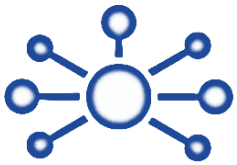
EXECUTIVE SUMMARY

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.