



NCEPOD - Crohn's study - Patient survey

Default Question Block

Crohn's disease study - Patient survey

Who is NCEPOD?

NCEPOD is a national organisation that runs confidential enquiries to improve the quality of care for people in the UK. For over 30 years we have had a real impact on how healthcare is now delivered.

What is this study about?

We are running a study to learn more about the quality of care that people with Crohn's disease receive when they have a hospital admission for an abdominal surgical procedure.

We want to find out what is working well, what could be improved and how that might be achieved. The study will be used to produce a report for clinicians and other healthcare staff about how to improve the care they deliver. We will also use it to write guidance for patients and their partners, families and care givers on the overall care someone should expect to receive when being admitted to hospital for a surgical procedure for treatment of their Crohn's disease. Information is being collected across England, Wales and Northern Ireland.

It is essential that we hear the views and experiences of people with lived experience for the surgical treatment of Crohn's disease to develop recommendations that will make a real difference.

If you would like a copy of the final report, please email: Crohns@ncepod.org.uk

Who should complete this survey?

- If you are aged over 16 years old
- Have been diagnosed with Crohn's disease
- Have undergone surgery for your Crohn's disease treatment in the UK

We recognise that different people will have different experiences. You might find some questions easier to answer than others. If you feel unable to answer a question, please

tick the box "unsure" in the answer questions.

ALL RESPONSES GIVEN AS PART OF THIS STUDY ARE CONFIDENTIAL AND WE ARE UNABLE TO COMMENT ON INDIVIDUAL CASES.

Please only complete this survey if all of the following apply to you.

Please select all that apply to you:

- You are aged over 16
- You have been formally diagnosed with Crohn's disease
- Have undergone surgery for your Crohn's disease treatment in the UK

Age?

Sex?

Male Female

Non-binary

Prefer not to say

How would you describe your ethnic origin?

- White: British/ Irish/ Gypsy or Traveller/ Any other white background
- Black: British/ African/ Caribbean/ Any other black background
- Asian: British/ Indian/ Pakistani/ Bangladeshi/ Chinese/ Any other Asian background
- Other Ethnic Group: Arab/ Any other ethnic background
- Mixed/ multiple ethnic groups
- Other ethnic origin
- Prefer not to say

Block 1

What is your Crohn's disease diagnosis?

Answers may be multiple

- | | | |
|--|---|---|
| <input type="checkbox"/> Terminal ileal and ileocaecal | <input type="checkbox"/> Colonic | <input type="checkbox"/> Oral |
| <input type="checkbox"/> Small bowel | <input type="checkbox"/> Gastroduodenal | <input type="checkbox"/> Unsure/ Can't remember |
| <input type="checkbox"/> Ileocolonic | <input type="checkbox"/> Peri-anal | <input type="checkbox"/> Other - Please specify |
| | | <input type="text"/> |

How long ago were you diagnosed with Crohn's disease?

What were your first symptoms of Crohn's disease?

Answers may be multiple

- | | | |
|---|---|---|
| <input type="checkbox"/> Diarrhoea | <input type="checkbox"/> Abdominal cramping | <input type="checkbox"/> Weight loss |
| <input type="checkbox"/> Fever | <input type="checkbox"/> Blood in your poo | <input type="checkbox"/> Unsure/ Can't remember |
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Mouth sores | <input type="checkbox"/> Other - Please specify |
| <input type="checkbox"/> Abdominal pain | <input type="checkbox"/> Reduced appetite | <input type="text"/> |

How long was it between your first symptoms and your first visit to a healthcare professional?

How long was it between your first symptoms and receiving a formal diagnosis of Crohn's disease?

A Crohn's disease diagnosis is usually confirmed by a healthcare professional, using a combination of blood tests and scans (e.g. MRI, CT scan, barium studies or chest x-rays) and endoscopies (such as colonoscopy or a sigmoidoscopy which uses a long flexible tube to take pictures of your insides and take biopsies).

Which healthcare professional confirmed your diagnosis of Crohn's disease?

- GP
- IBD Nurse specialist
- Gastroenterologist
- Colorectal Surgeon
- A&E Doctors
- Other - Please specify

Unsure/ Can't remember

Before being formally diagnosed with Crohn's disease, do you think your symptoms were taken seriously by healthcare professionals?

- Strongly agree - My symptoms were taken seriously
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree - My symptoms were not taken seriously
- Unsure

Please give further detail about your answer:

Do you feel that there was a delay in being diagnosed with Crohn's disease?

Yes No

-

Unsure/ Can't remember

-

Please give further detail:

Please select all the information that you were given when you were first diagnosed with Crohn's disease:

Answers may be multiple

- | | |
|---|--|
| <input type="checkbox"/> Written information sheet/ booklet | <input type="checkbox"/> Specific contact details of IBD helpline |
| <input type="checkbox"/> Information about what to expect about disease progression | <input type="checkbox"/> Information was mentioned in conversation |
| <input type="checkbox"/> Information about what to do upon a flare | <input type="checkbox"/> Other - Please specify |
| <input type="checkbox"/> Information of specific website address e.g CCUK | <input type="checkbox"/> None |
| <input type="checkbox"/> Information about local Peer support groups | <input type="checkbox"/> Unsure/ Can't remember |
-

Do you feel that you were given sufficient information about Crohn's disease when you were first diagnosed?

Yes No

Unsure/ Can't remember

Please give further detail:

When you were first diagnosed with Crohn's disease, were you referred to an IBD team?

Yes No Unsure

How long did you have to wait for an appointment with the IBD team?

Block 2

When was your last Crohn's disease *flare in symptoms?

Please leave blank if you cannot remember the date of your most recent flare/ symptoms

*A flare describes when symptoms worsen and can be defined in some of the following ways: a change in toilet habits, blood in poo, abdominal pain. Flares aren't always just in the gut and can also include other inflammatory symptoms outside the bowel e.g. mouth ulcers, joint pain, skin rashes etc.

	Month	Year
Please Select:	<input type="text"/>	<input type="text"/>

How did you manage your flare?

- | | |
|--|--|
| <input type="checkbox"/> Managed your condition at home | <input type="checkbox"/> Went to the emergency department |
| <input type="checkbox"/> Visited your GP | <input type="checkbox"/> Went directly to IBD/ gastroenterology ward |
| <input type="checkbox"/> Called your consultant gastroenterologist / surgeon | <input type="checkbox"/> Other - Please specify |
| <input type="checkbox"/> Called your IBD nurse | <input type="checkbox"/> <input type="text"/> |
| <input type="checkbox"/> Called the IBD helpline | <input type="checkbox"/> Not applicable - No flare in symptoms |
| | <input type="checkbox"/> Unsure/ Can't remember |

Were you satisfied with the care/ advice you received during your flare?

Yes No

Unsure

Not applicable -
no flare in
symptoms

Prefer not to say

Please give further details:

Block 3

Please think back to your most recent surgery for Crohn's disease and answer the following questions:

Was the surgery you had for Crohn's disease:

A planned elective
procedure

A planned procedure
that became an
emergency

An emergency
procedure

Unsure

When did you have your most recent surgery for Crohn's disease?

Please leave blank if you cannot remember the date of your most recent surgery

_____ | _____ Month | _____ Year

Month

Year

Please Select:

Prior to your most recent surgery, do you feel that you received clear and concise information about the operation and its risks and benefits?

- Strongly agree - I received clear and concise information
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree - I did not receive clear and concise information
- Unsure

Thinking back to your most recent surgery, do you feel that there was a delay in having your surgery?

Yes No Unsure

-
-
-

Please give further details:

Were you happy with the amount of care and support you received from your healthcare team after surgery?

Yes No Unsure

-
-
-

In your opinion, what could have been done better?

Answers may be multiple

- Mental health support provided
- Peer support provided
- Nutritional team input
- Dietetics team input
- Fertility advice (if applicable)
- Pain service input
- Other - Please specify
- Unsure

Did you have any complications/ problems after your surgery?

Yes No Unsure

Please give further details about the problems you had after your surgery:

Were you happy with the amount of care and support you received from your healthcare team after experiencing complications/ problems post-surgery?

Yes No Unsure

Please give further detail about what could have been done better

Block 4

Crohn's Disease Medication Information

Are you currently taking medication(s) for the management of your Crohn's Disease?

Yes No Unsure

Please comment on your experience of being on Crohn's disease medications:

This could include positive or negative personal experiences

Do you feel that you were given information and the opportunity to ask questions about your medication(s) and any possible side effects?

- Strongly agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree
- Unsure

Block 5

Overall rating of Crohn's disease care

Generally, how would you describe the quality of the healthcare you have received for your Crohn's disease care?

Very good

Good

Adequate

Poor

Unacceptable

Unsure

Please can you give some detail as to why you describe it this way:

Please list any areas where there was room for improvement in your care:

Answers may be multiple

Timing of diagnosis

Delays in treatment

Surgical intervention

Information about getting help for Crohn's disease

Information about living with Crohn's disease

Input from your IBD doctors

Dietary advice

Stoma advice

Medication

Mental health support

Treatment delays due to the Covid-19 pandemic

Lack of access to healthcare professionals during the Covid-19 pandemic

Other - Please specify

N/A - no improvements needed

Unsure

How could your care have been improved? Please give further details:

Please select the areas that you feel went well with the management of your Crohn's disease in the time since your diagnosis:

- | | |
|---|---|
| <input type="checkbox"/> Timing of diagnosis | <input type="checkbox"/> Medication |
| <input type="checkbox"/> Delays in treatment | <input type="checkbox"/> Mental health support |
| <input type="checkbox"/> Surgical intervention | <input type="checkbox"/> Treatment delays due to the Covid-19 pandemic |
| <input type="checkbox"/> Information about getting help for Crohn's disease | <input type="checkbox"/> Lack of access to healthcare professionals during the Covid-19 pandemic |
| <input type="checkbox"/> Information about living with Crohn's disease | <input type="checkbox"/> Other - Please specify |
| <input type="checkbox"/> Dietary advice | <input type="checkbox"/> <div style="border: 1px solid black; width: 380px; height: 18px;"></div> |
| <input type="checkbox"/> Stoma advice | <input type="checkbox"/> Unsure |

**Is there anything else you would like to comment on about your Crohn's disease care?
Please give further detail in the box below:**