# 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

| | | | |
|---|---|---|---|
| 1 | Ensure that all patients with Crohn's disease can access the holistic care they need. Including:<br>a. Medication management, including specialist pharmacist support*<br>b. Management of steroid withdrawal syndrome (adrenal suppression)**<br>c. Information on what to do in the event of a Crohn's disease flare<br>d. Pain management<br>e. Stoma care<br>f. Anaemia prevention and treatment<br>g. Access to peer support<br>h. Access to psychological support<br>i. Access to dietetic support | • 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.<br>• 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.<br>• 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.<br>• Evidence was found of efforts to encourage smoking cessation in 32/99 (32.4%) cases reviewed.<br>• The reviewers reported room for improvement in the pre-operative preparation for 55/162 (34.0%) patients where there | IBDUK: Inflammatory Bowel Disease Standards<br><br>NICE: NICE Guideline 129 - Crohn's Disease Management<br><br>BSG: Consensus Guidelines on the Management of Inflammatory Bowel Disease<br><br>NICE: Clinical Knowledge Summary – corticosteroids<br><br>NHS Digital: Access to patient records through the NHS App |

| | | | |
|---|---|---|---|
| | j. Support for wider health needs such as fertility issues<br>k. Smoking cessation services<br>l. Any other relevant lifestyle modification services<br><br>A patient passport that summarises the patient's care may help and could include information on the aspects listed above.<br><br>**This aligns with the IBDUK inflammatory Bowel Disease Standards*<br>***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*<br><br>***Primary target audience:*** *Clinical directors for gastroenterology and clinical directors for colorectal/gastrointestinal surgery.*<br>***Supported by:*** *All members of the multidisciplinary team caring for patients with Crohn's disease.* | was sufficient data to assess, and that in 17/55 patients better optimisation could have improved the surgical outcome.<br>• There was room for improvement in the holistic care that the patient received in 67/179 (37.4%) of the cases reviewed.<br>• 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.<br>• Only 278/553 (50.3%) patients saw a pain specialist and 267/553 (48.3%) patients saw a dietitian.<br>• 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.<br>• 135/551 (24.5%) patients had no direct access to the Crohn's disease team by either an advice line or an emergency contact number following discharge.<br>• 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. | |
| 2 | Optimise medications for patients with Crohn's disease. This should include review of:<br>a. The prescription and/or discontinuation of steroids, biologics and immunomodulators<br>b. The use of steroids, with specific reference to bone protection, and when to use proton pump inhibitors (PPIs)<br>c. The provision of a steroid treatment card for all patients receiving steroids for more than three weeks*<br>d. For patients undergoing scheduled surgery, a pre-operative medication review at the point the decision to operate is made | • 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%).<br>• 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%).<br>• Reviewers identified 139/414 (33.6%) patients who were taking steroids at the time of surgery. Of these, 45/139 (32.4%) patients were receiving bone protection. CHAPTER 3 PAGE 20<br>• 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. | NICE: Clinical Knowledge Summary – corticosteroids<br><br>BSG: Consensus Guidelines on the Management of Inflammatory Bowel Disease |

<table>
<tr>
<td></td>
<td>e. The avoidance of 5-ASA for the treatment of Crohn's disease**<br><br>*This aligns with the NICE clinical knowledge summary on corticosteroids<br>**This aligns with the British Society of Gastroenterology Consensus Guidelines on the Management of Inflammatory Bowel Disease<br><br>Primary target audience: Consultant gastroenterologists, consultant colorectal/gastrointestinal surgeons, inflammatory bowel disease nurses, and inflammatory bowel disease pharmacists.<br>Supported by: Clinical directors for gastroenterology and clinical directors for colorectal/gastrointestinal surgery.</td>
<td>• There were 92/129 (71.3%) hospitals that had a policy, protocol or guideline for the management of biologics and immunomodulators pre-operatively<br>• 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.<br>• A local guideline for steroid use in the management of Crohn's disease was not available in 67/129 (51.9%) hospitals.<br>• 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.</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Ensure that the members and timing of the multidisciplinary team meetings for patients with Crohn's disease adheres to current inflammatory bowel disease standards.<br><br>Primary target audience: Clinical directors for gastroenterology and clinical directors for colorectal/gastrointestinal surgery.<br>Supported by: All members of the multidisciplinary team caring for patients with Crohn's disease.</td>
<td rowspan="2">• It was reported from 134/138 (97.8%) 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<br>• Clinicians completing questionnaires, and 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.<br>• The reviewers reported insufficient input by the MDT meeting into the decision for surgery in 33/150 (22.0%) patients.<br>• 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.</td>
<td>ECCO-ESCP: Consensus on surgery for Crohn's disease<br><br>NHS Digital: Access to patient records through the NHS App<br><br>IBDUK: Inflammatory Bowel Disease Standards</td>
</tr>
<tr>
<td>4</td>
<td>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.<br><br>Primary target audience: Multidisciplinary team lead.<br>Supported by: Supported by consultant gastroenterologists, consultant colorectal/gastrointestinal surgeons, and inflammatory bowel disease nurses.</td>
<td>IBDUK: Inflammatory Bowel Disease Standards</td>
</tr>
<tr>
<td>5</td>
<td>Refer patients for surgical consideration when treatment with medication alone does not work. This is not an indication of 'failed medical management.'</td>
<td>• 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)</td>
<td>BSG: Consensus Guidelines on the Management of Inflammatory Bowel Disease</td>
</tr>
</table>

| | | | |
|---|---|---|---|
| | ***Primary target audience:*** *Consultant gastroenterologists.*<br>***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.* | and nine patients who were considered to be on the wrong medication.<br>• Reviewers reported that referral for a colorectal surgical opinion should have occurred earlier in 41/218 (18.8%) patients.<br>• There were 56/278 (20.1%) patients, identified in the reviews, who encountered more than one delay in the elective surgery pathway. Separately, delays occurred:<br>• 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.<br>• In the decision to operate, which should have happened earlier in the process for 43/214 (20.1%) patients (unknown for 64)<br>• Between the decision to operate and the date of the operation for 58/240 (24.2%) patients (unknown for 38) | |
| 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.<br><br>***Primary target audience:*** *Consultant anaesthetists.*<br>***Supported by:*** *Clinical leads for gastroenterology, and dietetics and all other relevant members of the multidisciplinary team caring for patients with Crohn's disease.* | • 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%).<br>• 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.<br>• The reviewers reported room for improvement in the pre-operative preparation for 55/162 (34.0%) patients where there was sufficient data to assess, and that in 17/55 patients better optimisation could have improved the surgical outcome.<br>• There was room for improvement in the holistic care that the patient received in 67/179 (37.4%) of the cases reviewed. | BSG: Consensus Guidelines on the Management of Inflammatory Bowel Disease<br><br>IBDUK: Inflammatory Bowel Disease Standards |
| 7 | Perform abdominal surgery for patients with Crohn's disease within one month of the decision to operate.*<br><br>**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.* | • Only 18/138 (13.0%) hospitals reported local targets in place for the scheduling of Crohn's disease surgery.<br>• 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.[23] Only 83/311 (26.7%) patients in this study would have met this standard (unknown for 53; Figure 4.3). | FSSA: Clinical Guide to Surgical Prioritisation in the recovery from the Coronavirus Pandemic |

| | | | |
|---|---|---|---|
| | ***Primary target audience:*** *Consultant colorectal/gastrointestinal surgeons.*<br>***Supported by:*** *Clinical directors for colorectal/gastrointestinal surgery and medical directors.* | • 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).<br>• A total of 30/311 (10.0%) patients waited more than six months for surgery. A consequence of such a long wait may be that the imaging upon which the decision to operate was based would be out of date by the time the operation is performed.<br>• There were 56/278 (20.1%) patients, identified in the reviews, who encountered more than one delay in the elective surgery pathway. Separately, delays occurred:<br>• 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.<br>• In the decision to operate, which should have happened earlier in the process for 43/214 (20.1%) patients (unknown for 64)<br>• Between the decision to operate and the date of the operation for 58/240 (24.2%) patients (unknown for 38)<br>• 25/198 (12.6%) patients presenting as an emergency were already on a waiting list for an elective operation.<br>• 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).<br>• Of the 25 patients who were on an elective pathway for surgery but became emergency admissions, 13/25 required higher level care post-surgery. | |
| 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.<br>***Primary target audience:*** *Medical directors.* | • 25/198 (12.6%) patients presenting as an emergency were already on a waiting list for an elective operation.<br>• 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).<br>• Of the 25 patients who were on an elective pathway for surgery but became emergency admissions, 13/25 required higher level care post-surgery. | FSSA: Clinical Guide to Surgical Prioritisation in the recovery from the Coronavirus Pandemic |

| | | | |
|---|---|---|---|
| | ***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:<br>a. Handover of care to the inflammatory bowel disease/ gastroenterology team who will look after the patient's ongoing medical care<br>b. Undertaking a medication review*<br>c. Providing information to the patient on who to contact in the event of an emergency<br>d. Providing information to the patient on pain management, including what can be taken, not just what to avoid<br>e. Booking follow-up appointments<br>f. Providing information to the patient on how to access to psychological support if needed<br>g. Communicating all of the above to the patient and their GP<br><br>A structured discharge summary could help facilitate this.<br><br>**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.*<br><br>***Primary target audience:*** *Consultant colorectal/gastrointestinal surgeons.*<br>***Supported by:*** *Consultant gastroenterologists, the chief pharmacist, and other members of the multidisciplinary team caring for patients with Crohn's disease.* | • 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.<br>• 299/553 (54.1%) patients saw neither an inflammatory bowel disease (IBD) nurse nor a gastroenterologist postoperatively.<br>• 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.<br>• Only 278/553 (50.3%) patients saw a pain specialist and 267/553 (48.3%) patients saw a dietitian.<br>• 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.<br>• 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.<br>• 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.<br>• 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. | IBDUK: Inflammatory Bowel Disease Standards |

| | | | |
|---|---|---|---|
| | | • While details of medications prescribed were not identified in the information given to 162/551 (29.4%) patients at discharge.<br>• 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.<br>• The reviewers commented that discharge planning could have been improved for 119/352 (35.1%) patients.<br>• 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.<br>• 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%). | |
| 10 | Develop a trust/health board policy for the care of patients with Crohn's disease. This should include:<br>a. The co-ordination of care between medical and surgical teams<br>b. Support for the multidisciplinary team process<br>c. Prioritisation of surgical treatment<br>d. An appropriate consent process for surgery<br>e. Pre-optimisation/assessment of patients scheduled for surgery<br>f. Medication management<br>g. Nutritional assessments and support<br>h. Pain management<br>i. Psychological support<br>j. Discharge planning<br><br>*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* | • There were 92/129 (71.3%) hospitals that had a policy, protocol or guideline for the management of biologics and immunomodulators pre-operatively.<br>• A local guideline for steroid use in the management of Crohn's disease was not available in 67/129 (51.9%) hospitals.<br>• It was reported from 134/138 (97.8%) 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 (Table 4.2).<br>• 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.<br>• Only 18/138 (13.0%) hospitals reported local targets in place for the scheduling of Crohn's disease surgery.<br>• 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).<br>• 91/311 (29.3%) elective patients gave their consent on the day of surgery, which is not an appropriate time point to take fully | IBDUK: Inflammatory Bowel Disease Standards<br><br>BSG: 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.* | informed consent, and does not comply with the standards required by the GMC and the Royal College of Surgeons of England.<br>• 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.<br>• 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 who are treating the same patient, 'digestive diseases care wards' may help. | |
| 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).<br><br>***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.* | • In total, 60/138 (43.5%) hospitals in this study had been self-identified as an inflammatory bowel disease (IBD) specialist centres.<br>• 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 in when complying with the standards around the leadership team, with only 48/60 hospitals having one, and 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. | 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.<br><br>***Primary target audience:*** *Association of Coloproctology of Great Britain and Ireland.* ***Supported by:*** *Consultant colorectal/gastrointestinal surgeons, and commissioners.* | • 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. | Colostomy UK: Stoma reversal |