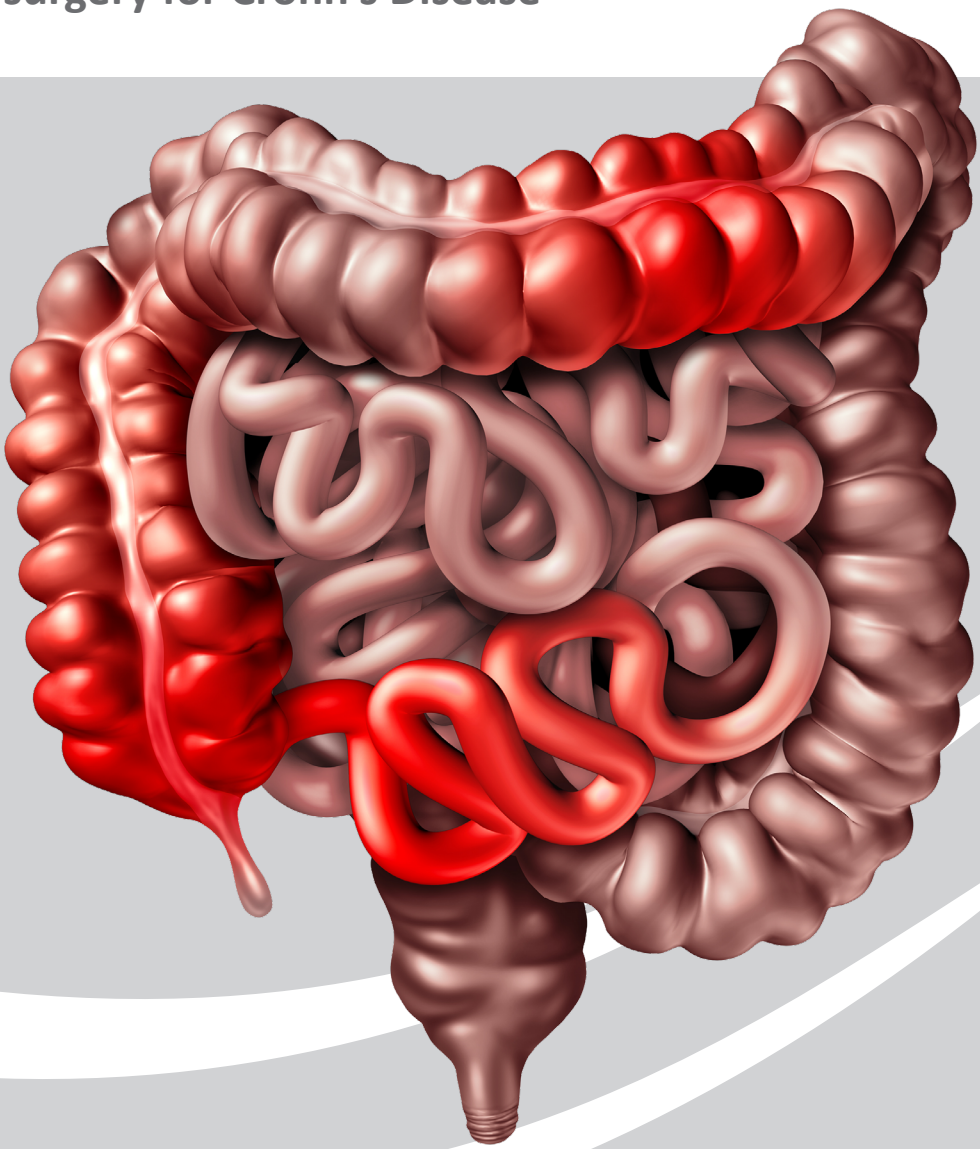
Making the Cut?

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

SUMMARY



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

The Medical and Surgical Clinical Outcome Review Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes. The Clinical Outcome Review Programmes, which encompass confidential enquiries, are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers, and policy makers to learn from adverse events and other relevant data. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical, and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies www.hqip.org.uk/national-programmes.

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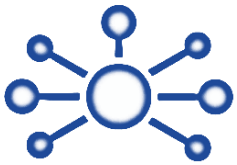
EXECUTIVE SUMMARY

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."

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.

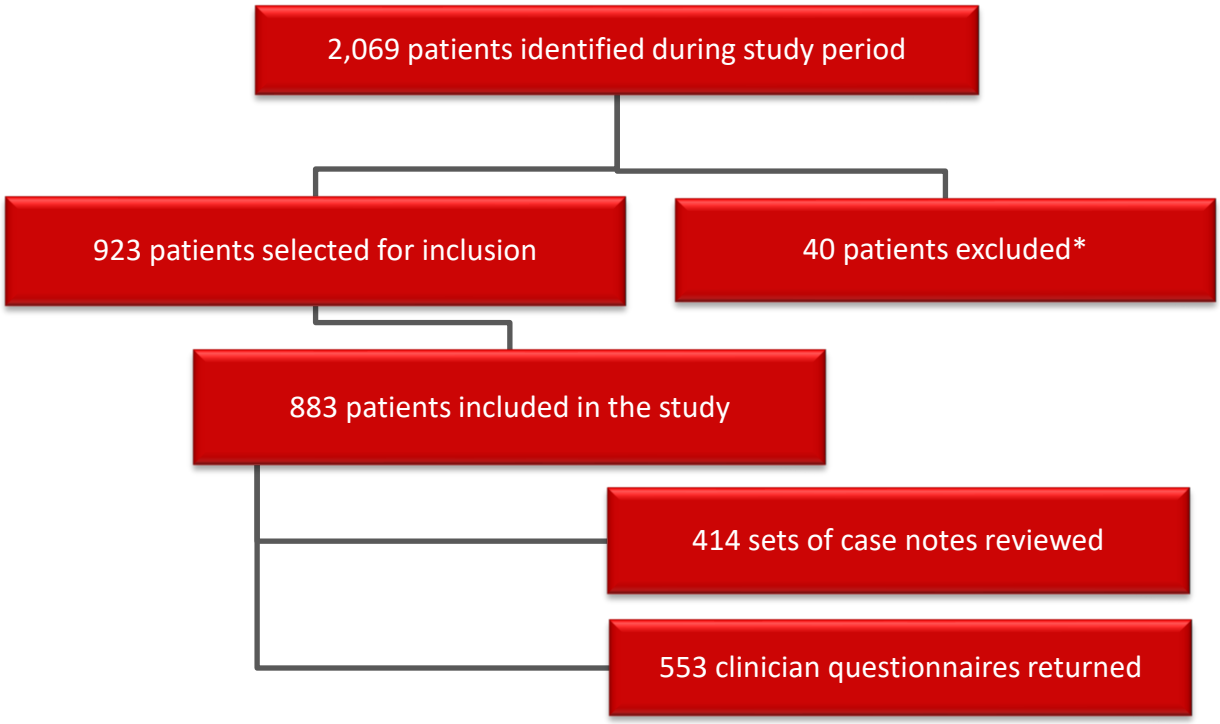


Figure 1.1 Data returned

**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.

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.

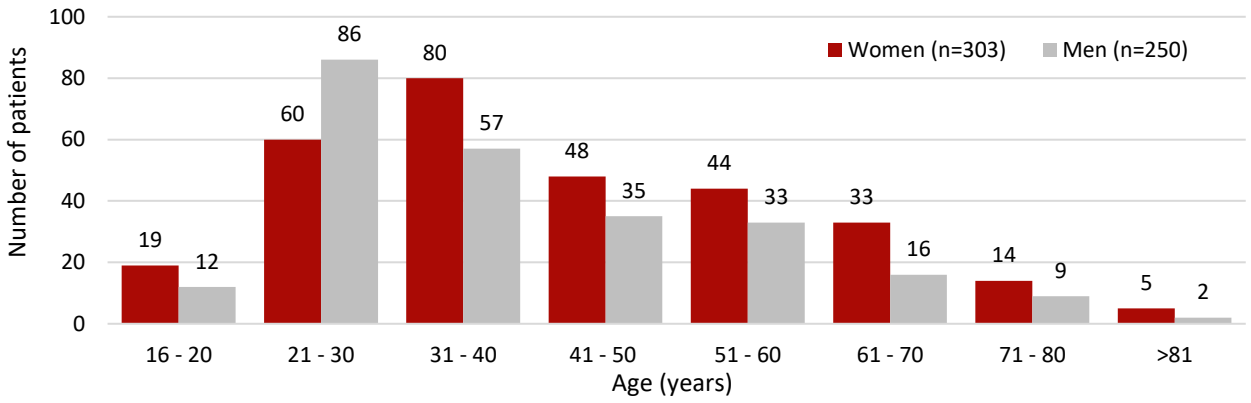


Figure 2.1 Age and sex of the study population
Clinician questionnaire data

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]

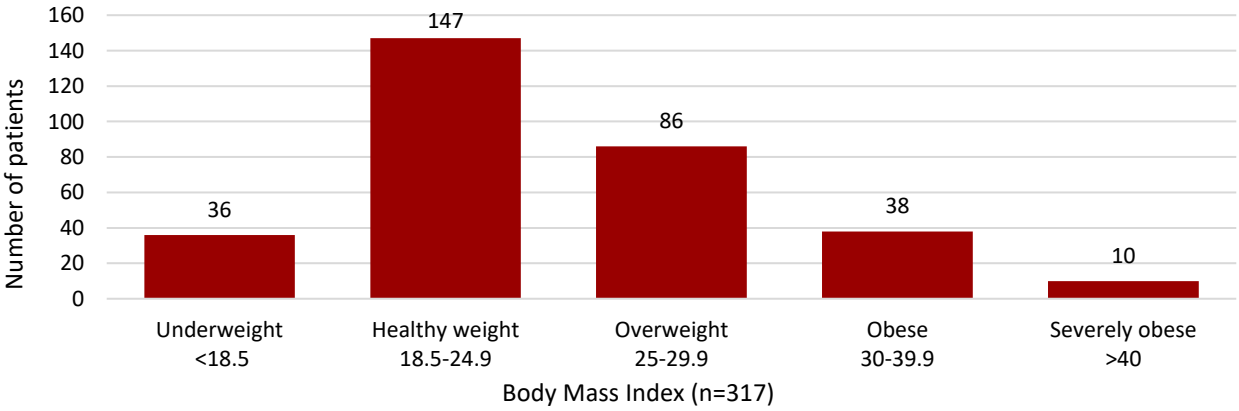


Figure 2.2 Body mass index of the study population
Clinician questionnaire data

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).

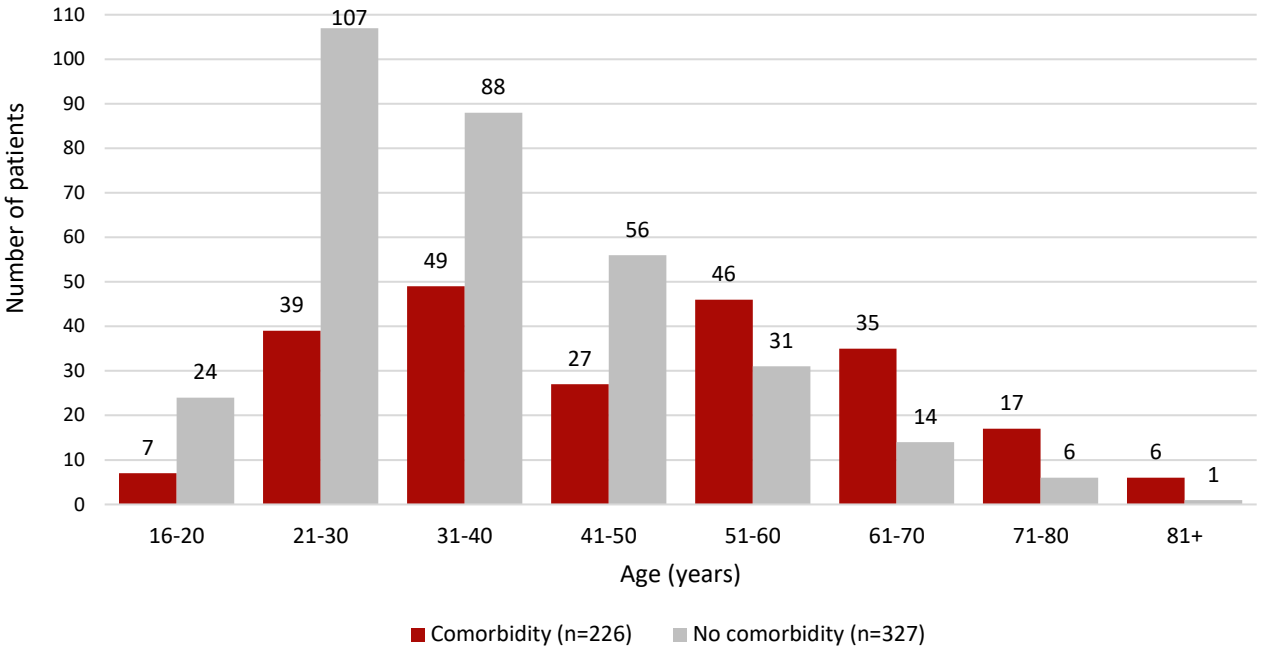


Figure 2.3 Comorbidities of the study population by age; n=550
Clinician questionnaire data

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.

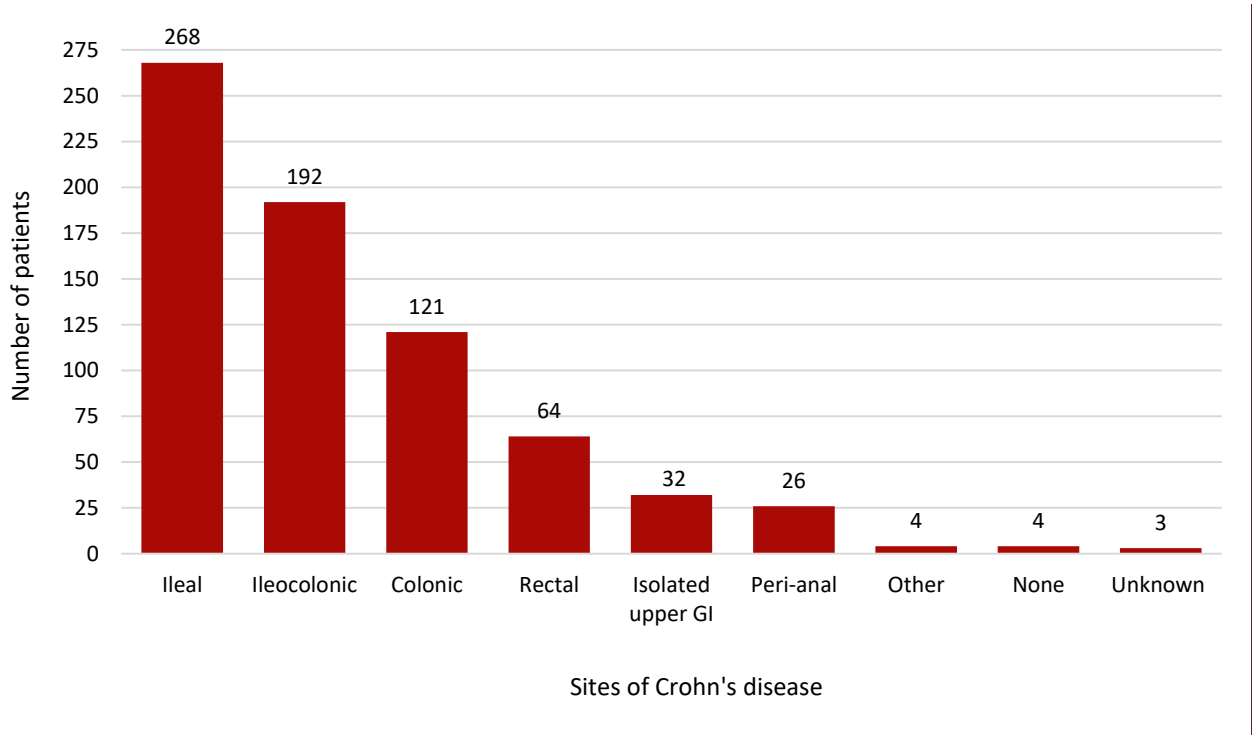


Figure 2.4 Site of Crohn's disease (Montreal classification)
Answers may be multiple; n=553
Clinician questionnaire data

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).

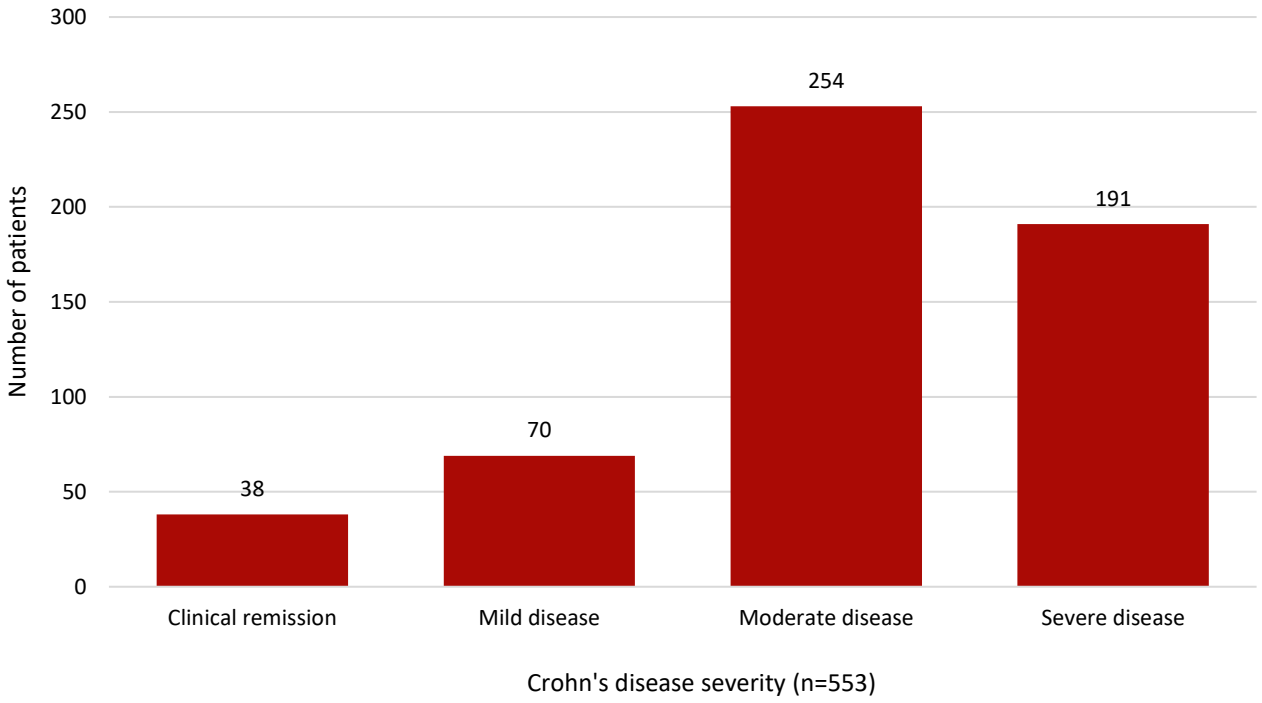


Figure 2.5 Severity of the Crohn's disease on admission

Clinician questionnaire data

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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

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