



IBD UK

Strategy
Partnership
Quality Improvement



Working together
for everyone affected
by inflammatory
bowel disease

IBD PATIENT SURVEY: YOUR NHS TREATMENT AND CARE

YOUR CHANCE TO TELL US ABOUT YOUR EXPERIENCE OF CROHN'S OR COLITIS CARE IN THE NHS

Thank you for participating in the first UK-wide national IBD Patient Survey. This is about your experience of care for your Crohn's or Colitis in the NHS. It will give healthcare professionals and NHS managers an understanding of what local services do well and what could be done better. Your views are very important in helping the NHS improve the quality of services for people living with Crohn's or Colitis, so that they better meet your needs.

Improving services in your area for people with Crohn's and Colitis

IBD UK is a group of patient and professional organisations who have come together to develop new IBD Standards and improve care. These standards set out what good services and care look like. Questions in this survey relate directly to particular standards. Your answers will be used to grade (or 'benchmark') services in terms of how well they are performing against the IBD Standards. They will also help to build the case for greater investment in Crohn's and Colitis care across the UK.

Completing the survey:

Survey extended, closes on 22nd November 2019

Crohn's and Colitis affect everyone differently, so not all the questions will be relevant to you. Depending on your answers, you may skip over some of the questions.

If you are under 18, you will need to ask a parent, carer or guardian to give consent and complete the survey with you. If you are filling it in on behalf of someone else, please do this together.

The overall results will be published on the IBD UK website where you and healthcare professionals will be able to see them. Please note your answers will remain **anonymous**. No personal information will be shared which can identify you as an individual.

Please answer all questions, unless otherwise specified.

If you have any further questions, please email info@ibduk.org

Thank you.

SECTION 1: ABOUT YOU

Firstly, please tell us about you...

1.1 Which of these options describes you or the person on whose behalf you are completing the survey?

Please choose one option



I have Crohn's Disease



Crohn's Disease causes inflammation of the gut (digestive system). Crohn's can affect any part of the gut including the mouth though the most common area affected is the end of the ileum (the last part of the small intestine), or the colon



I have Ulcerative Colitis



Ulcerative Colitis causes inflammation and ulceration of the inner lining of the rectum and colon (the large bowel)



I have Microscopic Colitis



Microscopic Colitis affects the large bowel (colon and rectum). There are two main forms: Lymphocytic Colitis and Collagenous Colitis



I have Inflammatory Bowel Disease Unclassified (IBDU)



Also known as Indeterminate Colitis, or as Colitis of uncertain type or etiology (CUTE). You may be described as having IBDU if it is unclear whether you have Crohn's Disease or Ulcerative Colitis



I have symptoms but a hospital specialist has yet to confirm that I have Crohn's or Colitis



I do not have Crohn's or Colitis

Please do not complete the survey if a hospital specialist has yet to confirm that you have Crohn's or Colitis.

Thank you for your interest in the IBD Patient Survey, however we are only collecting data from individuals with a confirmed diagnosis of Crohn's or Colitis, as the questions in this survey relate directly to the new IBD Standards. For further information on Crohn's or Colitis, our work and how to get involved, please visit the IBD UK website www.ibduk.org

Please note: For simplicity, we will refer to all diagnoses as Crohn's and Colitis for the rest of the survey.

1.2 In which hospital have you received the majority of your Crohn's or Colitis care?

Your answers will help us to understand how services are provided and coordinated. If you have NOT recently received hospital care or are not under the care of an IBD service, please write the hospital you live nearest to

1.3 When was your last contact with this service?

Please choose one option



Within the last 12 months



1 - 2 years ago



More than 2 years ago



Never had contact



Don't know / Can't remember

1.4 How old are you?

Please choose one option



0 - 17 years old



If you are under 18, you will need to ask a parent, carer or guardian to give consent and complete the survey together



18 - 24 years old



25 - 34 years old



35 - 44 years old



45 - 54 years old



55 - 64 years old



65 - 74 years old



Over 75 years old



Prefer not to say

SECTION 2: ABOUT YOUR DIAGNOSIS

The following questions will help us to understand how you were told about having Crohn's or Colitis, and the information, tests and care you were subsequently given.

2.1 How recently were you diagnosed with Crohn's or Colitis?

Please choose one option



Sometimes a patient's diagnosis may change (although it is not a common occurrence). If your diagnosis has changed please base your answers on your most recent confirmed diagnosis. A confirmed diagnosis is made within a specialist setting, usually at a hospital, using a combination of medical tests and investigations including 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)



Within the last 2 years



More than 2 years ago

Skip sections 2 & 3 and go to section 4



Don't know / Can't remember

Skip sections 2 & 3 and go to section 4

2.2 Before your diagnosis, did your GP offer you a faecal calprotectin or faecal immunochemical test (FIT) before you were referred to hospital for further investigations?

Please choose one option



This question refers to faecal calprotectin/ faecal immunochemical test FIT test for diagnostic purposes only, and not for the purposes of a regular check-up. A faecal calprotectin or faecal immunochemical test (FIT) is a stool (faeces/poo) test that measures the level of active inflammation in the intestine. If the inflammatory markers are high, it is more likely to lead to a diagnosis of Crohn's or Colitis



Yes



No



Don't know / Can't remember

2.3 If a GP referred you to a hospital specialist, how long did you wait for your first appointment?

Please choose one option

A referral is when a doctor feels you need specialist assessment, investigations or treatment. In these cases, the doctor will refer a patient to hospital to be seen by an appropriate consultant or specialist. Your doctor/nurse may already have done some simple tests, such as blood tests or a chest x-ray, but a hospital referral is usually (necessary but not always) for more specialised tests



Less than 4 weeks



1 month - 6 months



7 months - 12 months



More than a year



I was diagnosed privately (using non-NHS services)



Not applicable



Don't know / Can't remember

2.4 While waiting for my diagnosis to be confirmed, I was given clear information about what was going to happen next and who to contact if I had any questions.

Please rate the above statement



A confirmed diagnosis is made within a specialist setting, usually at a hospital, using a combination of medical tests and investigations, including blood test 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)



Strongly disagree



Tend to disagree



Neither agree nor disagree



Tend to agree



Strongly agree



Don't know / Can't remember

SECTION 2: CONTINUED

- 2.5** Before your diagnosis was confirmed, how many times did you visit Accident and Emergency services (A&E) with symptoms due to your Crohn's or Colitis?

Please choose one option

- ☐ None
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ More than 5 times
- ☐ Don't know / Can't remember

- 2.6** How long did it take from the time you first spoke to a healthcare professional about your symptoms, to the time your diagnosis was confirmed?

Please choose one option

- ☐ **i** A confirmed diagnosis is made within a specialist setting, usually at a hospital, using a combination of medical tests and investigations, including blood test 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)

- ☐ Less than 4 weeks
- ☐ 1 - 3 months
- ☐ 4 - 6 months
- ☐ 7 - 12 months
- ☐ 1 - 2 years
- ☐ 2 - 5 years
- ☐ More than 5 years
- ☐ Don't know / Can't remember

SECTION 3: NEWLY DIAGNOSED

- ☐ **!** Please skip this section if you were diagnosed more than 2 years ago.

The following questions will help us to understand how you were told you had Crohn's or Colitis, and the information, tests and care you were subsequently given.

- 3.1** Which healthcare professional confirmed your diagnosis of Crohn's or Colitis?

Please choose one option

- ☐ **Adult Gastroenterologist**

- ☐ **i** Gastroenterologists are doctors who investigate, diagnose and treat all gastrointestinal (stomach and intestines) and hepatological (liver, gallbladder, biliary tree and pancreas) diseases. They are also sometimes known as consultants or specialists

- ☐ **Paediatric Gastroenterologist**

- ☐ **i** Gastroenterologists are doctors who investigate, diagnose and treat all gastrointestinal (stomach and intestines) and hepatological (liver, gallbladder, biliary tree and pancreas) diseases in children. They are also sometimes known as consultants or specialists

- ☐ **Endoscopist / Radiographer / Diagnostic Imager**

- ☐ **i** (If the Endoscopist was also your Gastroenterologist or your IBD Nurse specialist please choose those options). An Endoscopist is a person trained in the use of the endoscope or flexible camera that takes pictures of inside the body. A Radiographer is a healthcare professional who uses x-rays to produce radiographs of patients in order to help diagnose the patient's medical condition

- ☐ **Adult IBD Nurse Specialist**

- ☐ **i** An IBD Nurse Specialist is a nurse who is trained to work with adults who have Crohn's or Colitis

- ☐ **Paediatric IBD Nurse Specialist**

- ☐ **i** An IBD Nurse Specialist is a nurse who is trained to work with children who have Crohn's or Colitis

3.1 continued

☐ Colorectal Surgeon

- ☐  A general surgeon who has had further training and is an expert in the diagnosis and treatment of diseases of the colon, rectum, and anus

☐ Paediatric Colorectal Surgeon

- ☐  A general surgeon who has had further training and is an expert in the diagnosis and treatment of diseases of the colon, rectum, and anus in children

☐ GP

- ☐  A doctor based in the community who treats patients with minor or chronic illnesses and refers those with serious conditions to a hospital

☐ I was diagnosed privately (non-NHS services)

☐ Other

☐ Don't know / Can't remember

3.2 Are the questions in this section related to the hospital you identified in section 1?

☐ Yes

☐ No, please specify which hospital this section relates to

3.3 When you were told you had Crohn's or Colitis, were you offered any written information about your condition? Please choose one option

3.3 continued

☐ Yes - it was helpful and easy to understand

☐ Yes - it was helpful but not easy to understand

☐ Yes - but it was not helpful nor easy to understand

☐ No - I was not offered written information

☐ Don't know / Can't remember

3.4 When you were told you had Crohn's or Colitis, were you given any of the following? Please choose all that apply

☐ Information about a local IBD service

- ☐  A local IBD Service is a specialist team of healthcare professionals who provide services and treatment for patients with Crohn's and Colitis. The team could include Gastroenterologists, IBD Nurse Specialists and Colorectal Surgeons

☐ Contact details for a local IBD service

☐ A list of all staff in a local IBD service

☐ None of the above

Skip question 3.4 and go to question 3.5

☐ Don't know / Can't remember

Skip question 3.4 and go to question 3.5

3.5 The information helped me to make the best of the services offered.

Please rate the above statement

☐ Strongly disagree

☐ Tend to disagree

☐ Neither agree nor disagree

☐ Tend to agree

☐ Strongly agree

☐ Don't know / Can't remember

☐ Not applicable

SECTION 3: CONTINUED

3.6 When you were told you had Crohn's or Colitis, did a healthcare professional give you any information about relevant patient organisations or charities?

Please choose all that apply

i Patient organisations or charities provide a supporting role for patients. They are not part of the NHS, although some organisations can work very closely with NHS services and may deliver specific services in agreement with the NHS. Examples of national patient organisations can include Crohn's & Colitis UK, CICRA, Colostomy UK, Ileostomy & Internal Pouch Association (IA)

- ☐ Crohn's & Colitis UK adult or family information pack
- ☐ CICRA parent pack
- ☐ Written information e.g. information sheet / booklet
- ☐ I was given specific contact details and / or a website address
- ☐ Information was mentioned in conversation
- ☐ Other

- ☐ None
- ☐ Don't know / Can't remember

3.7 When you were diagnosed, were you placed under the care of an Adult or Paediatric Gastroenterologist?

Please choose one option

i Gastroenterologists are doctors who investigate, diagnose and treat all Gastrointestinal (stomach and intestines) and hepatological (liver, gallbladder, biliary tree and pancreas) diseases. Paediatric Gastroenterologists treat babies, young children and adolescents up to 18 years old (depending on when they are ready to move into adult services)

3.7 continued

- ☐ Yes
- ☐ No
- ☐ Don't know / Can't remember

3.8 Following your diagnosis, were you assessed for any of the following?

Please choose all that apply

- ☐ How severe your Crohn's or Colitis was, e.g. through tests and asking about symptoms
- ☐ Signs of malnutrition and / or nutritional deficiencies e.g. iron, B12
- ☐ How healthy your bones were e.g. given a DEXA scan
- ☐ How well you were coping emotionally
- ☐ None of the above
- ☐ Don't know / Can't remember

3.9 Following your assessment, were you offered the opportunity to be referred to any of the following?

Please choose all that apply

- ☐ Dietitian
- i** A Dietitian is a qualified healthcare professional, who as well as providing general health advice, can also work with people with special dietary needs due to health conditions

☐ Psychologist / Mental Health Professional / IAPT service

- i** A Psychologist is a professional who specialises in diagnosing and treating mental, emotional and behavioural disorders.

The Improving Access to Psychological Therapies (IAPT) programme provides services for people with anxiety and depression (including OCD) via evidence based psychological therapies and treatments

3.9 continued

IBD Nurse Specialist

-  An IBD Nurse Specialist is a nurse who is trained to work with patients who have Crohn's or Colitis

Colorectal Surgeon

-  A general surgeon who has had further training and is expert in the diagnosis and treatment of diseases of the colon, rectum, and anus

None of the above

Don't know / Can't remember

3.11 Did you have a written first treatment plan?

Please choose one option

-  A first treatment plan is a clear plan for treatment, including what this will be, when it will start and how it will be monitored. It could be part of or be included in a personalised care plan

Yes

No

Skip 3.10 and go to question 3.11

Don't know / Can't remember

Skip 3.10 and go to question 3.11

3.12 Did your first treatment plan include any of the following? **Please choose all that apply**

A clear diagnosis

Information about what part of your gut, or elsewhere (e.g. skin, eyes, joints) was affected

Information on the likely course of your condition

Your drug treatments

Information about how your drug treatments would be monitored and any follow-up needed

3.12 continued

Surgical interventions

Dietary guidance

None of the above

Don't know / Can't remember

3.13 I was given enough information about potential treatments and care, including benefits and possible side-effects, to understand the options available to me and make an informed choice.

Please rate the above statement

Strongly disagree

Tend to disagree

Neither agree nor disagree

Tend to agree

Strongly agree

Don't know / Can't remember

3.14 I felt what mattered to me was taken into account when making decisions about treatments and care.

Please rate the above statement

Strongly disagree

Tend to disagree

Neither agree nor disagree

Tend to agree

Strongly agree

Don't know / Can't remember

PLEASE TURN OVER

SECTION 3: CONTINUED

3.15 Were you involved as much as you wanted to be in decisions about your care and treatment?

Please choose one option

- ☐ Yes - definitely
- ☐ Yes - to some extent
- ☐ No
- ☐ Don't know / Can't remember

3.16 How long after your diagnosis were you able to start treatment?

Please choose one option

- ☐ Within 48 hours
- ☐ 2 - 7 days
- ☐ 1 - 2 weeks
- ☐ 3 - 4 weeks
- ☐ More than 4 weeks
- ☐ Not applicable
- ☐ Don't know / Can't remember

SECTION 4: ONGOING CARE AND MONITORING

These questions will help us to understand how you are supported to manage, monitor and treat your Crohn's or Colitis over the long term.

Please base your answers on your experience over the last 12 months.

Please choose one option

4.1 What best describes the service responsible for treating and managing your Crohn's or Colitis?

- ☐ **IBD service (adult or paediatric)**
 - ☐ An IBD Service is a specialist team of healthcare professionals who provide services and treatment for patients with Crohn's and Colitis, which could include Gastroenterologists and IBD Nurse Specialists
- ☐ **General Gastroenterology clinic (adult or paediatric)**
 - ☐ Gastroenterologists are doctors who investigate, diagnose and treat all gastrointestinal (stomach and intestines) diseases. They have general clinics, where they treat both patients with and without Crohn's or Colitis
- ☐ **Surgical clinic (adult or paediatric)**
 - ☐ A Colorectal Surgeon is a general surgeon, who has had further training and is expert in the diagnosis and treatment of diseases of the colon, rectum, and anus
- ☐ **GP practice**
 - ☐ A GP is a doctor based in the community who treats patients with minor or chronic illnesses and refers those with serious conditions to a hospital
- ☐ **Private (non-NHS) healthcare**
- ☐ **Not clear to me**
- ☐ **Other**

4.2 Are the questions in this section related to the hospital you identified in section 1?

- ☐ Yes
- ☐ No, please specify which hospital this section relates to

4.3 Are you currently under the care of a named Gastroenterologist (adult or paediatric) who is responsible for your care?
Please choose one option

 You may see other healthcare professionals for your care, as well as your named Gastroenterologist

- ☐ Yes
- ☐ No
- ☐ Don't know / Can't remember

4.4 Have you been provided with any of the following?
Please choose all that apply

 For this question please consider any time from the beginning of your treatment at your chosen hospital

- ☐ Any written information about Crohn's and Colitis
- ☐ General information about the local NHS IBD service
- ☐ Contact details for the NHS IBD service
- ☐ A list of all staff in the NHS IBD service
- ☐ None of the above
- ☐ Don't know / Can't remember

4.5 Has a healthcare professional given you any of the following information about relevant national patient organisations or charities?

Please choose all that apply

 For this question please consider any time from the beginning of your treatment at your chosen hospital.

Patient organisations or charities provide a supporting role for patients. They are not part of the NHS, although some organisations can work very closely with NHS services and may also deliver specific services in agreement with the NHS. Examples of national patient organisations can include Crohn's & Colitis UK, CICRA, Colostomy UK, Ileostomy and Internal Pouch Association (IA)

- ☐ Crohn's & Colitis UK adult or family information pack
- ☐ CICRA patient pack
- ☐ Written information
- ☐ I was given specific contact details and / or website address
- ☐ Information was mentioned in conversation
- ☐ Other

- ☐ None
- ☐ Don't know / Can't remember

4.6 Do you have contact with an IBD nurse specialist?
Please choose one option

 An IBD Nurse Specialist is a nurse who is trained to work with patients who have Crohn's or Colitis. This question is asking if you have an IBD Nurse Specialist that you have contact with, such as face-to-face, through an IBD advice line or via email

SECTION 4: CONTINUED

4.6 continued

☐ Yes

☐ No – I do not have access to an IBD nurse
Skip questions 4.6 & 4.7 and go to question 4.8

☐ Don't know / Can't remember
Skip questions 4.6 & 4.7 and go to question 4.8

4.7 Have you been provided with any of the following?

Please choose all that apply

☐ **i** For this question please consider any time from the beginning of your treatment at your chosen hospital

☐ Telephone contact details for an NHS IBD advice line

☐ Email contact details for an NHS IBD service advice line

☐ Opening hours for an NHS IBD advice line

☐ None of the above

☐ Don't know / Can't remember

4.8 Have you ever contacted your NHS IBD service advice line?

Please choose one option

☐ Yes

☐ No

Skip question 4.8 and go to question 4.9

☐ Don't know / Can't remember

4.9 When I contact the NHS IBD service advice line, I get a response by the end of the next working day. **Please rate the above statement**

☐ Strongly disagree

☐ Tend to disagree

☐ Neither agree nor disagree

☐ Tend to agree

☐ Strongly agree

4.9 continued

☐ Don't know / Can't remember

☐ Not applicable

4.10 In my opinion, the IBD Nurse Specialists who treat me are knowledgeable about Crohn's and Colitis and how to treat the conditions.

Please rate the above statement

☐ Strongly disagree

☐ Tend to disagree

☐ Neither agree nor disagree

☐ Tend to agree

☐ Strongly agree

☐ Don't know / Can't remember

☐ Not applicable

4.11 In my opinion, my GP is knowledgeable about Crohn's and Colitis and how to treat the conditions.

Please rate the above statement

☐ **i** For example my GP understands what action to take if I flare, and how to escalate treatment

☐ Strongly disagree

☐ continued

☐ Tend to disagree

☐ Neither agree nor disagree

☐ Tend to agree

☐ Strongly agree

☐ Don't know / Can't remember

☐ Not applicable

4.12 In my opinion, my GP supports me to manage my Crohn's or Colitis and live as well as possible.

Please rate the above statement

-  For example, this is about your hopes and life aspirations, including having the information and skills to support you to work, have a family, travel and socialise

- ☐ **Strongly disagree**
- ☐ **Tend to disagree**
- ☐ **Neither agree nor disagree**
- ☐ **Tend to agree**
- ☐ **Strongly agree**
- ☐ **Don't know / Can't remember**
- ☐ **Not applicable**

4.13 My care is well-coordinated between my GP and Gastroenterologist (e.g. blood tests, monitoring drug levels).

Please rate the above statement

-  Coordinated care is guided by and organised effectively around your needs and preferences. It may be delivered by a number of healthcare professionals and departments working together, for example your GP and Gastroenterologist will always be informed of changes to your treatment, blood test results, post-operative wound and stoma care, or have a shared care agreement

- ☐ **Strongly disagree**
- ☐ **Tend to disagree**
- ☐ **Neither agree nor disagree**
- ☐ **Tend to agree**
- ☐ **Strongly agree**
- ☐ **Don't know / Can't remember**
- ☐ **Not applicable**

4.14 My treatment and care are well-coordinated between my IBD team and any other services I see for other medical needs I have.

Please rate the above statement

-  An IBD team is a team of healthcare professionals who provide services and treatment for patients with Crohn's and Colitis, which could include Gastroenterologists, IBD Nurse specialist and Colorectal Surgeons.

Crohn's or Colitis doesn't just affect the gut and can also include inflammatory symptoms outside the bowel such as mouth ulcers, joint pain, skin, rashes, uveitis. Coordinated care is guided by and organised effectively around the needs and preferences of an individual. It may be delivered by a number of healthcare professionals and departments working together, for example your GP and Gastroenterologist will be informed of changes in your treatment, blood test results, post-operative ward and stoma care, or have a shared care agreement

- ☐ **Strongly disagree**
- ☐ **Tend to disagree**
- ☐ **Neither agree nor disagree**
- ☐ **Tend to agree**
- ☐ **Strongly agree**
- ☐ **Don't know / Can't remember**
- ☐ **Not applicable**

4.15 I have access to specialist advice or support with diet and nutrition if I should want it.

Please rate the above statement

- ☐ **Strongly disagree**
- ☐ **Tend to disagree**
- ☐ **Neither agree nor disagree**
- ☐ **Tend to agree**
- ☐ **Strongly agree**
- ☐ **Don't know / Can't remember**
- ☐ **Not applicable**

SECTION 4: CONTINUED

4.15 I am supported by a team of IBD specialists who help me manage my condition.

Please rate the above statement

-  An IBD team is a team of healthcare professionals who provide services and treatment for patients with Crohn's and Colitis, which could include Gastroenterologists, IBD Nurse specialist and Colorectal Surgeons

- ☐ Strongly disagree
- ☐ Tend to disagree
- ☐ Neither agree nor disagree
- ☐ Tend to agree
- ☐ Strongly agree
- ☐ Don't know / Can't remember
- ☐ Not applicable

4.16 Do you have a personalised written care plan?

Please choose one option

-  This is different to a first treatment plan. A care plan is a document that sets out how your Crohn's or Colitis will be treated, managed and monitored. It should take into consideration your hopes and life aspirations. It is an agreement or plan between you and your healthcare professional to help meet those goals. This is different to the letters or correspondence that a doctor may send you or your GP after each appointment

- ☐ Yes
- ☐ No
- ☐ Don't know / Can't remember

4.17 I am given appropriate information about potential treatments and care (including potential benefits and side effects), to make informed decisions.

Please rate the following:

- ☐ Strongly disagree
- ☐ Tend to disagree

4.17 continued

- ☐ Neither agree nor disagree
- ☐ Tend to agree
- ☐ Strongly agree
- ☐ Don't know / Can't remember
- ☐ Not applicable

4.18 We discuss my wider life goals and priorities, as part of planning my Crohn's or Colitis care.

Please rate the above statement

-  For example, work, education, having a family, travelling and socialising

- ☐ Strongly disagree
- ☐ Tend to disagree
- ☐ Neither agree nor disagree
- ☐ Tend to agree
- ☐ Strongly agree
- ☐ Don't know / Can't remember
- ☐ Not applicable

4.19 I am involved as much as I want to be in decisions about my care and treatment.

Please rate the above statement

- ☐ Yes - definitely
- ☐ Yes - to some extent
- ☐ No
- ☐ Don't know / Can't remember

4.20 Has a healthcare professional provided you with any of the following?

Please choose all that apply

-  This information could be part of your care plan. A flare describes when symptoms worsen and can be defined in some of the following ways:

- Going to the toilet more than 5 times in 24 hours or more than is normal for you
- Loose stools or diarrhoea with any blood/ mucus for more than 3 days



- Abdominal pain

Flares aren't always just in the gut and can also include other inflammatory symptoms outside the bowel e.g. mouthulcers, joint pain, skin rashes etc.

Information on how to stay well or reduce your risks of a flare

Information on how to recognise the first signs of a flare

Steps you may be able to take to adjust medicine dosage, if medically appropriate for you

Written details about who to contact and when, if you think you are experiencing a flare

Written information on what to do if you have an emergency or more urgent enquiry

Don't know / Can't remember

None of the above

4.21 Do you have a regular review for your Crohn's or Colitis, regardless of whether you are well or not?

Please choose one option

These kinds of reviews or 'check-ups' are sometimes known as an 'annual review' and they can be face-to-face or on the phone. when you are well, as well as when you are poorly. They may involve any necessary tests and investigations, as well as making any adjustments to your treatment

Yes - I have regular reviews

Yes - I have reviews, but these are not as regular as I would like

No

I have never had a review

Skip questions 4.22 & 4.23 and go to question 4.24

Don't know / Can't remember

4.22 Who do you have your review with?

Please choose one option

IBD Nurse Specialist

Paediatric Nurse Specialist

Gastroenterologist

Paediatric Gastroenterologist

Colorectal surgeon

Paediatric Colorectal Surgeon

GP

Joint clinic e.g. Surgeon and Gastroenterologist

Other

It varies

Don't know / Can't remember

4.23 These reviews give me the opportunity to discuss what matters to me.

Please rate the above statement

Strongly disagree

Tend to disagree

Neither agree nor disagree

Tend to agree

Strongly agree

Don't know / Can't remember

Not applicable

4.24 During appointments, I am asked about fatigue / tiredness and treatment options are discussed to manage this.

Please rate the above statement

PLEASE TURN OVER

SECTION 4: CONTINUED

4.24 continued

-  This may involve referrals to other members of the IBD service, as well as tests and investigations and/or exploring medical or non-medical approaches

 Strongly disagree

 Tend to disagree

 Neither agree nor disagree

 Tend to agree

 Strongly agree

 Don't know / Can't remember

 Not applicable

4.25 During appointments, I am asked about pain and treatment options are discussed to manage this.

Please rate the above statement

-  This may involve referrals to other members of the IBD service as well as tests and investigations and/or exploring medical or non-medical approaches

 Strongly disagree

 Tend to disagree

 Neither agree nor disagree

 Tend to agree

 Strongly agree

 Don't know / Can't remember

 Not applicable

4.26 During appointments, I am asked about my mental health or emotional wellbeing and treatment options are discussed.

Please rate the above statement

-  This may involve referrals to other members of the IBD service as well as a Psychologist, as well as tests and investigations and/or exploring medical or non-medical approaches

 Strongly disagree

 Tend to disagree

4.25 continued

Neither agree nor disagree

Tend to agree

Strongly agree

Don't know / Can't remember

Not applicable

4.27 During appointments, I am asked about IBD related complications and / or conditions outside of the gut and treatment options are discussed.

Please rate the above statement

-  Complications or conditions outside the gut could include: joints, eyes or skin.

This may involve referrals to other members of the IBD service such as a Dietitian or Psychologist, as well as tests and investigations and/or exploring medical or non-medical approaches

 Strongly disagree

 Tend to disagree

 Neither agree nor disagree

 Tend to agree

 Strongly agree

 Don't know / Can't remember

 Not applicable

4.28 If you have Ulcerative Colitis or Crohn's Disease of the large bowel, has a healthcare professional discussed how regularly you should have a screening colonoscopy?

Please choose one option

-  Clinicians recommend that those living with Ulcerative Colitis or Crohn's Disease of the large bowel should have regular cancer surveillance screening carried out through a colonoscopy, as part of the long-term management of these types of conditions. How regularly you are screened will depend on a number of factors

4.28 continued

- ☐ Yes - I know when this is due and will receive a reminder
- ☐ Yes - I know when this is due
- ☐ Yes - but I don't know when this is due
- ☐ No
- ☐ Not applicable - I do not have Ulcerative Colitis or Crohn's Disease of the bowel
- ☐ Don't know / Can't remember

4.29 Have you been offered any of the following opportunities by any NHS service to learn more about treating and / or living with Crohn's or Colitis?

Please choose all that apply

☐ For example, diet, surgery and pregnancy

☐ I have been offered the opportunity to attend an IBD open day at my local hospital

☐ I have been offered the opportunity to attend an educational talk

☐ I have been offered the opportunity to attend a course on IBD

☐ Other

☐ None of the above

☐ Don't know / Can't remember

4.30 I have the information and skills to confidently manage everyday symptoms and live as well as possible.

Please rate the above statement

☐ For example, this is about reaching your hopes and life aspirations, including having the information and skills to support you to work, have a family, travel, and socialise

☐ Strongly disagree

☐ Tend to disagree

☐ Neither agree nor disagree

☐ Tend to agree

☐ Strongly agree

☐ Don't know / Can't remember

☐ Not applicable

PLEASE TURN OVER

SECTION 5: MOVING INTO ADULT SERVICES

5.1 Have you been moved or 'transitioned' into adult gastroenterology or IBD services within the last 12 months?

Please choose one option

 In healthcare, the word transition describes the process of preparing, planning and moving from children's to adult services

☐ **Yes**

☐ **No**

Skip section 5 and go to section 6

☐ **Don't know / Can't remember**

5.2 As part of your 'transition' or move, did you have any of the following?

Please choose all that apply

☐ **A named coordinator**

 A named coordinator should oversee your transition. It's normally your IBD nurse or another person who works with the IBD team

☐ **An individual transition plan**

 A transition plan is a document that you should receive as part of your transition to adult IBD services, it allows you to outline your needs, preferences and concerns

☐ **Joint clinics between the paediatric team and members of the adult IBD service**

 This is a chance for you to have an appointment with your old IBD team and the new team at the same time

☐ **Information about what to expect from transition**

 For example, face to face discussions, booklets, information sheets and online information. This could be from either the hospital or patient organisations

☐ **None of the above**

☐ **Don't know / Can't remember**

SECTION 6: FLARE MANAGEMENT

These questions will help us to understand your experiences of services and support when your symptoms worsen or become unmanageable, often described as a 'flare', active disease or relapse.

Please base your answers on your experience over the last 12 months.

6.1 How many flares have you experienced in the last 12 months?

Please choose one option

 If you are not sure, please give your best estimate. Please select NONE, if you have been recently diagnosed and have yet to get symptoms under more control or experience remission. A flare can be described in some of the following ways:

- Going to the toilet more than 5 times in 24 hours or more than is normal for you
- Loose stools or diarrhoea with any blood/mucus for more than 3 days
- Abdominal pain

Flares aren't always just in the gut and can also include inflammatory symptoms outside the bowel such as mouth ulcers, joint pain, skin rashes etc.

☐ **None**

Skip section 6 and go to section 7

☐ **1**

☐ **2**

☐ **3**

☐ **4**

☐ **5**

☐ **More than 5**

☐ **Don't know / Can't remember**

Skip section 6 and go to section 7

6.2 Thinking about your most recent flare, who did you contact in the first instance?

Please choose one option

- ☐ **I referred to my treatment / flare / care plan**
- ☐ **GP**
- ☐ **Gastroenterologist**
- ☐ **Paediatric Gastroenterologist**
- ☐ **IBD Nurse Specialist / IBD Helpline**
- ☐ **Paediatric IBD Nurse Specialist / IBD Helpline**
- ☐ **Colorectal Surgeon**
- ☐ **Paediatric Colorectal Surgeon**
- ☐ **Urgent or emergency care (e.g. ambulance / A&E / 111)**
- ☐ **I managed it myself**
- ☐ **Other**

- ☐ **Don't know / Can't remember**

6.3 Are the questions in this section related to the hospital you identified in section 1?

- ☐ **Yes**
- ☐ **No, please specify which hospital this section relates to**

6.4 How long was it before you received a response?

Please choose one option

- ☐ **Less 48 hours**
- ☐ **2 - 7 days**
- ☐ **8 - 14 days**
- ☐ **More than 2 weeks**
- ☐ **No-one came back to me**
- ☐ **Don't know / Can't remember**
- ☐ **Not applicable**

6.5 How long after were you able to start treatment?

Please choose one option

- ☐ **Less than 48 hours**
- ☐ **2 - 7 days**
- ☐ **8 - 14 days**
- ☐ **More than 2 weeks**
- ☐ **No-one came back to me**
- ☐ **Don't know / Can't remember**
- ☐ **Not applicable**

6.6 If you had an investigative test in the last 12 months, on average how long did you wait?

Please choose one option

- ☐ **Please do not include the waiting time for any investigative tests that you had as an inpatient. An inpatient is when you spent one or more overnight stays in hospital. Diagnostic tests can include ultrasound/ MRI/CT/contrast studies or/and endoscopic assessment**

PLEASE TURN OVER

SECTION 6: CONTINUED

6.6 continued

- ☐ Less than 4 weeks
- ☐ 1 - 3 months
- ☐ 4 - 6 months
- ☐ 7 - 12 months
- ☐ Over a year
- ☐ Not applicable
- ☐ Don't know / Can't remember

6.7 Have you taken steroid tablets for your Crohn's or Colitis at any time in the last 12 months? Please choose one option

 Steroids, also known as glucocorticoids, are sometimes prescribed by clinicians for the purpose of reducing inflammation in parts of the bowel. Please do not include intravenous steroids (by infusion directly into the vein) or those delivered directly to the site of inflammation, e.g. suppositories, foams or liquid enemas in your answer

- ☐ Yes
- ☐ No
Skip question 6.7 and go to section 7
- ☐ Don't know / Can't remember
Skip question 6.7 and go to section 7

6.8 What is the longest continuous stretch of time that you have taken a course of steroid tablets within the last 12 months? Please choose one option

- ☐ Less than 3 months
- ☐ 4 - 6 months
- ☐ 7 - 9 months
- ☐ 10 - 12 months
- ☐ Don't know / Can't remember

SECTION 7: INPATIENT CARE

These questions will help us to understand your experiences of surgery and/or receiving treatment and care in a hospital setting, involving at least one overnight stay.

Please do not include visits to A&E or day cases such as infusion appointments or day surgery.

Please base your experience on the last 12 months.

7.1 How many times have you been admitted to hospital because of Crohn's or Colitis-related symptoms in the last 12 months? Please choose one option

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ More than 5
- ☐ None
Skip section 7 and go to section 8

7.2 What was the reason for your most recent stay in hospital? Please choose one option

- ☐  Please include any IBD-related stay in hospital, this could include complications from your medications or treatment
- ☐ **A planned NHS operation**
A planned operation is surgery that is scheduled in advance. You may have been placed on a waiting list or been sent an appointment day, weeks or months in advance
- ☐ **A planned NHS inpatient stay (without surgery)**
Skip questions 7.6 - 7.11 and go to question 7.12

7.2 continued

☐ An emergency NHS operation

Emergency surgery is done because of an urgent medical condition. The condition may even be life threatening

☐ An emergency NHS inpatient stay (without surgery)

Skip questions 7.6 - 7.11 and go to question 7.12

☐ I was cared for in a private hospital (non-NHS)

Skip section 7 and go to section 8

☐ Don't know / Can't remember

Skip section 7 and go to section 8

7.3 Are the questions in this section related to the hospital you identified in section 1?

☐ Yes

☐ No, please specify which hospital this section relates to

7.4 Did you stay on a ward that cared mainly for patients with bowel conditions, also known as a 'gastroenterology' ward?

Please choose one option

☐  Hospital wards care for a range of specialities and conditions. A ward specialising in bowel conditions, like Crohn's or Colitis, is also known as a gastroenterology ward

☐ Yes - for the entirety of my hospital stay

☐ Yes - but I was transferred onto the specialist ward from another ward within 24 hours

☐ Yes - but I was transferred onto the specialist ward having spent more than 24 hours on another ward

☐ No

☐ Don't know / Can't remember

7.5 When you needed to use a toilet or bathroom, was a suitable one located close by on your ward?

Please choose one option

☐ Yes - very close

☐ Yes - quite close

☐ No

☐ Not applicable

☐ Don't know / Can't remember

7.6 When admitted to hospital, were you assessed for any of the following?

Please choose all that apply

☐  Being assessed can include a discussion, tests or investigations

☐ Signs of malnutrition and / or nutritional deficiency e.g. Iron, B12

☐ Whether your pain was under control / manageable

☐ How well you were coping emotionally

☐ None of the above

☐ Don't know / Can't remember

7.7 If you were referred for an operation, how long did you wait?

Please choose one option

☐ Less than 18 weeks

☐ 19 weeks - 6 months

☐ 7 months - 12 months

☐ Over a year

☐ Don't know / Can't remember

☐ Not applicable

PLEASE TURN OVER

SECTION 7: CONTINUED

7.8 My surgical and medical IBD teams worked well together

Please rate the above statement



Your surgical team can include the Colorectal Surgeon, Stoma Nurses and Specialist Surgery Nursing team. Your medical team can include your Gastroenterologist, IBD Nurse Specialist and IBD Specialist Pharmacist

- ☐ Strongly disagree
- ☐ Tend to disagree
- ☐ Neither agree nor disagree
- ☐ Tend to agree
- ☐ Strongly agree
- ☐ Don't know / Can't remember
- ☐ Not applicable

7.9 I was given information in a format that helped me understand the benefits and risks of surgery

Please rate the above statement

- ☐ Strongly disagree
- ☐ Tend to disagree
- ☐ Neither agree nor disagree
- ☐ Tend to agree
- ☐ Strongly agree
- ☐ Don't know / Can't remember
- ☐ Not applicable

7.10 I felt what mattered to me was taken into account when making decisions about my operation and care

Please rate the above statement

- ☐ Strongly disagree
- ☐ Tend to disagree
- ☐ Neither agree nor disagree
- ☐ Tend to agree
- ☐ Strongly agree
- ☐ Don't know / Can't remember
- ☐ Not applicable

7.11 Prior to surgery, were you offered the opportunity to:

Please choose all that apply



Please select the option if you were offered the opportunity, even if you did not take it

- ☐ Speak to someone who had the same kind of or similar procedure
- ☐ Speak to a Counsellor or Psychologist
- ☐ Understand outcomes data from the surgeon's previous surgeries and be able to choose another surgeon should you should wish to



Outcomes data is information about the results of surgery (e.g. mortality rates) that can be published and used by surgeons, patients and hospitals to ultimately improve safety and quality

- ☐ Consider the option of laparoscopic (keyhole) surgery



Laparoscopy is a type of surgical procedure that allows a surgeon to access the inside of the abdomen (tummy) and pelvis without having to make large incisions in the skin. This procedure is also known as keyhole surgery or minimally invasive surgery

- ☐ None of the above
- ☐ Don't know / Can't remember

7.12 Before your operation, were you assessed for nutritional or dietary support?

Please choose one option

-  This might have been part of a general assessment prior to your operation. It could have included being weighed, asked questions from a nutritional screening tool e.g. Malnutrition Universal Screening Tool (MUST) or a referral to a Dietitian

- ☐ Yes
- ☐ No
- ☐ Don't know / Can't remember

7.13 Were you offered the opportunity to speak to an IBD Nurse Specialist while you were an inpatient?

Please choose one option

-  This access could be in the form of a telephone conversation, email or visit to the ward

- ☐ Yes
- ☐ No
- ☐ Don't know / Can't remember

7.14 I was given clear information to help me manage my care after discharge from hospital, including post-operative care, medicines, wound and stoma care.

Please rate the above statement

- ☐ Strongly disagree
- ☐ Tend to disagree
- ☐ Neither agree nor disagree
- ☐ Tend to agree
- ☐ Strongly agree
- ☐ Don't know / Can't remember
- ☐ Not applicable

7.15 A healthcare professional explained the purpose of the medicines I needed to take at home and possible side effects, in a way I could understand.

Please rate the above statement

- ☐ Strongly disagree
- ☐ Tend to disagree
- ☐ Neither agree nor disagree
- ☐ Tend to agree
- ☐ Strongly agree
- ☐ Don't know / Can't remember
- ☐ Not applicable

PLEASE TURN OVER

SECTION 8: PATIENT ENGAGEMENT

These questions will help us to understand what opportunities you have had to feedback on your care, to be involved in improving your service or to get involved in research.

Please answer these questions based upon the hospital you selected at the beginning of the survey in section 1.

8.1 In the last 12 months, have you been given the opportunity to feedback specifically on your Crohn's or Colitis care in any of the following ways (even if you didn't participate)?

Please choose all that apply

- ☐ Patient survey(s) (please do not include this survey in your answer)
- ☐ Feedback form(s)
- ☐ Regular meetings with patients, parents and carers (e.g. Patient Panel)
- ☐ Other

- ☐ None of the above
- ☐ Don't know / Can't remember

8.2 Have you seen information about the IBD Registry in your hospital?

Please choose one option

 The purpose of the IBD Registry is to improve care. The IBD Registry supports the increase in knowledge about IBD in the UK. The Registry does this by collecting and analysing data from IBD patients nationally.

- ☐ Yes - It was clear and understandable
- ☐ Yes - It wasn't clear and understandable
- ☐ No
- ☐ Don't know / Can't remember

8.3 Have you been offered any of the following opportunities to participate in a clinical trial(s) and / or IBD research?

Please choose all that apply

- ☐ I received information about clinical trials and research and from my hospital
- ☐ I have been offered specific opportunities to participate in research by my hospital
- ☐ My hospital advertises information in their waiting rooms / clinics
- ☐ My hospital provides information on a website
- ☐ My hospital signposts me to opportunities from national patient organisations or charities
- ☐ None of the above
- ☐ Don't know / Can't remember

8.4 Have you been offered information about clinical trials and research from national patient organisations or charities?

Please choose one option

- ☐ Yes
- ☐ No
- ☐ Don't know / Can't remember

8.5 Have you participated in research as a result of accessing information about clinical trials and research from national patient organisations or charities?

Please choose one option

- ☐ Yes
- ☐ No
- ☐ Don't know / Can't remember

SECTION 9: QUALITY OF LIFE

8.6 Overall, how would you rate the quality of your Crohn's or Colitis care over the last 12 months?

Please choose one option

- ☐ Excellent
 - ☐ Very good
 - ☐ Good
 - ☐ Fair
 - ☐ Poor
 - ☐ I did not receive any care for my Crohn's or Colitis in the last 12 months
-

This section will help us to understand how Crohn's or Colitis impacts upon the quality of your life.

9.1 Thinking back over the past 12 months, how well do you feel the public understands Crohn's and Colitis?

Please choose one option

- ☐ Not at all
 - ☐ Limited understanding
 - ☐ Some understanding
 - ☐ Reasonable understanding
 - ☐ Good understanding
-

9.2 Over the past 12 months, have you experienced stigma or unfair treatment because of your Crohn's or Colitis?

Please choose one option

- ☐ Never
 - ☐ Occasionally
 - ☐ Regularly
 - ☐ Most of the time
 - ☐ All of the time
-

9.3 Over the past 12 months, have you found it hard to cope with having Crohn's or Colitis?

Please choose one option

- ☐ Never
- ☐ Occasionally
- ☐ Regularly
- ☐ Most of the time
- ☐ All of the time

PLEASE TURN OVER

SECTION 10: MORE ABOUT YOU

10.1 In which UK country do you live:

Please choose one option

- ☐ England
 - ☐ Scotland
 - ☐ Wales
 - ☐ Northern Ireland
 - ☐ I live outside the UK
-

10.2 Approximately how old were you when diagnosed?

Please write in the box below

- ☐ Don't know / Can't remember
-

10.3 How would you generally describe the severity of your Crohn's or Colitis over the last 3 months?

Please choose one option

- ☐ Not active - I have no symptoms and not been affected by my disease
 - ☐ Minimally active - I have symptoms, but my symptoms have not got in the way of everyday activities
 - ☐ Mildly active - my symptoms have got in the way of some everyday activities
 - ☐ Moderately active - my symptoms have significantly got in the way of everyday activities
 - ☐ Severely active - I have been unable to perform everyday activities
 - ☐ Don't know / Can't remember
-

10.4 Which gender do you identify with?

Please choose one option

- ☐ Female
- ☐ Male
- ☐ Prefer not to say
- ☐ Other

10.5 How would you describe your ethnic origin?

Please choose one option

White

- ☐ English / Scottish / Welsh / Northern Irish / British
- ☐ Irish
- ☐ Gypsy or Traveller
- ☐ Any other white background, please describe

Mixed / multiple ethnic groups

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed / Multiple ethnic background, please describe

Asian / Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese

10.5 continued

☐ Any other Asian background, please describe

Black / African / Caribbean / Black British

☐ Caribbean

☐ African

☐ Any other Black / African / Caribbean background, please describe

Other Ethnic Group

☐ Arab

☐ Any other ethnic background, please describe

☐ Prefer not to say

10.6 How did you hear about this patient survey?

Please choose one option

☐ IBD UK Website

☐ Leaflet

☐ Hospital / clinic

☐ Crohn's & Colitis UK

☐ CICRA

☐ Ileostomy & Internal Pouch Association (IA)

☐ Press

☐ Social media

☐ Other

10.7 Please state one thing your service could improve

10.8 Is there anything else you would like to say?

END OF SURVEY

Thank you for completing the survey.

If you have any questions or concerns, please contact info@ibduk.org

Alternatively, if you would like more information or support please visit the IBD UK patient information page at www.ibduk.org

Would you like to hear more from Crohn's & Colitis UK?

By selecting yes, you agree that we can email you with news and updates, as well as ways you can make a difference to people affected by Crohn's and Colitis. If you change your mind, you can unsubscribe at any time by emailing supporters@crohnsandcolitis.org.uk. To view our privacy policy, please visit <https://crohnsandcolitis.org.uk/about-us/your-privacy-and-data-protection>

☐ Yes

☐ No

How to send your completed survey to us?

If we have sent you the survey, please put your survey into the envelope provided and post it too us, you will not need to attach a stamp.

If you have downloaded your survey online, please put your survey in an envelope and write **Freepost IBDUK** on the front, you will need to write IBDUK in capital letters with no spaces. This is a freepost address; you will not need to attach a stamp..

Would you like to be kept up to date about this survey?

Your Patient Survey answers will remain anonymous, but if you wish to receive updates about IBD UK and the results of the survey, write your details in the boxes below

First Name

Surname

Email



IBD UK
Strategy
Partnership
Quality Improvement

Thank you for completing the survey

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of Great Britain and Ireland



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of UK Dietitians



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