This article has been accepted for publication in FLGASTRO following peer review.
The definitive copyedited, typeset version is available online at
10.1136/flgastro-2025-103168

Frontline Gastroenterology

Word count: *up to 4000 words* ***Structured abstract:*** *up to 250 words: 'Objective', 'Design/Method', 'Results', 'Conclusion'* ***Tables/Illustrations:*** *up to 4* ***References:*** *limited to those critical to the manuscript*

Please include the key messages of your article after your abstract using the following headings. This section should be no more than 3-5 sentences and should be distinct from the abstract; be succinct, specific and accurate.

- **What is already known on this topic** – Evidence suggests that patients with Crohn's disease prefer non-invasive diagnostic modalities, however, a systematic review[20] has highlighted a need for more studies on patients' perceptions and acceptability of different monitoring tools.
- **What this study adds** – Findings from this qualitative study embedded within a trial comparing the pan-enteric PillCam™ Crohn's capsule (PCC) with Ileo-colonoscopy (IC) and Magnetic resonance enterography (MRE) suggest that most, but not all, patients may have a preference for PCC. A range of advantages and disadvantages relating to all three modalities were reported.
- **How this study might affect research, practice or policy** – If effectiveness of different investigation modalities is confirmed, further work is needed to understand how best to integrate these within current management guidelines and care pathways in line with patient preferences.

Title: Panenteric Crohn's capsule versus Ileo-Colonoscopy and Scan: An embedded qualitative study exploring the views and experiences of patients with established Crohn's disease.

Author names and institutional addresses:

Dr Phey Shen Lee (South Tyneside District Hospital, South Shields)
Dr Nicola Hall (University of Sunderland, Sunderland and Newcastle University, Newcastle upon Tyne)
Ms Carolyn Davison (South Tyneside District Hospital, South Shields)
Prof Mark McAlindon (Royal Hallamshire Hospital, Sheffield)
Prof Reena Sidhu (Royal Hallamshire Hospital, Sheffield)
Prof Anjan Dhar (Darlington Memorial Hospital, Darlington and Teesside University, Middlesbrough)
Dr Amit Chattree (Sunderland Royal Hospital, Sunderland)
Dr Helen Close (Newcastle University, Newcastle upon Tyne)
Dr Simon Panter (South Tyneside District Hospital, South Shields)

Corresponding author: Dr Phey Shen Lee, South Tyneside District Hospital
Keywords (3-10 words)
Crohn’s disease; clinical trials; gastrointestinal endoscopy; inflammatory bowel disease; health service research

Abstract

Objective

This study aimed to explore patient experience and preferences for different investigation modalities for surveillance and assessment of disease activity and mucosal healing in patients with established Crohn's disease (CD).

Method

A qualitative interview study embedded within a UK-based pragmatic trial of pan-enteric capsule endoscopy (PillCam™ Crohn's capsule, PCC) compared to Ileo-Colonoscopy (IC) and Magnetic Resonance Enterography (MRE). Telephone semi-structured interviews were completed with 10 patients with established CD who had undergone all three modalities.

Results

A range of advantages and disadvantages relating to all three modalities were described. PCC was generally reported as being easy to swallow and associated with less discomfort, intrusiveness and pain than IC. Negative attributions associated with unpleasantness of IC were common, however, the intensity of associated emotions, rather than their presence, seems to have the greatest influence on procedure preference. Tolerance of investigative procedures can be moderated by acceptance and recognition of their necessity in management of CD, and perceived effectiveness of the procedures. Other key influences include the importance of support and trust in clinical and nursing staff and the ability to manage procedure and appointment requirements within daily life and responsibilities.

Conclusions

Findings suggest that for many, although not all, patients with CD, there would be a clear preference for PCC over IC and MRE, if effectiveness is proven to be equivalent. This supports the need for further work to demonstrate use and effectiveness with a view to integration within current management guidelines and care pathways in line with patient preference.

Title: Panenteric Crohn's capsule versus Ileo-Colonoscopy and Scan study: An embedded qualitative study exploring the views and experiences of patients with established Crohn's disease

Background

Patients with established Crohn's disease (CD) require assessment when a change in symptoms is suggestive of a disease flare or after 12 months of advanced biologic treatment to assess mucosal healing.[1] "Treat-to-target" approaches that require close monitoring and repeated assessment of disease activity to inform treatment adjustments until a therapeutic target is reached can be cost effective, reduce morbidity associated with CD and improve patient outcomes.[2] There are a number of potential options available to objectively monitor disease activity in CD, however these can be uncomfortable or inconvenient. These include blood and stool tests, ileo-colonoscopy, small bowel ultrasound, magnetic resonance enterography and capsule endoscopy. Capsule endoscopy represents an effective and less invasive modality to examine all segments of the GI tract.[3,4] The pan-enteric PillCam™ Crohn's capsule (PCC) is a pill-sized device containing a miniature double-headed video camera that is able to evaluate both small bowel and colonic mucosa in its entirety. [5,6] It offers a non-invasive test combining information gained from ileo-colonoscopy (IC) and magnetic resonance enterography (MRE) into a single test and may have a higher diagnostic yield for active Crohn's disease per subject (83.3%) compared to IC (69.7%).[7] A patency capsule is often required beforehand to ensure GI tract luminal patency as some patients have stricturing disease which may result in capsule retention, although the risk of this is low.[8,9] Whilst patients may be willing to undergo more invasive assessment (e.g. IC) when required and recognise their importance, many have a preference for more non-invasive ways of assessment (e.g. small bowel ultrasound; SBUS). [10] PCC can help address patient concerns regarding IC (e.g. fear of discomfort, embarrassment, dignity, loss of control, pain),[11,12] and reduce the number of tests that patients have from two to one. PCC also offers a wider healthcare organisational benefit in terms of cost and resource saving and reducing delays in management decisions.[13]

The need for more studies on patients' perceptions and acceptability of different monitoring tools has been highlighted.[12] This paper describes findings from a qualitative study embedded within a non-randomised multicentre prospective trial (The PANenteric Crohn's capsule versus Ileo-Colonoscopy and Scan study, PAN-ICS; ClinicalTrials.gov ID - NCT04274010) with a focus on exploring acceptability and preference of assessment modality. Specifically, it provides a unique insight into the views of patients with experience of PCC who can also directly compare this with other investigative modalities.

Methods

Aims

The aim of this study was to explore the views and experiences of three assessment modalities (PCC, IC and MRE) in a purposive sample of patients who took part in the PAN-ICS study.

Study Design

A qualitative interview study was embedded within the PAN-ICS trial to explore patient preference for those with experience of all three modalities. The trial was open for recruitment from December 2020 until November 2022 across four study sites located in North East England and South Yorkshire.

Sampling and recruitment

Participants were recruited based on maximum variation purposive sampling[14]. Inclusion and exclusion criteria matched those of the main trial but included completion of all three investigation modalities as part of the trial within 4 months prior to interview. To be eligible for the main trial, patients had to be aged between 18-75 years, have an established diagnosis of Crohn's disease, and have been referred for IC and MRE for CD assessment as deemed appropriate by a referring clinician from one of four study sites as part of standard care (see supplementary information for further details).

All participants in the main trial who had consented to be contacted for interview were identified by the study teams from each study site once they had completed all three investigation modalities. Trial participants were then purposively selected sequentially in relation to gender, age range and study sites by the central study team to ensure variation in accounts and identification of shared patterns across experiences. Diversity of accounts across study sites was deemed to be important as, due to the logistics of the trial, there was variation in clinical procedures and staffing across sites. The order of investigations, however, was the same for all participants with the MRE completed first, followed by the PCC and then the IC. Participant contact details were then passed to the qualitative researcher so a convenient time for interview could be arranged. Consent was checked at each contact point

and participants were asked to re-confirm their willingness to participate on the day of the interview following confirmation that they understood the nature of the study.

Data collection and analysis

An interview topic guide was developed in collaboration with the research team and patients with CD (See appendix 1). Questions were open-ended and focused on the acceptability of the PCC, related processes, its place in disease management, and investigative preferences. One-to-one interviews were conducted via telephone at a time convenient to participants. Written consent was obtained prior to participants being contacted for interview and this was verified verbally at the start of the interview. Recruitment and data collection continued until it was deemed data saturation had been reached (i.e. no new themes or information were identifiable in additional interviews). Interviews were digitally recorded and transcribed verbatim by a professional transcription company. Pseudonymised transcripts and audio recordings were kept digitally on a secure server at the University and archived at the host institution for the trial. Patient identifiable data was accessible only by the core research team.

Analysis was based on a framework approach.[14] This involved a thorough reading of the data and systematically coding experiences that appeared to be prominent in the text. A list of preliminary codes was developed which was added to and refined as coding progressed. Codes were grouped into framework categories and developed into a set of themes. Constant comparison within and between cases was applied to challenge the integrity of the boundaries of framework categories. Analysis was supported with the use of NVivo 13[15]. NH, a female experienced post-doctoral qualitative researcher employed at a university, completed all the interviews and led on the qualitative analysis. She was not previously known to participants and was independent from the trial team. Initial themes were shared with the project team for validation and feedback, but no further changes were made to the coding framework.

Results

Participants

Ten interviews were completed between January and July 2022 and lasted on average 30 minutes. Participants provided personal, in-depth accounts of their experiences of the different procedures and the reasoning behind their preferences. Participants varied in age,

preference and reasoning for their preference. Table 1 provides a summary of their preference and the main reported associated reasoning for this. This is a high-level summary for descriptive purposes of the sample and to help contextualisation of any quotes provided in the results section. The reasons summarised in this table are not exclusive of other issues raised and further in-depth analysis is provided below. Participants described diversity in relation to their experiences of diagnosis, disease status, previous investigations and treatments. Information about actual disease status, ethnicity or socio-economic status was not collected.

Experiences of, and preferences for, different testing modalities

Participants described advantages and disadvantages associated with all investigation modalities (See table 2). Only one participant reported they would not recommend PCC to other patients with CD and another felt it would depend on the person and their needs. More in-depth descriptions and interpretation of accounts relating to the key themes identified are provided below and evidenced with illustrative verbatim quotes.

i) Intensity of negative attributions

The intensity of beliefs and emotions relating to personal tolerance of each test seemed to play a more prominent role in investigation preference than their presence. All participants described IC as unpleasant in relation to embarrassment, intrusiveness, pain and discomfort. PCC was described mainly in comparison to experiences of IC and as being easier, less stressful, intrusive or invasive, and associated with less discomfort and pain. Intrusiveness of PCC was attributed as being less "personal" and invasive than IC.

> *" it feels kind of less invasive in a way, even though it's a pill with a camera inside going into you, you know it's coming out the other end, whereas the colonoscopy just felt quite invasive and in quite a personal way." (PAN-01)*

Participants described varied experiences in relation to the time taken to pass the PCC as well as the patency capsule, concerns and worries about it not passing, and the inconvenience associated with this. This was a key influence on preferences for those who reported preferring IC and MRE over PCC. There was some acknowledgment of potential for unpleasant and negative aspects of the experience of MREs, however, this did not seem to be an important focus for any of the participants. Any negative aspects mentioned were in relation to the potential for "others" to feel negatively about MREs, for example around feeling claustrophobic or the need for a cannula.

ii) *Physical and psychological responses to bowel preparation*

Unpleasant bowel preparation required for IC and PCC was discussed at length and was an important topic for participants. They described negative experiences in terms of taste, texture, and quantity as well as anticipated and unanticipated effects, including nausea and vomiting and the need to not eat or drink for an extended period of time.

> *"it just tastes so bad it makes you want to throw up every time you drink it and if you're already not well, it just makes the entire thing worse for you.. sometimes that's where all my anxiety comes from just having to prepare myself to have that and not have anything to eat or drink for the day." (PAN-05)*

Improvement in bowel preparation was the most commonly mentioned recommendation for improving PCC experience.

iii) Acceptance and recognition of necessity

Invasive investigations were seen as an essential part of disease assessment, surveillance and management. There was a widespread acceptance of the need for uncomfortable, intrusive, and embarrassing investigations such as IC and that this was part and parcel of living with a chronic gastrointestinal condition such as CD. One participant described this as suffering in the "*short term for long-term gain*".

This also applied to any discomfort associated with bowel preparation, which needed to be endured to ensure effectiveness of the investigations to allow clear views of the colonic mucosa.

Pain and discomfort were also viewed in relation to other ongoing and often severe symptoms associated with their daily life with CD. Experiences of unpleasant and intrusive investigations and preferences were described within this context.

> *You know the thing is when you're ill you'll do anything just to find out what's wrong. You know I think that's the problem, if I wasn't feeling well and they said do it again, I probably would.. it's never pleasant but you know it's the only way to get the data isn't it, so you've got to do it." (PAN-06)*

iv) Trust and perceived effectiveness

Accounts clearly reflected trust in the effectiveness of all of the procedures, despite participation in the trial having been based on understanding that effectiveness of the PCC was still being investigated. One participant explained her reasoning around why she considered the PCC and IC may be equally effective, but that the MRE may be less so.

> *"the MRI I don't know why but I feel like that one I trust the least, but only because I was worried if I'd moved around when I've been having it done…. whereas the pill cam and the colonoscopy because they're actually inside you, it feels like they would capture more and be a bit more accurate but I don't know if that's true … I don't know the science behind it." (PAN-02)*

Some individuals who were aware of their CD phenotype and disease distribution considered their modality preferences based on their perceptions of which was likely to be more effective for their own disease activity. A key consideration, however, was the reassurance provided by the investigations.

> *"I just think you need to know that it was really thorough examination right from top to bottom that there can be nothing missed, that was reassuring." (PAN-06)*

The opportunity to take biopsies and remove polyps during the IC was seen as a benefit but did not seem to have a major influence on preferences for most participants. Neither were perceptions of associated risk in relation to IC, apart from one participant who had specific and severe anxieties around medical procedures due to previous negative experiences.

v) Importance of clinical and nursing support

Support and information received from clinical and nursing staff had an important influence on experiences of all investigations. Access to more immediate results and potential for discussion with consultants at the time of the IC was viewed as an advantage compared to PCC and frustration with delayed results was reported.

> *"I mean I suppose for the colonoscopy you can pretty much you know ask the consultant there and then or they'll tell you if they can see anything, or if there's anything suspicious or what have you. Whereas you're waiting around a bit I guess for the PillCam™ results." (PAN-09)*

vi) Containment within daily life

How easy or difficult it was for participants to contain or integrate procedural requirements within everyday life and conflicting responsibilities (such as the distance patients lived from the hospital or needing to take time off work) influenced investigation preference and the way in which experiences were framed. Difficulties and concerns about passing the PCC and experiences of the time taken to pass, seemed to have a particularly important influence on preferences, for example, when time spent at the hospital interferes with work and everyday responsibilities. The lack of need for sedation was seen to be an additional advantage of PCC over IC for some participants. Accepting sedation for IC was not always possible if work, childcare or transport issues needed to be considered.

> *"It [refusal of sedation] was just because my partner wasn't able to pick me up for leaving the hospital ... I was very very nervous to be honest but they did give me gas and air so it didn't make it quite as bad as I thought it was, like it was panicking me a bit at first, but the gas and air did seem to be alright." (PAN-05)*

Multiple appointments and travel requirements were an important consideration, particularly when not feeling well and could exacerbate existing difficulties associated with living with a relapsing chronic illness such as CD.

Discussion

This paper highlights key issues relating to patient preferences and acceptability of PCC compared to IC and MRE in Crohn's disease assessment. Understanding patient preferences can help support strategies for improving patient engagement, optimising patient-centred approach to care, and informing development of alternative care pathways.[11,12] This qualitative study is the first we are aware of to elicit the views of patients who were able to reflect on their recent experiences and views of acceptability of all three modalities, including the newer pan-enteric PCC.

Although most, but not all interviewees stated a preference for PCC over IC, all demonstrated acceptance of the necessity for uncomfortable investigations and acknowledgment of their importance for clinical decision making in relation to their disease assessment and management. This supports findings from an international qualitative focus group study exploring patient experiences and preferences of CD monitoring, although this study did not include PCC.[12]

Key considerations in relation to investigation preference were the intensity of beliefs and feelings around unpleasantness, pain and discomfort associated with IC as well as experiences around how easy it was, and the time taken, for PCC to pass.
Unpleasantness of bowel preparation was an important issue for patients and was the most commonly reported suggestion for improvement. Evidence from a study with a clinical population of patients presenting with lower gastrointestinal symptoms referred for colonic investigation[16] suggests that the bowel preparation period is associated with a decrease in health-related quality of life utility scores. It is not clear however, if this decrease is associated with the unpleasantness associated with the bowel preparation or anxiety related to the prospect of undergoing an invasive procedure.[16]
Due to requirements of participation in the trial, the bowel preparation used for PCC at the time was a different brand to the one that is normally used for colonoscopy. The different taste, quantity and volume, which seemed to have resulted in important differences in experience of both procedures, therefore, may not be reflective of current standard clinical practice. Furthermore, despite the inclusion of issues associated with sub-optimal bowel preparation being covered within our interviews, it is not possible to assess whether differences in the way this was managed clinically between modalities influenced the patient experience.
For the people we spoke to, the requirement for a cannula during the MRE seemed to be the main concern associated with this investigation and any post-procedural bowel habit change was not highlighted as a key issue. This may have been due to symptoms being viewed in comparison to other ongoing and often severe symptoms associated with living with CD.

Other key considerations for patients included the time spent in hospital, number of appointments, practicalities such as work and transport needs, and the processes and time to receiving results. The trial took place during the COVID-19 pandemic which may have impacted on experiences in relation to practical and service pressure issues and reluctance of patients to attend multiple hospital appointments. Clinical and research appointment arrangements did not represent normal clinical pathways that would be available should PCC be integrated within standard care and may have impacted on participants' experiences and views about the investigations. Frustrations reported in relation to delayed results, although important to consider, may have been specific to study processes and procedures.

Evidence exists from studies and systematic reviews exploring patient-reported outcomes and preferences between colon capsule endoscopy (CCE), computed tomography colonography (CTC) and colonoscopy.[17-23] None of these specifically include evidence around PCC, however, and the purpose of the procedures were primarily for diagnostic assessment or cancer screening rather than monitoring of established disease. Our study therefore complements other existing evidence in this area. For example, a study comparing preference for CCE to colonoscopy for symptomatic investigation[17] found no difference in satisfaction between the two modalities, although 77.5% of patients reported that they would prefer a CCE if further bowel investigation was required and rated this higher for comfort. The main cause of dissatisfaction with CCE was reported to be bowel preparation which was also an important consideration for the participants in our study. Another study comparing CCE and CTC reported that patients preferred CCE due to bloating and mild pain perceived during CTC.[18] Findings from an observational cohort study comparing all three modalities (CCE, CTC and colonoscopy) suggest that there is a preference for CCE and CTC to colonoscopy in terms of comfort and tolerance.[19]

Recent reviews comparing different investigation modalities[20,21] have demonstrated that colon capsule endoscopy (CCE) is safe and has good acceptability, despite some challenges with variability in completion rates and high rates of re-investigation. A systematic review focusing on patient-reported outcomes and preferences for CCE and colonoscopy[21], however, concluded that patient tolerability was high for both modalities with no significant differences in preference.

Measures of tolerability and preference used within these studies may not have been able to capture the complexity of the balance between advantages and disadvantages of each modality, as highlighted in our findings. Furthermore, existing patient-reported outcome measures do not cover the entirety of the patient experience.[22]

Our sample was small and was not intended to be representative. However, we were confident that we have depth within our analysis and were able to reach thematic saturation and have identified key issues in relation to preferences and experiences of the investigations being considered. Exploration of the important issues and potential differences in decision-making across different communities and patient groups would require further research.

We were not able to capture the views of those who did not meet trial eligibility criteria, those who were withdrawn or unable to proceed due to significant small bowel strictures identified on MRE. In addition, we did not cover the use of other investigative modalities such as SBUS

or CT enterography, due to the focus of the trial in which the qualitative study was embedded. Participants reported experience of a range of previous investigative modalities prior to the study. Previous investigation experience was an influence that cut across all key themes and the variation across our sample provides confidence in the validity and transferability of our findings. However, we did not systematically collect data relating to which modalities had been previously experienced for comparison or descriptive purposes. In addition, exploration of views about the impact of different procedures on their disease management was limited as not all participants had received their PCC results at the time of interview.

Although evidence suggests that PCC could be an appropriate tool for diagnostic and monitoring purposes,[3,4] further evidence is required before inclusion of PCC within current diagnostic and management algorithms for CD can be considered. This potential shift in management would require changes to clinical practice to be supported by national and international bodies such as the British Society of Gastroenterology, European Society for Gastrointestinal Endoscopy and European Crohn's and Colitis Organisation. Further research to understand implementation challenges around integration with, or adaptation of, existing care pathways from the perspective of healthcare professionals may be helpful going forwards.

A national pilot of CCE has completed recruitment within the UK NHS to evaluate its use in patients referred for urgent assessment on the rapid cancer diagnostics ("2 week wait") pathway.[23] This has resulted in the significant expansion of the infrastructure, knowledge base and skills required to provide capsule endoscopy services across the UK and thus increasing opportunity for future assessment and implementation of PCC for patients with CD.

Conclusions

Findings suggest that for many, although not all, patients with CD, there would be a preference for PCC over IC and MRE if effectiveness is proven to be equivalent. The opportunity to include alternative investigation modalities within care pathways that meet patient preferences could have a potential beneficial impact on quality of care as well as improving quality of life.

List of abbreviations

CCE - Colon capsule endoscopy

CD – Crohn's disease

CTC – Computed tomography colonography

IC – Ileo-colonoscopy

SBUS – Small bowel ultrasound

MRE – Magnetic resonance enterography

PCC – PillCam™ Crohn's capsule

Declarations

Ethics approval and consent to participate

Ethical approval was gained by West of Scotland Research Ethics Committee 5, Health Research Authority (Ref 275854)

Consent for publication

"Not applicable"

Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available to maintain individual privacy but are available from the corresponding author on reasonable request.

Competing interests

SP has worked as a consultant for Medtronic and delivered educational activities supported by unrestricted educational grant. The other authors declare that they have no competing interests.

Funding

This study was funded by a grant from National Institute for Health and Care Research, Research for Patient Benefit programme (NIHR/PG-PB-0418-20017). The NIHR had no role in the conceptualisation, design, data collection, analysis, decision to publish, or preparation of the manuscript. Medtronic supported the PAN-ICS study by supplying the patency and pan-enteric capsules via the External Research Support Agreement (ERP-2017-11036).

Authors' contributions

HC, SP, MMc, RS, AD and PSL were responsible for the intellectual conceptualisation of the study. HC provided methodological expertise in the study design. NH, PSL, CD, SP, AC, MMc, RS and AD were involved in identifying and recruiting suitable participants. AC and MMc were the blinded reporters for all the pan-enteric capsule procedures. NH, SP, PSL, AC and CD developed the data collection tools and were responsible for study delivery. NH performed all qualitative interviews and completed the data collection and analysis. SP and PSL provided feedback and comments on the analysis. NH led on the preparation and writing

of the initial draft manuscript supported by PSL who provided intellectual input. All authors read, commented on and provided input into the final version of the manuscript. SP is the guarantor.

Acknowledgements

The authors would like to thank the NIHR and Medtronic for funding the study, the research nurses who supported participant recruitment and all the participants who agreed to be interviewed.

This project was funded by the National Institute for Health and Care Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number NIHR/PG-PB-0418-20017) and Medtronic via the External Research Support Agreement (ERP-2017-11036). The views expressed are those of the author(s) and not necessarily those of the NIHR, Medtronic or the Department of Health and Social Care.

REFERENCES

1. NICE. Crohn's disease: management (NICE Quality Standard CG 152). National Institute Health Care Excellence. 2019. Available online at: https://www.nice.org.uk/guidance/NG129 (Accessed 19 April, 2024).
2. Colombel JF, D'haens G, Lee WJ et al. Outcomes and Strategies to Support a Treat-to-target Approach in Inflammatory Bowel Disease: A Systematic Review, Journal of Crohn's and Colitis, Volume 14, Issue 2, February 2020, 254–266. Doi:10.1093/ecco-jcc/jjz131.
3. Bruining DH, Oliva S,Fleisher MR, et al. Panenteric capsule endoscopy versus ileocolonoscopy plus magnetic resonance enterography in Crohn's disease: a multicentre, prospective study. BMJ Open Gastro 2020;7:e000365. doi:10.1136/bmjgast-2019-000365.
4. Brodersen JB, Knudsen T, Kjeldsen J et al. Diagnostic accuracy of pan-enteric capsule endoscopy and magnetic resonance enterocolonography in suspected Crohn's disease. United European Gastroenterol J. 2022; 10(9): 973–82. doi: 10.1002/ueg2.12307.
5. Hale MF, Drew K, Ejenavi E, et al. OC-050 Panenteric capsule endoscopy: whole gut visualisation without intubation. Gut. 2015;64(Suppl 1):A26 LP-A26.
6. Carvalho PB, Rosa B, De Castro FD, et al. PillCam™ COLON 2© in Crohn's disease: A new concept of pan-enteric mucosal healing assessment. World J Gastroenterol. 2015;21(23):7233-7241. doi:10.3748/wjg.v21.i23.7233.
7. Leighton JA, Helper DJ, Gralnek IM, et al. Comparing diagnostic yield of a novel pan-enteric video capsule endoscope with ileocolonoscopy in patients with active Crohn's

disease: a feasibility study. Gastrointest Endosc. 2017;85(1):196-205.e1. doi:10.1016/j.gie.2016.09.009.

8. Liao Z, Gao R, Xu C, et al. Indications and detection, completion, and retention rates of small-bowel capsule endoscopy: a systematic review. Gastrointest Endosc. 2010;71(2):280-286. doi:10.1016/j.gie.2009.09.031.
9. Pasha SF, Pennazio M, Rondonotti E, et al. Capsule Retention in Crohn's Disease: A Meta-analysis. Inflamm Bowel Dis. May 2019. doi:10.1093/ibd/izz083.
10. Rohatinsky N, Boyd I, Dickson A et al. Perspectives of health care use and access to care for individuals living with inflammatory bowel disease in rural Canada. Rural and Remote Health 2021; 21: 6358.DOI: 10.22605/RRH6358.
11. Ryhlander J, Ringstrom G, Simrén M, et al. Undergoing repeated colonoscopies—experiences from patients with inflammatory bowel disease. Scand J Gastroenterol. 2019;54(12):1467–1472. doi:10.1080/ 00365521.2019.1698649.
12. Goodsall TM, Noy R, Nguyen TM, et al. Systematic review: patient perceptions of monitoring tools in inflammatory bowel disease. Journal of the Canadian Association of Gastroenterology. 2021 Apr;4(2):e31-41.
13. Lobo A, Torres RT, McAlindon M, et al. Economic analysis of the adoption of capsule endoscopy within the British NHS. International Journal for Quality in Health Care. 2020; 32 (5):332–341. doi: 10.1093/intqhc/mzaa039.
14. Ritchie J, Lewis J. Qualitative research practice: a guide for social science students and researchers. London: Sage; 2003.
15. QSR International Pty Ltd. (2020) NVivo (released in March 2020). Available at: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home
16. Andronis ., Waugh N, Zanganeh M *et al.* Impact of colonoscopy on health-related quality of life: findings from the RECEDE study. Health Qual Life Outcomes. 2024; 22 (49). doi.org/10.1186/s12955-024-02262-x
17. Ismail MS, Murphy G, Semenov, S *et al.* Comparing Colon Capsule Endoscopy to colonoscopy; a symptomatic patient's perspective. BMC Gastroenterol. 2022; 22(31). doi:10.1186/s12876-021-02081-0.

18. Rondonotti E, Borghi C, Mandelli G, et al. Accuracy of capsule colonoscopy and computed tomographic colonography in individuals with positive results from the fecal occult blood test. Clinical Gastroenterology and Hepatology. 2014 Aug 1;12(8):1303-10.
19. Ojidu H, Palmer H, Lewandowski, J et al. Patient tolerance and acceptance of different colonic imaging modalities: an observational cohort study. European Journal of Gastroenterology & Hepatology 30(5):520-525. doi: 10.1097/MEG.0000000000001090.
20. Gibbons E, Kelly OB, Hall B. Advances in colon capsule endoscopy: A review of current applications and challenges. Frontiers in Gastroenterology. 2023; 17(2): doi:1316334.
21. Deding U, Cortegoso Valdivia P, et al. Patient-Reported Outcomes and Preferences for Colon Capsule Endoscopy and Colonoscopy: A Systematic Review with Meta-Analysis. Diagnostics. 2021; 11(9):1730. DOI: 10.3390/diagnostics11091730.
22. Rosvall A, Annersten Gershater M, Kumlien C, et al. Patient-Reported Experience Measures for Colonoscopy: A Systematic Review and Meta-Ethnography. Diagnostics 2022; 12(2):242. DOI: 10.3390/diagnostics12020242.
23. Turvill J, McAlindon MO64 Interim update on the NHS England colon capsule endoscopy evaluation. Gut 2023;72:A40.

Table 1 – Participant characteristics and investigative preference

Interview ID	Sex	Age	Preference	Summary of main reasons for preference (not exclusive of other reported issues)
PAN-01	female	34	Crohn's capsule (PCC)	Less painful and less intrusive than colonoscopy (based on previous experiences of colonoscopy).
PAN-02	female	27	Crohn's capsule (PCC)	Less invasive and more comfortable than colonoscopy (based on previous negative experiences of colonoscopy).
PAN-03	female	37	Crohn's capsule (PCC)	Less pain and less intrusive than colonoscopy (based on previous negative experiences of colonoscopy).
PAN-04	male	37	Crohn's capsule (PCC)	Less pain and invasiveness than colonoscopy (based on previous negative experiences of colonoscopy) and less time in hospital.
PAN-05	**female**	**26**	**Ileo-colonoscopy and MRE**	**Colonoscopy causes anxiety but preferred as quicker procedure overall.**
PAN-06	**female**	**45**	**Ileo-colonoscopy and MRE**	**Colonoscopy embarrassing and painful but preferred as quicker procedure so fits better with daily responsibilities (work and childcare). Some difficulties passing PCC.**
PAN-07	**male**	**32**	**Ileo-colonoscopy and MRE**	**Colonoscopy intrusive but prefers quicker and more conclusive results. PCC took a long time to pass and previously results inconclusive.**
PAN-08	female	54	Crohn's capsule (PCC)	Less invasive and painful than colonoscopy (based on previous negative experiences of colonoscopy).
PAN-09	male	54	Crohn's capsule (PCC)	Easier, less discomfort and less embarrassing than colonoscopy (based on previous negative experiences of colonoscopy).
PAN-10	female	64	Crohn's capsule (PCC)	Anxiety about risk associated with colonoscopy procedures.

Table 2 – Summary of perceived advantages and disadvantages of assessment modalities

	PillCam™ Crohn's capsule (PCC)		Ileo-colonoscopy (IC)		Magnetic Resonance Enterography (MRE)	
Sub-themes	**Advantages**	**Disadvantages**	**Advantages**	**Disadvantages**	**Advantages**	**Disadvantages**

Tolerance of procedures	Easy to swallow and pass Less uncomfortable or painful than IC No need for sedation	*Time taken to excrete capsule* *Difficulty and concerns about passing capsule* *Need for fasting and bowel preparation*	Shorter procedure duration	*Unpleasantness – experiences of pain and discomfort* *Unpleasantness – embarrassment and intrusiveness* *Anxiety about risks and unpleasantness* *Need for fasting and bowel preparation*	Not intrusive or painful No fasting or bowel preparation required	*Claustrophobia* *Contrast can take time* *Cannula – fear of needles* *Cannula – issues with finding veins* *Anxiety of having to stay still* *Some physical discomfort*
Perceptions of procedure effectiveness and risk	Covers small bowel and colon in one single investigation	*No opportunities for taking biopsies or removing polyps* *Potential risks of capsule retention*	Can take biopsies and remove polyps during procedure	*Perceived risks (bowel perforation)* *Limitations of procedure, only assessing colon*	None mentioned	*Less accurate assessment – external imaging of small bowel*
Associated wider organisational aspects	Saves NHS resources	*Requirement for additional trips to the hospital for patency capsule requirements.* *Time taken to get results**	Instant results	*None mentioned*	None mentioned	*None mentioned*

*time taken to get results was important to participants, but delays may have been specific to the trial conditions