



Crohn's Disease Study – Info for Local Reporters

Introduction

Crohn's disease is a chronic, relapsing inflammatory condition of the gastrointestinal tract that typically affects the ileum and colon. The incidence of Crohn's disease in the UK is 83 per 106/year, with a population prevalence of approximately 284 per 105 and typically occurs between the second and fourth decades of life with another peak after age 60. The disease can cause significant psychosocial stress affecting education, employment and inter-personal relationships. The cost of care of IBD is considerable, estimated to be at least £720 million per annum - comparable to the cost of treating cancer or heart disease.

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. The likelihood of surgery has been reported to be 16.3% one year after diagnosis, rising to 47% at 5 years. Complication rates of surgery for Crohn's disease are high.

The increasing use of more potent immunosuppressive therapy in addition to thiopurines and methotrexate makes it possible that a decision to resect may be delayed longer than in the past, and emergency or urgent surgery, (if it becomes necessary) will be carried out with these drugs having been recently administered, with potential for increased risk of sepsis.

Of those responding to the IBD UK Patient Survey, 23% (2,292) had been admitted to hospital for an overnight stay or longer during the previous 12 months. Of this group, 72% were emergency admissions, while 9% had been admitted more than once during the same 12-month period. Emergency admissions and emergency surgery are often a result of missed opportunities for earlier treatment. Information, education and support for people with Crohn's disease who have surgery is generally provided, although the findings of the IBD UK report (2021) highlight opportunities to think about its impact, accessibility and quality in fully supporting informed choices and feeling well-prepared.

Patients with Crohn's disease do not fall neatly into the framework that governs most surgical practice. Cancer patients are powerfully prioritised by mandated targets yet patients with Crohn's disease, a severe and debilitating illness, are not afforded the same protection. Urgent, rather than emergency, surgical treatment is not reflected in



the way waiting lists are managed. People needing surgery for Crohn's disease find themselves given lower priority than cancer and long waiting patients.

The decision regarding the need for and timing of operative intervention is often difficult, requiring effective multi-disciplinary working and high-quality patient information and involvement. This can be particularly difficult to provide if a patient ends up requiring emergency surgical treatment for a problem that could have been managed as a planned procedure by a specialist team.

This study is particularly timely since the COVID-19 pandemic has seriously disrupted the flow of elective surgical patients. Crohn's patients are likely to have been shielding and the lack of face-to-face clinical time will have exacerbated the delays from which these patients so often suffer.

Primary aim: to review of 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:

- To identify patients with Crohn's disease who undergo surgery and to investigate the quality of care provided throughout the pathway from admission to discharge
- To evaluate the quality of preoperative care including the decision to undergo a procedure, pre-optimisation assessment, nutrition, medications, mental health etc
- To assess the emergency care pathway for patients admitted for surgery via the Emergency Department
- To assess the quality of perioperative and post operative care including delays to surgery, risk stratification, management of complications and nutrition
- To assess organisational aspects of care including staffing, education, local and national guidelines, and the infrastructure to deliver a high-quality service
- To look at the information, education and support provided to patients – understanding surgery, mental well-being and pre-surgery optimisation
- To investigate the effect of COVID-19 on the service
- To produce recommendations to improve the quality of care for this patient group



Sites

All acute hospital in England, Wales, Northern Ireland and public hospitals in Jersey that treat Crohn's patients and provide surgery.

Data collection

Patient identifier spreadsheet

We are looking to identify patients for the study who had Crohn's disease and were admitted to hospital for a surgical procedure, during either of the two listed study periods. These two 6-month study periods are designed to capture a snapshot of the service prior to, and during the COVID-19 pandemic. **All patients aged 16 or over who were admitted to hospital between 1st September 2019 - 29th February 2020 and 1st September 2020 - 28th February 2021 with a primary diagnosis of Crohn's disease (ICD10 codes K50-51.9) and who underwent a surgical procedure***

**Please note that our scoping exercise for this study showed that some Trusts were identifying a very low number of patients within the stated timeframe and parameters. Extrapolating from the data we have, there should be enough patients to proceed with selection and data collection. However, we may need to request additional data from a further 6-month period (TBC).*

The spreadsheet will collect data on several fields, many of which are key to the study. Please complete all the “**key fields**” requested on the spreadsheet, any problems then please contact our office.

A sample of ~500 patients (with a maximum of 7 patients per hospital -tbc) will then be selected for questionnaire dissemination and peer review.

Clinician questionnaire – To be disseminated in February 2022

A clinician questionnaire regarding the inpatient episode will be sent to the consultant responsible for carrying out the surgical procedure.

Case note extracts for peer review – To be disseminated in February 2022

Photocopied case note extracts will be requested for each patient included in the study sample.

Organisational questionnaire – To be disseminated in Spring 2022



Information about the organisation of services, care pathways (including specialist commissioned pathways), the use of guidelines and protocols, and multidisciplinary team working will be collected.

We would be grateful if you could return the completed **password protected patient identifier spreadsheet to ncepod@nhs.net by 10th January 2022.**
Please then phone the office with the password to open the spreadsheet.

Further information about the study and the protocol, including frequently asked questions, can be found on our website.

<https://www.ncepod.org.uk/crohns.html> or please contact the office on 0207 251 9060 or by email crohns@ncepod.org.uk