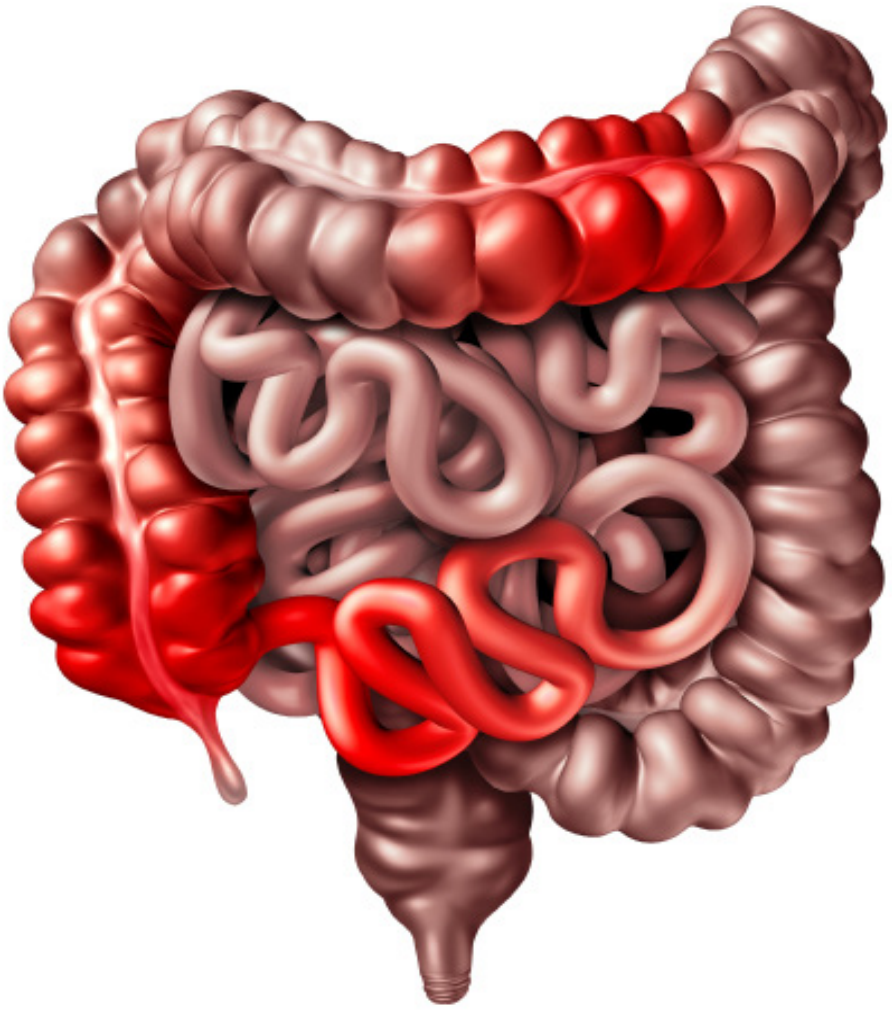
Making the Cut?

A review of the care received by patients undergoing surgery for Crohn's disease



NCEPOD

Improving the quality of healthcare

MAKING THE CUT?

A review of the care provided to patients aged 16 and over with a diagnosis of, and who underwent surgery for, Crohn's disease.

A report published by the National Confidential Enquiry into Patient Outcome and Death (2023)

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Cohort: 1st September 2019 to 29th February 2020 and 1st September 2020 to 28th February 2021

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FOREWORD

Dr B.B. Crohn described the disease which was to become synonymous with his name in 1932, after identifying 14 patients with uniquely similar symptoms and pathological findings in the gut.[1] At first thought to be a variant of tuberculosis because of the presence histologically of granulomata, Crohn recognised that many of the symptoms were somewhat non-specific and that physicians might well find it difficult to distinguish between neurosis and regional enteritis, as he preferred it to be called.

We now know that in addition to attacking the digestive tract, this often highly debilitating disease can also affect the eyes, mouth, and joints, and is not infrequently associated with mental health and psychosocial issues, which doubtless contribute to the all-too-frequent delay in diagnosis.

Living with Crohn's disease can be difficult and many of us will know friends or colleagues who have been diagnosed with the condition and have to manage the unpredictable symptoms and significant disruption to their lives.

There is a plethora of authoritative guidance from august bodies, highlighting the need for multidisciplinary care, and a co-ordinated approach to management, not least between gastroenterologists and surgeons. However, this report identifies that all too often this does not happen. In consequence, for example, many patients, clearly resistant to medical therapy who might well benefit from early surgical intervention are not receiving this choice, and instead exposed to long-term steroid therapy, with all its attendant complications, or end up being admitted and operated on as an emergency, which could have been avoided if better planning had occurred.

This is predominantly a disease that affects young adults during what should be their most productive years, and so quite apart from the chronic and often painful symptoms they experience, there can be profound socio-economic consequences. However, despite this, unlike cancer, it appears to have the status of a 'benign' disease, which may be why it has not so far received the same levels of attention, investment and organisation.

I sincerely hope that, as with many other areas NCEPOD has reviewed, this report will shine a little more light onto a widely misunderstood disease and increase the desire of commissioners and providers of services to heed its eminently sensible suggestions and recommendations.

As ever I would like to thank the staff, clinical co-ordinators, the Study Advisory Group, and reviewers who have made this report possible.

Ian C Martin, NCEPOD Chair

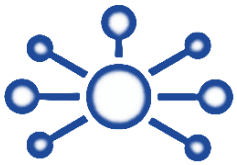
EXECUTIVE SUMMARY

To assess the quality of care provided to patients aged 16 years and over, who had a diagnosis of Crohn's disease and who underwent an operation, data were collected from two sample periods: 1st September 2019 to 29th February 2020 and 1st September 2020 to 28th February 2021 inclusive to account for influence of the COVID-19 pandemic. Analysis was undertaken on questionnaires from 553 clinicians, 414 sets of case notes, and 138 organisational questionnaires, supported by qualitative data from patient surveys and focus groups.

CONCLUSION

Surgery for patients with drug resistant Crohn's disease surgery should be considered earlier in the treatment pathway for patients, instead of surgery being perceived as a failure of medical care. Once a decision to perform surgery has been made it should be undertaken within a month to prevent patients on elective waiting lists deteriorating and requiring emergency surgery. Furthermore, closer working between all members of the multidisciplinary team would benefit patients, to reduce delays as well as providing all the holistic care that patients with Crohn's disease need.

1. PROVIDE HOLISTIC SUPPORT FOR ALL PATIENTS WITH CROHN'S DISEASE



Patients with Crohn's disease have many wider health needs e.g. psychological, dietary and peer support.

The reviewers found evidence of psychological support across the care pathway in just 30/332 (9.0%) cases reviewed, even though patients had undergone major surgery.

Services that the patients would have liked but did not receive included psychological support (132/310; 42.6%) and dietetic support (108/310; 34.8%).

2. MEDICATION FOR CROHN'S DISEASE SHOULD BE MANAGED EFFECTIVELY AT ALL STAGES OF THE PATHWAY

This would ensure patients are taking the correct medication before, during and after surgery.

253/414 (61.1%) patients were taking medications for their Crohn's disease, and of these, complications or side effects of the medication were recorded in 38/253 (15.0%).

There was room for improvement in the management of medication for 45/222 (20.3%) patients e.g. the use of prophylaxis (15) and/or a delay in starting/reviewing medication (10).

3. CONSIDER SURGERY AS A POTENTIAL TREATMENT OPTION FOR PATIENTS WITH CROHN'S DISEASE

Surgery should not be perceived as a failure of medical management and could be undertaken sooner.

Reviewers reported that referral for a colorectal surgical opinion should have occurred earlier in 41/218 (18.8%) patients.

56/278 (20.1%) patients, identified in the reviews, encountered more than one delay in the elective surgery pathway and 14/34 patients had adverse outcomes due to complications and the need for a stoma.

4. PERFORM SURGERY PROMPTLY ONCE A DECISION TO OPERATE HAS BEEN MADE

This would prevent elective patients becoming emergencies and reduce the risk of a Crohn's flare when medications are altered pre-operatively.

128/301 (42.5%) patients waited more than 18 weeks (126 days) before their operation was carried out (unknown for 63 patients) and 30/311 (10.0%) patients waited more than six months for surgery.

Only 18/138 (13.0%) hospitals reported local targets in place for the scheduling of Crohn's disease surgery.

5. MAKE SURE THAT THE HANDOVER OF CARE FROM THE SURGICAL TEAM TO THE MEDICAL TEAM IS ROBUST

Early involvement by the inflammatory bowel disease team would promote joined up care after surgery.

299/553 (54.1%) patients saw neither an inflammatory bowel disease (IBD) nurse nor a gastroenterologist postoperatively.

Re-adjustments of Crohn's disease medication may be required after surgery to reduce the postoperative risks of immunosuppression, yet a pharmacist was only involved for 258/553 (46.7%) patients.

RECOMMENDATIONS

These recommendations have been formed by a consensus exercise involving all those listed in the acknowledgements. The recommendations have been independently edited by medical editors experienced in developing recommendations for healthcare audiences to act on.

The recommendations highlight areas that are suitable for regular local clinical audit and quality improvement initiatives by those providing care to this group of patients. The results of such work should be presented at quality or governance meetings and action plans to improve care should be shared with executive boards.

Executive boards are ultimately responsible for supporting the implementation of these recommendations. Suggested target audiences to action recommendations are listed in italics under each recommendation. At a local level the recommendations are aimed at all members of the multidisciplinary team involved in the care of patients with Crohn's disease.

The recommendations in this report support those previously by other organisations, and for added value should be read alongside:
NICE: NICE Guideline 129 - Crohn's Disease Management
BSG: Consensus Guidelines on the Management of Inflammatory Bowel Disease
IBDUK: Inflammatory Bowel Disease Standards
ACPGBI: Consensus Guidelines in Surgery for Inflammatory Bowel Disease
ECCO-ESCP: Consensus on surgery for Crohn's disease

	Executive boards are ultimately responsible for supporting the implementation of these recommendations. Suggested target audiences to action recommendations are listed in italics under each recommendation.
1	Ensure that all patients with Crohn's disease can access the holistic care they need. Including: a. Medication management, including specialist pharmacist support* b. Management of steroid withdrawal syndrome (adrenal suppression)** c. Information on what to do in the event of a Crohn's disease flare d. Pain management e. Stoma care f. Anaemia prevention and treatment g. Access to peer support h. Access to psychological support i. Access to dietetic support j. Support for wider health needs such as fertility issues k. Smoking cessation services l. Any other relevant lifestyle modification services

	A patient passport that summarises the patient's care may help and could include information on the aspects listed above. **This aligns with the IBDUK inflammatory Bowel Disease Standards* ***This aligns with NICE Guideline 129 - Crohn's Disease Management and the British Society of Gastroenterology Consensus Guidelines on the Management of Inflammatory Bowel Disease* ***Primary target audience:*** *Clinical directors for gastroenterology and clinical directors for colorectal/gastrointestinal surgery.* ***Supported by:*** *All members of the multidisciplinary team caring for patients with Crohn's disease.*
2	Optimise medications for patients with Crohn's disease. This should include review of: a. The prescription and/or discontinuation of steroids, biologics and immunomodulators b. The use of steroids, with specific reference to bone protection, and when to use proton pump inhibitors (PPIs) c. The provision of a steroid treatment card for all patients receiving steroids for more than three weeks* d. For patients undergoing scheduled surgery, a pre-operative medication review at the point the decision to operate is made e. The avoidance of 5-ASA for the treatment of Crohn's disease** **This aligns with the NICE clinical knowledge summary on corticosteroids* ***This aligns with the British Society of Gastroenterology Consensus Guidelines on the Management of Inflammatory Bowel Disease* ***Primary target audience:*** *Consultant gastroenterologists, consultant colorectal/gastrointestinal surgeons, inflammatory bowel disease nurses, and inflammatory bowel disease pharmacists.* ***Supported by:*** *Clinical directors for gastroenterology and clinical directors for colorectal/gastrointestinal surgery.*
3	Ensure that the members and timing of the multidisciplinary team meetings for patients with Crohn's disease adheres to current inflammatory bowel disease standards. ***Primary target audience:*** *Clinical directors for gastroenterology and clinical directors for colorectal/gastrointestinal surgery.* ***Supported by:*** *All members of the multidisciplinary team caring for patients with Crohn's disease.*
4	Document all multidisciplinary team discussions in the patient's clinical record at the time of the meeting and provide a summary to the patient and their GP. ***Primary target audience:*** *Multidisciplinary team lead.* ***Supported by:*** *Supported by consultant gastroenterologists, consultant colorectal/gastrointestinal surgeons, and inflammatory bowel disease nurses.*
5	Refer patients for surgical consideration when treatment with medication alone does not work. This is not an indication of 'failed medical management.' ***Primary target audience:*** *Consultant gastroenterologists.* ***Supported by:*** *All members of the multidisciplinary team caring for patients with Crohn's disease, clinical directors for gastroenterology, colorectal/gastrointestinal surgery, and directors of nursing who are setting the local policies, and national/specialty guideline producing organisations.*
6	Review patients with Crohn's disease, who are undergoing elective surgery, in a consultant-delivered, pre-operative assessment and optimisation anaesthetic clinic. This appointment should

	include an updated nutritional status assessment with input from dietitians and other specialties as needed. ***Primary target audience:*** *Consultant anaesthetists.* ***Supported by:*** *Clinical leads for gastroenterology, and dietetics and all other relevant members of the multidisciplinary team caring for patients with Crohn's disease.*
7	Perform abdominal surgery for patients with Crohn's disease within one month of the decision to operate.* **This aligns with guidance from the Federation of Surgical Specialty Associations but the timeframe may be adapted if essential to optimise a patient's condition or to accommodate patient preferences. However, cancellations should be avoided as these increase the risk of complications as biologics, immunomodulators and steroids may have been altered for a planned date of surgery.* ***Primary target audience:*** *Consultant colorectal/gastrointestinal surgeons.* ***Supported by:*** *Clinical directors for colorectal/gastrointestinal surgery and medical directors.*
8	Investigate, and take appropriate action as necessary e.g. report as a serious incident, when a patient with Crohn's disease on an elective surgery waiting list undergoes emergency surgery for a complication of their Crohn's disease. ***Primary target audience:*** *Medical directors.* ***Supported by:*** *Clinical directors for colorectal/gastrointestinal surgery, clinical directors for gastroenterology, and all relevant members of the multidisciplinary team caring for patients with Crohn's disease.*
9	Plan for the postoperative discharge of patients with Crohn's disease including: a. Handover of care to the inflammatory bowel disease/gastroenterology team who will look after the patient's ongoing medical care b. Undertaking a medication review* c. Providing information to the patient on who to contact in the event of an emergency d. Providing information to the patient on pain management, including what can be taken, not just what to avoid e. Booking follow-up appointments f. Providing information to the patient on how to access to psychological support if needed g. Communicating all of the above to the patient and their GP A structured discharge summary could help facilitate this. **Pharmaceutical discharge planning should start at admission by the ward pharmacy team, under the supervision of the inflammatory bowel disease pharmacist. Any changes should be communicated to the patient's GP and inflammatory bowel disease team.* ***Primary target audience:*** *Consultant colorectal/gastrointestinal surgeons.* ***Supported by:*** *Consultant gastroenterologists, the chief pharmacist, and other members of the multidisciplinary team caring for patients with Crohn's disease.*
10	Develop a trust/health board policy for the care of patients with Crohn's disease. This should include: a. The co-ordination of care between medical and surgical teams b. Support for the multidisciplinary team process c. Prioritisation of surgical treatment d. An appropriate consent process for surgery

	e. Pre-optimisation/assessment of patients scheduled for surgery f. Medication management g. Nutritional assessments and support h. Pain management i. Psychological support j. Discharge planning *This recommendation aligns with the IBDUK inflammatory Bowel Disease Standards and the British Society of Gastroenterology Consensus Guidelines on the Management of Inflammatory Bowel Disease* ***Primary target audience:*** *Medical directors, directors of surgery, and directors of nursing.* ***Supported by:*** *Chief Executives and members of the multidisciplinary team caring for patients with Crohn's disease.*
11	Define the services and facilities that constitute a surgical inflammatory bowel disease centre in order to commission high quality care (see also recommendation 10). ***Primary target audience:*** *National and local commissioners.* ***Supported by:*** *Trust/health board medical directors, directors of surgery, and directors of nursing, members of the multidisciplinary team caring for patients with Crohn's disease, and with guidance from the IBDUK inflammatory Bowel Disease Standards.*
12	Develop guidelines to ensure temporary stomas are closed within 12 months of their formation unless there is a documented reason to justify delay. ***Primary target audience:*** *Association of Coloproctology of Great Britain and Ireland.* ***Supported by:*** *Consultant colorectal/gastrointestinal surgeons, and commissioners.*

INTRODUCTION

Crohn's disease is a chronic inflammatory condition of the bowel which most commonly affects the small intestine but can occur in any part of the gut. It follows a relapsing and remitting course with considerable morbidity when patients experience a flare. About 100,000 people in the UK have Crohn's disease, and it typically occurs between the second and fourth decades of life with another peak after the age of 60. The disease can cause significant physical symptoms and psychosocial stress affecting education, employment and inter-personal relationships.[2]

Despite rapid advances in drug therapy, progressive inflammation can still lead to complications such as strictures, fistulae and abscesses, in over 50% of patients, and 70-90% of patients will eventually need surgery.[3] Timely surgery will maintain or return many patients to remission, but surgery for Crohn's disease can be challenging with postoperative complications two times more common than in bowel cancer operations.[4] The decision regarding the need for, and timing of surgery requires effective multidisciplinary working and continuous patient involvement. This care planning can be particularly hard to deliver when providing emergency surgical treatment for a situation that could have been a planned procedure. The timing of surgery was included in the top ten non-cancer research priorities by the Association of Coloproctology of Great Britain and Ireland (ACPGBI) in a Delphi exercise of its entire membership.[5]

Extensive guidelines have been written to assist in the care of patients with Crohn's disease. NICE guideline 129[6] and Quality Standard 81[7] recommend that surgery should be considered early in the course of the disease for some patients. ACPGBI guidelines recommend a wide range of indications for operative treatment,[8] as do the British Society of Gastroenterology (BSG) consensus guidelines, which recommend that surgery should be discussed as an option where medical therapy hasn't worked or for those patients preferring surgery.[9] The European Crohn's and Colitis Organisation (ECCO) and European Society of Colo-Proctology (ESCP) consensus on surgery for Crohn's disease recommend that surgical treatment should be considered for patients with obstructive symptoms due to strictures, symptoms related to inflammation in the gut that has not responded to medical treatment, the need for long term steroids and complications such as abscess or fistula formation.[10] Furthermore, the Inflammatory Bowel Disease (IBD) UK standards cover the pathway of care from diagnosis, through to follow-up after surgery.[11] The standards recommend that patients should have access to co-ordinated surgical and medical clinical expertise, including regular combined or parallel clinics with a specialist colorectal surgeon and IBD gastroenterologist, and that elective IBD surgery should be performed by a colorectal surgeon who is recognised as a core member of the IBD team in a unit where such operations are undertaken regularly.

This NCEPOD study was developed with wide multidisciplinary input, reviewing the care of patients with Crohn's disease needing surgical treatment. It identifies several areas affecting the care of adult patients with Crohn's disease that require improvement.

WHAT THE PATIENTS SAID

"I received the best quality of care when I had to get an emergency ileostomy (i.e. when I was incredibly ill). Otherwise, when I was experiencing symptoms and trying to receive a diagnosis there were significant delays, and even after diagnosis my disease continued to progress to the point of needing emergency surgery despite appointments with gastroenterology and multiple GP visits where I tried to impress how ill I was and how little the steroids I was on were helping. While I was in remission I felt I was forgotten about and lost to the system despite still experiencing some symptoms and needing support. That said, the inflammatory bowel disease, and stoma nurses were and are always fantastic, incredibly empathetic and good at what they do."

"It was evident that I would need surgery, but my IBD team never referred me for a discussion with a surgeon, until one day I had a routine small bowel scan and was told to make my way to A&E immediately as the situation had become so severe. I was operated on four days later."

"My gastro team have been very accessible to me and prompt action is taken with diagnosis and treatment. They look at me as a whole person and my quality of life. For example, they have a psychologist who specialises in IBD patients attached to the team who has been invaluable in helping with my anxiety."

"I was on a waiting list for procedure and ended up with a bowel obstruction so had to have emergency surgery."

"I had to go through multiple medications before finding one that is apparently working. This resulted in a huge amount of lost time while my intestines became more and more damaged."

"I really needed more support with my recovery, and I wish I had been warned about the things I experienced. I still suffer from anxiety and trauma symptoms."

"I had emergency surgery at a hospital, which wasn't my local one and the information about my surgery wasn't passed on."

CHAPTER 1: METHOD AND DATA RETURNS

Study Advisory Group

The Study Advisory Group (SAG) comprised healthcare professionals in colorectal surgery, gastroenterology, emergency medicine, acute medicine, anaesthesia, intensive care medicine, clinical psychology, radiology, dietetics, pharmacy and specialist inflammatory bowel disease (IBD) nurses, lay and patient representatives. This group steered the study from design to completion and commented on the report and recommendations.

Aim

To identify remediable factors in the quality of care provided to patients aged 16 and over with a diagnosis of Crohn's disease who underwent an abdominal surgical procedure.

Objectives

The SAG identified the following areas to assess:

- The quality of care provided throughout the pathway from admission to discharge
- The emergency surgical care pathway
- Delays to surgery, risk stratification, management of complications and nutrition
- Organisational aspects of care including staffing, policies and use of guidelines
- The information, education and support provided to patients
- The effect of COVID-19 on the Crohn's disease service

Study population and case ascertainment

Inclusion criteria

Patients aged 16 years and older, who had a diagnosis of Crohn's disease (ICD10 codes: K50-50.9) and an elective or emergency admission to hospital for a stay of 48 hours or longer during which time they underwent intestinal surgery (OPCS codes: G58-83 or H01-H6).

Sampling period

1st September 2019 to 29th February 2020 inclusive (prior to the COVID-19 pandemic, as cases were rising) and 1st September 2020 to 28th February 2021 inclusive (including the peak of the COVID-19 admissions).

Exclusion criteria

Patients who did not have Crohn's disease or whose surgery did not relate to their Crohn's disease.

Sampling

A maximum of six patients were selected from each hospital. Where possible patients were selected equally between elective and emergency admissions and between the two timeframes.

Hospital participation

NHS hospitals in England, Wales, and Northern Ireland were invited to provide data for the study.

Data collection: peer review

Identification of a sample population

A pre-set spreadsheet was provided to every local reporter to identify all patients meeting the study criteria during the defined timeframe. From this initial cohort, the sampling for inclusion in the study took place.

Questionnaires

Two questionnaires were used to collect data for this study:

Clinician questionnaire

This questionnaire was sent electronically to the named consultant surgeon who was responsible for the patient's care at the time of the hospital admission.

Organisational questionnaire

This questionnaire was sent electronically to the local reporter to pass on to relevant people who could provide information on the guidelines, facilities and provision of services for patients with Crohn's disease within each hospital.

Case notes

Copies of case note extracts were requested from the secondary care provider for each patient in the study sample, including:

- Clinic letters, previous admission discharge summaries and correspondence to and from the patient relating to the three-year period prior to the index admission
- Referral letters and other correspondence from primary care for the index admission
- Outpatient clinic notes, including IBD nursing correspondence
- Pre-assessment clinic notes
- Clinical notes for the duration of the admission
- Operation notes/anaesthetic records/consent forms
- Nursing and allied health professional notes including any annotations from the stoma nurse
- Radiology, biochemistry and haematology reports
- Food, fluid balance, weight, observation, drug and Malnutrition Universal Screening Tool (MUST) charts
- Discharge summary
- Follow-up appointments and notes on any readmissions for 6-months following discharge

Peer review of the case notes and questionnaire data

A multidisciplinary group of case reviewers was recruited to peer review the case notes, comprising consultants (or equivalent) in colorectal surgery, gastroenterology, anaesthetics, radiology, dietetics, and inflammatory bowel disease nursing.

All patient identifiers were removed by the non-clinical staff at NCEPOD before the case notes or questionnaires were presented to the group. Using a semi-structured electronic questionnaire, each set of case notes was reviewed by at least one reviewer within a multidisciplinary meeting. At regular intervals discussion took place, allowing each reviewer to summarise their cases and ask for opinions from other specialties or raise aspects of the case for further discussion.

Data collection: patient online survey

An open-access, anonymous survey was circulated online to allow patients who had undergone surgery for Crohn's disease, to provide their views on the care they had received. This survey was designed with the help of the SAG and a patient focus group. A survey link was sent to a wide group of stakeholders to disseminate via local patient participation groups, nationally via Crohn's and Colitis UK and to promote using social media.

Information governance

All data received and handled by NCEPOD comply with all relevant national requirements, including the General Data Protection Regulation 2016 (Z5442652), Section 251 of the NHS Act 2006 (PIAG 4-08(b)/2003, App No 007), PBPP (1718-0328) and the Code of Practice on Confidential Information. Each patient included was given a unique NCEPOD number. All electronic questionnaires were submitted through a dedicated online application.

Data analysis

Following cleaning of the quantitative data, descriptive data summaries were produced.
Qualitative data collected from the reviewers' opinions and free text answers in the clinician questionnaires were themed, where possible to allow additional quantitative analysis.

As the general method adopted in this study provides a snapshot of care over a set point in time, with data collected from several sources to build a picture of care across the UK, denominators in the report will change depending on the data source. This deep dive uses a qualitative method of peer review from which anonymised case studies have been created and used throughout the report to illustrate themes. The sampling method of this enquiry, unlike an audit, means that data cannot be displayed at a hospital/trust/health board/regional level.

Data analysis rules

- Initial analysis revealed little difference between the two groups of patients that had been sampled in the two time periods, so for the purpose of the report they have been treated as one sample
- Small numbers have been suppressed if they risked identifying an individual
- Any percentage under 1% has been presented in the report as <1%
- Percentages were not calculated if the denominator was less than 100 so as not to inflate the findings
- There is variation in the denominator for different data sources and for each individual question as it is based on the number of answers given

The findings of the report were reviewed prior to publication by the SAG, case reviewers and the NCEPOD Steering Group which included clinical co-ordinators, trustees, and lay representatives.

Data returns

Clinical data

Figure 1.1 shows the number of patients included in the study and the data returns.

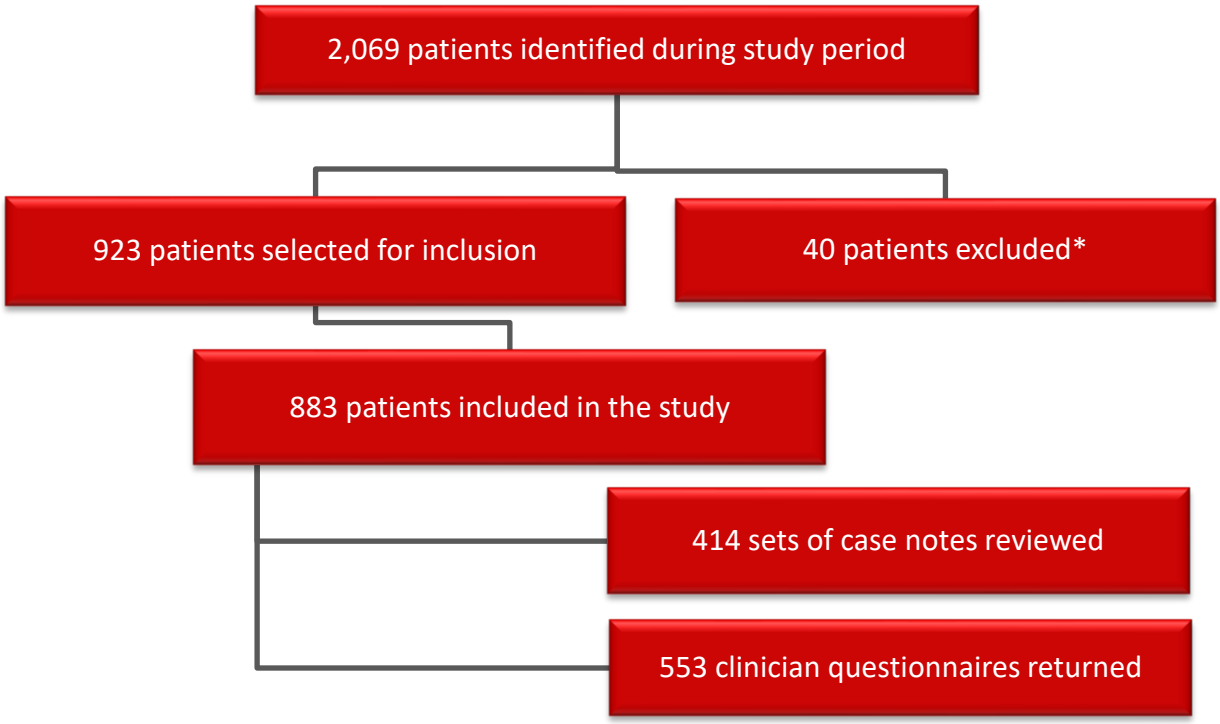


Figure 1.1 Data returned

**Patients who did not meet the study inclusion criteria*

Organisational data

A total of 138/210 (65.7%) hospitals returned an organisational questionnaire.

Patient survey data

A total of 316 patient surveys were completed.

CHAPTER 2: STUDY POPULATION

Figure 2.1 shows that the patients in this study were relatively young, reflecting the occurrence of Crohn's disease diagnosis in the general population.[2] In total, 314/553 (56.8%) patients were younger than 40 years of age. Men were slightly younger than women in this study with median ages of 35 and 40 years respectively.

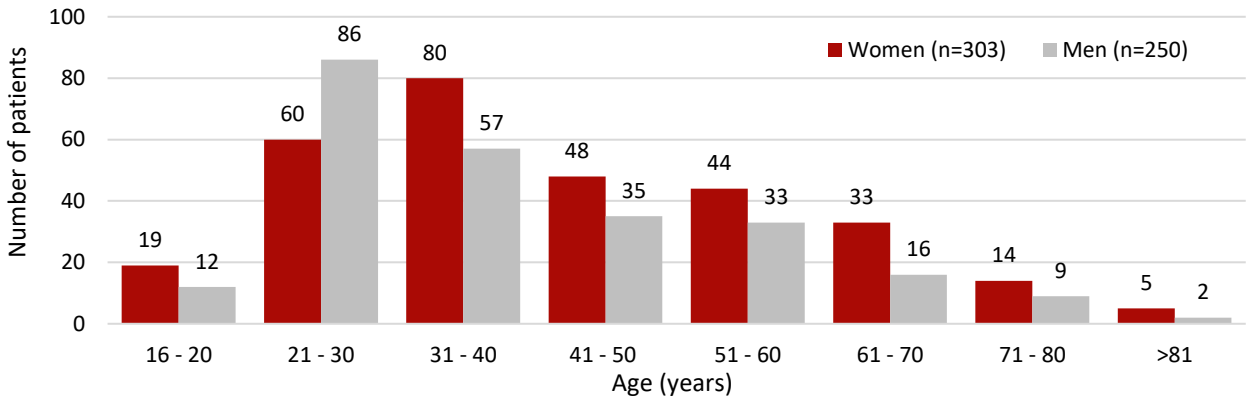


Figure 2.1 Age and sex of the study population
Clinician questionnaire data

Body mass index (BMI) was available for 317/553 (57.3%) patients and of these, 147/317 (46.4%) had a BMI in the healthy weight range and 36/317 (11.4%) were underweight, which is of note as a low BMI increases the risk of complications in Crohn's disease surgery including intra-abdominal sepsis.[12] (Figure 2.2). Those who were not underweight, including the 48/317 (15.1%) who were obese/severely obese, may still have been at an increased risk of peri-operative complications due to micronutrient deficiencies and loss of muscle mass.[13]

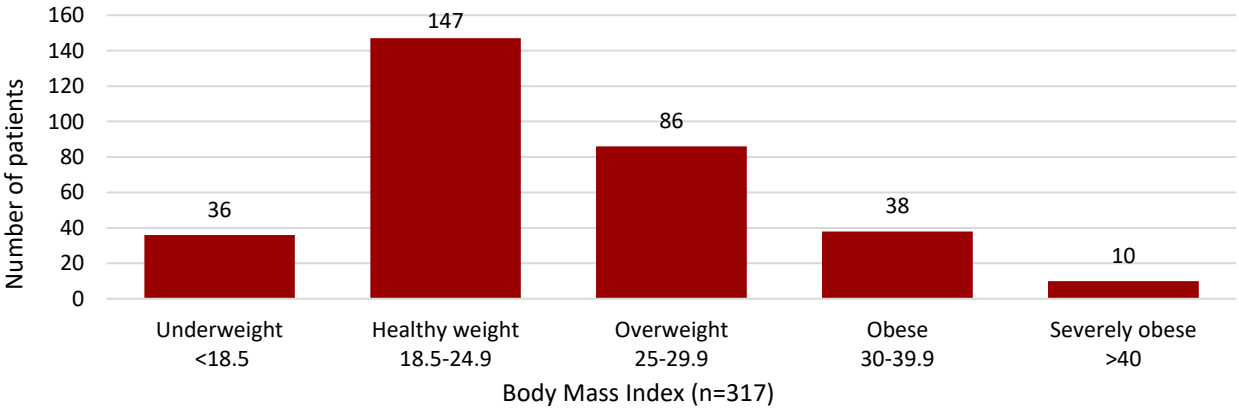


Figure 2.2 Body mass index of the study population
Clinician questionnaire data

In total, 203/553 (36.7%) patients had one or more significant comorbidities. The most common comorbid conditions were respiratory conditions (44/553; 8.0%), cardiovascular disease (37/553; 6.7%) and high blood pressure (27/553; 4.9%). While approximately a third of patients with Crohn's disease tend to have anaemia,[14] it was noted that anaemia was identified on admission in just 9/553 (1.6%) patients in this study. Patients over the age of 50 (122/397; 30.7%) were twice as likely to have a comorbidity than those under 50 years of age (104/156; 66.7%) (Figure 2.3).

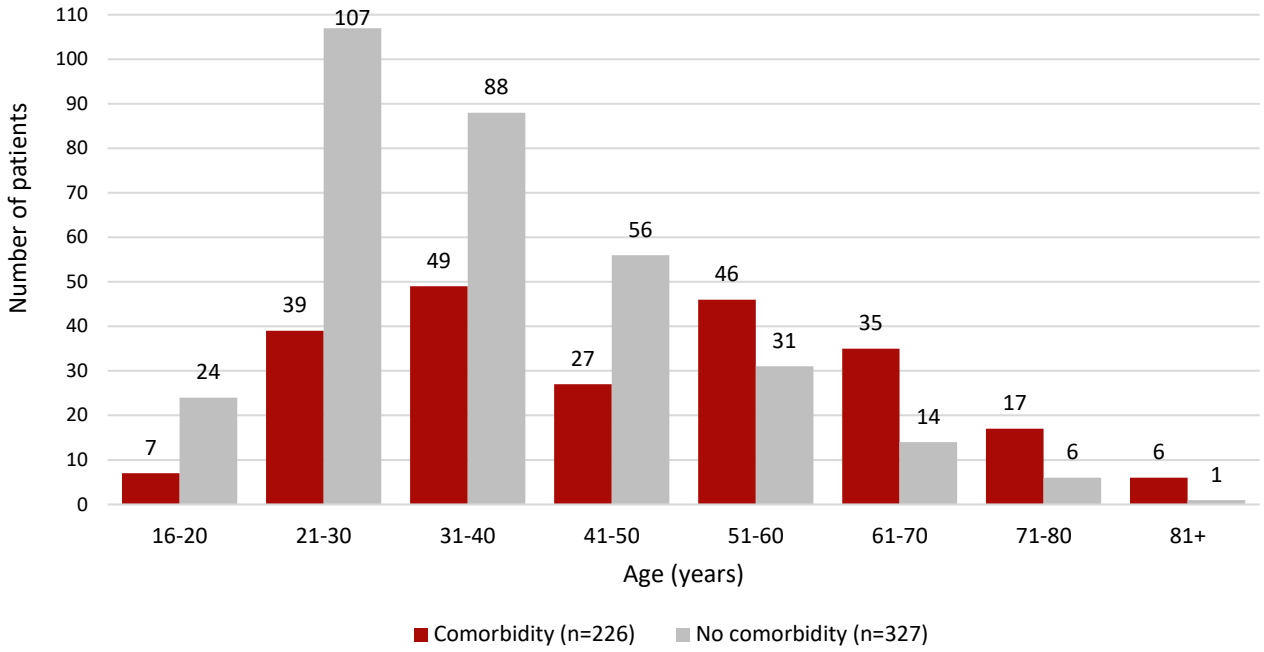


Figure 2.3 Comorbidities of the study population by age; n=550
Clinician questionnaire data

In total, 475/553 (85.9%) patients had been living with a diagnosis of Crohn's disease for one year or more prior to their surgery and 306/553 (55.3%) for more than five years (Table 2.1). Gastroenterologists or inflammatory bowel disease (IBD) teams had cared for 477/500 (95.4%) patients from the time of their Crohn's disease diagnosis (unknown for 53). There were 38/553 (6.9%) patients in the study who had surgery for newly diagnosed Crohn's disease and 30/38 presented as an emergency.

Table 2.1 Timing of initial diagnosis of Crohn's disease

	Number of patients	%
< 1 year	78	14.1
≥ 1 to 2 years	62	11.2
≥ 2 to 5 years	107	19.3
≥ 5 to 10 years	123	22.2
≥ 10 to 20 years	132	23.9
>20 years	51	9.2
Total	**553**	

Clinician questionnaire data

The relapsing nature of Crohn's disease, with its major health impacts, was seen in the majority of patients in the study (405/553; 73.2%). Only 27/405 (6.7%) patients had not attended hospital for anything other than just routine outpatient appointments for their Crohn's disease in the previous five years (Table 2.2).

Table 2.2 Admissions for Crohn's disease in the previous 5 years

	Number of patients	%
Emergency department attendances	208	51.4
Hospitalisations	268	66.2
Surgical procedures	166	41.0
One or more of the above but more than five years previously	27	6.7

Answers may be multiple; n=405
Clinician questionnaire data

Figure 2.4 shows that the sites affected by Crohn's disease (Montreal classification[15]) at the time of the surgical admission were comparable with the sites involved in the Crohn's disease population as a whole, with the exception of peri-anal disease which was under-represented due to the study methodology focusing on intestinal surgery. There were 133/553 (24.1%) patients who had two or more sites affected.

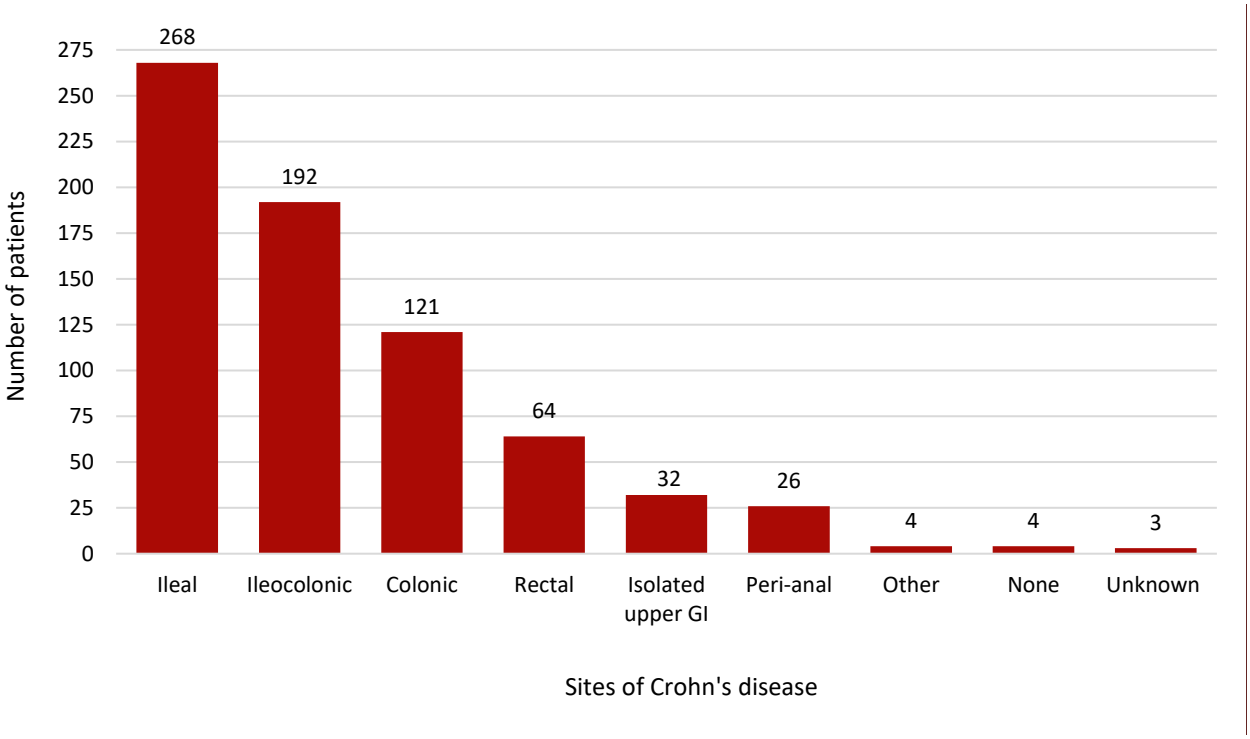


Figure 2.4 Site of Crohn's disease (Montreal classification)
Answers may be multiple; n=553
Clinician questionnaire data

Table 2.3 shows the type of Crohn's disease present in the cohort, as expected, due to the nature of the sampling, stricturing and penetrating disease dominated, with both present in 77/553 (13.9%) patients.

Table 2.3 Type of Crohn's disease

	Number of patients	%
Stricturing	336	60.8
Penetrating	197	35.6
Non-stricturing/non-penetrating	85	15.4
Other	66	11.9

Answers may be multiple; n=553
Clinician questionnaire data

Table 2.4 shows that only 65/382 (17.0%) patients had a documented severity score (Harvey-Bradshaw index (HBI) or Crohn's Disease Activity Index (CDAI)).[16,17] The CDAI is cumbersome to calculate, requires patient diary data and is not usable in patients with stomas.[9] The HBI is easier to measure but is heavily weighted towards diarrhoea, which may be caused by other factors. Given the low use of scores, it is possible to assume that they are primarily used as research, rather than clinical tools, as the scores were not calculated or not recorded. However, it was recognised, during a discussion between case reviewers and the Study Advisory Group, that in some services the severity scores are a prerequisite for the use of biologics and immunosuppressants, and therefore may have been recorded elsewhere, e.g. pharmacy records.

Table 2.4 Use of Crohn's disease activity score

	Number of patients	%
Yes - Crohn's Disease Activity Index	39	10.2
Yes - Harvey-Bradshaw index	26	6.8
No	317	83.0
Subtotal	**382**	
Unknown	171	
Total	**553**	

Clinician questionnaire data

The majority of patients in the study had moderate or severe Crohn's disease (445/553; 80.3%) (Figure 2.5). There were 108/553 (19.3%) patients with mild disease or who were in clinical remission, of whom 32/108 (29.6%) had surgery to reverse or re-fashion a stoma. The other operations in those in remission or with mild disease consisted of large bowel resections (41) or small bowel resections (34).

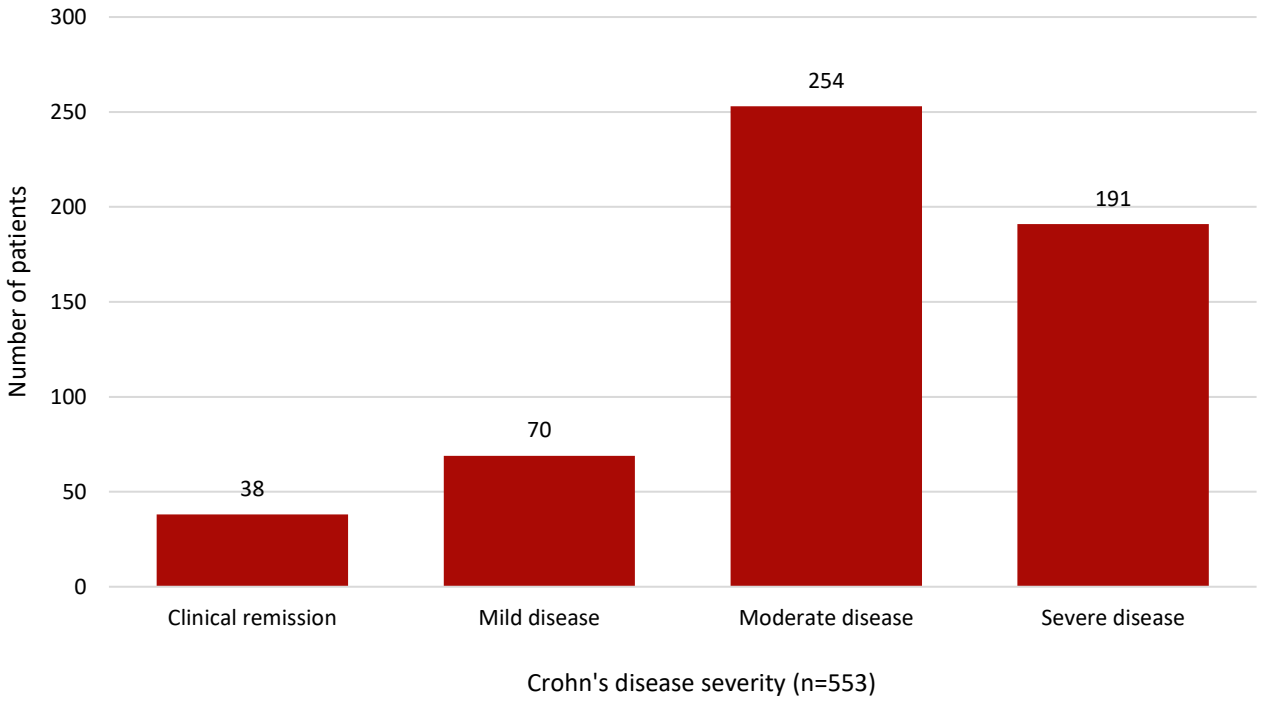


Figure 2.5 Severity of the Crohn's disease on admission

Clinician questionnaire data

CHAPTER 3: MEDICATION MANAGEMENT

Medication for Crohn's disease was being taken by 372/544 (68.4%) patients at the time of their surgical admission (Table 3.1). Similar proportions of patients admitted for elective and emergency care were taking Crohn's disease medication. There were 65/108 (60.1%) patients with mild disease or in remission taking mediation and 307/445 (68.9%) patients with moderate or severe disease (unknown for nine). In total, 281/372 (75.8%) patients were taking medication to induce a remission from the disease and for 82/372 (22.0%) patients the medication was to maintain a remission.

Table 3.1 Medications being taken for Crohn's disease on admission in elective and emergency patients

	Elective		Emergency		Total	
	Number of patients	%	Number of patients	%	Number of patients	%
Yes	242	69.5	130	66.3	372	68.4
No	106	30.5	66	33.7	172	31.6
Subtotal	**348**		**196**		**544**	
Unknown	7		2		9	
Total	**355**		**198**		**553**	

Clinician questionnaire data

Types of medication

Table 3.2 shows the type of medications patients were receiving. In addition, the reviewers identified 253/414 (61.1%) patients taking medications for their Crohn's disease, and of these, complications or side effects of the medication were recorded in 38/253 (15.0%).

Table 3.2 Type of Crohn's disease medication being taken

	Number of patients	%
Biologics/biosimilars	221	59.4
Azathioprine or mercaptopurine	186	50.0
Steroids	107	28.8
Mesalazine (5-aminosalicylic acid)	33	8.9
Other immunomodulators	8	2.2
Methotrexate	4	1.1
Antibiotics	4	1.1
Other	4	1.1

Answers may be multiple; n=372

Clinician questionnaire data

Biological therapies

Biologics are often used in moderate to severe Crohn's disease, when other drugs, such as steroids, drugs containing 5-aminosalicylic acid or immunomodulators (e.g. azathioprine and mercaptopurine) have been ineffective. Biologics may also be used when these other drugs have caused side effects which are hard to manage, or, in patients with an aggressive disease course or features suggestive of a poor prognosis, they can be considered earlier. The frequency of the use of biologics in this study population reflected the severity of Crohn's disease in patients who required surgery,[6,9] with 221/372 (59.4%) patients receiving biological therapies (monoclonal antibodies) or biosimilars (near identical copies of already approved biologic therapies). It was of note that 33/372 (8.9%) patients in the study were receiving Mesalazine (5-aminosalicylic acid) at the time of their admission for surgery despite evidence that is not recommended for the induction of remission or maintenance treatment in Crohn's disease,[9,18] (Table 3.2).

Steroids

Systemic steroids are effective at inducing a Crohn's disease remission, despite their well-recognised side effects, including increased mortality.[9] However, they do not have a role in maintaining a remission due to their toxicity and lack of efficacy,[6,9] yet steroid excess in patients with inflammatory bowel disease has been reported elsewhere.[19] The BSG guidelines recommend that to reduce the risk of postoperative infectious complications and anastomotic leaks, patients undergoing elective surgery should have their steroids stopped, or where this is not possible, have the lowest dose which does not result in a Crohn's disease deterioration.[9]

In this study, 107/553 (19.3%) of all patients and 107/372 (28.8%) of those on other Crohn's disease medications were taking steroids at the time of their admission for surgery, as reported by the clinicians completing the questionnaires. Steroids were almost exclusively prescribed for moderate (45/107; 42.1%) and severe disease (54/107; 50.5%).

Crohn's disease is a cause of secondary osteoporosis and steroid treatment is strongly associated with bone loss and increased risk of fractures (see appendix). A NICE treatment summary recommends starting bone-protection treatment on the initiation of steroid treatment in those at high-risk of a fracture.[20] Of note was the fact that reviewers identified 139/414 (33.6%) patients who were taking steroids at the time of surgery, slightly higher than that reported by the clinicians. Of these, 45/139 (32.4%) patients were receiving bone protection. A further 55/139 (39.6%) patients were taking gastric protection, although it should be noted that proton pump inhibitors (PPI) may also be used for gastro-oesophageal reflux (Table 3.3).

Table 3.3 Prophylactic management for patients taking steroids

	Number of patients	%
Gastric protection, including proton pump inhibitors	55	39.6
Bone protection	45	32.4
Blood pressure monitoring	6	4.3
None of these	5	3.6
Unknown	61	43.9

Answers may be multiple; n=139

Reviewer assessment form data

There were 92/129 (71.3%) hospitals that had a policy, protocol or guideline for the management of biologics and immunomodulators pre-operatively (unknown for nine). However, only 15/92 of those with such a guideline audited compliance with it. Likewise, a local guideline for steroid use in the management of

Crohn's disease was not available in 67/129 (51.9%) hospitals. Where there was a guideline (62/129; 48.1%), compliance with this was audited in only 21/62 hospitals.

CASE STUDY 1

A middle-aged patient with a terminal ileal Crohn's disease stricture had been taking steroids for six months with no improvement. The patient had previously had a hip fracture. Although the BMI was within normal range, the patient's serum albumin was 21. They were still taking steroids at the time of the elective surgery and required intravenous hydrocortisone.

The reviewers considered that this non-steroid responsive disease should have been recognised much earlier, that the patient should have been weaned from steroids preoperatively, and received dietetics support and bone-protection prophylaxis.

Pain

The reviewers identified 284/414 (68.6%) patients who were taking medication of any type, and 78/284 (27.5%) patients who were taking medication for pain, most commonly opiates (46/78; 59.0%). Opiate use is often recognised as a surrogate marker of Crohn's disease severity. For the 262 patients who reviewers had rated as having moderate or severe disease, 138/262 (52.7%) were not taking medication for pain at admission to hospital.

The reviewers stated that there was room for improvement in the management of medication for 45/222 (20.3%) patients, where it could be assessed. Most commonly this was around the use of prophylaxis (15), a delay in starting/reviewing medication (10) and nine patients who were considered to be on the wrong medication.

Drug resistant Crohn's disease

It is important to recognise that a sub-population of patients with Crohn's disease, including those with fixed strictures, will never respond to medical management alone and will require surgery. The need for surgery in this group of patients should not been seen as a 'failure of medical management.' This is a negative term and a concept that has been reinforced by some national guidance.[6] A better concept would be 'drug resistant disease.' This group of patients should be identified as early as possible, as persisting with ineffective drugs will both increase the risks of side-effects and contribute to pre-operative deconditioning. Effective medication review, greater use of self-directed care and integration between medical and surgical teams allowing earlier consideration of, and preparation for, surgery, would facilitate this.

CASE STUDY 2

A young patient with ileo-caecal Crohn's disease required admission and was treated with high dose steroids for 10 weeks. The patient missed one steroid dose and was readmitted with an Addisonian crisis due to steroid-induced adrenal suppression. Steroids were then weaned, and the patient had a resection of an ileal stricture five months later with a primary anastomosis.

In the opinion of the reviewers the patient had non-steroid responsive disease and this should have been recognised much sooner, with earlier surgery.

CHAPTER 4: ELECTIVE SURGERY

The aim of surgery for Crohn's disease is to relieve symptoms caused by it, rather than to cure it. Usually this entails removal of a length of bowel with the disease, although occasionally more conservative operations such as strictureplasty may be required. In the study sample, there were 364/553 (65.8%) patients who had an elective procedure as recorded in the clinician questionnaires and 278/414 (67.1%) identified by the reviewers.

The pathway for surgical treatment is represented in Figure 4.1. The team caring for the patient with Crohn's disease should discuss therapeutic options and consider referral for surgery as soon as it is clear that medication alone is not adequately controlling symptoms. Based on NHS standards for waiting times for all elective surgical practice, the Inflammatory Bowel Disease (IBD) UK standards recommend that no more than 18 weeks should elapse between referral for consideration of surgery and an operation taking place.[11]

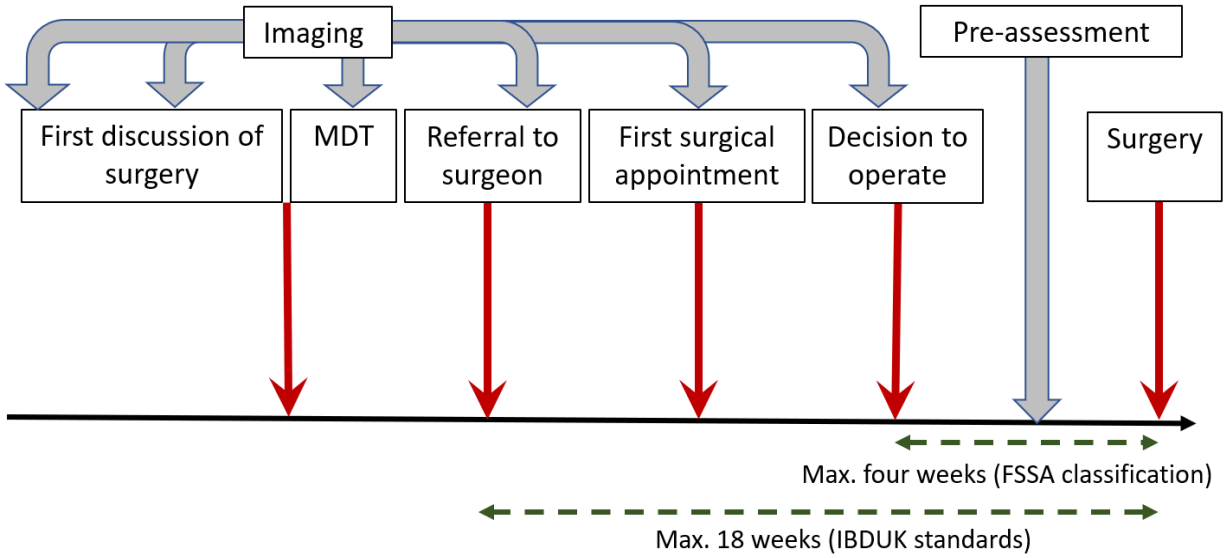


Figure 4.1 The elective surgical pathway

Decision for surgery

The timing of the initial discussion to consider undertaking surgery is shown in Table 4.1. Reviewers reported that referral for a colorectal surgical opinion should have occurred earlier in 41/218 (18.8%) patients.

Table 4.1 Timing of the initial discussion to consider surgery

	Number of patients	%
Occurred at the right time in the process	172	78.9
Would have benefited the patient if it had happened at an earlier stage	41	18.8
Occurred too early in the process	5	2.3
Subtotal	**218**	
Insufficient data	60	
Total	**278**	

Reviewer assessment form data

Delays in referral and in the time taken to carry out surgical treatment are often multifactorial. The patient might prefer to continue with medical treatment; alternatively, the physician might decide to continue with drug treatment when surgery represents a legitimate alternative, as mentioned in Chapter 3. A referral for consideration of surgery does not automatically translate into an operation; ideally it should occur when surgery is an option allowing the surgical team to lay out the risks and benefits of this approach.

CASE STUDY 3

A young patient with a new presentation of localised terminal ileal disease had an episode of small bowel obstruction that settled with conservative management. Medical and surgical options were discussed by both teams in a joint clinic. The patient had planned to spend the following year travelling and thus elected to undergo surgical treatment. Two weeks later they had a laparoscopic right hemicolectomy and were discharged after 48 hours without complications.

The reviewers felt that this represented good practice, with exemplary multidisciplinary team working and early decision-making resulting in a good outcome.

Multidisciplinary team input

People with a complex illness need the support of a multidisciplinary team (MDT) that is patient centred, dynamic and co-ordinated.[21] The IBDUK standards offer clear guidance on their expectations of MDT meetings regarding a patient with Crohn's disease.[11]

The standards call for all patients with a new diagnosis to be discussed by an MDT, as well as patients with complex needs or where a significant change in disease management is proposed. All patients referred for consideration of elective surgery should have that decision ratified by an MDT wherever possible. The results of the MDT meetings should be documented in the patient records and then communicated with the patient and their general practitioner (GP).

It was reported from 134/138 (97.1%) hospitals that regular MDT meetings took place to discuss patients with Crohn's disease. However, there was variation in the frequency of these meetings and in the patients who would be discussed (Tables 4.2 and 4.3).

Table 4.2 Frequency of MDT meetings to discuss the care of patients with Crohn's disease

	Number of hospitals	%
2 - 6 times a week	5	3.9
Weekly	66	51.2
Every 2 weeks	35	34.0
>2 - 4 weekly	22	17.1
Less frequently than 4 weekly	1	<1.0
Subtotal	**129**	
Unknown	5	
Total	**134**	

Organisational questionnaire data

Table 4.3 Patients who were discussed at MDT meetings

	Number of hospitals	%
All patients for whom surgery was being considered	128	95.5
All patients on certain medication	61	45.5
All patients with symptom flares	38	28.4
All inpatients after surgery	33	24.6
All newly diagnosed patients	17	12.7
All patients periodically	5	3.7

Answers may be multiple, n=134

Organisational questionnaire data

Evidence that a case note review had taken place could not be assessed for 93/278 (33.5%) patients as there were insufficient data. MDTs were identified in 55/185 (29.7%) sets of notes, and the case reviewers reported insufficient input by the MDT meeting into the decision for surgery in 33/150 (22.0%) patients. This might be explained by difficulties in capturing MDT output from electronic records systems. However, clinicians completing questionnaires, and who should have had access to all information, also reported that there was no MDT input in the decision for surgery for 74/326 (22.7%) patients. When they did occur, MDT meetings resulted in a change in the care plan for 105/242 (43.4%) patients, highlighting the crucial role that they play.

Comparison can be drawn with the MDT meetings that are integral in the care of cancer patients, with investment in co-ordinators and pathway managers. People in these roles ensure that all investigations are carried out within a specified interval and that patients' cases are discussed at the appropriate time. This is in stark contrast to the IBD MDT model. In this study, it was reported from 37/138 (26.8%) hospitals that there was no named co-ordinator to prepare and circulate agendas and minutes. For 67/138 (48.6%) hospitals it was reported that the results of the MDT were sent directly to the patient and for only nine hospitals it was reported that MDT decisions were routinely communicated to the patient's GP (Table 4.4).

Table 4.4 Documentation of MDT meeting notes (including the decisions made)

	Number of hospitals	%
Recorded in the electronic patient record	107	79.9
Made available to all core members of the MDT	85	63.4
Communicated to the patient	67	50.0
Recorded in the patient's paper medical record	29	21.6
Communicated to the patient's GP	9	6.7
Recorded separately by the consultant	3	2.2
Uploaded to a database	2	1.5

Answers may be multiple; n=138

Organisational questionnaire data

Surgical referral and delays

Timing of referral for surgery is critically important as all patients referred for surgery live with significant symptoms such as pain, intestinal blockages, weight loss or infective complications while they wait to complete the referral and treatment pathway. The unpredictability of Crohn's disease also means that delays in treatment can result in further complications.

Reviewers found that the time between the referral being made, and the first appointment was 'reasonable' for the majority of patients in the study (182/240; 75.8%). The median interval between referral for a surgical opinion and first appointment with the specialty was 30 days.

There is no specific timeline that has been adopted within the NHS for the surgical referral and the treatment of a patient already having their Crohn's disease managed medically. The IBDUK standards have adopted the government guideline for the management of elective non-cancer treatment. This states that '*Elective surgery for IBD should be performed as soon as the patient's clinical status has been optimised and within 18 weeks of referral for surgery.*'[11] Only 18/138 (13.0%) hospitals reported local targets in place for the scheduling of Crohn's disease surgery.

The median time from referral to surgery for patients in this study was 102 days (Figure 4.2) and was not impacted by the two sample periods. A total of 128/301 (42.5%) patients waited more than 18 weeks (126 days) before their operation was carried out (unknown for 63).

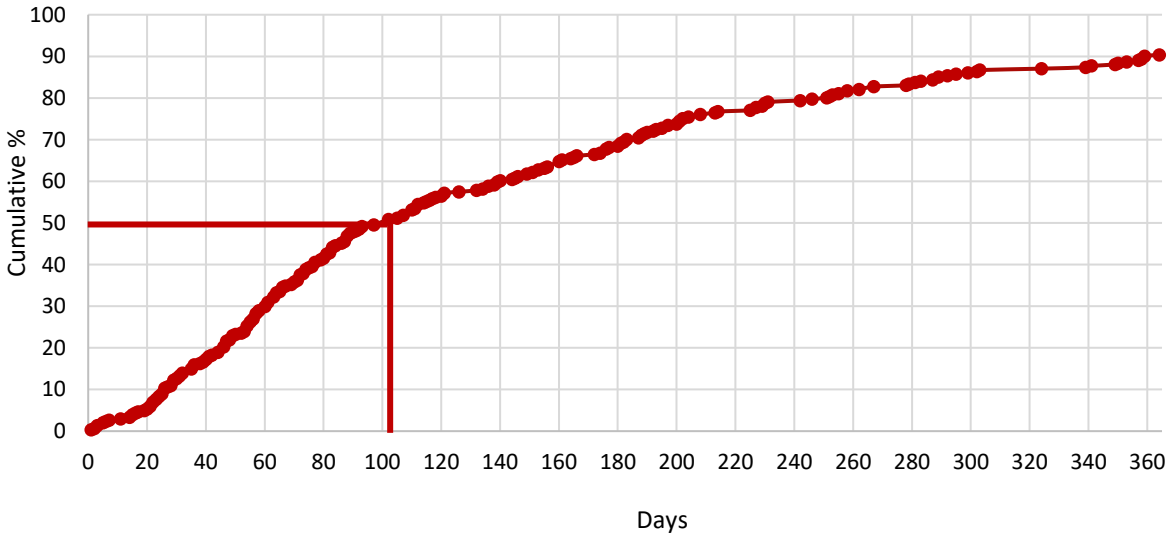


Figure 4.2 Time from referral for surgery to surgical procedure for 301 patients

Clinician questionnaire data

The Federation of Surgical Specialty Associations (FSSA) has developed an operative urgency classification that includes Crohn's disease surgery in the most urgent group of elective procedures. It recommends that an operation should be carried out within one month from the decision to operate.[22] Only 83/311 (26.7%) patients in this study would have met this standard (unknown for 53; Figure 4.3).

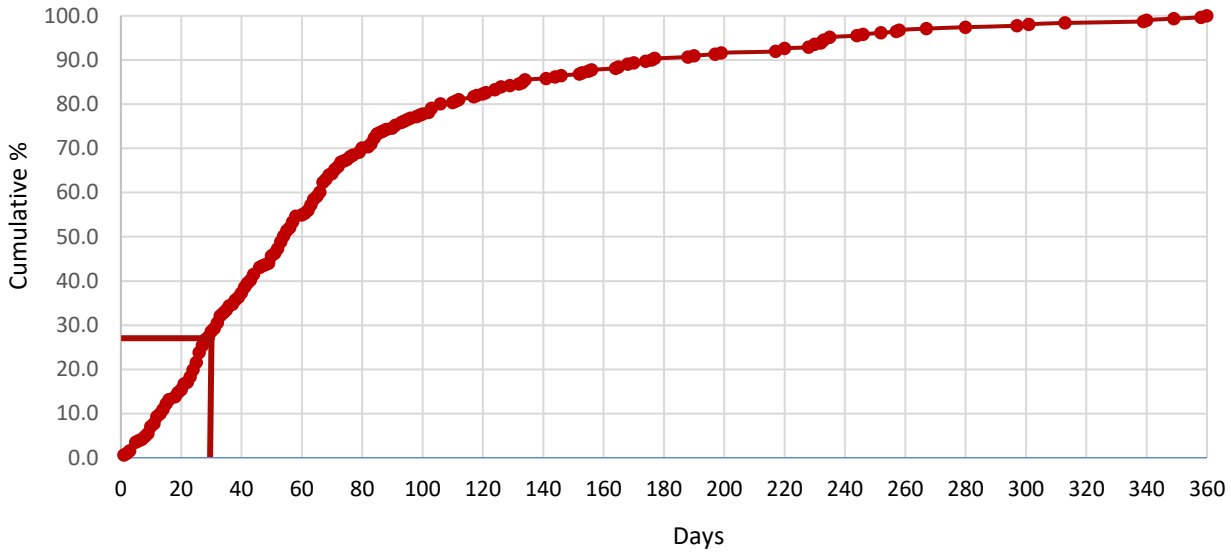


Figure 4.3 Time between decision to operate and surgical procedure for 311 patients
Clinician questionnaire data

A total of 30/311 (9.6%) patients waited more than six months for surgery. As a consequence of such a long wait, the imaging upon which the decision to operate was based could be out of date by the time the operation is performed. Repeat, up-to-date imaging may then be required to avoid unexpected findings at surgery. Reviewers stated that the extent of disease should have been reassessed prior to surgery for 19/207 (9.2%) patients where data were available.

There are many guidelines that should be driving the delivery of surgical care for patients with Crohn's disease,[6-11] yet the data in this report shows that delays can occur at all points in the pathway, and the case reviewers identified a total of 56/278 (20.1%) patients who encountered more than one delay in the elective surgery pathway. Notably, delays occurred:

- In referral to surgery for 34/193 (17.6%) patients (unknown for 85), with 14/34 patients having their outcomes adversely affected due to complications and the need for stoma formation.
- In the decision to operate, which should have happened earlier in the process for 43/214 (20.1%) patients (unknown for 64)
- Between the decision to operate and the date of the operation for 58/240 (24.2%) patients (unknown for 38)

Organisational data showed that only 54/138 (39.1%) hospitals from which a response was received, had a local policy or protocol to guide the decision-making about medical or surgical treatment for Crohn's disease and 61/138 (44.2%) hospitals did not have a policy stating the maximum timeframe that should occur between planning surgery and the operation taking place for patients with severe disease.

Surgical clinic appointment, consent and risk stratification

The majority of surgical clinic appointments were carried out in person, even during the COVID-19 pandemic sampling period (188/210; 89.5%) (Table 4.5).

Table 4.5 Mode of surgical appointment

	Number of patients	%
In person	188	89.5
Over the telephone	17	8.1
Video-call	5	2.4
Subtotal	**210**	
Unknown	68	
Total	**278**	

Reviewer assessment form data

The patient survey supported the finding that good information about surgery was given at their initial clinic appointment, although 34/316 (10.8%) said that they had not received sufficient information (Table 4.6).

Table 4.6 Clear and concise information about the operation risks and benefits was provided

	Number of responses	%
Strongly agree - I received clear and concise information	140	45.3
Agree	94	30.4
Neither agree nor disagree	41	13.3
Disagree	21	6.8
Strongly disagree - I did not receive clear and concise information	13	4.2
Subtotal	**309**	
Unsure	7	
Total	**316**	

Patient survey data

Consent

Consent for surgery of this nature is a dynamic process that evolves over time. The ideal time to take patient consent is at the point that a decision is made to proceed to surgical treatment. The decision to operate should only be made after full exploration of alternative treatment options as well as the potential risks and benefits of the surgery itself. Reviewer data showed that 112/227 (49.3%) patients had consent documented at the time that the decision to operate was agreed with them (unknown for 51). Despite this, the reviewers stated that the timing of consent was appropriate for only 139/205 (67.8%) patients. For 66/205 (32.2%) patients consent for surgery was not taken at the right time (unknown for 73).

Issues with consent were also seen in clinician questionnaire data, where 91/311 (29.3%) elective patients gave their consent on the day of surgery, which is not an appropriate time point to take fully informed consent, and does not comply with the standards required by the GMC and the Royal College of Surgeons of England.[23,24] Furthermore, important complications were often not documented on the consent form; the risk of death was only mentioned on 162/364 (44.5%) consent forms and the risk of mortality was only quantified using a percentage for 66/294 (22.4%) patients. Even though death is a rare consequence of surgery for Crohn's disease, the risk is measurable, and it should be discussed and recorded (Table 4.7).

Table 4.7 Surgical risks documented

	Number of patients	%
Wound infection	298	81.9
Deep vein thrombosis	281	77.2
Pulmonary embolism	280	76.9
Stoma	264	72.5
Anastomotic leak	264	72.5
Incisional hernia	174	47.8
Death	162	44.5
Obstruction	107	29.4
Bleeding	28	7.7
Effect on other organs	26	7.1
Risk of impotence (where applicable)	23	6.3
Risk to fertility (where applicable)	17	4.7
Re-operation	13	3.6
Recurrent disease	11	3.0
Pain	9	2.5
Ileus	8	2.2
Fistula	6	1.6
Anaesthetic complications	6	1.6
Myocardial infarction	5	1.4
No complications listed	3	<1.0
Other	11	3.0

Answers may be multiple; n=364
Clinician questionnaire data

Where the risks were quantified, recognised risk stratification tools were used for 163/364 (44.8%). Most used was the ASA score (118/163; 72.4%), which is primarily used by anaesthetists long after consent has been taken. The NELA tool was used for 36/163 (22.1%) patients, but it was used inappropriately for elective procedures since it has been developed for use in the emergency context. Risk estimation based on the NSQIP (6/163; 3.7%) or APACHE (2/163; 1.2%) scores are most effective; they should also be used to inform decisions about the need for high dependency postoperative care (Table 4.8).

Table 4.8 Elective surgery risk stratification tool used

	Number of patients	%
American Society of Anaesthesiologists (ASA)	118	72.4
National Emergency Laparotomy Audit (NELA)	36	22.1
Surgical Outcome Risk Tool (SORT)	15	9.2
Portsmouth-Physiological and Operative Severity Score for the enUmeration of Mortality and morbidity (P-POSSUM)	13	8.0
National Surgical Quality Improvement Program (NSQIP)	6	3.7
Cardiopulmonary Exercise Test (CPET)	5	3.1
Acute Physiology and Chronic Health Evaluation (APACHE) II	2	1.2

Answers may be multiple; n=163
Clinician questionnaire data

The information provided to patients seems to be more focused and relevant to the medical profession as it covers the risks and benefits and technical information regarding the procedure itself. More patient-focused information, e.g. how to access psychological support was only offered to 90/364 (24.7%) patients, 60/364 (16.5%) patients were given information regarding peer support groups and IBD nurse support was offered to only 5/364 (1.4%) patients (Table 4.9).

Table 4.9 Information given to the patient prior to surgery

	Number of patients	%
Risks of surgery	339	93.1
Information about the procedure	337	92.6
Benefits of surgery	334	91.8
Benefits/ risks of alternative treatments	285	78.3
Details of an advice line	113	31.0
How to access psychological support/counselling	90	24.7
Details of peer support groups	60	16.5
Unknown	11	3.0
Stoma team support	8	2.2
Inflammatory bowel disease nurse support	5	1.4

Answers may be multiple; n=364
Clinician questionnaire data

Pre-optimisation, pre-assessment and holistic pre-operative care

The needs of patients with Crohn's disease are complex, requiring careful assessment and pre-operative management. Careful optimisation not only reduces the risks associated with the surgery, but also increases the surgical options, and may improve a patient's condition to a point where a stoma can be avoided. Most patients in the study attended pre-operative-assessment clinics (307/364; 84.3%) and, where it was answered, the majority were anaesthetist-led (213/273; 78.0%). Both the clinicians completing questionnaires and reviewers recorded the areas where efforts were made to improve the patient's functional status and reduce the risks of surgery (Table 4.10).

Table 4.10 Pre-optimisation efforts made to reduce the patient's risks associated with surgery

	Case reviewers		Clinicians	
	Number of patients	%	Number of patients	%
Intervention to improve nutritional status	67	67.7	68	56.2
Smoking cessation	32	32.3	35	28.9
Haemoglobin levels/treatment of anaemia	32	32.3	32	26.4
Exercise regimen/increased physical activity	13	13.1	55	45.5
Reduction in alcohol consumption	12	12.1	6	5.0
Other	10	10.1	3	2.5

Answers may be multiple; n=99 for case reviewer data and n=121 for clinician questionnaire data

Nutrition

Many patients with Crohn's disease have nutritional issues. Stricturing disease can impact severely on dietary intake and the ability to maintain weight. Significant weight loss is an established risk factor for poor outcomes from surgical treatment, and the risk of anastomotic leak is markedly increased in this group. Nutritional assessment is needed at the time of referral for surgery and at the first surgical assessment. In this study, only 121/311 (38.9%) patients had their nutritional status assessed pre-operatively (unknown for 53), and 91/121 (75.2%) were referred to a dietitian for nutritional support.

The ECCO-ESCP guidelines state '*Malnutrition is a significant risk factor for postoperative complications. Nutritional status should be optimised before surgery via enteral or parenteral routes. If surgery is required in a malnourished patient, a staged procedure is advised*.'[10] In addition, it is worth noting that pre-operative replacement of the patient's usual diet with, for example, exclusive enteral nutrition (replacement of the usual diet with a liquid diet) and downstream stoma/fistula feeding, as well as with total parenteral nutrition, are all growing in prominence in both clinical practice and research.[25]

In this study there were 52/278 (18.7%) patients, who the reviewers identified as having received supplementary nutrition. In 24/52 patients this was administered pre-operatively.

Smoking

Patients with Crohn's disease who smoke are less likely to respond to immunosuppressive therapy, more likely to develop fistulas, twice as likely to require surgery and 2.5 times more likely to need further surgery. Smoking cessation should therefore, always be part of a medication plan.[9,26]

In this study, smoking status was only routinely recorded in newly diagnosed patients in 35/138 (25.4%) hospitals. Evidence was found of efforts to encourage smoking cessation in 32/99 (32.3%) cases reviewed. The reviewers were of the opinion that smoking cessation alone would have changed the operative outcome for eight patients. Given how well established the effects of smoking are on patients with Crohn's disease, these figures highlight the need for clear patient education and peri-operative management.[27]

CASE STUDY 4

A young patient who was a current smoker presented with recurrent episodes of small bowel obstruction, having had a resection 10 years previously. Investigations showed recurrent terminal ileal disease with evidence of fibrotic stricturing. The patient was listed for an elective resection but did not receive an admission date for four months. During this period the patient lost 15% body mass and continued to smoke. In view of the severity of the symptoms the patient underwent surgery, during which the diseased segment of bowel was removed with formation of an end ileostomy. The postoperative recovery was complicated by a superficial wound infection.

Reviewers stated that the severe weight loss after an excessive wait for surgery, and the fact that the patient had not been supported to stop smoking, resulted in the need for a stoma and a complication that could have been avoided.

Medications optimisation

In 129/186 (69.4%) cases a peri-operative Crohn's disease medication plan review was carried out and 71/129 (55.0%) patients had subsequent changes made to their medications (Table 4.11).

Reviewers thought that there should have been a peri-operative review of the medication plan in 23/57 of those who did not have one. Overall, reviewers stated that medications were inadequately optimised in 18/205 (8.8%) elective patients (unknown for 73) and in 3/129 (2.3%) of those who had their medication plan reviewed.

Table 4.11 Peri-operative review of Crohn's disease medication plan

	Number of patients	%
Yes	129	69.4
No	57	30.6
Subtotal	**186**	
Insufficient data	92	
Total	**278**	

Reviewer assessment form data

Overall quality of elective surgical care

The reviewers reported room for improvement in the pre-operative preparation for 55/162 (34.0%) patients where there were sufficient data to assess, and that in 17/55 patients better optimisation could have improved the surgical outcome; in six cases it was felt that a stoma could have been prevented. Notably, the reviewers could not make an assessment for 116/278 (41.7%) cases reviewed due to insufficient data.

There was room for improvement in the holistic care that the patient received in 67/179 (37.4%) of the cases reviewed, where it could be assessed (Table 4.12).

Table 4.12 Areas of pre-operative support that require improvement

	Number of patients
Dietetics	38
Psychological support/counselling	35
Patient information/peer support	28
Inflammatory bowel disease nurse	24
Pain management	15
Other	2

Answers may be multiple; n=67

Reviewer assessment form data

Lack of psychological support for patients with Crohn's disease was a theme arising throughout the pathway of care and was also one of the themes identified by patients, describing how the service could be improved. The organisational questionnaire identified that only 20/138 (14.5%) hospitals employed clinical psychologists as part of the IBD MDT.

CHAPTER 5: EMERGENCY SURGERY

Emergency presentation marks a sudden and severe change in a patient's condition. This study explored the possibility that there might have been opportunities to intervene earlier and pre-empt the emergency admission by offering an elective operation. There were 198/553 (35.8%) patients who presented as an emergency and 157/195 (80.5%) patients had had a previous presentation for Crohn's disease (Table 5.1).

Table 5.1 First presentation of Crohn's disease

	Number of patients	%
Yes	38	19.5
No	157	80.5
Subtotal	**195**	
Unknown	3	
Total	**198**	

Clinician questionnaire data

The study showed that 123/198 (62.1%) patients presenting to the emergency service were known to the inflammatory bowel disease (IBD) team and had been in regular contact with the hospital service in the year prior to their attendance (Figure 5.1).

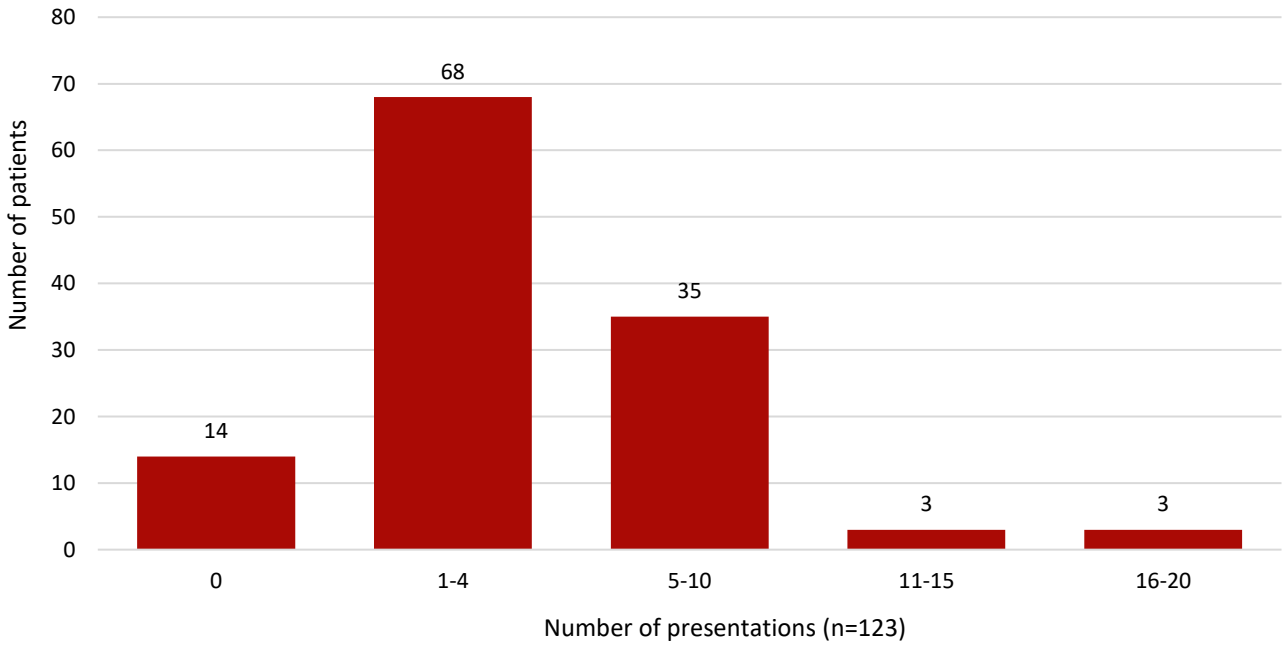


Figure 5.1 Presentations to gastroenterology/surgery clinic in the 12 months prior to admission
Clinician questionnaire data

A point of note was that 25/198 (12.6%) patients presenting as an emergency were already on a waiting list for an elective operation. Emergency abdominal surgery carries much higher risks than planned care with morbidity and mortality five to ten times greater. [28] Not delivering elective care for a patient who then becomes an emergency may result in a worse outcome for them.

The clinicians completing questionnaires (39/107; 36.4%) and reviewers (68/137; 49.6%) reported that patients presenting as an emergency should have had surgery considered/offered as an elective option (Table 5.2). The management of Crohn's disease in clinics and multidisciplinary (MDT) meetings could therefore be significantly improved.

Table 5.2 Surgery should have been considered earlier

	Clinicians		Case reviewers	
	Number of patients	%	Number of patients	%
Yes	39	36.4	68	49.6
No	68	63.6	69	50.4
Subtotal	**107**		**137**	
Unknown	60		20	
Total	**167**		**157**	

Clinician questionnaire and case reviewer data

CASE STUDY 5

A young patient presented with an acute exacerbation of terminal ileal Crohn's disease. The patient initially improved with steroid therapy but the symptoms rapidly recurred on withdrawal from steroids. Treatment with adalimumab proved similarly ineffective. CT scanning at this point showed gross thickening of the terminal ileum and ascending colon. The patient was placed on the waiting list for laparoscopic right hemicolectomy. Six weeks later the patient came to the emergency department with localised peritonitis. A CT scan showed a perforated terminal ileal mass with evidence of free air. The patient underwent an emergency laparotomy with formation of an end ileostomy, followed by post-operative critical care, and was discharged five weeks after their admission.

The reviewers stated that the emergency presentation and the protracted hospital stay could have been avoided by an expedited elective operation.

Most patients presented to their local emergency department (156/198; 78.8%). Only a tiny minority were transferred between units to be able to access care from specialist surgical and medical teams (8/198; 3.8%). There were 106/198 (53.5%) emergency patients who had imaging and 82/106 (77.4%) patients had a CT scan in the emergency department, although 21/106 (19.8%) also had a plain abdominal X-ray despite this investigation having little efficacy.[29]

Organisational data showed that 99/138 (71.7%) of hospitals had local treatment protocols and clear pathways in place for the management of IBD in patients experiencing flares in symptoms.

Admitting specialty

Most patients (188/198; 94.9%) were admitted under an expected specialty (Figure 5.2).

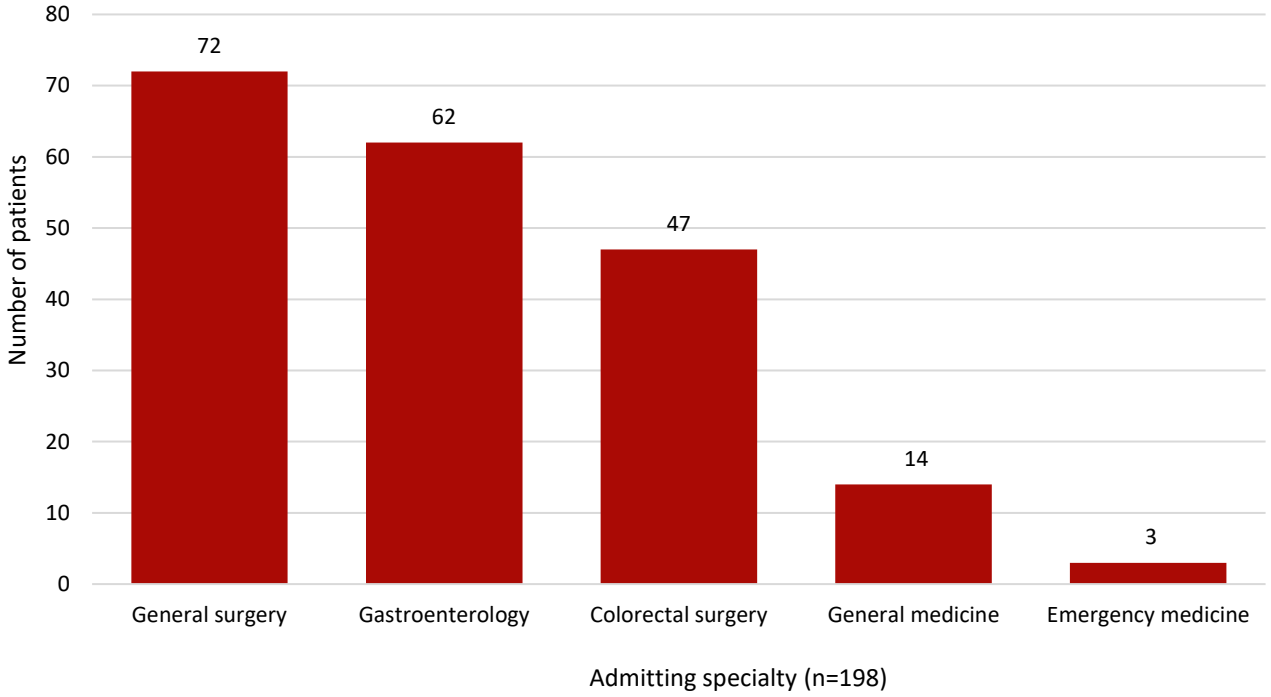


Figure 5.2 Specialty under which the patient was admitted
Clinician questionnaire data

Overall quality of emergency surgical care

The reviewers found that there was room for improvement in the acute care pathway in 34/141 (24.1%) cases reviewed (unknown for 16). Delays were encountered in emergency decision-making (12/34) and operating theatre availability (4/34). Of note were the 5/34 patients with an obstruction who were referred by non-specialist surgeons to medical teams for immunosuppression medication when an operation was indicated.

It was frequently noted by the reviewers that there had been missed opportunities to address issues in an elective setting. For 68/137 (49.6%) patients, reviewers noted that the emergency admission could have been prevented by earlier elective intervention. They also highlighted the frequency of patients presenting as an emergency while they were on an elective waiting list. Once a patient had been admitted as an emergency the pathway often did not flow smoothly, with irrelevant investigations and delays either through inappropriate medical treatment or difficulties accessing time in the emergency operating theatre.

CHAPTER 6: THE SURGICAL PROCEDURE

In total, 60/138 (43.5%) hospitals in this study had been self-identified as inflammatory bowel disease (IBD) specialist centres, and 331/553 (59.9%) patients in this study underwent surgery in such a hospital. There is no formally accepted definition of a specialist unit, however, in line with the IBDUK standards, all of the hospitals had a defined multidisciplinary team with appropriate specialty representation.[11] There was greater variation when complying with the standard around the leadership team, with 48/60 hospitals having one, and only 19/60 hospitals having patient involvement/engagement in the development of the IBD service. Only 5/60 hospitals were compliant with all the standards examined as part of this review.

Consultant colorectal surgeons undertook the operations in 515/553 (93.1%) patients. The operations performed were most commonly a right hemicolectomy (330/553; 59.7%) or small bowel resection with or without resection of the proximal colon (92/553; 16.6%).

The ECCO-ESCP guidelines state that *'Laparoscopy, when feasible, should be the preferred approach in surgery for Crohn's disease as it results in reduced morbidity, shorter hospital stay, reduction in adhesions and hernia formation, and improved cosmesis.'*[10] An encouraging finding was that a minimally invasive approach was considered in 178/248 (71.8%) patients and was completed in 283/553 (51.2%).

A large proportion of operations were for recurrent disease (257/553; 46.5%) or emergency indications (198/553; 35.8%), of which 74/198 (37.4%) patients had a laparoscopic procedure. This reflects the findings of the 'Getting it Right First Time' review of general surgery, showing that advanced laparoscopic skills are much more widely prevalent than they were previously.[30]

Organisational data highlighted that in 90/103 (87.4%) hospitals, a record was kept of the number and type of surgical procedures performed by each surgeon at that hospital, although this was unknown for 34 hospitals. Furthermore, data on all procedures to treat Crohn's disease were submitted to the IBDUK registry in only 16/109 (14.7%) hospitals where a response was given (unknown for 28 hospitals).

The operation record

The Royal College of Surgeons of England has issued clear guidance on the form and contents of an operation record.[31] Records from previous surgery for Crohn's disease are key pieces of information that should be available when planning subsequent operations. There were 396/414 (95.7%) operation records available to review. Accurate description of the tissue that was removed was missing in 97/396 (24.5%), this was of note since a long-term risk of surgically managed Crohn's disease is short bowel syndrome. It is best practice to measure and document both the length of bowel that has been removed and the length of bowel that remains. There was no documented assessment of small bowel length at the end of the procedure in 123/512 (24.0%) clinician reported data (unknown for 41) (Figure 6.1).

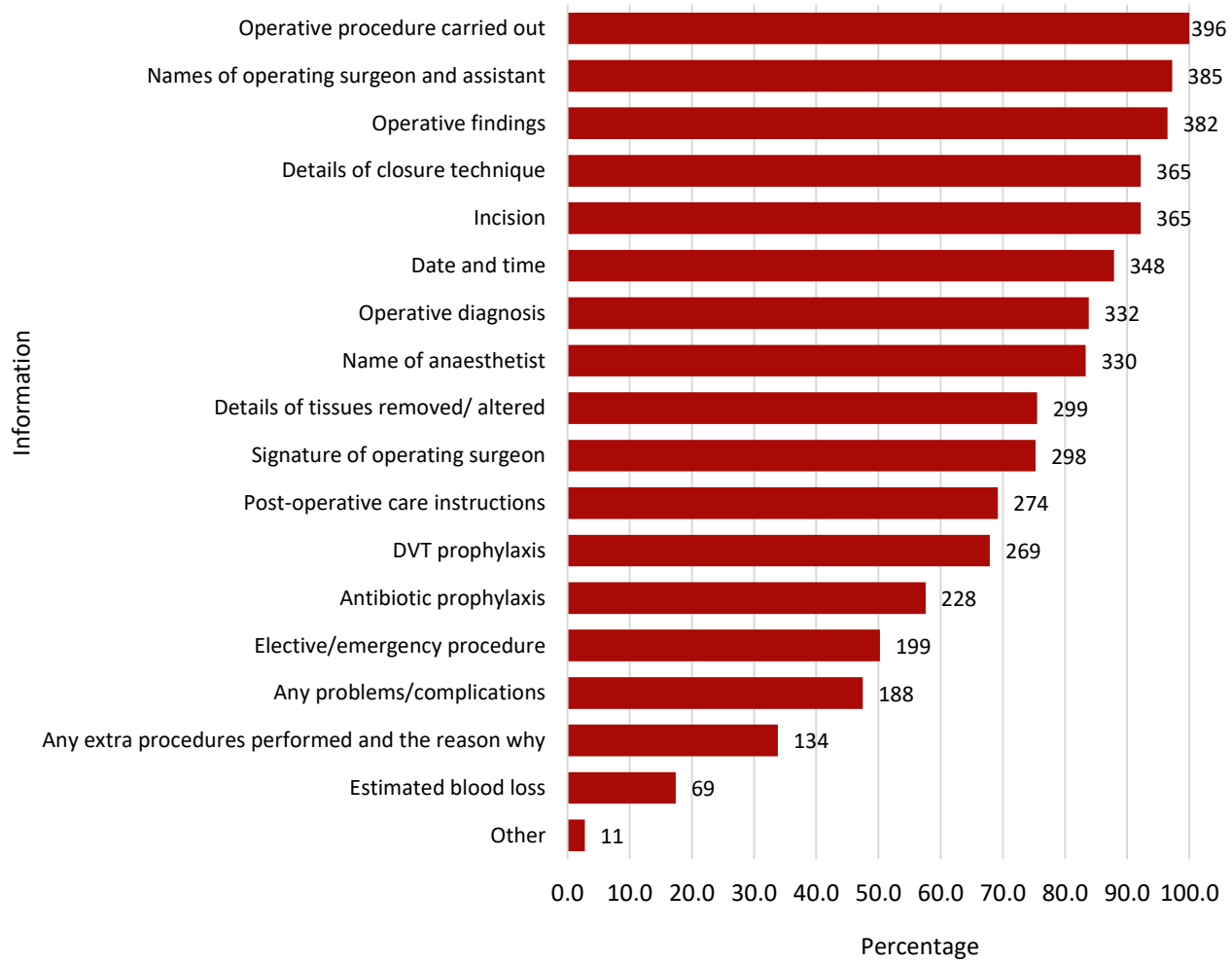


Figure 6.1 Information the operation note
Answers may be multiple; n=396
Reviewer assessment form data

Stomas

A high proportion of patients 202/553 (36.5%) were left with an abdominal stoma (ileostomy or colostomy) at the conclusion of their operation. This proportion was much higher in emergency surgery (105/198; 53.0%) than for patients undergoing elective procedures (97/364; 26.6%). The case reviews also highlighted examples of where patients had not been warned of the possibility that a stoma might be needed, but where one has had to be formed.

CASE STUDY 6

A young patient with a long sigmoid stricture on CT colonography was recommended by the surgeons for a sigmoid colectomy. The surgery was delayed for two years because the patient was asymptomatic and wished to complete a university course. Still asymptomatic, the patient was admitted for surgery without reinvestigation. At operation they were found to have developed disease extending down into the rectum so that a colostomy had to be fashioned.

Reviewers felt that a stoma was inevitable in this scenario; reinvestigation would have allowed the team to counsel the patient appropriately in advance of the operation rather than subjecting them to an unexpected permanent colostomy.

Temporary stomas may be required when it is unsafe to re-join the bowel due to the presence of an abscess, intestinal obstruction, weight loss or immune suppressive drug therapy. In this study 97/202 (48.0%) patients had a stoma that was intended to be temporary (Table 6.1).

Table 6.1 Type of stoma formed

	Number of patients	%
Permanent	105	52.0
Temporary	97	48.0
Total	**202**	

Clinician questionnaire data

For most patients, stoma closure should happen within a maximum of 12 months after the index operation. However, in this study the closure was performed more than 12 months after the stoma was formed for 64/97 patients, although this was influenced both by patients having not recovered sufficiently (physically or mentally) to be able to undergo a second operation at 12 months, as well as delays caused by the COVID-19 pandemic which initially generated considerable anxiety regarding the heightened risks of abdominal surgery.

Abdominal abscess

In this study 37/198 (18.7%) patients with an abdominal abscess presented as an emergency but only 7/37 underwent percutaneous drainage prior to surgery. The presence of an abdominal abscess can be a risk factor for poorer outcomes from emergency surgery for Crohn's disease. However, interventional radiology (IR) was not always available, only 46/119 (38.7%) hospitals reported one or fewer whole time equivalent radiologists with an interest in gastroenterology. This would be a crucial service to offer in centres considered as specialist units for the management of Crohn's disease.

Overall quality of peri-operative care

The reviewers stated that peri-operative care was of an acceptable standard for 308/359 (85.8%) patients, and this was echoed by the clinicians completing the questionnaires, perhaps reflecting the very high level of consultant input both in surgery and anaesthesia (Table 6.2).

Table 6.2 Room for improvement in peri-operative care

	Number of patients	%
Yes	31	6.1
No	474	93.9
Subtotal	**505**	
Unknown	48	
Total	**553**	

Clinician questionnaire data

CHAPTER 7: POSTOPERATIVE CARE

Following surgery, 237/538 (44.1%) patients required intensive monitoring, including 148/538 27.5%) patients who required level 2 or 3 care (Table 7.1).

Table 7.1 Where the patients went after theatre

	Number of patients	%
Ward/level 0	301	55.9
Enhanced care unit/level 1	89	16.5
High dependency unit/level 2	102	19.0
Intensive care unit/level 3	46	8.6
Subtotal	**538**	
Unknown	15	
Total	**553**	

Clinician questionnaire data

Of the 538 patients whose destination after theatre was known, most elective (205/355; 57.7%) and emergency (96/183; 52.5%) patients received routine ward care, while emergency patients were twice as likely to require level 3 care (25/183; 13.7% vs 21/355; 5.9%; Figure 7.1).

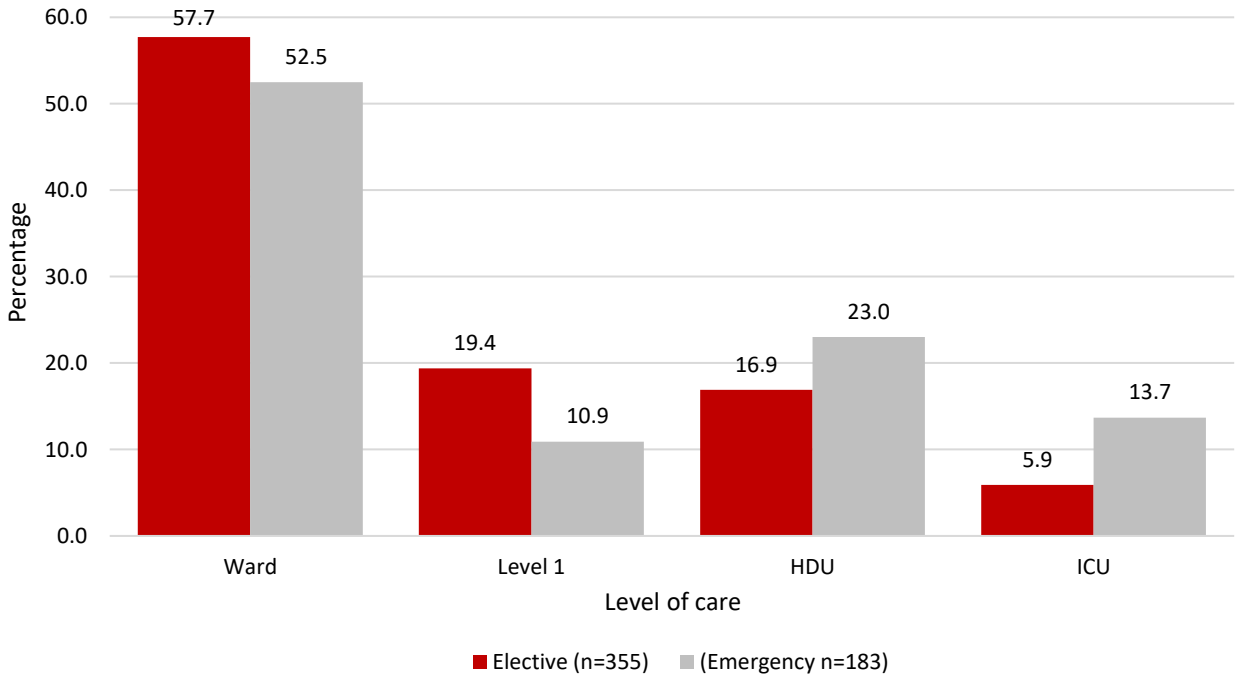


Figure 7.1 Postoperative ward level by admission type
Clinician questionnaire data

All patients with an end-of-operation predicted hospital mortality of ≥5% should receive level 3 care.[32] Emergency patients were also more likely to need level 2 resources (42/183; 23.0% vs 60/355; 16.9%) than elective patients. Reviewers were satisfied that for 336/340 (98.8%) patients who were not admitted to critical care did not require level 3 care. Of the 25 patients who were on an elective pathway for surgery but became emergency admissions, 13/25 required higher level care post-surgery.

CT scanning

Computerised tomography (CT) is the most common cross-sectional imaging modality used following abdominal surgery. CT may be used for surgery specific complications and more general complications of surgery and hospitalisation, such as pulmonary embolism and pneumonia. There are no expected rates of appropriate CT scanning following Crohn's disease surgery, but 145/553 (26.2%) patients in this study had a CT, with little difference between those admitted for elective or emergency procedures. The overall decision as to whether a CT scan was needed after surgery was considered to be appropriate for almost all patients (498/505; 98.6%) (unknown for 48).

Postoperative complications

Detail from the clinician questionnaires showed that 365/553 (66.0%) patients did not have a postoperative complication. Of the 188/553 (34.0%) patients who did, the most common complications were infection or dehiscence of the surgical incision in 70/188 (37.2%), an intra-abdominal complication (leak, abscess or obstruction) in 85/188 (45.2%) and pneumonia and/or sepsis in 15/188 (8.0%). Where the reviewers had sufficient information to make an assessment, they considered that the complication was managed appropriately in 124/137 (90.5%) cases reviewed.

The fact that both local and general infective complications were relatively common (81/553; 14.6%) was not an unexpected finding, as 368/553 (66.5%) patients were receiving immunomodulators at the time of their surgery; highlighting the need to stop steroids and biologics whenever possible pre-operatively.[9] If patients with Crohn's disease have their steroids or biologics reduced or tapered for an elective operation, they should be prioritised on that theatre list, as cancellations risk disease flares and infective complications if steroids and biologics have to be reintroduced.

CASE STUDY 7

An older patient, who was not taking any Crohn's disease-specific medication underwent an elective ileocolic resection nine months after the decision to operate. In the interim, the patient had two admissions under a gastroenterologist for incomplete bowel obstruction which resolved with conservative management. The patient was a smoker, but this was not documented in any clinic letters. Postoperatively the patient had an anastomotic breakdown.

The reviewers recognised that the surgery should have been performed much earlier and that liaison between the local gastroenterologist and the surgical centre did not occur. Opportunities to initiate smoking cessation, which may have prevented the anastomotic failure, were missed.

In total, 15/137 (10.9%) patients had a complication and 15/414 (3.6%) of the total population of patients with Crohn's disease required a second operation. Similar numbers of emergency (7/56) and elective (8/53) patients with a complication required a second operation. Most re-operations were for wound repair, anastomotic leak, or obstruction or to address sepsis.

Healthcare professionals involved in the postoperative care

Table 7.2 shows that all patients were seen by a consultant postoperatively (gastroenterologist or colorectal surgeon). Stoma nurses reviewed 215/553 (38.9%) patients and they were recorded as having attended 172/230 (74.8%) operations that involved the creation, reversal or refashioning of a stoma. Only 278/553 (50.3%) patients saw a pain specialist and 267/553 (48.3%) patients saw a dietitian. It was also noted that 299/553 (54.1%) patients saw neither an inflammatory bowel disease (IBD) nurse nor a gastroenterologist postoperatively. Re-adjustments of Crohn's disease medication may be required after surgery to reduce the postoperative risks of immunosuppression, yet a pharmacist was only involved for 258/553 (46.7%) patients.

Table 7.2 Healthcare professionals who reviewed the patient postoperatively

	Number of patients	%
Consultant colorectal surgeon	516	93.3
Physiotherapist	334	60.4
Pain specialist	278	50.3
Dietitian	267	48.3
Pharmacist	258	46.7
Stoma nurse - if applicable	215	38.9
Gastroenterologist	207	37.4
Inflammatory bowel disease nurse	126	22.8
Occupational therapist	121	21.9
Consultant general surgeon	117	21.2
Psychologist/counsellor	15	2.7
Critical care outreach team	13	2.4
Anaesthetic team	6	1.1
Enhanced recovery after surgery (ERAS) team	6	1.1
Colorectal team (nurse or registrar)	6	1.1
Nutrition team	3	<1.0
Upper gastrointestinal surgeon	2	<1.0
Other	10	1.8
Unknown	2	<1.0
None of the above	1	<1.0

Answers may be multiple; n= 553

Clinician questionnaire data

On-going maintenance management, to prevent further flares, may require the reintroduction of some drugs or new medications. When clinically indicated this requires gastroenterological IBD/Crohn's disease expertise. This expertise will not be required in the immediate postoperative period for every patient. Those on an elective pathway who have their operation on the anticipated date may already have an appropriate postoperative plan in place. However, of those who were not reviewed by a gastroenterologist postoperatively (291/371; 78.4%), reviewers identified 75/291 (25.8%) patients who they believed would have benefitted from it.

Post operative medication review

The reviewers identified 142/357 (39.8%) patients who did not have a postoperative medication review. This was similar for patients admitted as an emergency (49/137; 35.8%) or electively (93/220; 42.3%) (Table 7.3). Furthermore, 85/285 (29.8%) patients on Crohn's disease medication on admission had no medication

review or adjustment postoperatively, and 76/85 patients were also not reviewed by a gastroenterologist postoperatively.

Table 7.3 Medication plan reviewed postoperatively / patient presented as an emergency

	Patient presented as an emergency					
	Yes	**%**	**No**	**%**	**Unknown**	**Total**
Yes	88	64.2	127	57.7	0	**215**
No	49	35.8	93	42.3	0	**142**
Subtotal	**137**		**220**		0	**357**
Insufficient data	19		37		1	**57**
Total	**156**		**257**		1	**414**

Reviewer assessment form data

Ward pharmacists should request a postoperative medication plan where one is not available. The IBDUK standards state that '*The IBD leadership team should work with an expert pharmacists in IBD to ensure good medicines governance, including medicines optimisation.*'[11] In this study, only 35/60 self-identified IBD specialist centres had a pharmacist listed as part of the dedicated IBD MDT.

Data from the patient survey also highlighted medication review as a deficiency, with 58/310 (18.7%) respondents identifying medication management as an area where their personal care could have been improved.

Psychological support

The reviewers found evidence of psychological support across the care pathway in just 30/332 (9.0%) cases reviewed (unknown for 82), even though patients had undergone major, possibly life changing, surgery. The patient survey also raised the absence of psychological support, pre- and postoperatively, with 132/316 (41.8%) respondents identifying mental health support as an area where there was room for improvement in their personal care.

CASE STUDY 8

A young patient with a fixed colonic stricture expressed suicidal thoughts if a stoma were to be required. There was no offer of psychological or peer group support or any further dialogue documented. The site for the stoma was marked by the stoma nurse with no documented discussion with the operating surgeon.

The reviewers considered that the preparation for surgery was poor, and the patient should have received psychological support and would have benefited from peer support.

Pain assessment

Although 278/553 (50.3%) patients saw a pain specialist postoperatively, according to the clinician questionnaire the reviewers found evidence of a slightly higher involvement, with a pain team review in 267/368 (72.6%) cases reviewed. They also found evidence of a pain assessment in 365/388 (94.1%) cases.

Overall quality of postoperative care

The reviewers identified areas of postoperative care that could be improved in 142/370 (38.4%) cases reviewed (unknown for 44). The themes from their free text are shown in Table 7.4. The main areas for improvement were gastroenterology review (30/142; 21.1%), IBD nurse review (20/142; 14.1%), dietetic input (24/142; 16.9%), discharge planning (20/142; 14.1%) and follow-up (18/142; 12.7%). There were 16/142 (11.3%) patients who had two or more areas of postoperative care that could have been improved.

Table 7.4 Themes from the free text focusing on room for improvement postoperatively

	Number of patients	%
Gastroenterology review	30	21.1
Dietetics review	24	16.9
Inflammatory bowel disease nurse review	20	14.1
Discharge planning	20	14.1
Follow-up	18	12.7
Medications plan	13	9.2
Psychological support	12	8.5
Pain assessment/ pain team involvement	11	7.7
Inflammatory bowel disease team follow-up	5	3.5
Surgeon review	3	2.1

Answers may be multiple; n= 142

Reviewer assessment form data

CHAPTER 8: DISCHARGE AND FOLLOW-UP

The information provided to patients at the time of discharge is shown in Table 8.1. Included were details of the surgery (474/551; 86.0%), follow-up care post-surgery (416/551; 75.5%) and instructions for wound care (338/551; 61.3%), despite this being a common complication. Two patients died during the admission.

Table 8.1 Information given to patients at discharge

Information given to the patient on discharge	Number of patients	%
Details of the surgical procedure they had undergone	474	86.0
Clear follow-up care information for surgery	416	75.5
Details of the medications prescribed	389	70.6
Details of wound care	338	61.3
An emergency contact number	310	56.3
Details of common surgical complications	293	53.2
Details of an IBD advice line/contact	268	48.6
Details of how to access psychological support	35	6.4
Details of a peer support group	25	4.5
Stoma care details	4	<1.0
Other	2	<1.0
Unknown	49	8.9

Answers may be multiple; n=551
Clinician questionnaire data

The BSG guidelines recommend that all inflammatory bowel disease (IBD) patients should have access to a dedicated IBD telephone line or email service.[9] An emergency contact number was not provided to 163/551 (29.6%) patients and an IBD advice line/contact was not given to 182/406 (33.0%). Furthermore, following discharge from hospital, 135/551 (24.5%) patients had no direct access to the Crohn's disease team either via an advice line or an emergency contact number.

There was also a lack of compliance with national guidelines regarding treatment summaries and patient information at the time of discharge.[33] Organisational data showed that peer support and psychological support were available in 31/138 (22.5%) and 20/138 (14.5%) hospitals respectively. This means that patients in those hospitals that did not have these services were not being directed towards this support. It was particularly rare for patients to receive details of peer support groups (25/551; 4.5%) or how to access psychological support (35/551; 6.4%).

CASE STUDY 9

A young patient underwent an ileal resection and temporary stoma as an emergency for a new diagnosis of Crohn's disease. The discharge summary was patient-focused and sent directly to the patient. A plan for the reversal of the stoma was documented and details of discussion around contraception and fertility were included. Peer support details were included.

The reviewers considered that this was an excellent example of care, documentation and communication.

Medication plan

While details of medications prescribed were not identified in the information given to 162/551 (29.4%) patients at discharge, a medication plan was present for 517/534 (96.8%) patients. Consistent communication of the postoperative medication plan to the patient as well as the patient's IBD clinical team and GP represents an opportunity to improve medication administration and adherence. Patients with IBD have a 2.85 times increased risk of thromboembolic events.[8] In total 255/518 (49.2%) patients were discharged on extended deep vein thrombosis (DVT) prophylaxis, as shown in Table 8.2.

Table 8.2 Medication plan at discharge and extended DVT prophylaxis

	Documented medication plan at discharge		Discharged on extended DVT prophylaxis	
	Number of patients	%	Number of patients	%
Yes	517	96.8	255	49.2
No	18	3.4	263	50.8
Subtotal	**534**		**518**	
Unknown	17		33	
Total	**551**		**551**	

Clinician questionnaire data

Hospital policies and protocols for follow-up of patients with Crohn's disease

While 92/116 (79.3%) hospitals had a local policy, pathway or protocol for the follow-up of patients with Crohn's disease, this was overseen by a designated individual or team in just 36/91 (39.6%) hospitals.

Overall quality of discharge planning

The reviewers commented that discharge planning could have been improved for 119/352 (33.8%) patients. The main areas for improvement were planning a review with gastroenterology (64/119; 53.8%) or more generally with the IBD team (20/119; 16.8%), and the quality of the medications plan (23/119; 19.3%) (Table 8.3). Good communication of a robust and well-structured discharge plan to relevant healthcare professionals and the patient reduces uncertainty.

Table 8.3 Themes from the free text on room for improvement discharge planning

	Number of patients	%
Lack of follow-up planned with gastroenterologist	64	53.8
Quality of the medications plan	23	19.3
No plan for inflammatory bowel disease team follow-up	20	16.8
No plan for follow-up	5	4.2
No plan for surgical follow-up	8	6.7
Dietetics involvement in discharge planning	3	2.5
Quality of the discharge summary	7	5.9
Metrondiazole prescription	6	5.0
Lack of planned psychological support	7	5.9
Plan for colonoscopy follow-up	5	4.2

Answers may be multiple; n=119

Reviewer assessment form data

When asked to focus on particular details of the discharge plan the reviewers found that a surgical review was organised in 345/369 (93.5%) cases (unknown for 43 and two died prior to discharge) but a gastroenterology review was less common (213/321; 66.4%) (unknown for 91 and two died prior to discharge). There were 117/138 (84.8%) hospitals that had IBD clinics, the majority of which were gastroenterologist-led (42/92) (Table 8.4). This may have indicated a degree of separation in the services that are treating the same patient, 'digestive diseases care wards' may help. Furthermore, 36/119 (30.3%) patients had a follow-up colonoscopy organised 6-12 months following discharge, whereas it is recommended that this should be done at six-months to assess the neo-terminal ileum to consider treatment escalation.[9]

Table 8.4 Organisation of inflammatory bowel disease clinics

	Number of hospitals	%
Gastroenterologist-led clinics	42	45.7
Combined/joint clinics with a consultant gastroenterologist and colorectal surgeon	26	28.3
Parallel gastroenterologist and colorectal surgeon-led clinics	18	19.6
Other specialist-led clinics	4	4.3
Colorectal surgeon-led clinics	2	2.2
Subtotal	**92**	
Unknown	25	
Total	**117**	

Readmission

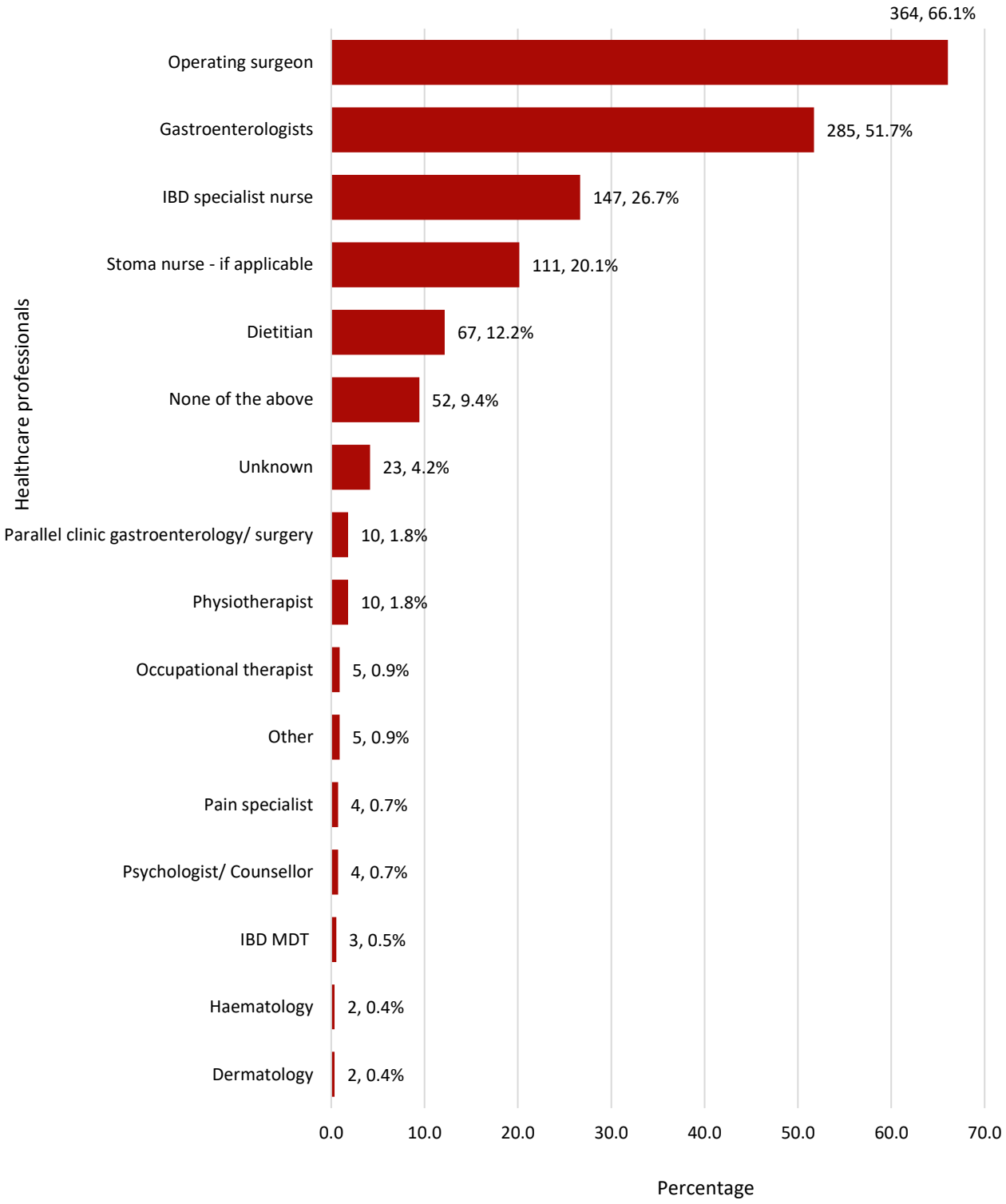
A total of 53/551 (9.6%) patients were readmitted within 30 days of their surgery. The most common reasons for readmission were infective complications (11) and pain (11).

Of the patients who were readmitted (26/53) did not have a gastroenterology review either postoperatively or arranged at follow-up. Overall, 136/553 (24.6%) patients in the study had neither a gastroenterology review nor IBD nurse review either postoperatively or at follow-up (Figure 8.1).

Figure 8.1 Follow-up appointments that were in place 30 days post discharge for the patient

Answers may be multiple; n=551

Clinician questionnaire data



CHAPTER 9: OVERALL QUALITY OF CARE

The grading system used by the reviewers to grade the overall care each patient received is described here:

Good practice: A standard that you would accept from yourself, your trainees and your institution
Room for improvement: Aspects of **clinical** care that could have been better
Room for improvement: Aspects of **organisational** care that could have been better
Room for improvement: Aspects of both **clinical and organisational** care that could have been better
Less than satisfactory: Several aspects of clinical and/or organisational care that were well below that you would accept from yourself, your trainees and your institution
Insufficient data: Insufficient information submitted to NCEPOD to assess the quality of care

In total, 190/414 (45.9%) cases were assessed as good practice, room for improvement in clinical care in 138/414 (33.3%) cases and in organisational factors in 113/414 (27.3%) cases (Figure 9.1).

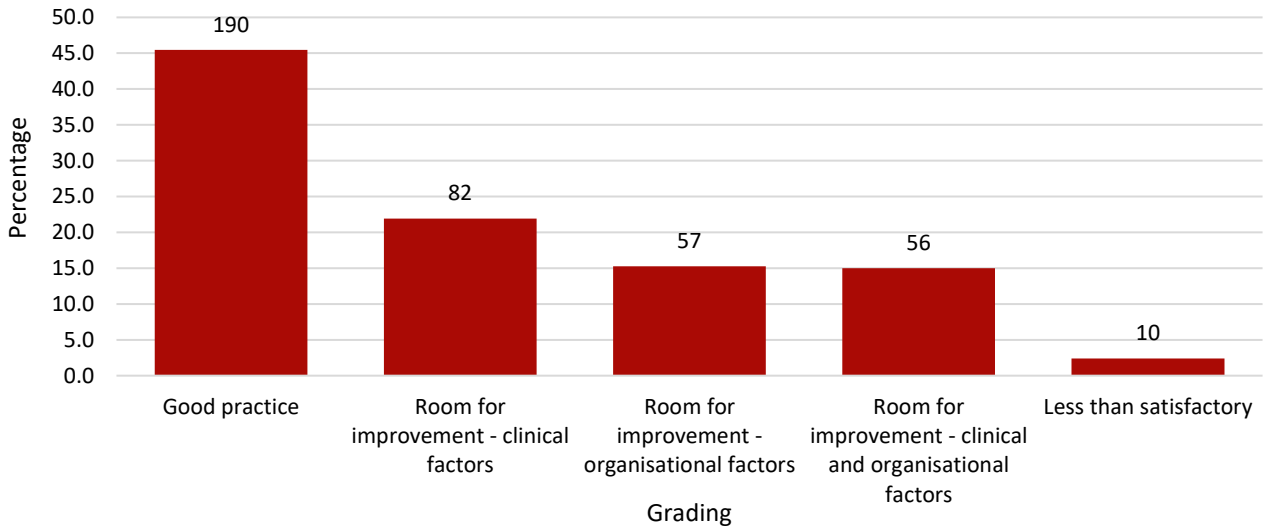


Figure 9.1 Overall quality of care
Reviewer assessment form data

Patient reported outcome measures (PROMs) are increasingly advocated as a means of supporting patient-centred care, informing decisions, and driving service quality. It was reported from just 9/138 (6.5%) hospitals that PROMs data were routinely collected. There is a clear opportunity to better engage with patients with Crohn's disease in terms of both their personal care and how Crohn's disease services perform. The BSG guidelines recommend the use of IBD-Control-8 PROM to monitor the patients' perspective of their disease. It is an easy to use and reliable eight item measure which shows a good correlation with other quality of life measures.[34] (see useful links)

PROMs were identified by the clinician leading the patient's care in 206/553 (37.3%) patients (Table 9.1). Of note was the fact that pain or discomfort was reported by 129/206 (62.6%) patients, highlighting the need for a greater focus on Crohn's disease pain management.

Table 9.1 Patient reported outcome measures (PROMs) recorded

	Number of patients	%
Pain/ discomfort	129	62.6
Complications	124	60.2
Functional outcome	117	56.8
Usual activities	88	42.7
Personal care	72	35.0
Return to work	63	30.6
Other	7	3.4

Answers may be multiple; n=206

Clinician questionnaire data

Patient survey

The patients who completed the patient survey were also asked to rate their overall quality of care on a five-point scale. Patients rated their care reasonably highly with 193/310 (62.3%) rating it as good or very good (Table 9.2). It was clear that the patients did not expect perfect care and were not unduly critical.

Table 9.2 Patients' rating of their quality of care

	Number of responses	%
Very good	77	24.8
Good	116	37.4
Adequate	74	23.9
Poor	32	10.3
Unacceptable	11	3.5
Subtotal	**310**	
Unsure	6	
Total	**316**	

Patient survey data

A less positive picture arose when the patients were asked if there were any areas of their care that could be improved. Only 16/310 (5.2%) respondents did not highlight areas to improve.

The most common area to improve was a delay in the diagnosis, with 152/310 (49.0%) patients having experienced diagnostic delays (although this was outside the scope of this study).

Services that the patients would have liked but did not receive included psychological support (132/310; 42.6%) and dietetic support (108/310; 34.8%). Delays in treatment was also raised as an issue by 111/310 (35.8%) respondents. In addition, 102/310 (32.9%) respondents wanted better information about living with Crohn's disease and 67/310 (21.6%) considered that the signposting of Crohn's disease services could be improved.

"Generally, care is great, but waiting times for surgery are appalling. My life was miserable for a year because of the wait time." A patient

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GLOSSARY

5-aminosalicylic acid	A drug used to reduce inflammation in the lining of the intestine.
Adalimumab	A medication for Crohn's disease.
Adrenal suppression	The adrenal glands do not make enough of the hormone cortisol.
Anaemia	A lack of iron in the body leads to a reduction in the number of red blood cells (Hb <130g/L in men and <120g/L in women).
Anastomosis/anastomotic leak	A procedure to connect healthy sections of the bowel after the diseased portion has been removed.
Biologics	A type of medicine to relieve symptoms in Crohn's disease and can be used a long-term treatment to help stop symptoms coming back.
Biosimilars	This is a biologic medical product that is almost an identical copy of an original product that is manufactured by a different company.
Colostomy	The colon (large intestine) is diverted through an opening in the tummy (abdomen). The opening is known as a stoma.
Crohn's Disease Activity Index (CDAI)	A research tool used to quantify the symptoms of patients with Crohn's disease.
Dehiscence	A partial or total separation of previously approximated wound edges, due to a failure of proper wound healing.
Enteritis	Inflammation of the small intestine.
Fistula	An abnormal passageway, or tunnel, in the body.
Granulomata	A mass of granulation tissue, typically produced in response to inflammation.
Harvey-Bradshaw index (HBI)	A simpler version of the Crohn's disease activity index (CDAI), used for data collection purposes.
Hernia	An internal part of the body pushes through a weakness in the muscle or surrounding tissue wall.
Ileo-caecal valve	A sphincter muscle situated at the junction of the ileum (last portion of the small intestine) and the colon (first portion of the large intestine).
Ileostomy	The small bowel (small intestine) is diverted through an opening in the tummy (abdomen). The opening is known as a stoma.
Ileus	A temporary lack of the normal muscle contractions of the intestines.
Immunomodulator drugs	A type of medicine to reduce the activity of the immune system.
Inflammatory bowel disease (IBD)	A term mainly used to describe Crohn's disease and ulcerative colitis. Both are long-term conditions that involve inflammation of the gut. Ulcerative colitis only affects the colon (large intestine). Crohn's disease can affect any part of the digestive system, from the mouth to the bottom (anus).
Infliximab	A medication for Crohn's disease
Laparoscopy	An operation performed in the abdomen or pelvis using small incisions with the aid of a camera.

Laparotomy	A surgical procedure involving a surgical incision through the abdominal wall to gain access into the abdominal cavity.
Methotrexate	An immunosuppressant drug.
Monoclonal antibodies	Laboratory-produced molecules engineered to serve as substitute antibodies that can restore, enhance, modify or mimic the immune system's attack on cells that aren't wanted.
Patient reported outcomes (PROMs)	A report of the status of a patient's health condition that comes directly from the patient without interpretation of the patient's response by a clinician or anyone else.
Penetrating disease	Radiographic, endoscopic, surgical, or clinical evidence of an abscess or fistula in any location.
Perianal disease	A type of Crohn's disease that causes inflammation around your anus.
Peritonitis	Redness and swelling (inflammation) of the lining of the belly or abdomen called the peritoneum. It is often caused by an infection from a hole in the bowel.
Prophylaxis	Treatment given or action taken to prevent disease.
Proton pump inhibitors (PPI)	Medicines that work by reducing the amount of stomach acid made by glands in the lining of the stomach.
Right Hemicolectomy	Colectomy surgery removes some, or all, of the colon (large intestine) which has been damaged due to Crohn's disease.
Steroids	A type of medicine to relieve symptoms by reducing inflammation in the digestive system.
Stoma	An opening on the abdomen that can be connected to either the digestive or urinary system to allow waste to be diverted out of the body.
Strictures/structuring disease	An area of narrowing in the intestines.
Thiopurines	A type of immunosuppressive drug.

USEFUL LINKS

BAPEN	Malnutrition Universal Screening Tool - MUST
bsg BRITISH SOCIETY OF GASTROENTEROLOGY	Consensus Guidelines on the Management of Inflammatory Bowel Disease
The Association of Coloproctology of Great Britain & Ireland	Consensus Guidelines in Surgery for Inflammatory Bowel Disease
CROHN'S & COLITIS UK	Crohn's & Colitis UK
Colostomy UK	Colostomy UK
IBD UK Strategy Partnership Quality Improvement	Inflammatory Bowel Disease Standards
ECCO European Crohn's and Colitis Organisation	IBD-Control-8 PROM Harvey-Bradshaw Index
NICE National Institute for Health and Care Excellence	NICE Guideline 129

APPENDIX: USE OF CORTICOSTEROIDS

Long-term oral corticosteroid use, defined by NICE as more than three weeks use, and those receiving frequent steroid courses (three or more per year) are at risk of a wide range of systemic side effects including increased adrenal suppression, diabetes mellitus, immunosuppression and increased risk of infection, bone effects (osteoporosis, fractures and osteonecrosis), weight gain, increased risk of cardiovascular disease including hypertension and psychiatric effects including depression, suicidal ideation and mania.

Steroids have been associated with a number of gastrointestinal adverse effects including gastritis, ulcer formation with perforation and haemorrhage, dyspepsia and oesophageal ulceration. Despite the commonly held perception that steroid use increases the risk of peptic ulcer disease, large meta-analyses of randomised, controlled trials have failed to show a significant association between steroid use and peptic ulceration. Evidence indicates corticosteroids alone have a low risk of peptic ulcer disease.

NICE recommend that proton pump inhibitors (PPI) are not routinely used for peptic ulceration prophylaxis in people using corticosteroids but that those taking NSAIDs, heavy smokers, alcohol users and those with prior peptic ulcer disease or gastrointestinal bleeding should have gastric protection with a PPI.

It seems likely that there is over-use of PPIs in Crohn's disease in the UK. PPIs increase the risk of clostridium difficile infection, pneumonia and contribute to micronutrient deficiencies, a problem already for many patients with Crohn's disease.

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