. Patients attributed procedural discomfort to air or gas insufflation.

Colonoscopy patients described anal lubrication as embarrassing and a *'cold shock'*, and anal intubation as uncomfortable. Patient descriptions of the sensory experience ranged from *'cramps'* and *'twinges'* to *'painful.'* They spoke about intermittent pain throughout the procedure which was attributed to air being pumped in and negotiation around bends; they said that abdominal hand pressure made pain worse.

CTC patients described *'jelly'* insertion before a tube was inserted rectally. Patients described discomfort due to gas being *'blown in,' 'severe cramps,'* or pain *'like a stitch,'* making some feel they needed the toilet. Some found changing position difficult on a small bed. Others found holding the same position for prolonged periods uncomfortable. Most patients felt back to normal quickly with little on-going discomfort.

Embarrassment & Dignity

Irrespective of procedure, patients spoke about embarrassment and dignity. A few patients perceived changing areas for CTC and colonoscopy as insufficiently private and described feeling that staff or patients *'could walk straight in'*. A few reported hospital-provided gowns not closing or covering them and said this was undignified. A small number described embarrassment at walking down a corridor to or from the procedure room while wearing a gown; they would have preferred the changing room to be closer to waiting area. Others felt it undignified to wait for the test in an area that wasn't private while dressed in a gown. Some disliked mixed sex waiting areas.

A few OGD patients were embarrassed about retching during the procedure feeling they had shown a lack of control. In CTC and colonoscopy groups, embarrassment was related to the sensitive nature of the procedure. Patients were more embarrassed when the operator was of the opposite sex; in particular men expressed embarrassment with regards to female operators. Colonoscopy patients reported that dignity shorts reduced embarrassment; these were not available to CTC patients and those who had previously had colonoscopy highlighted this. Following CTC, patients

described being taken to a toilet to relieve gas; this caused them embarrassment as they felt people in an adjacent waiting area might hear them.

DISCUSSION

This study provides patient perspectives of the GI procedural pathway and reveals which aspects of experience matter to patients. This is the first time that patient perspectives across three GI procedures have been explored using in-depth, qualitative methods. Whilst some qualitative literature exists, this tends to focus on specific populations (e.g. Barrett's oesophagus surveillance, colorectal cancer screening[26,27]) or specific aspects of experience (e.g. comfort during colonoscopy vs colon capsule endoscopy[27,28]). Furthermore, where more than one modality has been explored findings have been analysed and described separately[27]. Our study reveals that many themes and issues are common across modalities, implying that there is an opportunity to develop a PREM that is widely applicable across different GI endoscopy modalities and related procedures (such as CTC).

We used semi-structured one-to-one interviews to enable patients to describe *their* experience in detail and speak more freely about potentially sensitive topics. Indeed, patients did raise sensitive issues (e.g. insertion of the CTC catheter or endoscope). They also provided detailed descriptions of the effects of bowel preparation and discussed things which caused them embarrassment; such issues are clearly an important aspect of patient experience and may not have emerged using a different methodological approach.

The six themes identified did not appear at every stage of the pathway. However, they were often inter-linked and where a patient described a negative experience within one, this often affected others. This indicates the importance of assessing experiences across the entire patient journey within any PREM.

Past work found colonoscopy patients to be anxious about bowel preparation, the procedure itself and results [29]. Our findings develop this further, showing anxiety can be present across the entire journey, starting while patients await appointments, and that this applies to CTC and OGD as well as colonoscopy. Studies have also suggested that colonoscopy patients who have previously undergone endoscopy experience less anxiety as they know what to expect. [31] [32]. Our findings are more nuanced; anxiety was less of an issue for patients who attended for tests regularly, but those who had had previous bad experiences were more anxious, suggesting that it is important

that healthcare providers do not simply assume those who have attended previously will not be anxious.

Understanding patients' expectations is important to be able to interpret their evaluations of healthcare[33]. In previous studies, expectations have been reported as an element of another theme. Here, expectations emerged as a theme in its own right and, as might be anticipated, interacted with other themes, suggesting that better management of patient expectations might help prepare patients for endoscopy and reduce anxiety.

Preference for sex of the endoscopist has previously been described as an important choice for patients; prospective questionnaire studies administered prior to the procedure, have reported that female patients prefer a female colonoscopist [34,35]. In our study, while choice and control were important across the patient journey, choice regarding the sex of the operator was not generally considered important. However, interviews were conducted post-procedure and this may have impacted findings. Moreover, male patients, in particular, reported embarrassment regarding female operators, suggesting the issue is not limited to female patients.

Provision of information pre-colonoscopy has been linked to lower anxiety and BSG guidelines emphasise the importance of written information pre-procedure[36,37]. However, studies report variations in amount of information provided for colonoscopy and gastroscopy, and that reading levels often exceed recommended reading age standards [38–40]. Our results suggest patients desire different types and amounts of information and different modes of delivery (i.e. one size does not fit all).

Various tools to measure pain and/or discomfort already exist [41]; these vary in length, format, response options, terminology, and whether they are intended for patient or health professional completion (see, for example, [19][42][43]). We found that patients spoke about both pain and discomfort - sometimes interchangeably, sometimes as different concepts - and described three distinct aspects: intensity, duration and number of times experienced. As far as we are aware no tools currently exist to capture all of these aspects from the patient perspective, so this will be a focus of our future PREM.

Being treated with dignity is a key component of patient-centred care[44]. Previous endoscopy research has tended to focus on comparing overall embarrassment associated with different lower

GI test modalities [45]. In the current study, patients frequently described embarrassment and both positive and negative examples of preserving dignity. Notably this was not limited to during the test itself, but also related to pre- and post-test arrangements (e.g. waiting in public areas wearing gowns). In addition, OGD patients spoke about being embarrassed by their physical reaction to the endoscope being inserted. These findings suggest that embarrassment and dignity need to be considered as important aspects of experience across several phases of the GI endoscopy journey.

Participants were recruited from a single site. To mitigate any possible effects of this we included patients who had previously undergone endoscopy at other hospitals. We relied on health professionals to approach potential interviewees and it is possible that this may have influenced participation. However, the credibility of the recruitment process is evidenced by the varied experiences described by patients. It is possible that patients' responses to their experiences will vary over time from the procedure. Although we only interviewed people once, interviews took place between five and 52 days post-procedure, which may have helped capture any temporal variations in responses to experience.

In terms of next steps, these themes are being used to develop a question bank for the Newcastle ENDOPREM™, the first patient-derived PREM applicable across multiple GI endoscopy modalities. Questions within the instrument have been organised by procedure stage since most patients described their experience chronologically. The draft PREM will be refined with patients and then undergo psychometric validation.

Conclusion

We identified six key themes encapsulating patient experience of GI procedures and these themes were evident for colonoscopy, CTC and OGD and across multiple procedure stages. These findings will be used to inform the development of the Newcastle ENDOPREM™ which will be available for use in GI endoscopy research or evaluation of routine care.

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Competing Interests

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REFERENCES

1. Seeff LC, Manninen DL, Dong FB, et al. Is there endoscopic capacity to provide colorectal cancer screening to the unscreened population in the United States? *Gastroenterology* 2004; 127 (6): 1661–9
2. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open* 2013; 3 (1): e001570
3. Obaro AE, Plumb AA, Fanshawe TR, et al. Post-imaging colorectal cancer or interval cancer rates after CT colonography: a systematic review and meta-analysis. *Lancet Gastroenterol Hepatol* 2018; 3 (5): 326–36
4. Bowles CJA, Leicester R, Romaya C, et al. A prospective study of colonoscopy practice in the UK today: are we adequately prepared for national colorectal cancer screening tomorrow? *Gut* 2004; 53 (2): 277–83
5. Gavin DR, Valori RM, Anderson JT, et al. The national colonoscopy audit: a nationwide assessment of the quality and safety of colonoscopy in the UK. *Gut* 2013; 62 (2): 242–9
6. Rees CJ, Bevan R, Zimmermann-Fraedrich K, et al. Expert opinions and scientific evidence for colonoscopy key performance indicators. *Gut* 2016; 65 (12): 2045–60
7. Rees CJ, Thomas-Gibson S, Rutter MD, et al. UK key performance indicators and quality assurance standards for colonoscopy. *Gut* 2016; 65 (12): 1923–9
8. Oppong KW, Romagnuolo J, Cotton PB. The ERCP quality network benchmarking project: a preliminary comparison of practice in UK and USA. *Frontline Gastroenterol* 2012; 3 (3): 157–61
9. Beattie M, Murphy D, Atherton I, et al. Instruments to measure patient experience of healthcare quality in hospitals: a systematic review. *Syst Rev* 2015; 4 (1): 97
10. Black N, Jenkinson C. Measuring patients' experiences and outcomes. *Br Med J* 2009; 339: b2495
11. Dr Foster. The Intelligent Board 2010- Patient Experience. 2010
12. Francis R. The Francis Report (Report of the Mid-Staffordshire NHS Foundation Trust public inquiry) and the Government's response. 2013.
13. Price R, Elliott MN, Zaslavsky AM, et al. Examining the Role of Patient Experience Surveys in Measuring Health Care Quality. *Med Care Res Rev* 2014; 71 (5): 522–54
14. Dawson J, Doll H, Fitzpatrick R, et al. The routine use of patient reported outcome measures in healthcare settings. *Br Med J* 2010; 340: c186
15. Coulter A, Fitzpatrick R, Cornwell J. The Point of Care: Measures of patients' experience in hospital - The King's Fund, July 2009.
16. Tierney M, Bevan R, Rees CJ, et al. What do patients want from their endoscopy experience? The importance of measuring and understanding patient attitudes to their care. *Frontline*

Gastroenterol 2016; 7 (3): 191–8

17. Coulter A, Fitzpatrick R, Cornwell J. The Point of Care. Measures of patients' experience in hospital: purpose, methods and uses. 2009
18. Royal College of Physicians JAG Office. Global Rating Scale and Knowledge Management System [Internet]. 2011
19. Hutchings H, Cheung W-Y, Alrubaiy L, et al. Development and validation of the Gastrointestinal Endoscopy Satisfaction Questionnaire (GESQ). *Endoscopy* 2015; 47 (12): 1137–43
20. McEntire J, Sahota J, Hydes T, et al. An evaluation of patient attitudes to colonoscopy and the importance of endoscopist interaction and the endoscopy environment to satisfaction and value. *Scand J Gastroenterol* 2013; 48 (3): 366–73
21. Denters MJ, Deutekom M, Derkx B, et al. Patient satisfaction with the colonoscopy procedure: endoscopists overestimate the importance of adverse physical symptoms: Table 1. *Frontline Gastroenterol* 2012; 3 (3): 130–6
22. Rostom A, Ross ED, Dubé C, et al. Development and validation of a nurse-assessed patient comfort score for colonoscopy. *Gastrointest Endosc* 2013; 77 (2): 255–61
23. Strauss AL, Corbin JM. *Basics of qualitative research : techniques and procedures for developing grounded theory*. Sage Publications; 1998. 312 p.
24. Braun V, Clarke V. *Using thematic analysis in psychology*. *Qual Res Psychol* 2006; 3 (2): 77–101
25. Ritchie J, Lewis J. *Qualitative research practice : a guide for social science students and researchers*. 2nd ed. London: Sage Publications; 2003. 336 p.
26. Arney J, Hinojosa-Lindsey M, Street RL, et al. Patient Experiences with Surveillance Endoscopy: A Qualitative Study. *Dig Dis Sci* 2014; 59 (7): 1378–85
27. von Wagner C, Knight K, Halligan S, et al. Patient experiences of colonoscopy, barium enema and CT colonography: a qualitative study. *Br J Radiol* 2009; 82 (973): 13–9
28. Thygesen MK, Baatrup G, Petersen C, et al. Screening individuals' experiences of colonoscopy and colon capsule endoscopy; a mixed methods study. *Acta Oncol (Madr)* 2019; 58 (Suppl 1): S71–6
29. Shafer LA, Walker JR, Waldman C, et al. Factors Associated with Anxiety About Colonoscopy: The Preparation, the Procedure, and the Anticipated Findings. *Dig Dis Sci* 2018; 63 (3): 610–8
30. van Dam L, de Wijckerslooth TR, de Haan MC, et al. Time requirements and health effects of participation in colorectal cancer screening with colonoscopy or computed tomography colonography in a randomized controlled trial. *Endoscopy* 2013; 45 (3): 182–8
31. Ylinen E-R, Vehviläinen-Julkunen K, Pietilä A-M. Effects of patients' anxiety, previous pain experience and non-drug interventions on the pain experience during colonoscopy. *J Clin Nurs* 2009; 18 (13): 1937–44

32. Luck A, Pearson S, Maddern G, et al. Effects of video information on precolonoscopy anxiety and knowledge: A randomised trial. *Lancet* 1999; 354 (9195): 2032–5
33. Bowling A, Rowe G, Lambert N, et al. The measurement of patients' expectations for health care: a review and psychometric testing of a measure of patients' expectations. *Health Technol Assess* 2012; 16 (30)
34. Fidler H, Hartnett A, Cheng Man K, et al. Sex and Familiarity of Colonoscopists: Patient Preferences. *Endoscopy* 2000; 32 (6): 481–2
35. Shah DK, Karasek V, Gerkin RD, et al. Sex preferences for colonoscopists and GI physicians among patients and health care professionals. *Gastrointest Endosc* 2011; 74 (1): 122-127.e2
36. Beg S, Ragunath K, Wyman A, et al. Quality standards in upper gastrointestinal endoscopy: a position statement of the British Society of Gastroenterology (BSG) and Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland (AUGIS). *Gut* 2017; 66 (11): 1886–99
37. Luo YY. Effects of written plus oral information vs. oral information alone on precolonoscopy anxiety. *J Clin Nurs* 2013; 22 (5–6): 817–27
38. Gargoum FS, O'Keeffe ST. Readability and content of patient information leaflets for endoscopic procedures. *Ir J Med Sci* 2014; 183 (3): 429–32
39. Mason MC, Williamson JML. Readability of endoscopy information leaflets: Implications for informed consent. *Int J Clin Pract* 2018; 72 (5): e13099
40. Parahoo K, Ridley T, Thompson K, et al. A qualitative evaluation of information leaflets for gastroscopy procedure. *J Eval Clin Pract* 2003; 9 (4): 423–31
41. Melzack R. The McGill Pain Questionnaire: major properties and scoring methods. *Pain* 1975; 1 (3): 277–99
42. Hoff G, Bretthauer M, Huppertz-Hauss G, et al. The Norwegian Gastronet project: Continuous quality improvement of colonoscopy in 14 Norwegian centres. *Scand J Gastroenterol* 2006; 41 (4): 481–7
43. Cadoni S, Falt P, Gallittu P, et al. Water Exchange Is the Least Painful Colonoscope Insertion Technique and Increases Completion of Unsedated Colonoscopy. *Clin Gastroenterol Hepatol* 2015; 13 (11): 1972-1980.e1-3
44. Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. *Int J Qual Heal Care* 2002; 14 (5): 353–8
45. Gareen I, Siewert B, Vanness D, et al. Patient willingness for repeat screening and preference for CT colonography and optical colonoscopy in ACRIN 6664: the National CT Colonography trial. *Patient Prefer Adherence* 2015; 9: 1043–51

