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## ORIGINAL ARTICLE

# A survey of patient informational preferences when choosing between medical and surgical therapy for ulcerative colitis: a sub-study from the DISCUSS project

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## Abstract

**Aim:** People living with ulcerative colitis (UC) have two broad treatment avenues, namely medical or surgical therapy. The choice between these can depend on patient preference as well as the receipt of relevant information. The aim of this study was to define the informational needs of patients with UC.

**Method:** A postal survey was designed to capture respondent demographics, treatment experienced within the previous 12 months and informational preferences by rating a long list of items. It was delivered through two hospitals that provide tertiary inflammatory bowel disease services. Descriptive analyses were performed to describe demographics and experiences. Principal component analysis was carried out using a varimax rotation to investigate informational needs.

**Results:** A total of 101 responses were returned (20.1% response rate). The median age of respondents was 45 years and the median time since diagnosis was 10 years. Control preferences skewed towards shared (42.6%) or patient-led but clinician-informed (35.6%). Decision regret was low for the population (median 12.5/100, range 0–100). Key informational needs related to medical therapy were benefits and risks of long-term therapy, burden of hospital attendance, reproductive health, need for steroid treatment and impact on personal life. For surgery, these were stoma information, effect on daily life, effect on sexual and reproductive health, risks and benefits and disruption of life due to surgery.

**Conclusion:** This study has identified key areas for discussion when counselling patients about treatment decisions around medical therapy and surgery for UC.

## KEYWORDS

decision making, survey, ulcerative colitis

## INTRODUCTION

Ulcerative colitis (UC) is a form of inflammatory bowel disease (IBD) which affects the colon and rectum. Medical therapies can

be highly effective and lead to improved health-related quality of life [1]. Historically, up to 40% of patients undergo surgery [2], although this rate seems to be declining in modern cohorts [3]. This may be needed as an emergency for acute severe colitis refractory

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to medical treatment or for chronic relapsing disease [4]. In this latter situation, the decision may develop over a period of time, involving consideration of whether to undergo surgery, its nature and its timing.

Clinicians are encouraged to cover information that is relevant to the patient, but this can be challenging. Clinicians may feel unfamiliar with the range of outcomes or focus on specific outcomes that they perceive to be relevant. For example, surgeons tend to focus on short-term operative details and less on longer-term outcomes, including living with the consequences of surgery [5–7]. There is a time pressure on clinic appointments that might limit opportunities to discuss issues conveniently within a single attendance. The National Institute for Health and Care Excellence (NICE) in the UK identified a lack of evidence about the informational requirements of people considering surgery for chronic relapsing disease [8]. The importance of counselling prior to consent for surgery is well recognized, but reinforced in legal cases which have placed significant weight upon patient preferences and avoidance of outcomes that might be considered 'more' adverse to them [9].

In order to provide high-quality counselling and decision support, it is first important to understand the informational needs of patients. The primary aim of this study was to identify key informational items required to help patients decide between continuing medical therapy and surgery for UC in the nonemergency setting. Secondary aims were to explore experience of decision-making and decision-related regret, and how information should be presented to aid decision-making.

## METHOD

This survey was conducted as part of the DISCUSS study, which aimed to develop a decision aid for patients choosing between medical and surgical therapy for UC [10]. The questionnaire was developed by a multidisciplinary team including gastroenterologists, surgeons, specialist nurses, health psychologists and patient representatives. Source materials including qualitative interviews on informational needs [5], data from a systematic review on outcomes following surgery for UC [11], reviews of online information related to UC [12, 13] and a systematic review of decision-making in UC (CRD42019130295) were used to inform themes explored in the study. Items identified in these concurrent works were reviewed by the steering group (including patient members) and were operationalized into questions with appropriate response items. The content and breadth of the questionnaire was agreed by the group.

### Questionnaire design

An introductory section explained the purpose of the study, details of the research team and instructions on return of the questionnaire. It indicated that completion of the questionnaire constituted consent. Responses were anonymous.

### What does this paper add to the literature?

This paper examines the decision-making preferences and informational needs of those considering surgery for ulcerative colitis. It suggests topics that may be covered during counselling for both medical and surgical therapies in order to meet informational needs.

Section one captured respondent demographics, details of the disease and previous surgery.

Section two explored sources of information used prior to treatment decisions. Respondents were asked to rate the importance of informational items on a scale of 1–9, with 1 = 'not important' and 9 = 'essential'. Sources of information used to define these options were drawn from previous qualitative work [5, 12, 13], systematic review and with input from lay and clinical members of the research team.

Section three investigated participants' experience of making treatment decisions. It contained two questions about preferred decision-making style and the style they experienced when making the relevant treatment decision using the Control Preferences Scale (CPS) [14], a validated five-point scale to assess the degree of control an individual wishes to assume when decisions are being made about medical treatment.

Section four assessed whether the respondent had adequate information at the time the decision was made (i.e. the decision to commence biological therapy or the decision to undergo surgery, as outlined in the questionnaire rubric). It also assessed regret related to the treatment choice. This was assessed using the decision regret scale [15]. This is a validated five-item tool with each item scored on a Likert scale of 1–5. When all five items are completed, the tool can be weighted and scored to give a value between 0 (no regret) and 100 (maximum regret).

Section five explored how participants would like to receive information about treatment options. This included questions on the format of information (paper/electronic) and how information related to numbers should be presented. Respondents were permitted to express a preference for more than one format.

The patient information sheet indicated that completion of the questionnaire constituted implied consent. Responses were anonymous but were attached to pseudonymized references that ensured potential participants only received one questionnaire.

### Pilot testing

The proposed questionnaire underwent assessment of face validity with five participants. These participants met the eligibility criteria for the study and were identified through a single centre. This was conducted in a focus group setting, facilitated by two members of the research team who had no preexisting relationship

with participants. The purpose of the exercise was explained, and participants were asked to review the questionnaire, including attempting to complete it, and provide feedback on design as part of a group discussion. Participants were reassured that no data would be taken from their questionnaire responses. The questionnaire was completed by participants and its completion timed by facilitators. Feedback was elicited on the wording of questions and of response items. Recommended changes were discussed with the research team and made as appropriate.

## Recruitment

The survey was distributed across two UK NHS centres which provide secondary and tertiary IBD services for medicine and surgery. The target population was those who had either undergone elective surgery for UC or had commenced biological therapy. Participants were identified through local biological databases and theatre registries. A copy of the questionnaire along with a covering letter was posted out to potential participants. Completed forms were returned in a prepaid envelope to the research team, where responses were entered into a spreadsheet on Microsoft Excel (Microsoft).

## Ethics statement

This study received ethical approval from the North East NHS Research Ethics Committee (19/NE/0073) and Health Research Authority approval (IRAS reference 257044) prior to pilot testing.

## Analysis

The primary aim of the study was to identify which informational items should be covered in a decision aid. It is not feasible to include each individual reported item in a decision aid, to avoid informational overload. As multiple items may represent different dimensions of a single underlying or 'latent' construct, these were reduced down to latent constructs to allow a more pragmatic decision aid design. This was undertaken using the principal component analysis (PCA) item-reduction approach [16]. Briefly, this looks for correlations across all responses and identifies those with similar response profiles, allowing these items to be grouped together and identifying the latent construct that unites them. The items in groups are reviewed and a potential label or term applied to the component as a whole.

Statistical analysis was performed using SPSS Statistics 26 (IBM). Descriptive statistics were provided for participant descriptors, CPS and preferred format of information. Decision regret was calculated as outlined in the source material [15]. PCA was conducted as a form of exploratory factor analysis on each of the medical and surgical preference sets. A varimax model with 200 iterations was used (a

statistical method which rotates the model axes to maximize the distance between points, with the number of iterations allowing multiple attempts at rotation to produce the model). Sampling adequacy was checked using Bartlett's and Keyser–Meier–Olkin (KMO) tests. Visual inspection of correlation matrices was performed. Extraction communalities were inspected and values  $<0.4$  were excluded. Components with an eigenvalue  $>1$  were carried into the analysis. The eigenvalue measures how much of the common variance of dataset is explained by a component, meaning that a component with an eigenvalue  $\geq 1$  accounts for more variance than a single observed variable. The threshold for factor loadings to contribute to a component was set at 0.4. Cross-loading of values was assessed by the research team, and the item allocated to the most plausible group. Components were assessed for internal consistency using Cronbach's alpha, and total item correlation (the degree to which each item in a component correlates with overall ratings) was calculated for each constituent variable. Statistical significance was set at  $\alpha=0.05$  a priori.

## Sample size

The power of the study was estimated using a required ratio of responses to items of 5:1, and a minimum sample size of 100 achieved [17]. Assuming a response rate of 40% this was likely to need 250 questionnaires to be distributed.

## RESULTS

A total of 476 surveys were distributed and 101 were returned, giving a response rate of 21.2%.

### Pilot testing

Pilot testing gave generally favourable feedback, and showed that the questionnaire could be completed in less than 10min by all participants. Discussion of identified themes suggested that there were no questions related to fertility in the individual draft, and this was highlighted by both male and female participants. Minor rephrasing of some questions on treatment preferences was required to ensure clarity. Potential alternative options were discussed with participants until an appropriate replacement was identified. Participants confirmed that the topic was important to them and worth exploring further.

### Participant descriptors

The median age of participants was 45 years (range 17–82) and the median time since diagnosis with UC was 10 years (range 0–51 years). Of the respondents, 49 were male and 93 identified as heterosexual. White British was the most common ethnic identity (93/101) and

education was to at least Bachelors degree for 39 respondents. Of the participants, 20 had undergone previous surgery, of whom 9 had undergone reconstructive surgery. These characteristics are summarized in [Table 1](#).

## Control Preferences Scale

The expressed control preference of respondents was to make the treatment decision with input from their doctor/nurse [ $n=36$  (35.6%)] or to share the decision equally with their clinician [ $n=43$  (42.6%)]. A small number of respondents preferred their clinician to make a decision after discussion with them [ $n=7$  (6.9%)] and two (2.0%) preferred to delegate all decisions to their clinician. In contrast, the decision-making experienced was clinician-led for 13 (12.9%) respondents, who had expressed a range of preferences on decision-making. Decision-making was patient led for 31 (30.7%) and shared in 33 (32.7%; [Figure 1](#)).

## Decision regret

The median decision regret score for all respondents was 12.5 (range 0–100). Median decision regret was 15.0 (0–90) for those who had not undergone previous surgery and 0 (0–100) for those who had undergone surgery (Wilcoxon test  $p=0.11$ ). These median scores are towards the lower end of the scale, indicating low levels of regret ([Figure 2](#)).

## Preferred presentation of information

There was no clearly preferred format of numerical reporting. Presentation of numbers as, for example, '3 in 10' was most popular, with 38 (37.6%) favouring it. Presentation of numbers using fractions or as frequency type (bar/column) charts found little favour [2 (2.0%) and 4 (4.0%), respectively]. The majority of respondents also felt that graphical information in the form of pictures or diagrams was useful [66 (65.3%) and 58 (57.4%), respectively; [Table 2](#)].

Respondents were clear that they preferred presentation of data using patient stories [81 (80.2%)] and wished to have lots of factual information [81 (80.2%)].

## Necessary informational items

### Medical treatment information

Factors from the medical group were entered into a PCA analysis. Bartlett's test was significant ( $p<0.001$ ) and the KMO test returned a value of 0.796, indicating good sampling within the dataset. Initial communalities were inspected and were all  $>0.4$ . This identified five principal components with eigenvalues  $>1$ ,

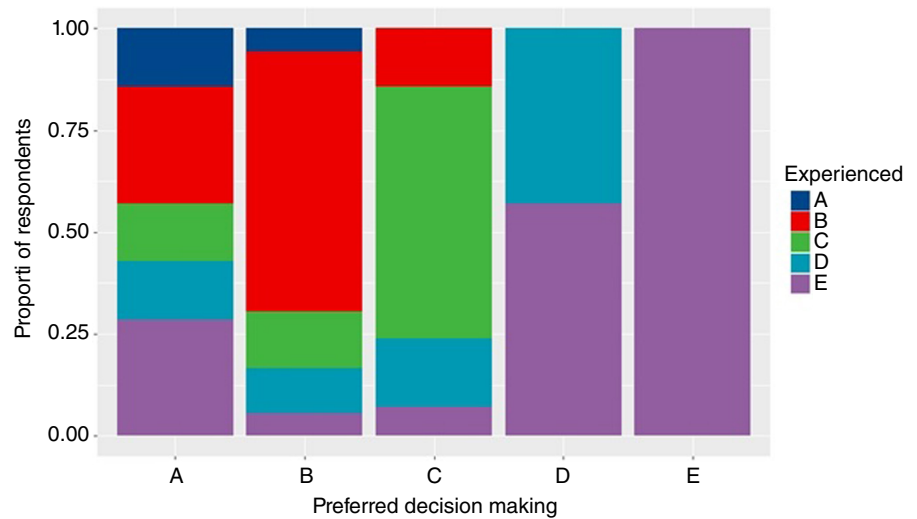
**TABLE 1** Respondent characteristics.

Characteristic	Overall (N = 101)	Previous surgery (n = 20) <sup>a</sup>	No previous surgery (n = 81) <sup>a</sup>
Age (years)	45 (34–60)	50 (40–64)	44 (33–56)
Missing	6	3	3
Age at diagnosis (years)	30 (23–44)	33 (26–42)	29 (22–45)
Unknown	5	2	3
Gender			
Male	49 (50)	10 (56)	39 (49)
Female	49 (50)	8 (44)	41 (51)
Unknown	3	2	1
Sexuality			
Heterosexual	93 (96)	18 (100)	75 (95)
Homosexual	0 (0)	0 (0)	0 (0)
Bisexual	1 (1.0)	0 (0)	1 (1.3)
Prefer not to say	3 (3.1)	0 (0)	3 (3.8)
Unknown	4	2	2
Education			
GCSE	21 (22)	7 (39)	14 (18)
A-Level	11 (12)	4 (22)	7 (9.2)
NVQ	12 (13)	3 (17)	9 (12)
Bachelors degree	24 (26)	2 (11)	22 (29)
Higher degree, e.g. Masters	13 (14)	1 (5.6)	12 (16)
Doctorate	2 (2.1)	0 (0)	2 (2.6)
Other	11 (12)	1 (5.6)	10 (13)
Unknown	7	2	5
Ethnicity			
White English/Welsh/Scottish/Northern Irish/British	93 (92)	20 (100)	73 (90)
White any other background	3 (3.0)	0 (0)	3 (3.7)
White and Asian	3 (3.0)	0 (0)	3 (3.7)
Any other mixed/multiple ethnic background	0 (0)	0 (0)	0 (0)
Indian	1 (1.0)	0 (0)	1 (1.2)
Any other Asian background	1 (1.0)	0 (0)	1 (1.2)
Did you have children at the time of diagnosis?			
Yes	38 (39)	6 (30)	32 (42)
No	58 (60)	14 (70)	44 (57)
Missing	5	0	5
Previous operation			
Appendicectomy		3 (15)	
Subtotal colectomy		7 (35)	
Panproctocolectomy		10 (53)	
Ileal pouch anal anastomosis		8 (47)	

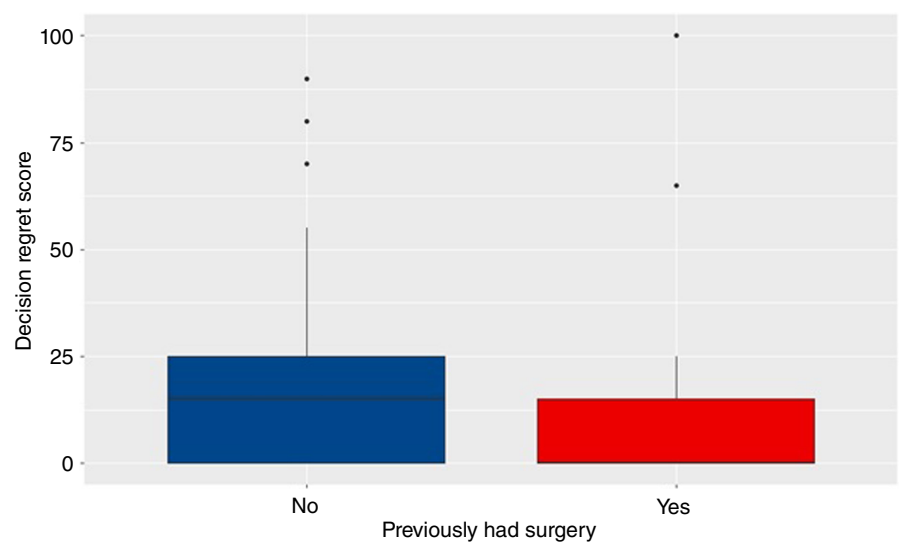
Abbreviations: A-level, advanced level; GCSE, General Certificate of Secondary Education; IQR, interquartile range; NVQ, National Vocational Qualification.

<sup>a</sup>Statistics presented: median (IQR),  $n$  (%).

**FIGURE 1** Comparison of desired decision-making versus experienced decision-making measured by the Control Preference Scale: A=I make the decision without my doctor, B=I make the decision after listening to my doctor, C=shared decision, D=my doctor makes the decision after listening to me, E=my doctor makes the decision.



**FIGURE 2** Box plot of decision regret according to experience of surgery. The horizontal bars show the median and vertical lines indicate the upper quartile.



accounting for 66.5% of the variance within the dataset. The components identified were:

1. Benefits and risks of long-term medical therapy (included side effects, long-term medication benefits, cancer risks, need for endoscopy, impact on sexual health, effect on school or work attendance, mental health and potential need for future surgery).
2. Burden of hospital attendance (frequency and costs of hospital attendances).
3. Effect of treatment on reproductive health (impact of treatment on fertility, impact of treatment on pregnancy).
4. Need for steroid treatment (need for concurrent or future steroids).
5. Impact on personal life (impact of treatment on sleep and family/carers).

The first, fourth and fifth components showed a high Cronbach's alpha ( $>0.8$ ), indicating good scale reliability in ratings, further supporting their grouping as a component. This is summarized in [Table 3](#).

### Surgical treatment information

Factors from the surgical information group were entered into a PCA analysis. Bartlett's test was significant ( $p < 0.001$ ) and the KMO test returned a value of 0.795, indicating good sampling within the dataset. Initial communalities were inspected and were all  $>0.4$ . This identified six principal components with eigenvalues  $>1$ , accounting for 72.1% of the variance within the dataset. The components identified were:

1. Ongoing care needs after surgery (pain, drug treatments including steroids, the need to miss school or work for symptoms or appointments, financial costs of hospital attendance, need for future endoscopy).
2. Stoma-related information (whether a stoma is required after surgery, practicalities of caring for it, options for stoma reversal and whether multiple operations are required).
3. Effect on daily life and well-being (time before resuming normal activities and subsequent impact on these, potential dietary impact and effect on mental health).

**TABLE 2** Preferred presentation of information.

Information format	Respondents preferring
Presentation of numbers	
A statement in words: e.g. eventually some people with UC will require surgery	18 (17.8%)
A number: e.g. around 3 in 10 people with UC will require surgery	38 (37.6%)
A percentage: e.g. 30% of people with UC will require surgery	25 (24.8%)
A fraction: e.g. 3/10th of people with UC will require surgery	2 (2.0%)
A (pie)chart: e.g. to show what fraction of people with UC require surgery	12 (11.9%)
A graph to show what fraction of people with UC require surgery	4 (4.0%)
Represented as a pictogram/picture: e.g. 3 in 10 people with UC will require surgery	21 (20.8%)
Presentation of general information	
I would like to see/hear the stories of other patients who have had surgery for UC	81 (80.2%)
I like to see pictures of relevance to make the information more real and useful	66 (65.3%)
I find lots of factual information useful	81 (80.2%)
I find lots of diagrams useful	58 (57.4%)
I would like to see diagrams of what an operation involves	75 (74.3%)

- Effect of surgery on sexual and reproductive health (impact on body image, impact on sexual activity, fertility and impact on pregnancy).
- Risks and benefits of surgery (risks of surgery, impact of surgery on symptoms and impact of surgery on continence).
- Disruption of life due to surgery (duration of hospital admissions, impact on sleep, impact of surgery on family and carers).

One item had a Cronbach alpha >0.7, and the remaining components had a Cronbach alpha >0.8, indicating good scale reliability. This is summarized in [Table 4](#).

## DISCUSSION

This study has identified 11 broad areas of information that should be considered for patients considering surgery or biological therapy for UC. It has also provided information on how these data might be best presented. By utilizing the PCA approach, informational themes have been more clearly described allowing easier conversion into the clinical setting, for example as a consultation guide for patients or clinicians in discussing treatment options. This will aid compliance with best practice and case law linked to consent [9].

The complex decision-making in treatment of UC should push clinicians towards a model of shared decision-making where the clinician

and patient share information and explore risks, benefits and preferences. They use these exchanges to reach a decision about whether to treat or not, and what treatment(s) should be used [17]. One method to support this is the use of a decision aid; a patient-facing document that addresses common patient values or questions and is developed using appropriate language. The research team are developing such a decision aid for patients facing the decision of escalation of care to use biological or small molecule drugs or considering surgery [10]. The 'DISCUSS' study has three stages: (i) decision aid development, which includes systematic reviews, (ii) face validity assessment and (iii) evaluation. The data from this survey are intended to inform initial drafting of the decision aid alongside systematic reviews.

The key components identified highlight the importance of information which will impact on patients long after the treatment decision is made. For example, fertility and sexual function were important to respondents. Previous qualitative studies have suggested that these may not be discussed unless the patient asks about them specifically [5]. This is not limited to UC, and these areas may not be addressed for other surgery in the pelvis [18, 19].

The importance attached to risks and benefits of drug treatment is expected. The importance attached to avoidance of steroid use and impact of treatments on home life has been highlighted in previous studies [5, 20], as have absenteeism and presenteeism [21] together with longer-term burdens such as need for endoscopy and risk of colon cancer [5, 12]. Reproductive health may be neglected in current counselling [5].

The first component of surgical informational needs grouped those items related to the immediate impact of surgery, particularly focusing on pain, hospital attendance and impact on work. These are often well covered in patient-facing information [5, 12]. The need for a stoma was identified as an important aspect of information, including the practicalities of managing this, supporting NICE guidelines [22]. This is an area where counselling is important, and there are several studies available that can inform these discussions [23–25]. The third factor reports issues related to recovery from surgery, and perhaps mirrors the ideas of absenteeism and presenteeism seen in the medical information group. Factors related to intimate relationships, including body image and pregnancy, were grouped together. The impact of the postsurgical body on these areas has been explored in several studies [26, 27]. The final two components of surgical information mirrored those seen in medicine, with the risks and benefits of the procedure and life disruptions due to surgery, including impact on sleep, being important to patients.

The findings of the CPS reinforce previous findings, with patients expressing a desire to participate in decision-making about their conditions but sometimes feeling excluded [5, 6]. We have identified respondents who expressed a desire for shared or patient-led decision-making but experienced a version where the locus of control was closer to their doctor. This may not mean that there was no attempt to properly counsel and share the decision, but that the clinician's and patient's ideas of shared decision-making did not overlap [28].

**TABLE 3** Components and scale reliability of items in principal component analysis of informational needs for ongoing medical therapy in ulcerative colitis.

Component	Factors	Corrected total item correlation	Cronbach's alpha
Component 1: Benefits and risks of long-term medical therapy	Drug side effects that I might experience	0.453	0.829
	Long-term benefits of medicines	0.502	
	The need to miss work, school, college or activities for hospital appointments	0.617	
	The need to miss work, school, college or activities because of symptoms	0.603	
	The chances of needing surgery if I continue with medical treatment	0.564	
	The chances of developing colon cancer if I continue with medical treatment	0.620	
	The chance and frequency of needing repeated camera tests of my bowel (endoscopy or colonoscopy)	0.557	
	The impact of medical treatment on my mental health	0.490	
	The route of administration of the medication	0.470	
Component 2: Burden of hospital attendance	The impact of medical treatment and continuing ulcerative colitis on my sexual activity	0.413	0.614
	The frequency with which I would need to attend hospital for clinic appointments, treatments and investigations	-	
Component 3: Effect of treatment on reproductive health	The financial costs of hospital trips or admissions	-	0.676
	The impact of medical treatment and continuing ulcerative colitis on my ability to have children in the future	-	
Component 4: Need for steroids	The impact medical treatment would have on pregnancy	-	0.933
	Whether I would need to take steroids	-	
Component 5: Impact on personal life	Whether I would need steroid treatment in the future	-	0.704
	The impact of medical treatment on my sleep	-	
	The impact of medical treatment on my family and/or carers	-	

Decision regret was low but comparable to other areas of IBD [29], surgery [30] and the wider literature [31]. There was no difference in regret between the medicine and surgery group. This may be a true measure of regret, a function of adequate counselling about treatment choices or time to accept and accommodate a treatment decision. It may reflect responder bias, where those with low regret are more likely to have completed the survey.

There was no clear preference for the way that numerical information should be presented, although, surprisingly, use of a number or percentage was preferred more frequently than a pictorial representation. Pictorial representations, including graphs and pie charts [32], are thought to improve patient understanding [33] but were not felt appropriate by patients in this context. This may represent the perceived nature of the treatment choices where, for example, multiple-figure pictograms have limitations [34–36]. However, we asked participants about general preference. The finding is unexpected and warrants further, more specific, investigation.

There are some limitations to the study. The study sampled enough patients to reach the calculated sample size for PCA. There is ongoing methodological discussion about the appropriate sample size for PCA, for example relating to rules of number of respondents per item or total numbers to achieve an identity matrix within the data [37].

However, sampling tests indicated appropriate data sampling and initial communalities were high, which suggests a low risk of missing key factors [38]. The study was set in two large centres in the north of England with diverse populations. Response rates were 20%, which is lower than anticipated and may limit external validity. The number of respondents did seem skewed towards those with higher education levels and there were limited responses from patients from minority ethnic groups. It should also be noted that the centres delivering this study have rates of high deprivation affecting 15%–22% of their population [39]. The engagement of only those with higher levels of education may reflect a bias towards those with higher levels of literacy and health literacy. This is likely to be a consequence of a methodology based on a postal questionnaire. Further work should consider these issues and explore other methods for recruitment and delivery of such surveys. Furthermore, decision regret was analysed using a univariate approach and measured at inconsistent times. It is possible that attitudes to treatment may change over time. Indications for surgery or medical therapy can be quite different, for example symptomatic disease or dysplasia can have different decision processes. Indications for treatment were not captured, and its conceivable that regret associated with these might vary. A large-scale survey with multivariable regression is required to explore this further.



**TABLE 4** Components and scale reliability of items in principal component analysis of informational needs about surgery for ulcerative colitis.

Component	Factors	Corrected total item correlation	Cronbach's alpha
Component 1: What are my ongoing care needs after surgery?	How much pain I would have after the operation	0.659	0.878
	Whether I would need ongoing drug treatment after surgery	0.759	
	Whether I would need steroid treatment in the future	0.501	
	The frequency with which I would need to attend hospital for clinic appointments, treatments and investigations	0.665	
	The need to miss work, school, college or other activities for hospital appointments	0.660	
	The need to miss work, school, college or other activities because of symptoms	0.607	
	The financial costs of hospital trips and admissions	0.529	
	The need for repeated camera tests of my bowel after surgery (endoscopy or colonoscopy)	0.759	
Component 2: Stoma-related queries	Whether I would have a stoma after surgery and whether this would be permanent	0.860	0.896
	The practicalities of caring of a stoma	0.753	
	The ability for further operations to remove the stoma and join the ends of the bowel together ('reversal')	0.823	
	Whether I would need more than one operation	0.654	
Component 3: Effect of surgery on my daily life and well-being	How long until I can resume normal day-to-day activities	0.708	0.834
	How much of an impact surgery would have on my daily activities, e.g. exercise	0.668	
	Whether I would need to change my diet after surgery	0.663	
	The impact of surgery on my mental health	0.659	
Component 4: Sexual and reproductive health	The impact surgery would have on my ability to have children in the future	0.668	0.735
	The impact of surgery on my body image	0.415	
	The impact of surgery on sexual activity	0.590	
	The impact surgery would have on pregnancy	0.484	
Component 5: Risks and benefits of surgery	The risks of the operation/risks of failure of surgery	0.769	0.830
	The effect of surgery on my symptoms	0.691	
	The effect of surgery on continence	0.617	
Component 6: Disruption due to surgery	The length of time I would be in hospital for due to surgery	0.701	0.828
	The impact of surgery on my sleep	0.747	
	The impact of surgery on my family and/or carers	0.620	

The strengths of the study include a design that drew on a range of sources including qualitative research and reviews, assessment of face validity with potential respondents, and conduct of the study at more than one centre. The use of PCA has allowed for review of more complex relationships between individual informational statements.

This study provides important information on areas of importance to patients in considering a choice between ongoing medical and surgical therapy. It has addressed the gap identified by NICE in the UK with regard to such information [22]. It is a useful reference for units designing written information for their patients. It therefore identifies areas about which the clinician should be adequately informed to help provide information in consultations. This could be

usefully supported by a patient decision aid that takes these informational needs into account.

#### AUTHOR CONTRIBUTIONS

All authors contributed to the design, conduct, analysis, interpretation, drafting, and approval of the final manuscript.

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#### CONFLICT OF INTEREST STATEMENT

Mr. Lee reports speaker fees from Janssen. Dr. Sebastian reports grants from Takeda, Amgen, Pfizer, AbbVie, Tillott Pharma,



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## DATA AVAILABILITY STATEMENT

No further data are available.

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## REFERENCES

- LeBlanc K, Mosli MH, Parker CE, MacDonald JK. The impact of biological interventions for ulcerative colitis on health-related quality of life. *Cochrane Database Syst Rev*. 2015;9:CD008655.
- Cosnes J, Gower-Rousseau C, Seksik P, Cortot A. Epidemiology and natural history of inflammatory bowel diseases. *Gastroenterology*. 2011;140:1785–94.
- Parragi L, Fournier N. Colectomy rates in ulcerative colitis are low and decreasing: 10-year follow-up data from the swiss IBD cohort study. *J Crohns Colitis*. 2018;12:811–8.
- Ungaro R, Mehandru S, Allen PB, Peyrin-Biroulet L, Colombel J-F. Ulcerative colitis. *Lancet*. 2017;389:1756–70.
- Baker DM, Lee MJ, Jones GL, Brown SR, Lobo AJ. The informational needs and preferences of patients considering surgery for ulcerative colitis: results of a qualitative study. *Inflamm Bowel Dis*. 2017;24:179–90.
- Lee MJ, Marshall JH, Jones GL, Lobo AJ, Brown SR. The informational and decisional preferences of patients undergoing surgery for Crohn's anal fistula: a qualitative study. *Colorectal Dis*. 2020;22(6):703–12.
- McNair AGK, MacKichan F. What surgeons tell patients and what patients want to know before major cancer surgery: a qualitative study. *BMC Cancer*. 2016;16:258.
- Recommendations for Research. Ulcerative Colitis: Management. NICE Guideline [NG130]. Published 03 May 2019. Accessed January 1, 2023. <https://www.nice.org.uk/guidance/ng130/chapter/Recommendations-for-research>
- Montgomery. The Montgomery Judgement. Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland). Preprint at 2015. Accessed January 1, 2023. <https://www.supremecourt.uk/cases/uksc-2013-0136.html>
- Baker DM, Lee MJ. Development and evaluation of a patient decision aid for patients considering ongoing medical or surgical treatment options for ulcerative colitis using a mixed-methods approach: protocol for DISCUSS study. *BMJ Open*. 2020;10:e031845.
- Baker DM, Folan AM. A systematic review and meta-analysis of outcomes after elective surgery for ulcerative colitis. *Colorectal Dis*. 2021;23:18–33.
- Baker DM, Marshall JH. YouTube as a source of information for patients considering surgery for ulcerative colitis. *J Surg Res*. 2017;220:133–8.
- Baker DM, Marshall JH. A systematic review of internet decision-making resources for patients considering surgery for ulcerative colitis. *Inflamm Bowel Dis*. 2017;23:1293–300.
- Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. *Can J Nurs Res*. 1997;29:21–43.
- Brehaut JC, O'Connor AM. Validation of a decision regret scale. *Med Decis Making*. 2003;23:281–92.
- Lever J, Krzywinski M, Altman N. Principal component analysis. *Nat Methods*. 2017;14:641–2.
- Osborne JW, Costello AB. Sample size and subject to item ratio in principal components analysis. *Pract Assess Res Eval*. 2004;9:11.
- Benedict C, Philip EJ. Body image and sexual function in women after treatment for anal and rectal cancer. *Psychooncology*. 2016;25:316–23.
- Stabile C, Goldfarb S. Sexual health needs and educational intervention preferences for women with cancer. *Breast Cancer Res Treat*. 2017;165:77–84.
- Rapport F, Clement C. Patient views about the impact of ulcerative colitis and its management with drug treatment and surgery: a nested qualitative study within the CONSTRUCT trial. *BMC Gastroenterol*. 2019;19:166.
- Constantin J, Atanasov P, Wirth D, Borsi A. Indirect costs associated with ulcerative colitis: a systematic literature review of real-world data. *BMC Gastroenterol*. 2019;19:179.
- Overview. Ulcerative Colitis: Management. NICE Guideline [NG130]. Published 03 May 2019. Accessed January 1, 2023. <https://www.nice.org.uk/guidance/ng130/chapter/Recommendations-for-research>
- Horgan L, Richards H, Joy A. The young adult male's perception of life with inflammatory bowel disease and a stoma: a qualitative examination. *J Clin Psychol Med Settings*. 2020;27:560–71.
- Aluzaitė K, Nuttall JW, O'Connor M, Harvie R, Schultz M. Quality of life in postostomy surgery patients: a cross-sectional survey. *JGH Open*. 2020;4:987–94.
- Dibley L, Czuber-Dochan W. Patient decision-making about emergency and planned stoma surgery for IBD: a qualitative exploration of patient and clinician perspectives. *Inflamm Bowel Dis*. 2018;24:235–46.
- Salter MJ. What are the differences in body image between patients with a conventional stoma compared with those who have had a conventional stoma followed by a continent pouch? *J Adv Nurs*. 1992;17:841–8.
- Whiteley I, Gullick J. The embodied experience of pregnancy with an ileostomy. *J Clin Nurs*. 2018;27:3931–44.
- De Mik SML, Stubenrouch FE, Balm R, Ubbink DT. Systematic review of shared decision-making in surgery. *Br J Surg*. 2018;105:1721–30.
- Lee MJ, Jones GL, Lobo AJ, Brown SR; pCD collaborators. Survey to define informational needs of patients undergoing surgery for Crohn's anal fistula. *Colorectal Dis*. 2021;23(1):132–44. <https://doi.org/10.1111/codi.15423>
- Wilson A, Winner M. Factors associated with decisional regret among patients undergoing major thoracic and abdominal operations. *Surgery*. 2017;161:1058–66.
- Becerra Pérez MM, Menear M, Brehaut JC, Légaré F. Extent and predictors of decision regret about health care decisions: a systematic review. *Med Decis Making*. 2016;36:777–90.
- Bunge M, Mühlhauser I, Steckelberg A. What constitutes evidence-based patient information? Overview of discussed criteria. *Patient Educ Couns*. 2010;78:316–28.
- Edwards A, Elwyn G, Mulley A. Explaining risks: turning numerical data into meaningful pictures. *BMJ*. 2002;324:827–30.
- Kasper J, Köpke S, Mühlhauser I, Nübling M, Heesen C. Informed shared decision making about immunotherapy for patients with multiple sclerosis (ISDIMS): a randomized controlled trial. *Eur J Neurol*. 2008;15:1345–52.
- Köpke S, Kern S, Ziemssen T, Berghoff M, Kleiter I, Marziniak M, et al. Evidence-based patient information programme in early multiple sclerosis: a randomised controlled trial. *J Neurol Neurosurg Psychiatry*. 2014;85:411–8.

36. Köpke S, Kasper J, Mühlhauser I, Nübling M, Heesen C. Patient education program to enhance decision autonomy in multiple sclerosis relapse management: a randomized-controlled trial. *Mult Scler*. 2009;15:96–104.
37. Shaukat SS, Rao TA, Khan MA. Impact of sample size on principal component analysis ordination of an environmental data set: effects on eigenstructure. *Ekológia (Bratislava)*. 2016;35:173–90.
38. MacCallum RC, Widaman KF, Preacher KJ, Hong S. Sample size in factor analysis: the role of model error. *Multivariate Behav Res*. 2001;36:611–37.
39. Exploring local income deprivation. <https://www.ons.gov.uk/visualisations/dvc1371/#/E08000019>

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