Article:
Husnoo, N., Whitman, A.E., Morgan, J.L. et al. (2026) 'Surgery is a last resort measure': a qualitative study of patient views on treatment for ileocaecal Crohn's disease. Frontline Gastroenterology. ISSN: 2041-4137

https://doi.org/10.1136/flgastro-2025-103572

OPEN ACCESS

Original research

‘Surgery is a last resort measure’: a qualitative study of patient views on treatment for ileocaecal Crohn’s disease

Nilofer Husnoo ,[1,2] Alexandra E Whitman,[3] Jenna L Morgan,[1,4] Lynda Wyld,[1,4] Alan Lobo,[5] Steven R Brown,[2] on behalf of E-BRIC collaborators

► Additional supplemental material is published online only. To view, please visit the journal online (https://doi.org/10.1136/flgastro-2025-103572).

For numbered affiliations see end of article.

Correspondence to
Nilofer Husnoo; nhusnoo1@sheffield.ac.uk

Data from this study have been presented at the Surgical Research Society Meeting (Cambridge, UK, January 2025), the Association of Coloproctology of Great Britain and Ireland Annual Meeting (Harrogate, UK, July 2025) and the European Society of Coloproctology Meeting (Paris, France, September 2025).

Received 17 December 2025
Accepted 5 March 2026

To cite: Husnoo N, Whitman AE, Morgan JL, *et al*. *Frontline Gastroenterology* Epub ahead of print: [please include Day Month Year]. doi:10.1136/flgastro-2025-103572

ABSTRACT

Objective Growing evidence supports earlier surgery for isolated terminal ileal Crohn’s disease, yet clinicians perceive patient reluctance as a barrier to surgery. This study explored patients’ perspectives on surgery in this context to understand factors shaping treatment preferences and decision-making.

Method Semistructured interviews were conducted with patients from seven English and Welsh hospitals diagnosed with isolated terminal ileal Crohn’s disease. Purposive sampling ensured representation across treatment experiences, demographics and care settings. Interviews were audio-recorded, transcribed verbatim and analysed using thematic analysis.

Results 28 patients were interviewed (mean age 42 years, 17 with previous surgery). Three themes emerged: (1) Surgery as a measure of last resort—participants preferred medical therapy first, viewing surgery as a major step with significant risks, but their views were influenced by clinicians’ approach to discussion of surgery; (2) Information-seeking as a means of being in control—patients desired involvement in decision-making, but this need was not always met and (3) ‘Normal life’ as the ultimate treatment goal—restoration of quality of life and social functioning was paramount, with surgery seeming unnecessary while medical therapy is effective enough to maintain normal activities, but preferences changed in favour of surgery as their condition deteriorated.

Conclusions Patients are reluctant to consider surgery without adequate trial of medical therapy. However, their views may be shaped by biased or incomplete information from clinicians who position surgery as ‘last resort’. Early, open discussions about surgery using multidisciplinary approaches and peer support systems are needed to enable truly informed, patient-centred decisions.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ There is growing evidence in favour of earlier surgery in the treatment of isolated Crohn’s disease of the terminal ileum, as an alternative to medical therapy. A qualitative study of healthcare professionals revealed that surgery is still offered late due to multiple barriers, including patients’ own aversion to surgery.

WHAT THIS STUDY ADDS

⇒ This qualitative study of patients with terminal ileal Crohn’s disease affords insight into the patient perspective. While they express a strong preference for medical therapy and prefer to avoid surgery, their view of surgery is shaped by incomplete and biased information.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ There is an urgent need to optimise shared decision-making through early, unbiased discussions of surgery with patients, using multidisciplinary approaches.

INTRODUCTION

Crohn’s disease (CD) is a chronic condition causing debilitating symptoms. The terminal ileum (with or without caecal involvement) is most commonly affected, and isolated involvement occurs in at least one-third of patients.[1] The localised nature of this phenotype means that surgical resection can remove the entire diseased segment and associated inflammatory

burden, effectively leaving patients disease-free for a period of time.[2–4]

Surgery has traditionally been reserved for disease complications or medical treatment failure. However, growing evidence favouring earlier surgery (before the onset of complications) for isolated short-segment ileocolic CD suggests that it produces more stable long-term remission than ongoing medical therapy.[5 6] In the landmark LIR!C trial (laparoscopic ileocaecal resection vs infliximab for terminal ileitis in Crohn's disease), 1-year quality of life (QoL) outcomes were comparable between treatment arms, with surgery even producing superior mean physical component scores on the Short Form-36 QoL questionnaire.[7] Modified resection and anastomotic techniques may further reduce the risk of postoperative recurrence.[8]

Conversely, multiple effective medical treatments are now available for CD. Early initiation of biologics within 2 weeks of CD diagnosis achieved steroid-free and surgery-free remission in 79% of patients at 1 year in a recent trial—a rate previously unachieved.[9] The evolving landscape further complicates the positioning of surgery relative to medical therapy in routine practice. Clinical guidelines increasingly advocate the earlier consideration of surgery as an alternative to medical therapy when treating short-segment terminal ileal CD and encourage shared decision-making.[10] We previously explored healthcare professionals' (HCPs') perspectives on the role of surgery in this context—surgery was still considered late in the treatment pathway despite the evidence.[11] While several practical barriers to early surgery were identified, clinicians consistently perceived patients to be reluctant to have surgery when medical options are available.

This study aims (1) to explore patients' perspectives on surgery, particularly early surgery, for isolated terminal ileal (or ileocaecal) CD and (2) to understand the factors that shape patient preferences and decision-making, thus assessing whether their values and beliefs align with those of their clinicians.

METHODS

The protocol was previously published, and a summary is provided here.[12] Reporting of the study follows the Consolidated criteria for Reporting Qualitative research.[13] Written consent was obtained from participants.

Study design

A qualitative approach was selected to gain an in-depth and nuanced understanding of participants' views, attitudes and experiences.[14 15] Semistructured interviews were conducted because this method involves using a schedule with predetermined prompts to facilitate exploration of the research topic, while allowing deviation from the guide to discuss unexpected themes.[16]

Patients from seven English and Welsh hospitals, aged 18 and above, diagnosed with isolated terminal ileal CD (with or without right colonic involvement) in the 10 years prior to the launch of the study were eligible. Participants should also have had experience of either medical or surgical treatment or both for CD. Detailed eligibility criteria are in box 1 of the previously published protocol.[12] Sampling was purposive to ensure adequate representation of prespecified characteristics,[17 18] including level of inflammatory bowel disease (IBD) care provided by the participating centre (tertiary or secondary) and patients' treatment experiences (medical vs surgical), ethnicity and socioeconomic status (determined using the English or Welsh index of multiple deprivation of the participant's postcode area). Patients were identified by the Principal Investigator for each site from medical records or clinical settings. Details of disease and treatment characteristics (table 1) were obtained from medical records.

Box 1 'Normal life' as the ultimate treatment goal—representative quotes

"I think for me it would have to be a good 10 years of not needing anything." P28, no previous surgery

"my performance was dipping at work. […] the fatigue, being friends-less, being on the toilet more and feeling unwell, and tired. […] We can have surgery bring [the inflammation] back down and then [continue biologics]—that's how it was put forward to me, which made the operation seem like a no-brainer." P25, previous surgery

The initial interview schedule was produced based on themes identified from a literature review[5] and our previous study with IBD clinicians,[11] with input from clinician and patient experts. It has been included in online supplemental file 1. After five initial interviews, data were coded and analysed, the data collection strategy was refined, and further interviews were conducted. This iterative process and recruitment continued until data saturation occurred (more specifically until coding saturation occurred, ie, until no new code was identified)[19 20] and was confirmed in three subsequent interviews. We also ensured adequate representation of participants across all sites and characteristics of interest before stopping recruitment.

Participants chose their preferred mode of interviewing (online videoconferencing or telephone) and joined in from a location of their choice. Each participant was interviewed once. Interviews were audio-recorded and transcribed verbatim, as previously described.[12] Field notes made during the interview aided data interpretation and refined data collection strategies, for example, questions which yielded new themes were noted.[13]

Research team and reflexivity

Interviews and data analysis were conducted by NH (female clinician/PhD student experienced in qualitative research) and AEW (female medical student trained in the conduct of interviews by NH and LW).

Table 1 Participant characteristics and details of interviews

Participant number	Level of IBD care	Age (years)	Gender	Ethnicity	IMD decile	Duration of disease (years)	Previous/current experience of medical therapy				No of ileocolic resections for CD	Interview length (minutes)	Mode of interview
							Steroids	Enteral nutrition	Immune modulators	Biologics			
P01	Ter	31	F	WB	9	7	Y	N	Y	Y	0	36	T
P02	Ter	29	F	WB	10	0.8	Y	N	N	Y	0	44	O
P03	Ter	22	M	M - WA	10	4	Y	Y	N	Y	1	51	O
P04	Sec	43	F	WB	2	1	Y	N	N	Y	0	30	T
P05	Sec	25	M	WB	1	1	Y	N	Y	Y	0	39	T
P06	Sec	24	M	WB	6	4	Y	N	Y	Y	0	36	T
P07	Sec	50	M	WB	10	6	Y	N	Y	Y	1	38	O
P08	Sec	33	M	WB	9	8	Y	N	N	Y	0	36	T
P09	Sec	25	F	WB	5	6	Y	N	N	N	1	38	O
P10	Sec	29	M	WB	10	8	Y	N	Y	Y	1	40	O
P11	Ter	55	M	WB	8	9	N	N	Y	Y	1	29	O
P12	Ter	30	F	WB	7	7	N	N	Y	Y	1	32	O
P13	Sec	54	M	WB	5	3	Y	N	Y	Y	0	46	T
P14	Ter	51	M	WB	1	5	Y	N	Y	Y	2	61	O
P15	Ter	64	F	WB	6	2	Y	N	N	N	1	24	T
P16	Sec	64	F	WB	8	8	Y	N	Y	Y	1	41	T
P17	Sec	32	F	WB	3	10	Y	N	Y	Y	1	49	T
P18	Ter	35	F	WB	8	8	Y	N	Y	Y	1	43	T
P19	Ter	71	M	WB	8	0.7	Y	N	N	Y	1	40	T
P20	Ter	63	M	WB	3	4	Y	N	Y	N	1	49	O
P21	Sec	43	F	WB	8	9	Y	N	Y	Y	1	72	O
P22	Ter	34	F	WB	6	10	Y	Y	Y	Y	1	63	O
P23	Ter	61	F	WB	7	6	N	N	Y	N	0	28	T
P24	Sec	60	M	WB	5	2	Y	N	N	Y	0	35	T
P25	Ter	33	M	WB	6	10	Y	N	Y	Y	1	54	O
P26	Ter	29	F	W–O	4	10	Y	N	Y	Y	1	41	O
P27	Ter	28	M	A/AB–P	7	8	Y	N	Y	Y	0	29	T
P28	Ter	32	F	A/AB–I	9	2	Y	N	N	Y	0	64	O

A/AB–I (Ethnicity), Asian/Asian British–Indian; A/AB–P (Ethnicity), A/AB–Pakistani; CD, Crohn's disease; F (gender), female; IBD, inflammatory bowel disease; IMD, Index of Multiple Deprivation; M (gender), male; M–WA, Mixed–White and Asian; O (mode of interview), Online (videoconferencing); Sec, secondary care centre; Ter, tertiary centre; T (mode of interview), Telephone; WB, White British; W–O, White–other.

The researchers were not part of the participants' care teams but acknowledged the influence of their role and research interest on the interpretation of findings. More specifically, as proponents of early surgery, they had an interest in understanding the barriers to surgery. Independent coding of data and thorough discussion about generation of themes ensured that personal biases did not affect data interpretation. Each interview ended with participant debrief as an opportunity for feedback and for identifying confusing or leading lines of questioning, allowing researchers to adapt their techniques.

Data analysis

Transcripts were imported into QSR NVivo V.15. An inductive approach to thematic analysis was adopted, following Braun and Clarke's principles.[21] Thematic analysis was selected because of its flexibility (as it is not tied to any theoretical construct) and because it can be applied to a range of research questions and topics.[17 22] Initial codes were agreed by NH and AEW after analysing five transcripts. Codes were assigned to data and a framework generated (as per the Framework Method of analysis) to aid interpretation, generate themes and explore differences between groups.[23] 14 transcripts (50%) were coded independently by both researchers, ensuring intercoder reliability.[24] An assessment for coding saturation was made after every three interviews, following the initial analysis of the first five interviews. Transcripts were not returned to participants for review due to time constraints.

RESULTS

29 patients were interviewed between September 2023 and September 2024. One patient was unable to separate her experiences of CD from other chronic illnesses—her interview was excluded from analysis. We analysed 28 interviews. The mean interview length was 42 min (24–72). Details of the interviews and participant characteristics are provided in table 1. There were 14 male participants; 17 were patients in a tertiary centre and 11 in a secondary care centre. Only four had no previous experience of a biologic. 17 had previously had an ileocolic resection for CD. The mean duration of disease at the time of interview was 6 years (8 months–10 years).

Data saturation was achieved after the 23rd interview and confirmed after the 26th. The last two participants were enlisted through targeted recruitment to ensure broader representation of minority ethnic groups. Three themes relevant to the research question were generated, two with subthemes (figure 1). The themes and subthemes are described below and the full coding tree is provided in online supplemental file 2.

Theme 1: surgery as a measure of last resort

Overall, participants wanted to avoid surgery, viewing it as a 'big' step while medical therapy seemed more 'reversible'. This preference stemmed from concerns about surgical risks, limited surgical counselling, clinician bias towards medical therapy and misinformation about outcomes. These factors combined reinforced surgery as an option to be delayed until absolutely necessary.

Subtheme 1.1. medical therapy first; surgery as necessity

Only one patient (P20) would have preferred surgery over prolonged medical therapy. Medical therapy was otherwise consistently the preferred first-line approach, and surgery the option to be 'resorted to' after the unsuccessful trial of multiple drugs or when disease complications developed. All interviewees with surgical experience had undergone a resection under these circumstances.

> surgery is a last call. If I'm that ill and I can't do what I need to do to provide and to survive […], then yes P08, no previous surgery

> I probably need convincing more on the surgery than I did [with] any medication. […] the medication wasn' t too harsh for me […]. But the surgery, I think, it' s a bit bigger. P06, no previous surgery

Three patients (P09, P15, P20) who had stricturing disease at diagnosis accepted surgery more readily,

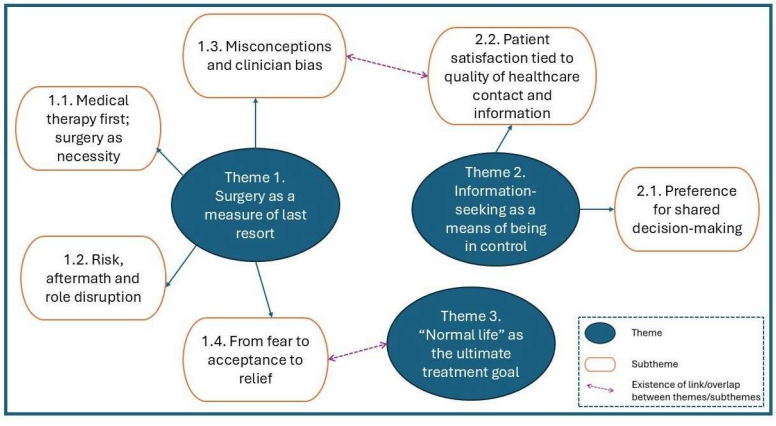

Figure 1 Overview of themes and subthemes.

appreciating the futility of medical therapy in their situation. However, they regretted not trialling medication first.

> I don't feel like I properly trialled out the medication […] it' s a shame that I didn't have a chance to try out X-Y-Z. […] there' s at least three options out there that I never got the opportunity to try P09, previous surgery

Although other participants expressed their frustration with the 'trial and error' burden of medical therapy, its variable effectiveness and significant side effects, they still preferred this approach over surgery. Even those with good surgical outcomes stated that, given the choice, they would prefer to continue medical treatment instead of having surgery.

> Interviewer: If it wasn' t narrowed down and scarred to the point where medication [couldn' t help], […] do you think you would still want to have an operation at that stage?
>
> Interviewee: No offence to the surgeon, but 100 per cent I would have gone on another medication. P03, previous surgery and in drug-free remission

Subtheme 1.2. risks, aftermath and role disruption

Surgical risks were deemed to significantly outweigh those of medical treatment. Participants feared the risk of complications and worried about postoperative recovery and its impact on their social roles and responsibilities. The potential for a stoma was the most important risk considered—concerns about body image and lifestyle restrictions were rife. Participants also expressed uncertainties about lifestyle adaptations that may be required after a bowel resection.

> I know that complications can happen. I didn' t want to not be here for my children if something went wrong P17, previous surgery
>
> It' s just the way it [stoma] looks […] I don't want to be judged. […] My life isn't as flexible in my job to be able to accommodate [a stoma] P08, no previous surgery
>
> but if there was no bag I' d go straight for it [an operation]. […] but dating when you' ve got a stoma bag is impossible P13, no previous CD surgery, previous ostomate for unrelated pathology

The risk of recurrence after surgery, potentially requiring multiple operations over time, was also a cause for concern. Delaying surgery therefore seemed important to minimise the number of operations needed in their lifetime.

> if I'm meant to be having three or four surgeries in a lifetime, it just means that the sooner you have it, the sooner you're going to be having the next one. […] P21, previous surgery

Subtheme 1.3. misconceptions and clinician bias

Interviewees relayed that a treatment hierarchy was often described by gastroenterologists, with surgery being the 'last resort'. Participants described gastroenterologist-led care; they were only introduced to surgeons when medical treatment failed, and surgery was unavoidable. Apart from P04, who was awaiting surgery at the time of interview, none of the surgery-naïve patients had received surgical input in their care. Only one patient (P06) was aware of the evidence in favour of early surgery.

> She [my gastroenterologist] said she would try other things and then surgery will be last resort P26, previous surgery
>
> I should have been spoken to about surgery [sooner] by my gastro consultants. I think I'd been left too long for medication to work properly. P16, previous surgery

Surgery was often discussed superficially, if at all, by medical teams until a surgeon became involved. Misinformation and uncertainties about the risks of surgery and the recovery process were prevalent among patients with no surgical experience. Many opinions about surgery and stomas were based on anecdotes and patients' own research online and on social media. These uncertainties compounded patients' fears.

> I know a girl who' s also got it [a stoma] . It really affected her badly. So that put me off. P06, no previous surgery
>
> my previous consultant had been so anti-surgery, […] it made me very afraid. […] It would have saved me a lot of anxiety if I just had someone be a lot more straight up. […] he would be very vague [about surgery], which just made it more scary P22, previous surgery

Conversely, patients' knowledge of medical therapy was mostly shaped by information from gastroenterologists and IBD nurse specialists. In-depth consultations with a surgeon, peer discussions (online) and positive stories from social media influencers helped to dispel concerns around surgery or a stoma.

> she [surgeon] was going over all the risks. She gave me all these graphs with her own data of her own surgeries […] so, I trust her P26, previous surgery
>
> there' s a subreddit [social media forum] dedicated to Crohn' s disease and I spent a lot of time on there asking people about the surgery which was actually really, really useful because they' re people who have been through similar things P03, previous surgery

Subtheme 1.4. from fear to acceptance to relief

Participants who had surgery after trialling medical treatment described a gradual change in their perspective, from fear to an acceptance of surgery as the next logical step. This change occurred as their disease and symptoms progressed, QoL worsened and drug side

effects became unacceptable. The prospect of 'getting rid of the disease' in this cohort of patients with isolated disease became attractive.

> I was so tired of being in pain. After somebody told me that I needed to have surgery I was really looking forward to it. P21, previous surgery

> you could be Crohn' s free and not have to take the terrible medication as well. P16, previous surgery

All interviewees who had surgery described drastic improvements in symptoms and QoL after their operation. Beyond the recovery period, the main issues that dampened the overall positive experience included bile acid diarrhoea and stoma-related problems (leaks, skin damage, delayed closure).

> I haven't really had any severe symptoms since the surgery. My life is completely different. P16, previous surgery

Theme 2: information-seeking as a means of being in control

Information-seeking behaviours revealed factors that shape patients' treatment preferences and perspectives on surgical timing. Factors influencing patient decision-making processes and gaps between patient information needs and clinician communication approaches were frequently discussed and have been described in the two subthemes below.

Subtheme 2.1. preference for shared decision-making

Participants expressed varying preferences for involvement in treatment decision-making, some seeking active participation, while others preferring to defer to clinician recommendations. However, even the latter expressed frustration when completely left out of decisions, especially if there is a change in their condition for the worse.

> if [that treatment] is best for me, I don' t want to know about it. Just tell me what I need to do. […] The information is sporadic. One minute you' ll get, we' re going to try this treatment and this tablet, and then the next you' ll hear, we changed that a week or two ago. So you don' t know what' s going on P13, no previous surgery for CD

Subtheme 2.2. patient satisfaction tied to quality of healthcare contact and information

Participants described varying satisfaction with their care. Dissatisfaction was consistently linked to poor healthcare contact (difficulty obtaining appointments, limited access to clinical teams, inadequate follow-up leading to treatment delays). Notably, four patients preferred an infusion over a self-injected biologic to maintain direct contact with their care team.

> I don't think with me self-injecting, I'm getting the same level of care because nobody' s monitoring me. Nobody knows. Nobody cares P21, previous surgery

Participants used other sources of information (eg, websites) but expected their healthcare providers (especially gastroenterologists and IBD nurses) to be their primary source, and valued multidisciplinary involvement, evidence-based discussions and care continuity through consistent team members.

> I got a letter in the post saying that we' ll be switching your medication to a biosimilar. […] For the first three months I wasn' t taking medication. Because I wanted to speak to [my gastroenterologist] in person. […] Talking to a doctor in person is a lot more reassuring than hearing second-hand from a different person P28, no previous surgery

When prompted on the aspects of preoperative counselling that require improvement, participants with a previous resection commonly described feeling unprepared for the length of recovery and its impact on daily tasks or work and finances and being ill-equipped to manage post-operative pain. Two patients (P11, P14) were unaware that a stoma might be required until the day of surgery.

> they give you a vague idea of recovery time […]. But it' s not quite the reality […]. What you want to know is, how do I do this basic task after? P22, previous surgery

> It was only once I was recovering, I realised how significant the wound was. […] it' s the length of time it takes to recover. It' s a long time. […] you've got to financially support yourself for four months with no income […] which I wasn' t prepared for. P14, previous surgery

Theme 3: 'normal life' as the ultimate treatment goal

The goal of treatment for participants was to restore their 'normal life'. Accordingly, interviewees whose symptoms were controlled with medical therapy and who experienced few or tolerable side effects, such that their daily activities were unrestricted, felt no need to consider treatment as invasive as a bowel resection. Even when prompted with theoretical benefits of longer-term stable remission or a reduced need for medication, surgery-naïve participants who were well did not find surgery appealing, unless several years of drug-free remission could be 'guaranteed' (box 1).

Participants with surgical experience had similar views initially, prepared to make significant lifestyle and dietary adaptations and changes in professional and social roles to manage debilitating symptoms and avoid surgery. As they became increasingly limited in their functioning, the need for quality-of-life restoration became the main driver of change in attitude towards surgery (box 1).

Differences between participant groups

Participants with experience of surgery were largely more prepared to accept and manage future recurrences because of the counselling that they received when offered surgery. They also felt more confident

that disease recurrence would be detected sooner due to regular monitoring and their own understanding of their condition.

Two participants had their care transferred from a secondary care unit to a tertiary centre (P20, P27). Both described the care in the tertiary centre as more proactive in that they had early involvement of a surgeon (P20) and rapid escalation of medical therapy (P27) when transferred to tertiary care centres. No significant differences in patterns of data were otherwise noted when comparing participant groups stratified by other characteristics.

DISCUSSION

Our study provides an in-depth understanding of patients' perspectives on surgery for isolated terminal ileal CD. Participants preferred medical therapy with surgery becoming acceptable after disease progression or treatment failure. These findings align with our previous study where HCPs identified patient aversion as a significant barrier to early surgery.[11] This attitude is driven by a fear of the risks of surgery but is also reinforced by HCPs' approach to discussion of surgery. Participants felt that it was introduced late or discussed superficially. This contrasts with clinicians' accounts in our prior study, where they described themselves as proponents of early surgery.[11]

Our data highlight a communication gap between clinicians' intentions and patients' perceptions, possibly reflecting clinicians' unconscious biases against operative management. Despite routinely accessing alternative sources of information, participants trusted their healthcare providers the most. Clinicians therefore have a responsibility to provide accurate and impartial information about treatment options. They should reconsider the language used when discussing surgery. According to our participants, it was often described as 'last resort' and the 'avoidance of surgery' framed as success. Early, open discussions about surgical risks are important as interviewees' fears were compounded by uncertainties and misinformation. Routine early involvement of a surgeon would be ideal but may be limited by service pressures. As patients' primary sources of information, gastroenterologists and IBD nurses should signpost patients to reliable resources. Notably, our participants often justified concerns about surgical risks with anecdotes, while displaying factual reasoning when discussing the risks of medical therapy. This suggests a discrepancy in the quality of patient information on surgery compared with medical therapy, which is consistent with prior studies highlighting problems with online information about surgery for CD.[25 26]

Fears of complications and a stoma are some of the most pertinent concerns of IBD patients facing surgery.[27 28] These were echoed in our study. The main worries around a stoma centred on body image and lifestyle restrictions. A multidisciplinary approach to consultations was valued by interviewees—these should routinely include stoma nurses for patients considering surgery. Participants with surgical experience also highlighted unmet informational needs around recovery. This should be considered by HCPs involved in counselling and in producing written patient information about surgery. Informational and psychological support from patients with lived experiences of similar surgery was seen as helpful. Participants in our study only had experience of such support through online forums. Peer support programmes have shown positive effects on chronic disease self-management and patient activation.[29] Despite their recognised benefits, patient peer support programmes are not widely available and accessible in the UK and elsewhere.[30 31]

Importantly, our data highlight the gap between the evidence supporting early surgery and the reality of clinical practice. Early intensive therapy with biologics also faced barriers from IBD patients when anti-TNF (tumour necrosis factor) agents were new due to concerns about side effects.[32] As efficacy and safety data accumulated, early biologic use became standard practice. It is unclear whether 'early surgery' might follow a similar trajectory. Surgical and medical treatment for CD have fundamentally different risk profiles. Conducting further trials comparing medical therapy and surgery, that might reinforce the evidence base in favour of surgery, may be a challenge due to recruitment difficulties.[33–35] With the exception of one participant (P20) who wished she had surgery sooner, even participants with good surgical outcomes in our study stated that given the choice, they would persevere with medical treatment instead of having surgery, and patients who had early surgical intervention for strictures regretted being unable to trial medication. These findings suggest that recruitment challenges stem at least partly from patients' strong preference for medication, possibly compounded by clinicians' biases.[11] Prospectively collected data on patients who are appropriately counselled using shared decision models or a decision aid may be one way of further contributing to the evidence base and improving patient care.

While equipoise between the two treatment modalities remains, decisions in short-segment terminal ileal or ileocolic CD remain preference-sensitive, making a shared decision-making approach appropriate.[32] Participants expressed varied preferences for involvement in decision-making, yet their frustration with uncertainty when excluded from decisions suggests that clinicians underestimate patients' desire for participation in their own care. Along with providing clear information, shared decision-making also requires clinicians to consider patients' personal goals.[36] Restoration of QoL was identified by participants as the primary treatment goal. Surgery for CD produces significant medium to long-term improvements in QoL; however, randomised trial data directly

comparing QoL outcomes between medical therapy and ileocolic resection for CD are limited.[7 33 37 38] It is uncertain whether the QoL benefits of surgery are currently communicated to patients. If omitted, treatment choices may be shaped more by communication gaps than by patients' true preferences. More robust comparative QoL evidence is needed, and its integration into consultations is required to support patient-centred decision-making. However, our data suggest that even if they are aware of the benefits of early surgery, many would possibly still opt to continue with medical therapy while their QoL is acceptable. It is important to re-evaluate treatment preferences throughout the disease course as these may change with a deterioration in QoL.

Our study has some limitations. Index of Multiple Deprivation deciles correlate only moderately with household income and are biased against certain groups and may not accurately reflect socioeconomic status.[39 40] Responder bias may have favoured participation of patients with strong opinions on this topic, limiting the generalisability of the findings. Most participants (86%) were white British, which is in keeping with the demographics of IBD patients in the UK[41]; however, as cultural factors are likely to impact attitudes to treatment, the views represented in this study may differ from those of other cultural groups. An interesting point about the inconsistencies in quality of care between secondary and tertiary centres was raised by two patients. Despite known associations between centre volume and outcomes in IBD,[42] we did not have sufficient data to explore this further. Nonetheless, this large multicentre study included tertiary and secondary centres from a wide geographical area in the UK and had representation of views from a diverse group of participants. Despite the study being restricted to UK patients, our patients' perspectives of surgery and their experiences of receiving information were consistent with findings from international studies.[28] As the first study to explore patients' views on the role of surgery in isolated terminal ileal CD, it identifies key areas of care that can be improved to align better with patients' values.

CONCLUSIONS

Patients are reluctant to consider surgery for isolated terminal ileal CD without adequate trial of medical therapy. However, their views may be shaped by biased or incomplete information, sometimes from their own clinicians, and their treatment preferences usually change in favour of surgery when their QoL deteriorates. Patients wish to be involved in treatment decision-making, generally preferring the least 'risky' option that preserves well-being and social functioning. Clinicians should have fair and open discussions about surgery early in the disease course, using a multidisciplinary team approach when appropriate, to enable truly informed and patient-centred decisions. Local peer support systems should be established to improve patient decision-making and care.

Author affiliations
[1]School of Medicine and Population Health, The University of Sheffield Faculty of Medicine Dentistry and Health, Sheffield, UK
[2]Academic Directorate of General Surgery, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK
[3]Hull York Medical School, Hull York Medical School, Hull, UK
[4]Doncaster Royal Infirmary, Doncaster, UK
[5]Sheffield Gastroenterology Unit, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK

Collaborators The E-BRIC Collaborators list is provided in online supplemental file 1. E-BRIC Collaborators: Brown SR (Sheffield Teaching Hospitals NHS Foundation Trust), Cooney R (University Hospitals Birmingham NHS Foundation Trust), Faiz O (London North West University Healthcare NHS Trust), Fawole A (Mid Yorkshire Hospitals NHS Foundation Trust), Grey T (Calderdale and Huddersfield NHS Foundation Trust), Hawkins D (Sheffield Teaching Hospitals NHS Foundation Trust), Henderson S (Calderdale and Huddersfield NHS Foundation Trust), Husnoo N (Sheffield Teaching Hospitals NHS Foundation Trust; University of Sheffield), Limdi J (Northern Care Alliance NHS Foundation Trust), Shamshudin Z (Mid Yorkshire Hospitals NHS Foundation Trust), Shamsiddinova A (London North West University Healthcare NHS Trust), Whitman AE (Hull York Medical School), Williams G (Aneurin Bevan University Health Board).

Contributors NH: study design, participant recruitment, data collection, analysis and interpretation of data, writing up of first draft of the paper. AEW: data collection, analysis and interpretation of data. JLM: study design, supervision. LW: study design, supervision. AL: study design, supervision. SRB: study design, interpretation of data, supervision. All authors revised the article for important intellectual content, provided final approval of the version to be published and agreed to be accountable for all aspects of the work. NH and SRB are the guarantors.

Funding This study was funded by Crohn's and Colitis UKM2022-2.

Competing interests AL receives speaker and/or consulting fees for Takeda, BMS, Abbvie, Medtronic, Vifor, Janssen, Sandoz, MSD, Pfizer and Shield Therapeutics.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by the London-Brent NHS Research Ethics Committee (23/PR/0568). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. The interview transcripts cannot be shared publicly for ethical reasons—there is a risk of participants and/or their units being identified. The complete list of coding generated from analysis of the data will be shared on reasonable request to the corresponding author.

ORCID iD
Nilofer Husnoo https://orcid.org/0000-0002-8402-6560

REFERENCES

1 Caprilli R. Why does Crohn's disease usually occur in terminal ileum? *J Crohns Colitis* 2008;2:352–6.
2 Michielan A, D'Incà R. Intestinal Permeability in Inflammatory Bowel Disease: Pathogenesis, Clinical Evaluation, and Therapy of Leaky Gut. *Mediators Inflamm* 2015;2015:628157.
3 Peyrin-Biroulet L, Chamaillard M, Gonzalez F, *et al*. Mesenteric fat in Crohn's disease: a pathogenetic hallmark or an innocent bystander? *Gut* 2007;56:577–83.
4 Maruyama BY, Ma C, Panaccione R, *et al*. Early Laparoscopic Ileal Resection for Localized Ileocecal Crohn's Disease: Hard Sell or a Revolutionary New Norm? *Inflamm Intest Dis* 2022;7:13–20.
5 Husnoo N, Gana T, Hague AG, *et al*. Is early bowel resection better than medical therapy for ileocolonic Crohn's disease? A systematic review and meta-analysis. *Colorectal Dis* 2023;25:1090–101.
6 Agrawal M, Ebert AC, Poulsen G, *et al*. Early Ileocecal Resection for Crohn's Disease Is Associated With Improved Long-term Outcomes Compared With Anti-Tumor Necrosis Factor Therapy: A Population-Based Cohort Study. *Gastroenterology* 2023;165:976–85.
7 Ponsioen CY, de Groof EJ, Eshuis EJ, *et al*. Laparoscopic ileocaecal resection versus infliximab for terminal ileitis in Crohn's disease: a randomised controlled, open-label, multicentre trial. *Lancet Gastroenterol Hepatol* 2017;2:785–92.
8 University of sheffield: clinical trials unit. MEErKAT (mesenteric excision and kono-s anastomosis trial. 2022. Available: https://www.sheffield.ac.uk/scharr/research/centres/ctru/meerkat#Central%20Study%20Staff
9 Noor NM, Lee JC, Bond S, *et al*. A biomarker-stratified comparison of top-down versus accelerated step-up treatment strategies for patients with newly diagnosed Crohn's disease (PROFILE): a multicentre, open-label randomised controlled trial. *Lancet Gastroenterol Hepatol* 2024;9:415–27.
10 Moran GW, Gordon M, Sinopolou V, *et al*. British Society of Gastroenterology guidelines on inflammatory bowel disease in adults: 2025. *Gut* 2025;74:s1–101.
11 Husnoo N, Morgan JL, Wyld L, *et al*. The challenges of implementing earlier surgery for terminal ileal Crohn's disease—A qualitative study of the clinician's perspective. *Colorectal Dis* 2025;27:e70027.
12 Husnoo N, Wyld L, Lobo AJ, *et al*. The patient and clinician perspective on "early" bowel resection for terminal ileal Crohn's disease (EBRIC): protocol for a multicentre mixed-methods study. *Colorectal Dis* 2025;27:e70042.
13 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57.
14 Hammarberg K, Kirkman M, de Lacey S. Qualitative research methods: when to use them and how to judge them. *Hum Reprod* 2016;31:498–501.
15 Lester JN, Cho Y, Lochmiller CR. Learning to Do Qualitative Data Analysis: A Starting Point. *Hum Resour Dev Rev* 2020;19:94–106.
16 Catherine Pope NM. *Qualitative research in health care*. 3rd ed. Blackwell Publishing, BMJ Books, 2006.
17 Ritchie J, Lewis J, Nicholls CM, *et al*. *Qualitative research practice*. London: Sage, 2003.
18 Bryman A. *Social research methods*. 4th ed. Oxford: Oxford University Press, 2012.
19 Fossey E, Harvey C, Mcdermott F, *et al*. Understanding and Evaluating Qualitative Research. *Aust N Z J Psychiatry* 2002;36:717–32.
20 Saunders B, Sim J, Kingstone T, *et al*. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 2018;52:1893–907.
21 Virginia Braun VC. *Thematic analysis: a practical guide*. 1st ed. London: SAGE Publications Ltd, 2022.
22 Castleberry A, Nolen A. Thematic analysis of qualitative research data: Is it as easy as it sounds? *Curr Pharm Teach Learn* 2018;10:807–15.
23 Gale NK, Heath G, Cameron E, *et al*. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:117.
24 Raskind IG, Shelton RC, Comeau DL, *et al*. A Review of Qualitative Data Analysis Practices in Health Education and Health Behavior Research. *Health Educ Behav* 2019;46:32–9.
25 Yeung TM, Sacchi M, Mortensen NJ, *et al*. Assessment of the Quality of Patient-Orientated Information on Surgery for Crohn's Disease on the Internet. *Dis Colon Rectum* 2015;58:857–61.
26 Whitman A, Husnoo N, Johnston J, *et al*. Online information on bowel resection for Crohn's disease. *Ann R Coll Surg Engl* 2026.
27 Lesage AC, Hagège H, Tucat G, *et al*. Results of a national survey on quality of life in inflammatory bowel diseases. *Clin Res Hepatol Gastroenterol* 2011;35:117–24.
28 Spinelli A, Carvello M, Adamina M, *et al*. Patients' perceptions of surgery for inflammatory bowel disease. *Colorectal Dis* 2021;23:2690–8.
29 Druss BG, Zhao L, von Esenwein SA, *et al*. The Health and Recovery Peer (HARP) Program: A peer-led intervention to improve medical self-management for persons with serious mental illness. *Schizophr Res* 2010;118:264–70.
30 Joo JH, Bone L, Forte J, *et al*. The benefits and challenges of established peer support programmes for patients, informal caregivers, and healthcare providers. *Fam Pract* 2022;39:903–12.
31 Groves J, Cahill J, Sturmey G, *et al*. Patient support groups: A survey of United Kingdom practice, purpose and performance. *J Intensive Care Soc* 2021;22:300–4.
32 Siegel CA. Shared decision making in inflammatory bowel disease: helping patients understand the tradeoffs between treatment options. *Gut* 2012;61:459–65.
33 Gerdin L, Eriksson AS, Olaison G, *et al*. The Swedish Crohn Trial: A Prematurely Terminated Randomized Controlled Trial of Thiopurines or Open Surgery for Primary Treatment of Ileocaecal Crohn's Disease. *ECCOJC* 2016;10:50–4.
34 Ryska O. Early surgery versus conservative treatment in patients with ileocaecal crohn's disease (ESPRIT): ClinicalTrials.gov. 2016. Available: https://clinicaltrials.gov/ct2/show/record/NCT02716454
35 de Groof EJ. *Surgery and medical therapy in crohn's disease: improving treatment strategies*. University of Amsterdam, 2017.
36 IBD UK: IBD standards. 2019. Available: https://www.ibduk.org/ibd-standards
37 Meyers S, Walfish JS, Sachar DB, *et al*. Quality of life after surgery for Crohn's disease: a psychosocial survey. *Gastroenterology* 1980;78:1–6.
38 Wright EK, Kamm MA, De Cruz P, *et al*. Effect of intestinal resection on quality of life in Crohn's disease. *J Crohns Colitis* 2015;9:452–62.

39 Jerrim J. *Measuring disadvantage*. Research Brief, 2021.
40 Appel C. Understanding the index of multiple deprivation (IMD) in public health research: health equity evidence centre. 2024.
41 Balarajah S, Martinez-Gili L, Alexander JL, *et al*. Diverse Phenotypes, Consistent Treatment: A Study of 30 997 South Asian and White Inflammatory Bowel Disease Patients Using the UK Inflammatory Bowel Disease BioResource. *J Crohns Colitis* 2025;19:jjae186.
42 Weizman AV, Nguyen GC. Quality of care delivered to hospitalized inflammatory bowel disease patients. *World J Gastroenterol* 2013;19:6360–6.