

Crohn's Disease: Organisational Questionnaire

A. Introduction

What is this study about?

The aim of this study is to review the remediable factors in the quality of care provided to patients aged 16 and over with a diagnosis of Crohn's disease who underwent a surgical procedure.

Who should complete this questionnaire?

This questionnaire has been designed to collect data on the organisational structures surrounding the surgical care provided to patients with Crohn's disease .

It should be completed for hospitals where patients with Crohn's disease might be treated. One questionnaire should be completed for each hospital within a Trust/Health board.

It should be completed by or with input from, clinicians(s) that provide care to this group of patients. This is likely to include, but not limited to the Specialist IBD team, Gastroenterologists, Colorectal and General surgeons or Specialist IBD nurses.

Questions or help:

A list of definitions can be found here:

https://www.ncepod.org.uk/pdf/current/Crohn/NCEPOD_Crohns_definitions.pdf

Further information regarding this study can be found here: <https://www.ncepod.org.uk/crohns.html>

If you have any queries about this study or this questionnaire, please contact: crohns@ncepod.org.uk or telephone 020 7251 9060.

About NCEPOD

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviews healthcare practice by undertaking confidential studies, and makes recommendations to improve the quality of the delivery of care, for healthcare professionals and policymakers to implement.

Data to inform the studies are collected from NHS hospitals and Independent sector hospitals across England, Wales, Northern Ireland and the Offshore Islands.

NCEPOD are supported by a wide range of bodies and the Steering Group consists of members from the Medical Royal Colleges and Specialist Associations, as well as observers from The Coroners Society of England and Wales, and the Healthcare Quality Improvement Partnership (HQIP).

Impact of NCEPOD

Recommendations from NCEPOD reports have had an impact on many areas of healthcare including: Development of the NICE 'Acutely ill patients in hospital guideline' (CG50) - following publication of the 2005 'An Acute Problem' report.

Appointment of a National Clinical Director for Trauma Care - following publication of 'Trauma: Who Cares?' 2007.

Development of NICE Clinical Guidelines for Acute Kidney Injury, published in 2013 - 'Adding Insult to Injury' 2009.

Development of ICS Standards for the care of adult patients with a temporary Tracheostomy, published 2014 - 'On the right trach?' 2014.

Development of guidelines from the British Society of Gastroenterology: diagnosis and management of acute lower gastrointestinal bleeding, published 2019 - 'Time to Get Control' 2015.

Development of the British Thoracic Society's Quality Standards for NIV, published 2018 - 'Inspiring Change' 2017.

Development of a new service specification for paediatric cancer services, 2019- 'on the right course' 2018

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Medical & Surgical care.

B. Hospital details

1. Please state who was involved in the completion of this questionnaire:

Please select all that apply. Please select "other" for any additional options

- | | |
|--|--|
| <input type="checkbox"/> Consultant gastroenterologist | <input type="checkbox"/> Consultant colorectal surgeon |
| <input type="checkbox"/> Consultant general surgeon | <input type="checkbox"/> Specialist IBD nurse consultant |
| <input type="checkbox"/> Member(s) of the specialist IBD leadership team | |
| <input type="checkbox"/> Member(s) of the clinical governance team | <input type="checkbox"/> Administrator |
| <input type="checkbox"/> Senior manager | |

Please specify any additional options here...

2. How many inpatient beds does this hospital have?

Beds

Unknown

3. Does this hospital have an emergency department?

Yes

No

4. Is this hospital, or part of this hospital designated as an elective surgery centre for gastrointestinal surgery?

Yes

No

Unknown

The IBD service

1. Is there a specialist service for patients with inflammatory bowel disease (IBD) at this hospital?

**Please see definitions*

- Yes - care is provided primarily at this hospital site
- Yes- care is provided across multiple sites in the Trust/ Health board
- Not at this hospital but care is provided at another/ others within the Trust/ Health board
- No- patients are referred/ transferred to the nearest IBD centre (there is a formal network arrangement)
- No - patients are referred/ transferred to the nearest IBD centre (there is an informal network arrangement)
- No- patients are referred/ transferred to the nearest IBD centre (no network agreement)

If not listed above, please specify here...

2. If answered "Yes - care is provided primarily at this hospital site" or "Yes- care is provided across multiple sites in the Trust/ Health board" to [1] then: How many adult patients are covered by the IBD service?

 patients

- Not Applicable Unknown

3. If answered "Yes - care is provided primarily at this hospital site" or "Yes- care is provided across multiple sites in the Trust/ Health board" to [1] then: How many newly diagnosed patients with Crohn's disease have there been in the period 01/04/2021-31/03/2022?

 patients

- Not Applicable Unknown

4. If answered "Yes - care is provided primarily at this hospital site" or "Yes- care is provided across multiple sites in the Trust/ Health board" to [1] then: To which of the following supporting services can a direct referral be made by the IBD service for a patient with Crohn's disease:

please select all that apply (use the "other" option to add additional text)

- | | |
|---|---|
| <input type="checkbox"/> Rheumatology | <input type="checkbox"/> Dermatology |
| <input type="checkbox"/> Ophthalmology | <input type="checkbox"/> Urology |
| <input type="checkbox"/> Gynaecology (fertility/ contraception) | <input type="checkbox"/> Neurology |
| <input type="checkbox"/> Physiotherapy | <input type="checkbox"/> Occupational therapy |
| <input type="checkbox"/> Clinical psychology | |

Please specify any additional options here...

5a. If answered "Yes - care is provided primarily at this hospital site" or "Yes- care is provided across multiple sites in the Trust/ Health board" to [1] then: At this hospital, are patients with Crohn's disease cared for by a defined IBD multidisciplinary team?

- Yes No Unknown

5b. If answered "Yes" to [5a] then:

Please select all the clinicians who are a part of the IBD multidisciplinary team:

Please select all options that apply (use the "other" option to add additional text)

- Consultant gastroenterologist(s)
- Consultant colorectal surgeon(s)
- Consultant general surgeon(s)
- IBD clinical nurse specialist(s)
- Clinical nurse specialist with competencies/ special interest in stoma therapy
- Pharmacist(s) with expertise in IBD
- Dietitian(s) allocated to gastroenterology
- Parental nutrition team
- Radiologist(s) with a special interest in gastroenterology
- Histopathologist(s) with a special interest in gastroenterology
- Clinical psychologist(s) with a special interest in gastroenterology

Please specify any additional options here...

6a. If answered "Consultant gastroenterologist(s)" to [5b] then:

How many whole time equivalent (WTE) gastroenterologists with interest / specialism in IBD are part of the IBD service?

Not Applicable Unknown

6b. If answered "Consultant colorectal surgeon(s)" or "Consultant general surgeon(s)" to [5b] then:

How many surgeons (WTE) with an interest in IBD are part of the IBD service?

Not Applicable Unknown

6c. If answered "IBD clinical nurse specialist(s)" to [5b] then:

How many (WTE) IBD clinical nurse specialists are part of the IBD service?

Not Applicable Unknown

6d. If answered "IBD clinical nurse specialist(s)" to [5b] then:

Would every patient with Crohn's disease admitted to hospital have access to an IBD clinical nurse specialist

Yes

No

Unknown

6e. If answered "Clinical nurse specialist with competencies/ special interest in stoma therapy" to [5b] then:

How many (WTE) clinical nurse specialists with competencies/ special interest in stoma therapy are part of the IBD service

Not Applicable Unknown

6f. If answered "Pharmacist(s) with expertise in IBD" to [5b] then:

How many (WTE) pharmacists with expertise in IBD are part of the IBD service?

Not Applicable Unknown

6g. If answered "Dietitian(s) allocated to gastroenterology" to [5b] then:

How many (WTE) dietitians are part of the IBD service?

Not Applicable Unknown

6h. If answered "Radiologist(s) with a special interest in gastroenterology" to [5b] then:

How many (WTE) radiologists with a special interest in gastroenterology are part of the IBD service

6i. If answered "Histopathologist(s) with a special interest in gastroenterology" to [5b] then: How many (WTE) histopathologists with a special interest in gastroenterology are part of the IBD service?

Not Applicable Unknown

6j. If answered "Clinical psychologist(s) with a special interest in gastroenterology" to [5b] then: How many (WTE) clinical psychologists are part of the IBD service?

Not Applicable Unknown

7a. If answered "Yes - care is provided primarily at this hospital site" or "Yes- care is provided across multiple sites in the Trust/ Health board" to [1] then: Are there dedicated IBD clinics held at this hospital?

Yes No Unknown

7b. If answered "Yes" to [7a] then: Please describe how these IBD clinics are organised:

- Combined/ joint clinics with a consultant gastroenterologist and colorectal surgeon
- Parallel gastroenterologist and colorectal surgeon-led clinics
- Gastroenterologist-led clinics
- Colorectal surgeon-led clinics
- Other specialist-led clinics
- Unknown

If not listed above, please specify here...

8a. If answered "Yes - care is provided primarily at this hospital site" or "Yes- care is provided across multiple sites in the Trust/ Health board" to [1] then: Is there a senior leadership team* for the IBD service?

Please see definitions

Yes No
 Unknown Not applicable- No IBD service

8b. If answered "Yes" to [8a] then: Who is on the leadership team for the IBD service?

- Senior gastroenterologist Senior surgeon Senior IBD nurse specialist
 Other senior clinician Senior manager

Please specify any additional options here...

9a. If answered "Yes - care is provided primarily at this hospital site" or "Yes- care is provided across multiple sites in the Trust/ Health board" to [1] then: Is there a designated lead clinician?

Yes No Unknown

9b. If answered "Yes" to [9a] then: What is the grade/ specialty of the lead clinician?

- Consultant gastroenterologist Consultant colorectal Surgeon Consultant general surgeon
 Nurse consultant

Please specify any additional options here...

9c. If answered "Yes" to [9a] then: Does the clinical lead have designated PAs in their job plan for this leadership activity?

Yes No Unknown

10. If answered "Yes" to [8a] and "Yes - care is provided primarily at this hospital site" or "Yes- care is provided across multiple sites in the Trust/ Health board" to [1] then: How often does the IBD leadership team report to the Trust/ Health board?

- Monthly Quarterly Bi-annually Annually
 Never Unknown

If not listed above, please specify here...

11. If answered "Yes - care is provided primarily at this hospital site" or "Yes- care is provided across multiple sites in the Trust/ Health board" to [1] then: Which quality improvement activity/ audits/ data collection/ regarding the care of patients with Crohn's disease are carried out at this hospital?

Please select all that apply (please use the "other" box to add additional options)

- IBD UK service self assessment
 Data provided to the IBD registry (all IBD patients)
 Local audit/s on the care of patients with IBD/ Crohn's disease (surgical treatment)
 Local audit/s on the care of patients with IBD/ Crohn's disease (immunomodulatory treatment)
 Patient reported outcome measures (PROMS)
 None of these

Please specify any additional options here...

12. If answered "Yes" to [8a] and "Yes - care is provided primarily at this hospital site" or "Yes- care is provided across multiple sites in the Trust/ Health board" to [1] then: Is there a Trust/Health Board wide strategy for improving care of patients with Crohn's disease?

- Yes No Unknown

13. If answered "Yes - care is provided primarily at this hospital site" or "Yes- care is provided across multiple sites in the Trust/ Health board" to [1] then: Which of the following aspects of professional development/ training regarding the specialist care of patients with IBD are provided?

Please select all that apply (please use the "other" box to add additional options)

- A professional development plan with access to support and supervision for each member of the IBD team
 Regular reviews of clinical practice/ clinical outcomes for members of the IBD team
 Funding/ protected time to attend relevant conferences for members of the IBD team
 Training provided for other healthcare professionals who come into contact with IBD patients (not part

Please specify any additional options here...

MDT meetings

14. Are regular MDT meetings held at this hospital to discuss patients with Crohn's disease?

- Yes No Unknown

15. If answered "Yes" to [14] then:

How often do MDT meetings take place to discuss the care of patients with Crohn's disease?

- Daily 2-6 times a week Weekly
 Every 2 weeks >2-4 weekly Less frequently than monthly
 Unknown

If not listed above, please specify here...

16. If answered "Yes" to [14] then:

Which Crohn's disease patients are discussed at the MDT meetings?

Please select all options that apply and write in the text box if you need to select additional options

- All newly diagnosed patients All patients periodically
 All patients with symptom flares All patients on certain medication
 All patients for whom surgery is being considered
 All inpatients post surgery

Please specify any additional options here...

17. If answered "Yes" to [14] then:

Is there a named IBD MDT meeting coordinator responsible for the agenda and the dissemination of the minutes?

- Yes No Unknown

18. If answered "Yes" to [14] then:

Are the notes from MDT meetings (including documentation of decisions made):

Please select all that apply (please use the "other" option to add additional text)

- Recorded in the electronic patient record
 Recorded in the patient's paper medical record
 Made available to all core members of the MDT
 Fed back to the patient None of these options

Please specify any additional options here...

Services/ facilities

20. Please select the types of surgery for patients with Crohn's disease that are carried out at this hospital?

Please select all that apply

- Elective gastrointestinal surgery - some procedures
 Elective gastrointestinal surgery - including complex procedures
 Emergency gastrointestinal surgery - some procedures
 Emergency gastrointestinal surgery - including complex procedures
 Laparoscopic gastrointestinal surgery
 No gastrointestinal surgery is carried out at this hospital

**21. If answered "Elective gastrointestinal surgery - some procedures", "Elective gastrointestinal surgery - including complex procedures", "Emergency gastrointestinal surgery - some procedures", "Emergency gastrointestinal surgery - including complex procedures" or "Laparoscopic gastrointestinal surgery" to [20] then:
Is a record kept of the number of each surgical procedure performed by each surgeon employed at this hospital?**

- Yes No Unknown

**22. If answered "Elective gastrointestinal surgery - some procedures", "Elective gastrointestinal surgery - including complex procedures", "Emergency gastrointestinal surgery - some procedures", "Emergency gastrointestinal surgery - including complex procedures" or "Laparoscopic gastrointestinal surgery" to [20] then:
Is data on all procedures performed to treat Crohn's disease submitted to the UK IBD registry?**

- Yes No Unknown

**23. If answered "Elective gastrointestinal surgery - some procedures", "Elective gastrointestinal surgery - including complex procedures", "Emergency gastrointestinal surgery - some procedures", "Emergency gastrointestinal surgery - including complex procedures" or "Laparoscopic gastrointestinal surgery" to [20] then:
Is there a designated/ funded specialist IBD anaesthetic service at this hospital?**

- Yes No Unknown

24. Which imaging modalities are available on-site at this hospital?

- | | |
|--|--|
| <input type="checkbox"/> Computerised tomography (CT) scan | <input type="checkbox"/> CT scan with contrast |
| <input type="checkbox"/> Magnetic resonance imaging (MRI) | <input type="checkbox"/> Magnetic Resonance Enterography (MRE) |
| <input type="checkbox"/> Ultrasound | <input type="checkbox"/> Abdominal X-Ray |

Please specify any additional options here...

**25a. If answered "Computerised tomography (CT) scan", "CT scan with contrast", "Magnetic resonance imaging (MRI)", "Magnetic Resonance Enterography (MRE)", "Ultrasound" or "Abdominal X-Ray" to [24] then:
What is the maximum wait time for acutely unwell Crohn's disease patients/ with severe disease to undergo cross sectional imaging/ ultrasound?**

- within 24 hours
 within 48 hours
 within 72 hours
 within 1 week
 within 4 weeks
 there is no maximum wait time specified
 Cross sectional imaging/ ultrasound is not available at this hospital

If not listed above, please specify here...

25b.If answered "Computerised tomography (CT) scan", "CT scan with contrast", "Magnetic resonance imaging (MRI)", "Magnetic Resonance Enterography (MRE)", "Ultrasound" or "Abdominal X-Ray" to [24] then:

What is the maximum wait time for patients with mild disease to undergo cross sectional imaging/ ultrasound ?

- Within 48 hours
- Within 72 hours
- Within 1 week
- Within 4 weeks
- Within 8 weeks
- There is no maximum wait time specified
- Cross sectional imaging/ ultrasound is not offered at this hospital

If not listed above, please specify here...

26a.If answered "Elective gastrointestinal surgery - some procedures", "Elective gastrointestinal surgery - including complex procedures", "Emergency gastrointestinal surgery - some procedures", "Emergency gastrointestinal surgery - including complex procedures" or "Laparoscopic gastrointestinal surgery" to [20] then:

Is there a pain management clinic that patients with Crohn's disease can be referred to pre- and post-surgery?

- Yes No Unknown

26b.If answered "Yes" to [26a] then:

What is the average waiting time for a referral to the clinic?

this is an estimate

 weeks

- Not Applicable Unknown

27. What is the maximum wait time for routine histological processing and reporting at this hospital?

 Day(s)

- Not Applicable Unknown

28. What is the maximum wait time for reporting on urgent biopsy samples at this hospital?

 Days

- Not Applicable Unknown

29a.What is the maximum wait time for acutely unwell Crohn's disease patients/ with severe disease to undergo endoscopy?

- within 24 hours
- within 48 hours
- within 72 hours
- within 1 week
- within 4 weeks
- No maximum wait time specified
- Not applicable- No endoscopy is performed at this hospital
- Unknown

If not listed above, please specify here...

29b. What is the maximum wait time for patients with mild disease to undergo endoscopy?

- within 1 week
- within 2 weeks
- within 4 weeks
- within 6 weeks
- within 12 weeks
- within 18 weeks
- No maximum wait time specified
- Not applicable- No endoscopy is performed at this hospital
- Unknown

If not listed above, please specify here...

30. Patients with Crohn's disease who are admitted to this hospital for treatment would be admitted to a:

Please select all that apply (and select "other" to add further options)

- General medical ward
- Specialist gastroenterology ward
- Specialist IBD ward
- General surgical ward
- Specialist surgical ward

Please specify any additional options here...

31. What access to toilet facilities would inpatients with Crohn's disease have on the gastroenterology ward?

- All beds on the ward have en-suite facilities
- All beds on the ward have en-suite facilities or a minimum of 1 accessible toilet per 3 beds
- A mix of facilities: some en-suite rooms, some wards with 1 or more toilets/ 3 beds, some less than this
- There are generally more than 3 beds per accessible toilet on the ward
- Unknown

If not listed above, please specify here...

32. Please describe the communication between this hospital and primary care providers regarding patients with Crohn's disease:

please select all that apply

- Discharge summary shared to the patient's general practitioner within 48 hours of discharge from hospital
- Primary care electronic access to results/ scans etc.
- Complete shared electronic access to full case note records in primary and secondary care
- Telephone links between primary and secondary care providers
- Written communication to the general practitioner of review of medication/ treatment within 48 hours

Please specify any additional options here...

33a. Is 24 hour intensive (level 3) care* provided onsite at this hospital?

please see definitions

- Yes
- No
- Unknown

33b. If answered "No" to [33a] then:

If not, is there a network agreement with a nearby hospital providing level 3 care to cover the transfer of patients requiring level 3 care?

- Yes
- No
- Unknown

This section refers to any local policies/ protocols/ pathways guiding the care of patients with Crohn's Disease

Diagnosis of Crohn's disease and care planning

1a. Is there a pathway/protocol for investigating patients with persistent lower gastrointestinal symptoms agreed with local primary care providers?

- Yes No Unknown

1b. If answered "Yes" to [1a] then:

If yes, does this include guidance on the use of faecal biomarker tests in primary care?

- Yes No Unknown

2. Following diagnosis with Crohn's Disease, is there a policy/ pathway/protocol that states that all newly diagnosed patients are:

please select all options that apply (and use the "other" option to add further answers in the free text box)

- Examined by a gastroenterologist
 Examined by an IBD clinical nurse specialist
 Examined by a member of the IBD specialist team
 Not applicable- there is no specific policy/pathway/protocol stating this at this hospital
 Examined in a IBD clinic
 Assessed for their individual needs

Please specify any additional options here...

3. If answered "Assessed for their individual needs" to [2] then:

Does the assessment of patients' individual needs include the following:

Please select all that apply. Please use the "other" box to add any additional options

- Nutritional status Bone health assessment Baseline infection screen
 Mental health assessment Smoking status Alcohol status
 Pain assessment

Please specify any additional options here...

4. If answered "Examined by a member of the IBD specialist team" to [2] then:

What is the maximum timeframe for newly diagnosed patients with Crohn's disease to be reviewed by the IBD team?

weeks Not Applicable Unknown

5. Following diagnosis, is it the policy that all outpatients with Crohn's disease start a defined treatment plan?

- Yes No Unknown

6a. If answered "Yes" to [5] then:

What is the maximum timeframe for commencing the treatment plan for patients with mild disease?

days Not Applicable Unknown

6b. If answered "Yes" to [5] then:

What is the maximum timeframe for commencing the treatment plan for patients with moderate to severe disease?

 days

- Not Applicable Unknown

7. If answered "Yes" to [5] then:

Are primary care providers informed of new diagnoses and the care plan (within 48 hours?)

- Yes- this usually happens within less than 48 hours
- Yes- this happens routinely within 48 hours
- Primary care providers are informed, but not generally within 48 hours
- Primary care providers are not routinely informed of new diagnoses/ the care plan
- Unknown
- Not applicable - there is no IBD service at this hospital

If not listed above, please specify here...

8. If answered "Yes" to [5] then:

Which of the following are routinely recorded in the care plan?

Please select all options that apply (an select the "other" option to add additional further answers in the free text box)

- Nutritional status
- Bone health
- Mental health
- Evidence of infection- bowel /abdominal
- Evidence of infection- other than bowel /abdominal
- Pain status
- Treatment options
- Imaging report/s

Please specify any additional options here...

9a. Is there a local policy/ protocol/ guideline to give guidance on the decision making process of choosing surgical or medical treatment options?

- Yes No Unknown

9b. If answered "Yes" to [9a] then:

Please provide details (guideline)

10. Are there local treatment protocols and clear pathways in place for the management of IBD patients experiencing flares in symptoms?

- Yes No Unknown

11. Is there a clear policy/ protocol/ guideline overseeing the prescription and review of preoperative biologics and immunomodulator management

- Yes No Unknown
-

12a. Is there a local guideline for the management of steroid treatment for patients with Crohn's disease?

- Yes No Unknown

12b. If answered "Yes" to [12a] then: Is this audited regularly?

- Yes No Unknown
-

Surgery for Crohn's disease

13. Is there a defined maximum timeframe from the referral to the appointment with the surgeon/s?

- Yes No Unknown Not applicable
-

14. Prior to elective surgery, does every patient undergo a full assessment and optimisation of medical treatment and physical condition

- Yes No Unknown
-

15a. For patients with mild/ moderate disease, is there a policy for a maximum timeframe between planning surgery and the operation taking place?

- No policy exists
 Yes - As soon as the patient is optimised
 Yes - Within 6 weeks
 Yes - Within 8 weeks
 Yes - Within 12 weeks
 Yes - Within 18 weeks
 Unknown
 Not applicable - elective surgery is not carried out at this hospital

If not listed above, please specify here...

15b. For patients with severe disease, is there a policy for a maximum timeframe between planning surgery and the operation taking place?

- No policy exists
 Yes - As soon as the patient is optimised
 Yes - Within 4 weeks
 Yes - Within 6 weeks
 Yes - Within 8 weeks
 Yes - Within 12 weeks
 Yes - Within 18 weeks
 Unknown
 Not applicable - elective surgery is not carried out at this hospital

If not listed above, please specify here...

16a. Is it policy that (where appropriate and in accordance with local guidance) that patients are offered laparoscopic resection as an option?

- Yes No policy Unknown Not applicable

16b. Is there at least one surgeon on each team, who can perform laparoscopic procedures?

- Yes No Unknown Not applicable

17. Is there a local policy/pathway/protocol/guideline stating that patients with Crohn's disease requiring inpatient care relating to their condition:

Please select all options that apply (please use the "other" box to add further answers)

- are admitted to a specialist IBD ward
- are admitted directly to the IBD ward or transferred to the IBD ward within 48 hours
- are admitted under a named consultant gastroenterologist/ colorectal surgeon
- are reviewed by the specialist IBD team within a specified timeframe
- are assessed on admission for their nutritional status
- have access to a IBD nurse specialist during their inpatient stay
- are referred to a dietitian on admission
- are assessed regarding their mental health
- are routinely assessed for pain and referred to a pain specialist where necessary
- have access to specialist mental health support if required
- have all medications (prescribed and over the counter) reviewed on admission by a pharmacist
- have medication reviewed throughout the inpatient stay and on discharge
- are referred for cross-sectional imaging/ ultrasound (unless recent imaging exists)
- not applicable- there is no policy/ pathway/ protocol/ guideline covering any aspect of care listed

Please specify any additional options here...

18a. Is there a local policy/ pathway/ protocol stating that patients with Crohn's disease who have undergone surgery for their condition have a follow-up appointment following discharge

- Yes No Unknown

18b. If answered "Yes" to [18a] then:

Who is the follow-up appointment with?

Please select all that apply. Please select "other" to add further options

- The consultant surgeon who performed the operation
- A consultant colorectal surgeon (not necessarily who performed the operation)
- The named consultant gastroenterologist
- The named IBD nurse specialist
- A combination of the above at a joint/ parallel dedicated follow-up clinic

Please specify any additional options here...

19. If answered "Yes" to [18a] then:

For a patient who has undergone surgery for Crohn's disease, what is the maximum timeframe after discharge for a follow-up appointment?

- weeks Not Applicable Unknown

20. If answered "Yes" to [18a] then:

Is there a coordinator to ensure that patients have post-operative care and follow-up arranged?

- Yes No Unknown

21a. Is the compliance with the policies/ pathways/ protocols/ guidelines outlined in this section regularly audited?

- Yes No Unknown

**21b.If answered "Yes" to [21a] then:
Please provide further details:**

22. Regarding the care of patients with Crohn's disease, are there agreed clear local protocols in place at this hospital for administration of vaccinations (including the vaccination for COVID-19):

Yes

No

Unknown

1. Is it policy that patients with Crohn's disease are signposted/ referred to education, groups and support?

- Yes No Unknown

2. Are any peer support groups for patients with IBD run at this hospital?

- Yes No Unknown

3. Which of the following means of providing information/ support to patients about Crohn's disease are available in this hospital:

Please select all options that apply (and use the "other" option to add further answers in the free text box)

- patient information leaflets/ booklets about Crohn's disease/ IBD
- access to specialist contraceptive/fertility advice.
- posters about Crohn's/ IBD in clinic areas/ waiting rooms
- signposting to organisations (such as Crohn's & Colitis UK) who provide information and support
- access to an advice line
- access to a patient peer support group/ befriending service
- clear written information about all available treatment options including risks/ benefits
- clear written information about post-operative care including wound/ stoma care

Please specify any additional options here...

4. Which of the following do you provide to patients regarding what to do in the event of a flare in symptoms:

- Information sheet with clear instructions
- Advice line to call - response within 24 hours
- Email advice line/ chat - response within 24 hours
- None of these

Please specify any additional options here...

5a. Is there a policy that patients are supported to make informed, shared decisions about their treatment and care to ensure these take their preferences and goals fully into account?

- Yes No Unknown

**5b. If answered "Yes" to [5a] then:
Please provide further details:**

6a. Are patients with Crohn's disease involved in the development of the IBD service?

Yes

No

Unknown

6b. If answered "Yes" to [6a] then:

Please provide further details on how this is done:

The following questions refer to organisation of services during the Covid-19 pandemic

2. During the COVID-19 pandemic* did this hospital admit symptomatic Covid-19 patients?

**COVID-19 pandemic refers to between 1st February 2020 - 31st April 2021*

- Yes No Unknown

3. During the COVID-19 pandemic was elective surgery suspended at this hospital?

**COVID-19 pandemic refers to between 1st February 2020 - 31st April 2021*

- Yes No Unknown Not applicable

4a. Did the Trust/ Health Board develop or accelerate any positive innovations, with regards to the care of patients with Crohn's disease, in response to the pandemic? (e.g. new pathways, roles, procedures etc)

- Yes No Unknown

**4b. If answered "Yes" to [4a] then:
Please provide further details (innovations)**

5. What has been the biggest challenge faced by this hospital since the outbreak of COVID-19?

Further comments regarding the care of patients with Crohn's disease

6a. Are there any gaps/ ongoing development in the service provided to patients with IBD/ Crohn's disease at this hospital that you would like to highlight?

- Yes No

**6b. If answered "Yes" to [6a] then:
If so, please provide further details (gaps)**

7a. Are there any areas of good practice at this hospital, regarding the care of patients with Crohn's disease that you would like to highlight?

Yes

No

**7b. If answered "Yes" to [7a] then:
If so, please provide further details(good practice)**

8. Do you have any other comments on the care of patients with Crohn's disease?

This could include service organisation or care pathways

Thank you for taking the time to complete this questionnaire

By doing so you have contributed to the dataset that will form the report and recommendations due for release in the Spring 2023.