Article:

Lee, M.J. orcid.org/0000-0001-9971-1635, Jones, G.L., Lobo, A.J. et al. (12 more authors) (2021) Survey to define informational needs of patients undergoing surgery for Crohn’s anal fistula. Colorectal Disease, 23 (1). pp. 132-144. ISSN 1462-8910

https://doi.org/10.1111/codi.15423

This is the peer reviewed version of the following article: Lee, M.J., Jones, G.L., Lobo, A.J., Brown, S.R. and (2021), Survey to define informational needs of patients undergoing surgery for Crohn’s anal fistula. Colorectal Dis, 23: 132-144, which has been published in final form at https://doi.org/10.1111/codi.15423. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions.

The informational and decision preferences of patients undergoing surgery for Crohn's anal fistula: A qualitative study

Running title: Crohn's fistula treatment preferences

Matthew J Lee MRCS PhD[1], Jack H Marshall BMedSci[2], Georgina L Jones PhD[3], Alan J Lobo MD[4], Steven R Brown MD[1]

1. Academic Department of General Surgery, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK
2. The Medical School, University of Sheffield, UK
3. Dept of Psychology, Leeds Beckett University, UK
4. Academic Unit of Gastroenterology, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK

Matthew Lee ORCiD: 0000-0001-9971-1635

Corresponding author:

Matthew Lee, Academic Dept of General Surgery, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK
Email: m.j.lee@sheffield.ac.uk
Tel: +44 (0)114 243 43 43
Twitter: @wannabehawkeye @stevebrownsheff

Tables:2

Figures:1

Word count:3319

Keywords: Qualitative, Crohn's, anal fistula, information preferences, decision making

Conflicts of interest
Alan Lobo has received lecture fees from Takeda and Abbvie. Matthew Lee has acted as an adviser for Takeda.

Funding:
This project was funded by a grant from the Bowel Disease Research Foundation & the Royal College of Surgeons of England/Crohn's and Colitis UK One Year Research Fellowship.

Author contributions: Study concept & design: ML/JM/GL/AL/SB. Data acquisition: ML/JM Analysis and interpretation: ML/JM/GL/AL/SB. Manuscript draft and approval: ML/JM/GL/AL/SB

Acknowledgements:

We are grateful to Miss Azmina Verjee for her input into the design of the interview schedule, and Mr Alex Blackmore and team at Blackpool Teaching Hospitals NHS Foundation Trust for help with recruitment to this study.

Keywords: Crohn’s disease; anal fistula; Decision Support Techniques; Health Knowledge, Attitudes, Practice

Data from this study has been presented at the Association of Surgeons in Training April 2018 Conference in Edinburgh UK, Society of Academic & Research Surgery Jan 2018 Conference in Nottingham, UK, and Association of Coloproctology of Great Britain and Ireland 219 conference in Dublin, Ireland

What this study adds:

This study provides valuable patient centred information on how surgeons communicate treatment options and make decisions in areas of uncertainty. It might help clinicians to consider key items of information to communicate to patients before surgery in Crohn’s anal fistula.

Abstract

Background: Anal fistula affects one in three Crohn’s patients, and few achieve long term healing. Treatment involves a combination of medical and surgical operations. There is no ‘best’ operation for this condition, so patient preferences are important in selecting appropriate treatments. The aim of this study was to investigate informational and decisional preferences of patients related to surgical therapy of fistulizing perianal Crohn’s disease.

Method: Patients who had undergone surgery for Crohn's anal fistula underwent face-to-face semi-structured interviews. Interviews explored experience of treatments for fistula, experiences of receiving information and participation in decision making. Transcripts were analysed by two investigators through inductive thematic analysis. Saturation was assessed for at 12 interviews and then after each subsequent interview.

Results: Seventeen patients completed interviews and saturation was achieved. Five themes were identified, two of which (desired information and decision making) were relevant to the study aim. Other themes included experience of Crohn’s disease, experience of receiving information and procedure specific comments. Participants desired information to address risks of procedure, high level outcomes (e.g. success), impact on day to day life, and aftercare. Participants felt they did not always receive the information they needed to select the best treatment option. Participants felt uninvolved in treatment decisions, and would like to trade-off operations to reach their treatment goal.

Conclusions: Information provided to patients about surgical treatment of Crohn’s anal fistula does not meet their needs. Clinicians should address aftercare, impact on quality of life, likely success and risks of the procedure.

Background

A perianal fistula is an abnormal connection between the anorectum and perianal skin. One in three patients with Crohn's disease will develop a perianal fistula[1], and as few as one in three will achieve long term fistula healing[2]. This is a condition which is typically managed by a team including surgeons and physicians, using a combination of medications and operations[3]. Initial surgical therapy focuses on sepsis control and typically uses setons to achieve this. Following medical therapy to decrease Crohn's disease activity, procedures to close a fistula may be attempted including fistula plug or advancement flap[4]. Some patients may require a stoma in medically refractory disease. A high number of patients might never achieve remission of their fistula symptoms leading to lost days of work, reduced quality of life[5 6], requiring multiple operations including stoma formation, or proctectomy[7].

A systematic review of surgical interventions did not identify a clear front-running technique for the cure of Crohn's anal fistula[4]. With equivalence of outcomes, and differences in intervention characteristics, selection of a procedure might be adjusted to account for patient preferences & values. Current guidance encourages doctors to place significant weight on patient preferences and values when considering any treatment, including surgery[8], moving decision making from a clinician centred model to one which takes input from both parties – a shared decision model[9]. Shared decision-making can be considered a hall-mark of quality care[10]. It may help to reduce waste in surgical services by ensuring investigations or interventions are tailored to a patient's treatment goals, rather than using a 'one size fits all' approach[11]. This requires clinicians and patients to share the relevant 'best available evidence', and to ensure discussion of relevant items of information[9].

Related qualitative literature has investigated decision making preferences of adolescents when considering biologic therapy, and shown a desire to participate in decisions about treatments[12]. A separate study explored the informational needs of patients on living with inflammatory bowel disease, which included information on disease processes and managing the impact on daily activities[13]. There are no studies exploring patient information and decision preferences in Crohn's anal fistula.

Aim

The aim of this study was to investigate informational and decisional preferences of patients related to surgical therapy of fistulizing perianal Crohn's disease.

Materials and Methods

This study received ethical approval from the Greater Manchester (South) NHS Research Ethics Committee (16/NW/0640), Informed consent was obtained from all individual participants included in the study. It is reported in line with the Consolidated criteria for reporting qualitative research (COREQ) guidelines[14].

Research team and reflexivity

Interviews were carried out by JM (BMedsci student) or ML (PhD student/clinician). Both JM and ML undertook interview training and feedback with GJ, a health psychologist prior to commencing the study. Researchers established their relationship with participants at the point of recruitment. Participants were made aware of the clinical background of the interviewer, and of their interests in the topic. Reflexivity (the inherent bias carried by the conduct of the researcher in interviews or interpretation of transcripts) was addressed in several ways; the researchers were transparent with patients about their roles and interviewers underwent a debrief after interviews. Transcripts underwent dual review and coding by the investigators to address reflexivity related to interpretation. Transcripts were revisited later in the study to reassess findings with consideration of emerging themes.

Methodological Framework

A qualitative methodology was adopted using semi-structured interviews and inductive thematic analysis. Qualitative research was selected as there is no evidence around patient information needs in fistulating anal Crohn's disease. Exploratory research is therefore an appropriate first step. Semi-structured interviews use a common framework or structure but allow the researcher to explore ideas and concepts that arise through further prompts or questioning. A structured interview would allow only the questions presented on the interview schedule. As this study adopted a qualitative methodology, the study is not designed to have power to demonstrate a statistical difference.

Participant Selection

The participant sample was selected through purposive sampling i.e. sampling of the population to ensure variation amongst those interviewed by ensuring a mix of active and inactive fistula, and experience of different surgical procedures. Recruitment was targeted at biologic infusion clinics (nurse-led unit for ambulatory attendees receiving infusions of biologic therapy for Crohn's disease), and surgical-IBD clinics. Participants were eligible if they were adults who had undergone previous surgery for Crohn’s anal fistula and able to converse in English. Additional targeted recruitment was carried out during the study to balance the number of patients with a stoma against other groups, as this group was under-represented. This was targeted at a target population rather than individual patients. The study used an opt-in approach which was completed by the participant at home to avoid coercion. Participants were identified following clinic attendance at one of two UK hospitals.

Setting

Research interviews were conducted in a non-clinical area at each of the hospitals. The interview schedule is presented in appendix A. As the interview might address sensitive issues, only the participant and interviewer were present during the interview. If a participant became distressed, the researcher would offer to suspend or terminate the interview and arrange for access to local IBD nurse specialists. Participating hospitals were approximately 100 miles apart in different regions of the UK, meaning there should be no effect or influence of one on practice in the other.

Data Collection

Descriptors of participant age, sex, duration of Crohn’s disease, prior fistula operations, and current fistula status were recorded. An interview guide was prepared by ML and GJ with input from a patient representative. Each participant undertook a single interview, which was audio recorded. Supporting field notes were taken by the interviewer where appropriate to identify any aspects of questions that did not work and to identify potential issues related to reflexivity.

Data Analysis & Coding

Interviews were transcribed by their respective interviewer. Coding was undertaken independently by JM and ML using NVivo 11 Computer-Assisted Qualitative Data Analysis Software (QSR International, Australia). Data analysis was via an inductive thematic approach utilizing a systematic approach as outlined by Braun and Clarke[15]. After five interviews, codes were compared and discussed with the research team, and a provisional coding framework was agreed. This was constantly reviewed during analysis to give the final coding framework, with the addition of themes where appropriate. This framework was applied to subsequent transcripts. Participants did not provide feedback on the findings. Data coding was conducted by ML and JM. As data saturation can occur with as few as twelve interviews[16], saturation was first assessed at this point, and then after each subsequent interview. Saturation was reached when ML & JM agreed that five subsequent interviews did not reveal any new themes. Transcripts were not returned to participants for comment as the research team was concerned about logistical and time restraints related to the study.

Results

Seventeen people completed interviews aged 19-71 (nine male). Interview length ranged from 16- 47 minutes. Participants had undergone treatment for Crohn’s disease over a period ranging from 6 months to 40 years. Treatment experience included setons (thirteen cases), fistula plug (three patients), and stoma formation for fistulating disease (four cases). Ten participants had an active fistula i.e. fistula with ongoing discharge requiring further treatment. Participants reported treatment experiences from four different hospitals (one participant had transferred their care from another hospital to a participating unit, another participant had started treatment in the participating unit and received care in a regional centre before returning to participating unit for additional care) ;ten different surgeons were named during interviews, showing a range of treatment experience. A summary of participant characteristics is shown in Table 1. Of those approached, 28 patients declined or did not contact the research team following initial approach. No reasons were given.

The initial coding framework is presented in appendix B. Saturation was assessed at interview 12 and confirmed following interview 17. Analysis identified five over-arching themes: i) Experience of Crohn's disease, ii) experience of receiving information, iii) procedure specific comments, iv) decision making, and v) desired information. A summary of these themes along with their sub themes and number of participants referencing them is shown in the data saturation grid (Table 2). This manuscript focusses on the themes related to receiving information, decision making and desired information in depth. A summary of all themes, including third tier themes is presented in Appendix C.

Experience of receiving information

Six subordinate themes were identified related to receiving information. These were information from clinicians, delivery of information, conflicting information, the internet as a source of information, peer support and written information.

Delivery of information

Many participants felt that the quality of counselling prior to surgery was poor, and could be delivered at a slower pace.

‘It just seems like everything is really rushed and they haven’t got time to really talk to you. They don’t actually sit down half of the time and it’s like duh, duh, duh, and they go into their offices, and it’s like…are we done?’
I.5, F, Active fistula

‘It was quite rushed, and she sort of just gave me [leaflets] or whatever. I think I would have preferred someone to just sit down with me properly.’
I.11, F, Inactive fistula

Information from clinicians

Information from clinicians typically focussed on short risks and outcomes of procedures and long-term outcomes of the condition.

‘At the time, that was sort of the thing that was most worrying to me…obviously I know it’s a small risk, of cutting your sphincter muscle…’
I.6, M, Active fistula

'I was always told it's unlikely, well not unlikely, it's never certain that a fistula is going to heal, and likewise, if someone has had fistulas from something like Crohn's, it's also likely that it recurs.'

I.10, M, Active fistula

Two participants specifically mentioned a discussion of risk of incontinence prior to surgery, but other participants reported a focus on short term success and failure from surgical procedures.

The internet as a source of information

The internet was used by most participants to seek information on their condition and treatment options. Other information sources included discussion forums, written leaflets, and charity sources. Participants typically fell into those who found the internet useful, and those who did not.

'I looked on Google, and that made me even more scared.'

I.1, M, Inactive fistula

'On the stoma sites, a lot of people do Vlogs, so I've watched them before. There's some good ones that are helpful.'

I.15, F, Active fistula

Peer support

Peer support was often discussed as a way of finding out information which clinicians did not routinely offer. Internet peer support e.g. internet forums were typically considered to provide useful content. They also provided social support for participants as they reported feeling better after talking to others with similar problems.

> ‘Obviously, there’s forums and bits like that which you always seem to go to. People were great. Some people go…you get the odd horror story in here and there but you sort of expect [that].’
>
> I.6, M, Active fistula
>
> ‘I’m on so many support groups on Facebook…there’s so many people going through what I’m going through – it’s crazy.’
>
> I.15, F, Active fistula

Written information.

Written information, in the form of leaflets, was not seen as being a preferred format for delivery of information for many participants. It was felt to have a supporting role in the delivery of information.

> ‘[It’s] secondary, supportive, rather than primary, because you can’t ask questions of a piece of paper.’
>
> I.17, F, Active

Conflicting information

Participants reported receiving conflicting information from different sources. The areas where conflicting advice had been given around major implications of treatment decisions.

> ‘I’ve seen different consultants, all lovely, but I felt like each person was telling me something different.’
>
> I.11, F, Inactive fistula

Decision making

Two subthemes were identified: ‘trade off’ and ‘who makes the decision’.

Trade off

Several participants alluded to trading off different aspects of treatment for different outcomes, referencing symptoms, quality of life, or repeated procedures as factors in their choices. Participants were typically willing to accept a procedure which limited disruption to their lives and achieved some symptomatic relief from the fistula compared to those which were intended to be curative but disruptive to life or associated with increased risks. Two participants had experienced medically refractory Crohn’s disease and undergone stoma formation or proctectomy. Both indicated that the trade-off of a stoma for improved quality of life was worthwhile, despite the temporary impact on quality of life.

> ‘I suppose I’d weigh up that against your success percentage and look at what suited me best. I obviously want the most successful treatment, but if it’s going to be six months of to and fro between the hospital….’
>
> I.6, M, Active fistula
>
> ‘If…my quality of life was worse and that was a permanent state, then I would say yeah, the quality of life improvement would maybe be worth just having a stoma’

I.10, M, Active fistula

Who makes the decision?

The process of decision-making was discussed by several participants. Several people indicated that they preferred a clinician-centred or clinician guided decision model. Others felt that they wanted a more active and decisive role in the process. Participants recognised the uncertainty associated with decisions, and this is perhaps why they willing to rely on clinician input.

> 'I like to be led by somebody who knows what they're on about. I like to make my own decision, but I like to be led in the right direction….as long as they're honest with me and lay all the information out, and not concentrating too much on worst and best. [Talk] about the middle ground where most people end up. I think I can make a pretty informed decision.'
>
> I.9, M, Inactive fistula

Notably, many participants felt that they had not been offered a choice in the treatment of their fistula. Whilst no immediate choice was apparent, participants indicated that clinicians often mentioned a sequence of treatments of increasing invasiveness or severity to attempt to improve symptoms.

> 'They didn't give me an option of what they were going to do. They were going to do this…but they didn't go 'there's A,B,C and D'.'

I.6, M, Active fistula

Desired information

Interviews explored the kind of information participants would like to support them when making decisions about their care. This identified five sub themes; procedural information, treatment goals, sexual and reproductive health, aftercare, and delivery of information. A summary of desired information is shown in figure 1.

Procedural information

Participants broadly wanted to know about success and failure rates of fistula closure, and likelihood of fistula recurrence for specific procedures. They also wanted to know how likely it was that a treatment would improve their symptoms. There was a recognition that fistula can recur in the future, hence the focus on symptom control. Participants indicated that procedural information was widely covered by surgeons.

‘Success rate is number one…what sort of percentage chance my surgery would succeed.’

‘Because [recurrence] is sort of one thing you imagine…I don’t have to worry about it, and then a few years down the line, you’ve got another one….is it worth actually going off and closing it at all?’

I.10, M, Active fistula

Treatment goals

Participants discussed treatment objectives beyond fistula closure, including symptom improvement, and aspects related to daily activities and quality of life. These ideas were prominent for all patients, with emphasis on the effect of treatment on the ability to work, go shopping, and socialise normally. Participants indicated that the relevance of surgical treatments to their own treatment goal was not often explored by clinicians.

‘Recovery time. I want to know about aftercare and exactly what’s going to happen….Speed and effectiveness really.’

I.14, M, Active fistula

‘I’d need to know that I can carry on doing the things that I do. I basically want to be able to sit on a bike seat for a start.’

I.16, M, Active Fistula

Sexual and reproductive health

Three participants (all female), raised concerns about the impact of treatments on sexual and reproductive health, and felt that this should be part of any discussion. During interviews with these participants, it was clear that information about fertility or sexual function had only been discussed because they had raised the topic. Participants were sometime surprised by the statements on the potential negative effect of treatment on sexual health and fertility, with clinicians highlighting a negative effect that was ‘obvious’ to them, but not to the patient.

‘It obviously affects my sex life ‘cause it’s all closely linked isn’t it?’

‘Some people have said you can have children, some people have said you can’t so…’

I.15, F, Active fistula

Aftercare

Participants discussed the need for information about aftercare following treatment of their fistula. This included information on how to manage ongoing discharge from fistula tracks whilst setons were in situ, advice related to dressings care, and plans for follow-up. Participants indicated that this was often dealt with as an afterthought or by someone not familiar with the patient or the condition. This led to significant uncertainty and feeling discarded by their healthcare team.

'If I was ever going for anything then [I'd ask] 'What is your aftercare procedure?'

I.6, M, Active fistula

Delivery of information

Several participants offered thoughts on the modality of sharing information. Many preferred a face-to-face discussion with a health care professional, typically a surgeon. They preferred that this was a two-way interaction to explore and share information to reach a decision, rather than unidirectional sharing of information. This would allow them to elicit the points of information that were important to them. They indicated that written information could be provided to take away and reinforce details from the consultation. Participants felt that this information should be delivered primarily by a surgeon, but also indicated that nurse specialists in inflammatory bowel disease could help to provide some of the missing information. As part of a separate theme, the participants identified the importance of the therapeutic relationship when discussing treatment decisions, particularly related to how a good relationship led to trust about the quality of information and the decisions being made.

'It's just sitting down and taking the time….it would be helpful to give a leaflet…maybe even some pictures of stuff.'

I.7, F, Active fistula

'Face-to-face, verbally. I like to ask a lot of questions, so to be able to have a dialogue has always been really useful.'

I.17, F, Active fistula

Discussion

This study has explored patient preferences for content and delivery of information about surgical treatment for Crohn’s anal fistula. Despite long histories of fistulating disease, participants discussed their recent experiences of receiving information about surgical treatments, meaning that this information reflects relatively current practice. They also focussed more on their experiences of discussing treatment in the elective setting rather than the emergency setting. It has generated a short list of important items to consider in selecting procedures and highlights patient desire to be involved in treatment decisions. Despite long histories of fistulating disease, participants discussed their recent experiences of receiving information about surgical treatments, meaning that this information reflects relatively current practice.

This study benefits from broad participation demographics, including male and female participants of varying age, with a mix of active and inactive fistula, and a broad range of procedural experience, including stoma formation. This means that the expressed desires of information delivery and content might aid the transferability of findings. Whilst the procedures experienced by participants may not reflect ideal practice, it does reflect the real-world experience of patients. This study has also been conducted with appropriate methodological oversight, dual review of interviews, and reported to meet existing guidelines[14]. Dual coding of transcripts is a form of between researcher triangulation and should be considered a further strength of this study.

The main limitation of this study is that it was undertaken across only two hospitals. This means that experiences reported reflect only those from these sites and may not be directly extrapolated to those outside of these centres. As participants were recruited through several clinical contact points following treatment, there is a risk of recall bias affecting the experience, owing to time elapsed since the last surgical procedure. We did not record time since last surgical procedure in this study. There is also the risk of responder bias; this means that only those with strong positive or negative experiences of disease or treatment participated, leading to reporting of only extreme experiences. This could account for non-participation of 28 of those approached, although it may also reflect discomfort with the topic, dissatisfaction with clinical care, or practical issues such as time off work, as well as a lack of desire to participate [17 18]. However, the sample size is comparable to other studies in the field[19-21]. We acknowledge that not all possible surgical interventions available are represented in this study, although this will reflect local clinician treatment preferences. Previous work has shown a wide range of procedures is offered to patients with Crohn's anal fistula[22]. This study has captured commonly used treatments such as seton, but we accept that several forms of treatment are missing. The study reports only the experiences of those who have undergone surgical intervention, not those who have been managed without surgery. The authors believe that it is highly unlikely that the majority of patients with anal fistula in the context of Crohn's disease will not have undergone a surgical procedure at some point, even if this is limited to a seton. This may however reflect a missing population in this study.

The main desired information items were related to procedural conduct and high-level outcomes of success and failure, impact of the procedure on quality of life and other functions, time needed to recover and aftercare considerations, some of which have been indicated in studies of the wider inflammatory bowel disease cohort[23]. During interviews, participants discussed different trade-offs between treatment options related to factors such as fistula healing and improved quality of life. When discussing hypothetical treatment choices, participants typically stated they would favour the least invasive and least disruptive intervention, not necessarily the option with the highest probability of fistula healing. This fits with the broader patterns seen in shared decision making, where deployment of this approach tends to reduce the number of invasive tests or procedures[11]. Clinicians could explore these factors with patients when considering treatment options. This might lead to changes in treatment choices. Many participants expressed dissatisfaction with the limited amount of information given on non-technical features of procedures such as aftercare, impact on fertility, and activities of daily living. There is an opportunity for surgeons to explore these aspects with patients as part of the decision-making process to select appropriate treatment options. These experiences match with those reported in surveys of patients with IBD[24]. A study which assessed audio recordings of consultations about surgery for oesophago-gastric cancers found similar trends – surgeons focussed on technical factors and overall success (or mortality), whereas patients were more interested in time to recovery and impact on quality of life[25]. Furthermore, participants highlighted the importance of a strong and well-established therapeutic relationship with their clinicians in the establishment of trust when sharing information and making decisions.

The findings of this study are relevant for surgeons. Patients wish to participate in the decisions about their surgical treatments. The items presented in figure 1 might provide a reference list of items to discuss with patients, including infrequently addressed items such as impact on sexual function and return to regular activities of daily living. These were reported across the sample of participants who had experienced a wide range of surgical procedures for their fistulating disease. Presentation of these items might allow patients to trade-off the risks and benefits of different operations from their own perspective and to select the most appropriate operation based upon their current treatment and life priorities. The procedures presented might include stoma as an option, if clinically appropriate. One way to ensure this is integrated in care would be to ensure that patients are seen by a multidisciplinary team with a focus on Crohn's anal fistula, who are able to dedicate necessary time to explore values and options with the patient.

There is also a need to standardise the content of information, and this might be achieved through a core information set[26]. In the meantime, surgeons providing care to this patient population should consider the items listed here when offering surgery for Crohn's anal fistula. They should ensure that they have elicited the patient's treatment goal to offer the 'best' treatment for the patient. Further research should be directed towards matching patient treatment goals with surgical procedures. Additional work involving separate interviews of patients and their surgeon would allow comparison of perspectives, and identify the items of information that both parties believe are key to decision making.

Conclusion

Current information provision and counselling about surgical treatment options for Crohn's anal fistula does not meet patient needs, in delivery and content.

References

1. Safar B, Sands D. Perianal Crohn's disease. *Clin Colon Rectal Surg* 2007;20(4):282-93. doi: 10.1055/s-2007-991027
2. Molendijk I, Nuij V, van der Meulen-de Jong A, et al. Disappointing durable remission rates in complex Crohn's disease fistula. *Inflamm Bowel Dis* 2014;20(11):2022-8. doi: 10.1097/MIB.0000000000000148
3. Yassin NA, Askari A, Warusavitarne J, et al. Systematic review: the combined surgical and medical treatment of fistulising perianal Crohn's disease. *Aliment Pharmacol Ther* 2014;40(7):741-49. doi: 10.1111/apt.12906
4. Lee MJ, Heywood N, Adegbola S, et al. Systematic review of surgical interventions for Crohn's anal fistula. *BJS Open* 2017;1(3):55-66. doi: 10.1002/bjs5.13
5. Williet N, Sandborn WJ, Peyrin-Biroulet L. Patient-reported outcomes as primary end points in clinical trials of inflammatory bowel disease. *Clin Gastroenterol Hepatol* 2014;12(8):1246-56 e6. doi: 10.1016/j.cgh.2014.02.016
6. Schwartz DA, Loftus E, Tremaine WJ, et al. The natural history of fistulizing Crohn's disease in Olmsted County, Minnesota. *Gastroenterology* 2002;122(4):875-80.
7. Gecse K, Bemelman W, Kamm M, et al. A global consensus on the classification, diagnosis and multidisciplinary treatment of perianal fistulising Crohn's disease. *Gut* 2014;63(9):1381-92. doi: 10.1136/gutjnl-2013-306709
8. Consent: Supported decision-making. A guide to good practice. London: Royal College of Surgeons of England, 2016.
9. Elwyn G, Durand MA, Song J, et al. A three-talk model for shared decision making: multistage consultation process. *BMJ* 2017;359:j4891. doi: 10.1136/bmj.j4891
10. Barry M, Edgman-Levitan S. Shared Decision Making — The Pinnacle of Patient-Centered Care. *NEJM* 2012;366(9):780-81.
11. Stacey D, Legare F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017;4:CD001431. doi: 10.1002/14651858.CD001431.pub5
12. Lipstein EA, Muething KA, Dodds CM, et al. "I'm the one taking it": adolescent participation in chronic disease treatment decisions. *J Adolesc Health* 2013;53(2):253-9. doi: 10.1016/j.jadohealth.2013.02.004

13. Lesnovska KP, Borjeson S, Hjortswang H, et al. What do patients need to know? Living with inflammatory bowel disease. *J Clin Nurs* 2014;23(11-12):1718-25. doi: 10.1111/jocn.12321
14. 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(6):349-57.
15. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77-101.
16. Guest G, Bruce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. . *Field Methods* 2006;18:59-82.
17. Bradley DT, Treanor C, McMullan C, et al. Reasons for non-participation in the Northern Ireland Bowel Cancer Screening Programme: a qualitative study. *BMJ Open* 2015;5(9):e008266. doi: 10.1136/bmjopen-2015-008266
18. Attwood S, Morton KL, Mitchell J, et al. Reasons for non-participation in a primary care-based physical activity trial: a qualitative study. *BMJ Open* 2016;6(5):e011577. doi: 10.1136/bmjopen-2016-011577
19. Baker D, Lee M, Jones G, et al. The Informational Needs and Preferences of Patients Considering Surgery for Ulcerative Colitis: Results of a Qualitative Study. *Inflamm Bowel Dis* 2017;24(1):179-90.
20. Harrop E, Kelly J, Griffiths G, et al. Why do patients decline surgical trials? Findings from a qualitative interview study embedded in the Cancer Research UK BOLERO trial (Bladder cancer: Open versus Lapararoscopic or RObotic cystectomy). *Trials* 2016;17(35)
21. Schildman J, Ritter P, Salloch S, et al. 'One also needs a bit of trust in the doctor … ': a qualitative interview study with pancreatic cancer patients about their perceptions and views on information and treatment decision-making *Ann Oncol* 2013;24(9):2444-49.
22. Lee M, Heywood N, Sagar P, et al. Surgical Management of Fistulating Perianal Crohn's Disease – A UK Survey. *Colorectal Dis* 2017;19(3):266-73. doi: 10.1111/codi.13462
23. Pittet V, Vaucher C, Maillard MH, et al. Information Needs and Concerns of Patients with Inflammatory Bowel Disease: What Can We Learn from Participants in a Bilingual Clinical Cohort? *PLoS One* 2016;11(3):e0150620. doi: 10.1371/journal.pone.0150620
24. Siegel CA, Lofland JH, Naim A, et al. Novel Statistical Approach to Determine Inflammatory Bowel Disease: Patients' Perspectives on Shared Decision Making. *Patient* 2016;9(1):79-89. doi: 10.1007/s40271-015-0126-z
25. McNair AGK, MacKichan F, Donovan JL, et al. What surgeons tell patients and what patients want to know before major cancer surgery: a qualitative study. *BMC Cancer* 2016;16:258. doi: 10.1186/s12885-016-2292-3
26. Main BG, McNair AGK, Huxtable R, et al. Core information sets for informed consent to surgical interventions: baseline information of importance to patients and clinicians. *BMC Med Ethics* 2017;18(1):29. doi: 10.1186/s12910-017-0188-7

Tables

Case	Sex	Age (years)	Time since first fistula	Previous operations	Fistula status
I.1	M	19	15 years	Seton	Inactive
I.2	F	60	6 years	Seton	Active
I.3	F	45	14 years	Panproctocolectomy & ileoanal pouch	Inactive
I.4	M	23	9 years	Seton	Inactive
I.5	F	60	40 years	Seton, End Ileostomy	Active
I.6	M	25	7 years	Drainage of abscess	Active
I.7	F	26	7 years	Seton	Active
I.8	F	27	5 years	Seton, fistula plug, advancement flap	Active
I.9	M	56	20 years	Seton, fistula plug	Inactive
I.10	M	25	9 years	Seton, fistula plug,	Active
I.11	F	22	7 years	End Ileostomy	Inactive
I.12	M	31	1 year	Seton	Active
I.13	M	71	6 months	Seton, proctectomy	Inactive
I.14	M	22	6 months	Drainage of abscess, loop ileostomy	Inactive
I.15	F	24	3 years	EUA, seton, Loop colostomy	Active
I.16	M	67	15 years	EUA, seton	Active
I.17	F	35	10 years	Subtotal colectomy, temporary ileostomy, ileorectal anastomosis, EUA, drainage of abscess, seton	Active

Table 1: Summary of participant characteristics.

Over-arching theme	Sub theme	Number of participants referencing subtheme (%)
Experience of Crohn's disease	Impact of disease	15 (88.2%)
	Quality of life	9 (52.9%)
	Effect of operation	12 (70.6%)
	Aftercare	10 (58.8%)
	Fistula expectations	9 (52.9%)
	Relationship with healthcare professionals	10 (58.8%)
Experience of receiving information	Delivery of information	8 (47.1%)
	Information from clinicians	15 (88.2%)
	The internet as an information source	15 (88.2%)
	Peer support	10 (58.8%)
	Written information	8 (47.1%)
	Conflicting information	4 (23.5%)
Procedure specific	Seton	12 (70.6%)
	Stoma	15 (88.2%)
Decision making	Trade-offs	14 (82.4%)
	Decision making preferences	15 (88.2%)
Desired information	Procedural information	9 (52.9%)
	Treatment goals	12 (70.6%)
	Sex and reproductive health	3 (17.6%)
	Aftercare	9 (52.9%)
	Delivery of information	8 (47.1%)

Table 2: Summary of emergent themes, subthemes and data saturation.

Figure legends

Figure 1: What do patients want to know when discussing fistula surgery?