

Commissioner's Guide to the NCEPOD Report 'Making the Cut?'

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. 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] 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. 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.

The recommendations in this report support previous recommendations in this area, particularly the IBDUK standards and BSG guidelines, which should be read in conjunction with this report. The Report recommends that the services and facilities that constitute a surgical inflammatory bowel disease centre are defined, in order to commission high quality care and that this should be done in relation to the IBD standards and recommendation 10 from this report, which states that Trusts should 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**
- k. Follow-up**

KEY FEATURES OF A GOOD INFLAMMATORY BOWEL DISEASE SERVICE

As outlined in the IBD standards, patients should be cared for by a defined multidisciplinary team led by a named consultant gastroenterologist. The specialist IBD service should be able to support people with every aspect of their IBD care: from initial IBD assessment and diagnosis to medical treatment, rapid care during flares, nutritional support, and surgery if required. Patients with Crohn's disease have many wider health needs e.g. psychological, dietary, fertility and peer support. Their needs should be addressed throughout the pathway. A good service will provide support for these health needs, screening for the patient's individual requirements at each contact and having the provision to refer them without delay to appropriate holistic services.

a. The co-ordination of care between medical and surgical teams

Patients undergoing surgery for Crohn's should have high quality shared care between the medical and surgical teams caring for them. This means medical and surgical input into the decision for surgery and review by the gastroenterologist and surgeon (as needed) prior to surgery, post-operatively and at follow-up. The use of joint or parallel clinics can aid this process.

b. Support for the multidisciplinary team process

As stated in the IBD standards, MDT meetings should take place regularly (preferably weekly) to ensure that the care of patients with Crohn's disease is coordinated properly. They should be held for patients with Crohn's disease as outlined in the IBD standards, including those with complex needs, which includes those awaiting surgery or for whom surgery may be necessary. The meeting should include all those involved in the patient's care. The surgeon, gastroenterologist, IBD specialist nursing staff and pharmacy and dietetics staff should be present. The meetings should be supported by a coordinator and outputs should be shared with the patient and their GP.

c. Prioritisation of surgical treatment

The surgical procedures performed for treatment of strictures and fistulas associated with Crohn's disease are classed as priority 2 according to the FSSA clinical guide to surgical prioritisation during the coronavirus pandemic. As such they should be completed within 1 month of the decision to operate, or sooner if possible or if clinical need dictates. Prioritisation on surgical lists should reflect this and there should be adequate staffing of the surgical team and bed allocation to allow it. If a patient with Crohn's disease on an elective surgery waiting list undergoes emergency surgery for a complication of their Crohn's disease, there should be a process to investigate this, and take appropriate action as necessary e.g. report as a serious incident.

d. An appropriate consent process for surgery

The patient should be given comprehensive information about the risks and benefits of surgery and be involved in the decision-making process. The consent process for Crohn's surgical patients should be structured and standardised according to the GMC's guidance on decision-making and consent. Consent should be taken prior to the day of surgery and the risks of morbidity and mortality should be noted on the consent form.

e. Pre-optimisation/assessment of patients scheduled for surgery

Patients with Crohn's disease, who are undergoing elective surgery, should be reviewed 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.

f. Medication management

Given the potential for medications for Crohn's disease to affect the outcome from surgery, as standard, patient's medications should be reviewed prior to surgery, post-operatively and at discharge. The use of steroids should be regularly reviewed, with specific reference to bone protection, and when to use proton pump inhibitors (PPIs) The provision of a steroid treatment card for all patients receiving steroids for more than three weeks would aid this process. Reviewers found that there was room for improvement in the management of medication for 45/222 (20.3%) patients with the main reason being insufficient frequency of review. Of those patients taking steroid medication, 45/139 (32.4%) patients were receiving bone protection. Policies should be in place to govern the prescription and review of biologic medications and steroid prophylaxis, and these policies should be regularly audited.

g. Nutritional assessments and support

Nutrition is an important consideration for patients with Crohn's disease throughout their pathway of care and a nutritional assessment should form part of their pre-optimisation clinic appointment and the anaesthetic preassessment clinic. There should be dietetic support available if required.

h. Pain management

Abdominal pain is a common symptom of Crohn's disease affecting up to 70% of patients. It is essential that patient's pain is adequately assessed throughout the pathway and that they are provided with comprehensive information on the most effective pain medication to take, as well as potential side effects and what should be avoided. There should be adequate access to support a referral to a pain specialist and/or the pain team if required during the surgical admission.

i. Psychological support

People with Crohn's disease are at an increased risk of experiencing depression and anxiety. People with active Crohn's symptoms are also more likely to experience depression than those whose symptoms are in remission. It follows that patients with Crohn's disease will potentially have a greater need for psychological support than patients without the condition. There should be sufficient provision to allow referral to specialist psychological support throughout the pathway of care. The need for this should be screened as part of each clinic appointment and information should be provided on how the patient can access the support they need.

j. Discharge planning

Post operatively, there should be a plan in place for the discharge of patients with Crohn's disease who have had surgery. This should include a robust handover of care back to the inflammatory bowel disease gastroenterology team who will look after the patient's ongoing medical care. There should be a review of the patient's medications for Crohn's disease, with input from a pharmacist where necessary. Patients with a stoma should be seen by specialist stoma nursing staff. The patient should also be assessed for their nutritional, psychological and pain management needs and any onward referrals that are required should be made. All patients should have a follow-up appointment following discharge, if possible, at a joint or parallel gastrointestinal / colorectal surgical clinics. For patients with temporary stomas, there should be a plan in place for the reversal. Information should be provided to the patient on pain management, (including what can be taken, not just what to avoid). They should also be informed about who to contact in the event of an emergency. A structured discharge summary could help facilitate this. The discharge summary should be shared with the patient and the patient's GP.

KEY FINDINGS OF THE STUDY

Patient population

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) to treat their Crohn's disease. The sampling period was 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).

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.

Organisation of services

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

- A total of 138/210 (65.7%) hospitals returned an organisational questionnaire.
- 60/138 hospitals were described as a specialist IBD centre

The IBD team

- 136/138 (95.6%) had a defined MDT to care for IBD patients
 - 136/136 (100%) of these included a gastroenterologist, 129/136 (94.9%) included a colorectal surgeon, 134/136 (98.5%) included an IBD specialist nurse, 86/138 (63.2%) included a pharmacist 88/136 (64.7%) included a dietitian and 20/136 (14.5% included a clinical psychologist)
 - 17/20 of the clinical psychologists present had <1 WTE
- Dedicated IBD clinics held in 117/138 (85.4%) hospitals
 - 26 of these were joint clinics
 - 18 of these were parallel clinics
- 126/138 (93.2%) had a designated lead clinician for IBD
 - They had PAs designated for the role in 63/126 (50%)
- 95/138 (68.8%) hospitals had professional development plan/ training in care of IBD patients

MDT meetings

- 134/138 (97.8%) hospitals that regular MDT meetings took place to discuss patients with Crohn's disease.
 - These meetings occurred weekly in 66/134, fortnightly in 22/134 and less frequently in 23/134
 - Patients considering surgery were discussed in 128/134 hospitals
- The Reviewers reported insufficient input by the MDT meeting into the decision for surgery in 33/150 (22.0%) patients.
- 37/138 (26.8%) hospitals that there was no named co-ordinator to prepare and circulate agendas and minutes.
- For only nine hospitals it was reported that MDT decisions were routinely communicated to the patient's GP

Policies, protocols and guidelines

- Local guideline/ policy exists to give guidance on decision for surgical or medical treatment in 54/127 (42.5%) hospitals
- Treatment protocols for flares in Crohns disease exist in 99/132 (75.1%)
- A policy/protocol/guideline covering the prescription and review of pre-operative biologics/ immunomodulators exists in 92/129 (71.3%)
- A guideline managing the prescription / review of steroids exists in 62/129(48.1%)
 - This was audited in 21/62

- There was a defined maximum time for referral to surgery in 18/138 (13.0%)
- There is a policy covering pre-op optimisation in 83/138 (60.1%)
- For patients with severe disease, there is a maximum time frame between planning surgery and surgery taking place in 72/138 (52%)
 - For 38/72 the policy states that this should be as soon as the patient is optimised
 - For 1/72 the policy states that this should be within 1 month
- There is a policy for laparoscopic resection in 92/122 (79.3%)
- For 45/138 hospitals there was no policy covering the inpatient care of surgical patients with Crohn's disease
- There was a policy for follow-up in 65/138 (47.1%) hospitals
- A coordinator for follow-up appointments existed in 36/138 (26.1%)
- Policies were audited in 15/102 (unknown in 36) 14.7%

Patient centred care

- Patients were signposted to education/ groups / support in 115/132 (87.1%)
- Peer support groups exist onsite in 31/131 (23.7%)
- Advice on what to do in event of a flare was provided in 107/138 (77.5%)
- Policy that patients are supported to make informed shared decisions about their care found in 781/116 (61.2%) hospitals.
- Policy that patients are involved in the development of the IBD service in 35/138 hospitals.

SUPPORTING DOCUMENTS

- British Society of Gastroenterology: [Consensus Guidelines on the Management of Inflammatory Bowel Disease](#)
- ECCO: ECCO guidelines <https://academic.oup.com/ecco-jcc/article/14/2/155/5631809?login=false>
- ECCO: [IBD-Control-8 PROM](#)
- GMC: Guidance on decision-making and consent <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/decision-making-and-consent>
- IBDUK: IBDUK standards <https://ibduk.org/ibd-standards>
- NICE: [NICE Guideline 129](#)
- FSSA: Prioritisation of surgery https://fssa.org.uk/userfiles/pages/files/covid19/prioritisation_master_240720.pdf