IBD UK
Strategy
Partnership
Quality Improvement

Working together
for everyone affected
by inflammatory
bowel disease

IBD Standards 2026

For people with Inflammatory Bowel Disease (IBD)

Inflammatory Bowel Disease (IBD) is a term used to describe long-term conditions that cause inflammation in your gut. Symptoms can include diarrhoea, blood or mucus in your poo, tummy pain and fatigue. The main types of IBD are Crohn’s Disease, Ulcerative Colitis and Microscopic Colitis.

This information explains the 2026 IBD Standards. The IBD Standards say what high-quality IBD care should look like. They cover your care from your first symptoms to your diagnosis, treatment, and ongoing care. The IBD Standards can help your healthcare service understand where they need to improve.

This information is for people with, and parents or carers of people with:

- Crohn’s Disease
- Ulcerative Colitis
- Microscopic Colitis
- Other forms of IBD, such as IBD Unclassified
- Symptoms of IBD who do not have a diagnosis yet

This information might use words you have not heard before. The Crohn’s & Colitis UK page on medical words can help provide an explanation.

This information is based on the 2026 IBD Standards. You can read these in full on the IBD UK website. There’s information on how the IBD Standards were created towards the end of this resource.

Contents

What the IBD Standards mean for you

- The IBD Standards aim to make sure everyone with IBD receives safe, consistent, high-quality and personalised care.
- The IBD Standards are for everyone in the UK, whatever your identity, background or needs.
- The IBD Standards are about how your healthcare team delivers your care. They are not about how your IBD should be treated.
- The IBD Standards are aspirational. This means that they are how we would like things to be, and not necessarily how they are right now. They are the standard of care that IBD services should be aiming to offer patients.
- The IBD Standards help healthcare services see what they are doing well and where they need to improve.

IBD Standards 2026, edition 1

Section 1. Your IBD Service

1.1 You should have a multidisciplinary IBD team.

Your IBD team should be made up of different healthcare professionals. This is called a multidisciplinary team (MDT). They can support you with every aspect of your IBD care, including:

- Diagnosis
- Treatment
- Care during flare-ups
- Support with diet and nutrition
- Surgery, if needed

Your IBD team should include:

- A consultant gastroenterologist. A doctor who specialises in diagnosing and treating gut problems.
- An IBD nurse specialist. A nurse who specialises in supporting and caring for people with IBD.
- A colorectal surgeon. A doctor who specialises in carrying out surgery on the bowel.
- A dietitian. A healthcare professional who specialises in diet and nutrition. They will usually have experience of IBD.
- A specialist pharmacist in IBD. A healthcare professional who specialises in the medicines used to treat IBD.
- A psychologist. A mental health professional who specialises in the mind, emotions and behaviour.
- A radiologist. A doctor who uses images to diagnose, treat and manage medical conditions.
- A histopathologist. A doctor who looks closely at organs, tissues and cells.
- A stoma care nurse. A nurse who specialises in supporting and caring for people who have a stoma, or will be having stoma surgery.
- An MDT coordinator. An administrator who tracks patient tests and results, resolving any delays. They organise and run MDT meetings.

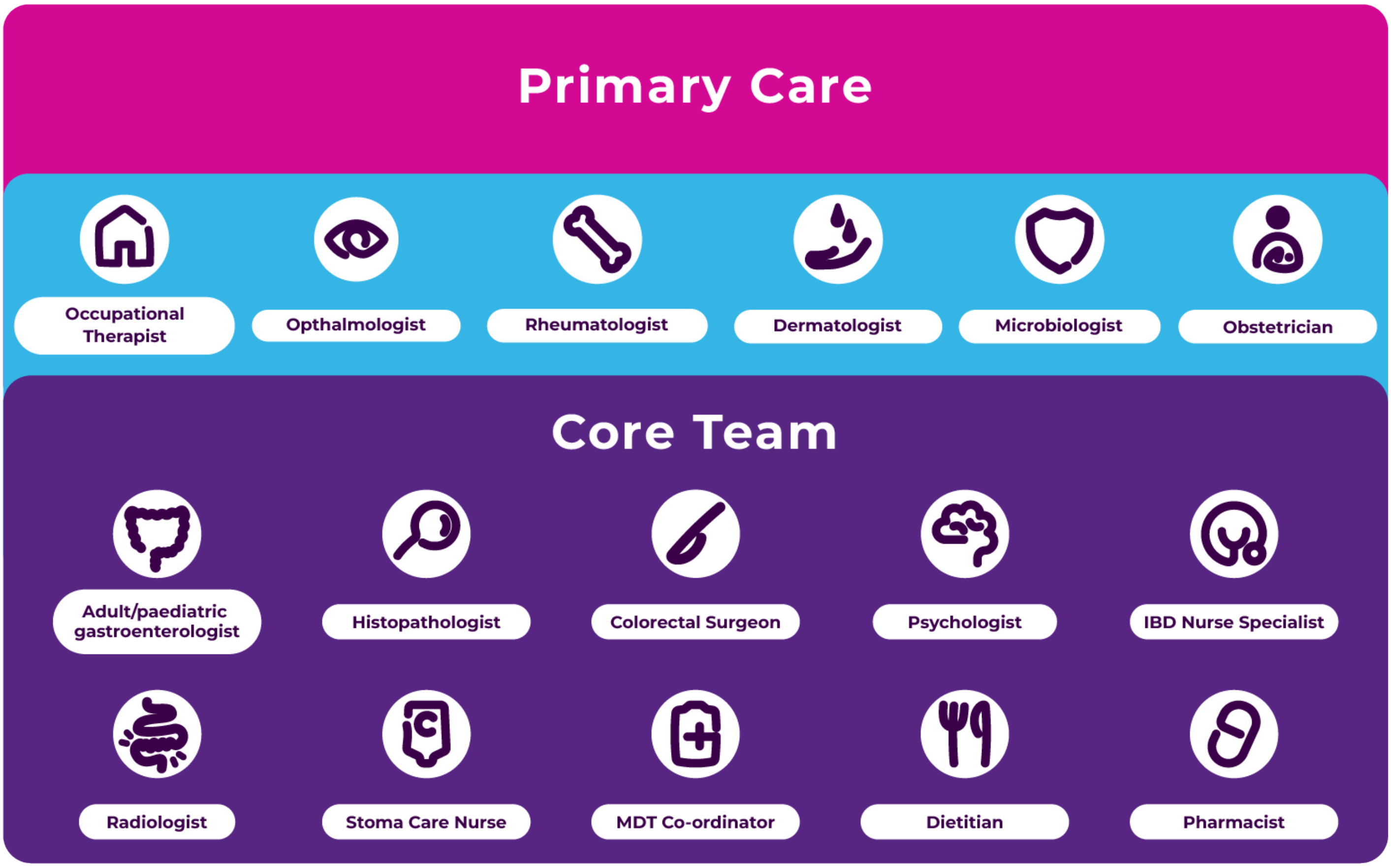
Children and young people must have a paediatric gastroenterologist in their IBD team. This is a doctor who specialises in diagnosing and treating gut problems in children.

You might also see other healthcare professionals. They should work alongside your IBD team. These could include:

- A rheumatologist. A doctor who specialises in the diagnosis and treatment of people with joint and muscle problems.
- An ophthalmologist. A doctor who specialises in the diagnosis and treatment of eye disorders.
- A dermatologist. A doctor who specialises in the diagnosis and treatment of skin disorders.
- An obstetrician. A doctor who specialises in pregnancy, labour and care after birth.

- A hepatologist. A doctor who specialises in the diagnosis and treatment of disorders of the liver, gallbladder, pancreas, and bile ducts.
- A gynaecologist. A doctor who specialises in the female reproductive system.
- A microbiologist. A healthcare scientist who studies organisms that cause infections, including bacteria, viruses and fungi.
- An oral medicine specialist. A doctor who specialises in the diagnosis and treatment of long-term conditions of the mouth, face and jaws.
- An occupational therapist. A healthcare professional who aims to help people do everyday tasks they find difficult.
- A nutrition support team. This may be made up of doctors, nutrition nurse specialists, dietitians and pharmacists. They work together to care for people needing nutritional support.

An example of a multidisciplinary IBD team:



Primary Care

- Occupational Therapist
- Opthalmologist
- Rheumatologist
- Dermatologist
- Microbiologist
- Obstetrician

Core Team

- Adult/paediatric gastroenterologist
- Histopathologist
- Colorectal Surgeon
- Psychologist
- IBD Nurse Specialist
- Radiologist
- Stoma Care Nurse
- MDT Co-ordinator
- Dietitian
- Pharmacist

Your GP is also known as your primary care. They should be involved in supporting your IBD care. Your GP and IBD team should be in contact with each other.

1.2 You should be told the name of your specialist healthcare professionals. This includes your consultant gastroenterologist, or paediatric gastroenterologist.

1.3 Your IBD team should meet regularly to discuss the patients they care for. A named coordinator should manage these meetings. Someone in your IBD team should give you feedback from these meetings.

Multidisciplinary team meetings allow your IBD team to make the best decisions for patients together. Everyone in your IBD team should be involved.

At these meetings your IBD team may talk about:

- Newly diagnosed patients.
- Patients with extra emotional, social or mental health needs.
- Patients with complex disease.
- Patients with perianal Crohn’s. This is Crohn’s in the area around the anus, where poo leaves the body.
- Patients who are at high risk of needing surgery.
- Patients with fistulas who keep having flare-ups. A fistula is when a tunnel develops that connects one organ to another part of your body. These tunnels can connect one internal organ to another or to the skin. A fistula can develop in any part of the body, but many involve the gut.
- Patients who will be starting biologic medicines. Biologic medicines, also called biologics, are treatments that block particular proteins involved in inflammation. This reduces inflammation. Biologics may be an option for people with moderate to severe Crohn’s Disease or Ulcerative Colitis.
- Young patients with slow growth or delayed puberty.

1.4 Every IBD team should have a plan to support transition. Transition is when you move from the children's to the adult IBD team. A paediatric gastroenterologist and/or an adult gastroenterologist should take the lead on this.

Transition

- Transition is for people who are diagnosed with IBD as a child.
- You will usually transition to the adult team when you are 16 to 18 years old.
- Planning for transition will usually start when you are 14 to 15 years old.
- You should be involved in planning for transition with your IBD team.

1.5 Your IBD service should have a leadership team which includes:

- A gastroenterologist and/or a paediatric gastroenterologist
- A colorectal surgeon
- An IBD nurse specialist
- A manager

The leadership team are responsible for managing, monitoring and developing the IBD service.

1.6 The IBD leadership team should work with, or include:

- A specialist pharmacist in IBD. They will help to manage how medicines are prescribed and monitored.
- An expert dietitian. They will help to manage and oversee changes to diet and nutrition.
- A psychologist with an interest in IBD. They will help to organise psychological care.

1.7 Your IBD team should always look for ways to improve their service. They should take part in local and national audits. This should include collecting feedback from patients.

1.8 Patients, or their parents or carers, should be asked to give feedback on using their IBD service. They should be involved in improving the IBD service.

1.9 Once you have a confirmed diagnosis of IBD, your details should be recorded in an electronic clinical management system.

An electronic clinical management system can be used to:

- Store patient contact details and medical history
- Manage appointments
- Have secure communication between patients and their healthcare team

1.10 Your IBD team should tell you where to find information about:

- IBD
- Your IBD service, such as the roles of each team member and contact details
- Trusted patient organisations, such as Crohn's & Colitis UK, CICRA and the Ileostomy & Internal Pouch Association

The information should be personalised to your needs. It should be easy to understand and in a format that is best for you. This could be face-to-face, written, visual, online, audio or video.

1.11 If appropriate for your condition, you may be offered MRI or ultrasound imaging tests. You should have these tests within:

- 6 weeks of being referred for routine care
- 2 weeks for urgent IBD referrals
- 24 hours if you are admitted to hospital

MRI and ultrasound tests are safe as they do not use radiation. There may be times when you'll need imaging tests that use radiation, such as X-rays or CT scans. If MRI or ultrasound is available and can give the same information, it should be recommended.

Routine care

Routine care is medical care that is not urgent. It is when you can wait for an appointment. Your condition should not get much worse while you wait.

1.12 When you need an endoscopy, you should have this within:

- 6 weeks of being referred for routine care
- 2 weeks for urgent IBD referrals
- 24 hours if you are admitted to hospital

Endoscopy

Endoscopy is a test that uses a long, thin, flexible tube called an endoscope. It has a small camera on the end to look closely at the lining of your gut. The main types of endoscopy are:

- **Gastroscopy, also known as upper gastrointestinal (GI) endoscopy.** An endoscope is passed into your mouth to look at the upper part of your digestive system. This includes your throat, stomach and small bowel, also known as the duodenum.

- **Colonoscopy.** An endoscope is inserted into your bottom to look at your large bowel, including your rectum and colon.

- **Sigmoidoscopy (or proctosigmoidoscopy).** This is like a colonoscopy but only examines the rectum and lower part of the colon.

1.13 Your IBD team should get the results for any biopsies within one week. If it's an urgent biopsy they should get the results within two working days.

Your IBD team will review your results. A healthcare professional may get in touch to let you know what your results are. You may be able to view your results on the NHS App.

Biopsies

Biopsies are small pieces of tissue taken from a part of the body. They are sent to a laboratory and looked at under a microscope. Biopsies are often taken from the gut during an endoscopy to check for inflammation.

1.14 Your IBD service should have a plan for people taking immunomodulators, biologics and other targeted medicines.

This should include:

- Tests you will need before starting treatment
- Vaccinations you may need before or during treatment
- Details about prescribing these medicines
- How to take these medicines
- Monitoring you will have while taking these medicines

Immunomodulators, biologics and targeted medicines

- Immunomodulators include azathioprine, mercaptopurine and methotrexate.
- Biologics include adalimumab, infliximab, golimumab, guselkumab, risankizumab, ustekinumab and vedolizumab.
- Other targeted medicines include filgotinib, tofacitinib, upadacitinib and ozanimod.

You can find out more about the different medicines used to treat IBD on the Crohn's & Colitis UK website.

1.15 Your IBD team should help you to understand the benefits and risks of all treatments. This includes medicines, nutritional treatments and surgery.

1.16 You should be offered nutritional treatments, if needed and suitable for you.

Nutritional treatments give you the energy and nutrients your body needs. You might need nutritional treatments or supplements if:

- You're in a Crohn's Disease flare-up
- You're struggling to get enough nutrients from your diet
- Your bowel is not working

There are two main ways to have nutritional treatments:

- Enteral nutrition. Liquid nutrition you drink or have through a feeding tube.
- Parenteral nutrition. Liquid nutrition that you have through a drip into a vein.

1.17 Everyone in your IBD team should be well trained, supervised and supported. They should be given the chance to keep developing their skills.

1.18 Your IBD team should:

- Be involved in research
- Offer you the chance to take part in research

Your IBD team should support you to:

- Ask them about taking part in research
- Find information about:
    - The benefits of taking part in research
    - Opportunities to take part in research
    - How to take part in research
    - What taking part in research involves
- Make informed choices about taking part in research

Section 2. Getting a diagnosis

2.1 GPs should have a clear plan for referring adults and children with suspected IBD to see IBD specialists in hospital. GPs should ask you to do a poo test if you are an adult who they suspect has IBD. This could be a faecal calprotectin test or a faecal immunochemical test (FIT).

Poo tests, also known as stool tests

- Faecal calprotectin. This measures the level of calprotectin in your poo. Calprotectin is a protein found in white blood cells. It can show whether you have inflammation in your gut. Generally, a high faecal calprotectin level would suggest that you should have further tests for IBD.
- Faecal immunochemical test (FIT). This can check for small amounts of blood in your poo, which may be found when there is inflammation in your gut.

GPs can sometimes find it hard to spot IBD. IBD symptoms can sometimes be similar to other conditions, such as irritable bowel syndrome (IBS). Symptoms are different for everyone, and IBD can look different in children. Clear plans for referring children and adults can speed up diagnosis. A quicker diagnosis means getting treatment sooner, so you can start to feel better.

Poo tests are good at detecting when there is inflammation in the gut. But you'll need further tests to say whether or not you have IBD. Your healthcare professional will check your results and decide if you need more tests, such as an endoscopy. Endoscopy is a test that uses a long, thin, flexible tube called an endoscope. It has a small camera on the end to look closely at the lining of your gut.

You can find out more about getting a diagnosis for gut problems on the 'What's up with my gut?' website.

2.2 Within four weeks of being referred by your GP, you should either:

- See an IBD specialist in hospital, or
- Have a test in hospital, such as an endoscopy or imaging

This could happen more quickly if your healthcare professional thinks it is an urgent or emergency situation.

2.3 If you have symptoms of acute severe colitis, you should be admitted to a hospital that specialises in IBD. Medical and surgical IBD specialists should be available at all times.

Acute severe colitis

- People with Ulcerative Colitis or Crohn's Colitis may experience acute severe colitis.
- The term 'colitis' by itself means inflammation in the colon.
- If you have Crohn's Disease affecting your colon, you may be told you have 'Crohn's Colitis'. This is a type of Crohn's. It does not mean you have both Crohn's Disease and Ulcerative Colitis.

Acute severe colitis is a serious medical emergency. You may show signs that your body is being significantly affected by the disease. This could include a fever or increased heart rate. It requires a stay in hospital for treatment and monitoring.

2.4 After having tests, you should be told what will happen next and when you will get your results. You should be given the details of someone you can contact about your tests.

Your GP will be your main contact if you:

- Have not been referred to an IBD service
- Are waiting for the results of blood and poo tests that were arranged by your GP
- Are on the waiting list to have an endoscopy and you have not been seen by the IBD service

If your tests have been arranged by your hospital IBD service, they will be your main contact. They should give you the details of how to get in touch and when to do this.

Section 3. Newly diagnosed

3.1 You should see a specialist IBD healthcare professional after you are diagnosed.

3.2 You should have a full check, including:

- How active your IBD is.
- Your nutritional status, to see if you are at risk of malnutrition.
- Your mental health.
- How fatigue affects you.
- Whether you have any extra intestinal manifestations (EIMs). EIMs are when IBD affects other parts of your body, including your joints, mouth, eyes or skin.
- How well children and teenagers are growing and developing.
- Test for certain current or previous infections, if you are likely to start taking biologics or other targeted medicines.

3.3 Your IBD team should support you to make informed choices about your treatment and care. Your IBD team should consider your goals and what matters most to you.

Your IBD team should support you to:

- Understand your care and treatment options
- Understand the risks and benefits
- Make decisions together about your care and treatment

3.4 After you have been diagnosed, you should be given a treatment plan.

Your treatment plan could include:

- Your diagnosis. This could be Crohn’s Disease, Ulcerative Colitis, Microscopic Colitis or IBD Unclassified.
- Which parts of your gut are affected.
- Which parts of your body are affected outside of your gut, such as joints, mouth, eyes or skin.
- Your treatment. This could include how and when to take any medicines, changes to your diet or planned surgery. It may also include benefits or possible side effects of treatments.
- Any tests or monitoring you’ll have.
- Lifestyle advice. This could cover:
    - Smoking
    - Alcohol
    - Exercise
    - Diet
    - Education
    - Employment
    - Social activities
    - Sex, contraception, family planning or pregnancy.

- What you can do to manage symptoms at home, such as pain or fatigue.
- What to do if you have a flare-up.
- How your condition could progress in the future. This could include potential complications or other conditions.

3.5 Where appropriate, you should start treatment straight away. This could include:

- Oral or topical 5-ASAs
- Oral or topical steroids

Medicines are used to treat Crohn's and Colitis symptoms. They can help prevent your condition from getting worse or causing complications.

- 5-ASAs include mesalazine, olsalazine, balsalazide and sulfasalazine.
- Steroids include prednisolone, methylprednisolone, beclometasone dipropionate and budesonide.

Some of the medicines prescribed for Crohn's and Colitis come in different forms. This is so they can be taken in the way that helps them to work most effectively. Sometimes these medicines are given orally, which means swallowed by mouth. Sometimes these medicines are given topically, using a suppository or enema. These are put into your bottom, or anus. They treat inflammation in the lowest part of your bowel.

It may be longer before you can start other treatments, such as immunomodulators, biologic or targeted medicines. This includes starting a combination of an immunomodulator with a biologic. You usually need safety tests before starting these medicines. You should:

- Have any tests you need
- Start these medicines within two weeks of having the tests

Some people with Crohn's or Colitis use more than one medicine at a time to manage their condition. This is known as combination therapy.

Immunomodulators, biologics and targeted medicines

- Immunomodulators include azathioprine, mercaptopurine and methotrexate.
- Biologics include adalimumab, infliximab, golimumab, guselkumab, risankizumab, ustekinumab and vedolizumab.
- Other targeted medicines include filgotinib, tofacitinib, upadacitinib and ozanimod.

You can find out more about the different medicines used to treat IBD on the Crohn's & Colitis UK website.

3.6 Your IBD team should tell you and your GP that you have been diagnosed with IBD within two days.

When your treatment plan is agreed, your IBD team should also share this with your GP.

Section 4. Managing a flare-up

4.1 You, your GP and your IBD team should have a clear plan of what to do if you have a flare-up.

4.2 Your IBD team should tell you what to do if you have a flare-up. They should tell you who to contact.

Your IBD team will usually be your main contact if you are having a flare-up. You could also ask your IBD team who to contact if you're not able to get in touch with them.

A flare-up is when symptoms come back and you feel unwell. Everyone experiences flare-ups differently, but signs could include:

- Loose poo or diarrhoea, which may contain blood
- Urgently needing to poo
- Pain in the tummy area
- Generally feeling unwell

You may also experience symptoms outside the gut during a flare-up. For example:

- Joint pain and swelling (arthritis)
- Swelling in the eyes
- Mouth ulcers
- Skin rashes
- Fatigue
- Poorer mental wellbeing

4.3 You should be able to contact your IBD team if you are having a flare-up. This could be by phone or email. Your IBD team should get back to you by the end of the next working day.

4.4 After talking to you about your flare-up, your IBD team should:

- Plan to contact you again to check how you are, when needed
- Let you know when this will happen
- Start to make any agreed changes to your treatment plan within two days

4.5 If you take steroids, your GP and IBD team should work together to monitor and care for you.

If you have a flare-up, steroids can help to quickly reduce the inflammation in your gut. This can help you feel better and get your symptoms under control. Steroids are usually taken as a short-term treatment. Once your symptoms are under control, your healthcare professional will aim to switch you to a different medicine.

Your healthcare professional should give you clear information about taking steroids. This should include:

- Benefits and risks of taking steroids
- Checks and monitoring you'll need
- Alternatives to taking steroids
- How to get further help or support

Section 5. Having surgery

5.1 Your medical and surgical teams should work together before and after you have surgery. This should include your:

- IBD gastroenterologist, and
- IBD nurse specialist, and
- Specialist colorectal surgeon

Or paediatric specialists for children and young people.

5.2 A colorectal surgeon who specialises in IBD should carry out your planned surgery for IBD. This should be a paediatric colorectal surgeon for children or young people. They should be an expert in IBD and a core member of your IBD team. You should have your planned surgery in a hospital where they often do surgery for IBD.

Planned surgery is any surgery that is not an emergency. It is surgery that is planned for a later date. You may also hear it called elective surgery.

5.3 You should be referred to a hospital with expertise in surgery for IBD if:

- Your IBD service does not have expertise in surgery for IBD
- Your planned surgery is complex

5.4 If you are thinking about having surgery, your IBD team should:

- Give you information about having surgery. This should be in a format and language you can understand.
- Support you to make an informed choice about having surgery. This includes giving your consent to have surgery.
- Arrange an appointment with a stoma nurse, if you will be getting a stoma.
- Help you to get psychological or mental wellbeing support.

Stomas

A stoma is an opening on the wall of your tummy made during surgery. A stoma connects an internal organ, like the bowel, to the outside skin of the body. If you have a stoma, the contents of your gut do not travel all the way through your bowel to come out of your bottom. Instead, they come out of the stoma into a bag you wear on your tummy.

Ileostomies and colostomies are types of stomas seen in Crohn’s and Colitis.

5.5 Before planned surgery, your IBD team should do a full check of your:

- Current treatments and any changes that may be needed.
- Physical condition, or how well you are.
- Nutritional status, to see if you need any extra nutrients or supplements.

This is to reduce the risk of complications and help your recovery after surgery.

5.6 If possible, your IBD team should talk to you about minimally invasive options. This could include keyhole surgery or robotic surgery.

Keyhole surgery is also called laparoscopy. It uses very small cuts and cameras to control tools, so the surgeon’s hands do not go into the tummy. This is instead of open surgery, where one larger cut in the tummy is made.

The benefits of this type of surgery include:

- Less pain after the operation.
- Smaller scars.
- Faster recovery. For example, being able to eat and drink more quickly after the operation.
- Lower risk of a wound infection or a hernia. This type of hernia happens when bowel tissue pokes through the tummy wall where your healed surgical scar is.
- A shorter stay in hospital.
- Better fertility outcomes in women.

Minimally invasive surgery may not be an option in all hospitals. It may also not be possible if you have had open surgery or major surgery on your tummy area before.

5.7 If possible, your IBD team should plan for an enhanced recovery after surgery.

Some hospitals have enhanced recovery programmes for some types of surgery. These programmes aim to:

- Lower the risk of complications after surgery
- Get people home safely and more quickly after surgery

Enhanced recovery programmes make sure you are as healthy as possible before surgery. They also try to get you moving as soon as possible after surgery.

5.8 Before you go home, your IBD team should give you clear information on:

- Looking after yourself after surgery.
- Caring for your wound at home.
- Caring for your stoma, if you had stoma surgery.
- Getting psychological or mental wellbeing support.

5.9 Planned surgery should happen within 4 weeks of deciding to operate. It could happen sooner if:

- You've had all the checks and changes needed before surgery (see 5.5), and
- You are as well as you can be before surgery

5.10 Your IBD service must record any incidents that affect patient safety. For example, if your planned surgery was delayed and because of this, you develop a complication. This complication means that you need to have emergency surgery instead.

Your IBD service should act to make improvements.

Section 6. Care in hospital

6.1 If you are admitted to stay in hospital, you should:

- See a consultant gastroenterologist or colorectal surgeon within 24 hours
- Be moved to a specialist ward area within 2 days

6.2 You should have an ensuite room, if available. If not, your ward should have at least one easy-to-access toilet for every three beds.

6.3 Your hospital should have an agreed plan for your care and treatment if you are admitted to hospital with a flare-up.

6.4 You should be checked by IBD specialists every day if you are staying in hospital with acute severe colitis.

Acute severe colitis

- People with Ulcerative Colitis or Crohn's Colitis may experience acute severe colitis.
- The term 'colitis' by itself means inflammation in the colon.
- If you have Crohn's Disease affecting your colon, you may be told you have 'Crohn's Colitis'. This is a type of Crohn's. It does not mean you have both Crohn's Disease and Ulcerative Colitis.

6.5 When you are admitted to hospital, your healthcare professional should check:

- Your nutritional status, to see if you are at risk of malnutrition.
- Your psychological health or mental wellbeing.
- How pain is affecting you.
- Whether you have any extra intestinal manifestations (EIMs). EIMs are when IBD affects other parts of your body, such as your joints, eyes or skin.

Your hospital should have an agreed plan on how to refer you to get other specialist care, if needed.

6.6 An IBD nurse specialist should be able to see you while you are staying in hospital. The IBD nurse specialist should be told when someone is admitted to hospital because of their IBD.

6.7 Any pharmacist reviewing your treatment while you stay in hospital should be able to get advice from a pharmacist who specialises in IBD. Your hospital should have an agreed plan for managing IBD medicines in people before and after they have surgery for IBD.

You should be given information about your IBD medicines. This information should be offered in a variety of formats, such as written, audio, visual or online. The information should be in a language you understand.

6.8 Before you go home, you should get clear, written information about your follow up care. This should include a phone number or email for questions you have about your condition or treatments. Your healthcare professional should also explain any new medicines, medical appliances or changes to your medicines.

Section 7. Ongoing care and monitoring

7.1 You should have your own personalised IBD care plan. You and your IBD team should discuss and agree on it together. Your IBD team should make this available to everyone in your IBD team and your GP.

Your IBD care plan is a plan of your care, tests, treatments and monitoring. It is developed over time and should change with your needs. It should include:

- Your health and wellbeing needs
- Shared decisions about your treatment and tests
- Goal-setting or next steps
- Contact details for an IBD nurse specialist and telephone or email advice line
- What matters to you

A personalised IBD care plan can help you prepare for appointments. It can include things to think about and questions that will help you focus on what matters to you. It can support your healthcare professional to ask you about things in your daily life, such as:

- Mental wellbeing
- Relationships
- Employment
- Sexual health

Your IBD care plan could be paper-based or digital.

7.2 Your IBD team should support you to self-manage your condition, where possible. Your IBD team should tell you where you can learn about IBD. The information should be personalised to your needs. It should be easy to understand and in a format that is best for you. They should share events, groups and other support with you.

Self-management

Self-management is anything you can do to understand, treat and manage your own health. You'll do this with the advice and support of your healthcare professionals. It includes managing your symptoms and treatments, as well as looking after your emotional and mental wellbeing.

7.3 Your IBD service and GP should have a clear plan in place for:

- The monitoring, prescribing and supply of your IBD medicines
- How your GP should contact your IBD team for advice about IBD medicines
- How and when your GP should refer you back to your IBD service, if changes to your medicines are needed

7.4 Your IBD service and GP should have a clear plan for monitoring and reviewing your nutritional therapies and supplements.

7.5 Your IBD team should give you a main contact for any questions you have about your IBD or treatments. They should tell you:

- Who to contact
- How to contact them
- When they are available

Your IBD team should also tell you who to contact out of hours and at the weekend.

7.6 Your IBD team should ask you what matters most to you. For example:

- Pain
- Fatigue
- Other health conditions
- Extra intestinal manifestations (EIMs). EIMs are when IBD affects other parts of your body, including your joints, mouth, eyes or skin.
- Incontinence, when you pass liquid or solid poo without meaning to.
- Sexual function

Your IBD team should suggest a range of ways to manage these.

This could include medicines, other treatments, changes to your diet or mental health therapies.

7.7 Any reviews and changes to your treatment should be clearly recorded by your healthcare professional. They should tell you, your GP and your IBD team within 2 working days.

7.8 You and your IBD team should agree together how often you will have routine appointments. They should tell you how you can support your own self-management in between your appointments. They may talk to you about Patient Initiated Follow-Up (PIFU), if suitable for you.

Patient Initiated Follow-Up (PIFU)

PIFU gives you the flexibility to book a follow-up appointment when you need it.

Your routine appointments should include:

- Talking about your mental wellbeing and what matters to you.
- Checks of your symptoms and how well your condition is being controlled.
- A review of your medicines. This could include:
    - How well they are working
    - How you are finding taking them and the dosing schedule
    - Any monitoring or tests you need to have
- A review of your risk factors for complications. This could include smoking, osteoporosis or bowel cancer screening.
- Talking about any ongoing issues, even when you’re in remission. This could include:
    - Diet
    - Exercise
    - Fertility and pregnancy
    - Travelling
    - Growing older
    - Medicines you take for other conditions
    - Incontinence
    - Fatigue
    - Pain
- Talking about what to do:
    - To prevent a flare-up
    - If you have a flare-up
- A clear, documented agreement about when your next test or appointment will be.

7.9 Your IBD team should have an agreed plan for surveillance colonoscopies. This plan should be based on national guidance. Your IBD team should tell you if and when you will have surveillance colonoscopies. They should help you understand your risk factors for bowel cancer.

You may be at increased risk of bowel if you have:

- Total or left-sided Ulcerative Colitis
- Crohn's affecting your colon

You do not have an increased risk of bowel cancer if you have:

- Proctitis, when Colitis affects only the rectum or lowest part of the large bowel
- Crohn's that does not affect your colon
- Microscopic Colitis

Surveillance colonoscopies

A surveillance colonoscopy is a 'check-up' colonoscopy. It aims to look for any changes in the lining of the bowel that might suggest a higher risk of bowel cancer.

Treatment has the best chance of working if bowel cancer is found at an early stage. Surveillance colonoscopy is the best way to detect bowel cancer early.

You should be offered your first surveillance colonoscopy:

- About eight years after your symptoms started, if you have Ulcerative Colitis or Crohn's affecting your colon or rectum
- At diagnosis, if you have Ulcerative Colitis or Crohn's affecting your colon or rectum and are diagnosed with primary sclerosing cholangitis (PSC)

How the IBD Standards were created

The IBD Standards were first published in 2009. They were updated in 2024 and 2025 ready for publication in 2026. These updates make sure the IBD Standards are relevant today and for the future.

IBD UK formed a working group to create the 2026 IBD Standards. This group included the full range of healthcare professionals who care for people with IBD, alongside people with lived experience of IBD.

The working group reviewed and discussed each of the existing Standards. They changed some to make them clearer. They also deleted some Standards and added new Standards.

Next, there was an open consultation. This meant that anyone could feedback on the draft version of the 2026 IBD Standards. The open consultation included healthcare professionals and people with lived experience of IBD.

The working group used this feedback to review and agree on the 2026 IBD Standards.

What to do if your feel your care is not meeting the IBD Standards

We know that not every healthcare team will be meeting all of the IBD Standards at this time. The IBD Standards are aspirational. This means that they are about how we would like things to be and not necessarily how they are right now. Your healthcare team should be working towards offering this level of care to all of their patients.

Based on data from the 2023 IBD UK benchmarking surveys, you can see:

- How your local IBD service is doing against the Standards
- What IBD care looks like across the UK

We all have the right to good healthcare. We also have the right to complain if we don't think we've received this. You may want to make a complaint if:

- You're unhappy with the service you've received
- There's been an unreasonable delay in treatments or investigations
- There's been a misdiagnosis
- A healthcare professional has made a serious error
- A healthcare professional has acted inappropriately

There's detailed information on how to make a complaint and what to include in Crohn's & Colitis UK's resource, How to get a diagnosis.

Making a complaint about your GP surgery

All NHS services are required to have a complaints procedure. You may be able to find this on your GP website. Or you could speak to a receptionist about how to make a complaint. You should make your complaint as soon as possible.

Making a complaint about a hospital

If you want to raise an issue about something within a hospital, you could speak to the hospital Patient Advice and Liaison Service (PALS). This is a service that most hospitals have and is free, confidential and independent.

Further information

- Making a complaint in England
- Making a complaint in Scotland
- Making a complaint in Northern Ireland
- Making a complaint in Wales

About IBD UK

IBD UK is a partnership of 16 professional bodies, royal colleges and patient organisations working together to improve care and treatment for everyone affected by Inflammatory Bowel Disease (IBD). Their main aim is to ensure that everyone with IBD has consistent, safe, high-quality personalised care, whatever their age and wherever they live in the UK.

IBD UK was formed in August 2017. Their first priority was to develop and publish new IBD Standards that define what good care should look like for people with IBD. Since then, they have created a range of practical tools and resources to support implementation of the IBD Standards, assessed through a Benchmarking Tool.

Crohn’s & Colitis UK chairs IBD UK and acts as secretariat.

IBD UK partner organisations

Association of Coloproctology of Great Britain and Ireland
https://www.acpgbi.org.uk/

British Association for Parenteral and Enteral Nutrition
https://www.bapen.org.uk/

British Dietetic Association
https://www.bda.uk.com/

British Society of Gastroenterology
https://www.bsg.org.uk/

British Society of Gastrointestinal and Abdominal Radiology
https://www.bsgar.org/

British Society of Paediatric Gastroenterology, Hepatology and Nutrition
https://bspghan.org.uk/

CICRA: better lives for children with Crohn’s and colitis
https://www.cicra.org/

Crohn's & Colitis UK
https://crohnsandcolitis.org.uk/

Ileostomy & Internal Pouch Association
https://iasupport.org/

Primary Care Society for Gastroenterology
https://www.pcsg.org.uk/

Royal College of GPs
https://www.rcgp.org.uk/

Royal College of Nursing
https://www.rcn.org.uk/

Royal College of Pathologists
https://www.rcpath.org/

Royal College of Physicians
https://www.rcplondon.ac.uk/

Royal Pharmaceutical Society
https://www.rpharms.com/

UK Clinical Pharmacy Association
https://ukclinicalpharmacy.org/

About Crohn’s & Colitis UK

We’re changing what it means to live with these lifelong, incurable gut conditions. Around one in 120 people in the UK have Crohn’s Disease or Ulcerative Colitis, navigating life with an unpredictable condition that could flare up at any time. The impact can be devastating: plans turned upside down; work and education on hold; relationships and wellbeing under strain; dreams for the future paused. No one should face that alone. That’s where we come in.

What we do

We provide trusted information, support cutting-edge research and lead bold campaigns designed to get people talking about Crohn’s and Colitis like never before. We’re transforming understanding, building the recognition these conditions deserve and uniting our community to drive real change. We’re fighting for a tomorrow where everyone living with Crohn’s or Colitis has everything they need to live well, and for a future where we don’t have to live with it at all. Crohn’s? Colitis? We’ll face it together.

Our information is available thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn’s and Colitis by calling **01727 734465**. Or you can visit our website.

About our information

We follow strict processes to make sure our information is based on up-to-date evidence and is easy to understand. We produce it with patients, medical advisers and other professionals. It is not intended to replace advice from your own healthcare professional. You can find out more on our website.

IBD Standards 2026, edition 1

Last review: March 2026

Next review: March 2029