

Q & A from the 2023 Patient Involvement in Research Virtual Event

Are biologics safe to use on a long term basis? My hospital is keen on having drug holidays after 5 years?

You may find our information on biologic medicines useful, which you can read [here](#). Your IBD team should review your treatment at least once a year. If it is working and you are not getting serious side effects, they are likely to recommend that you carry on taking it. If your Crohn's or Colitis stays under control for a long time, your IBD team might suggest stopping your biologic or other medicine, and they should discuss this with you so you can make a decision together which is right for your individual situation.

We need young IBD Colitis groups. My daughter wants to connect with people her age and with her condition as she feels misunderstood.

Our Local Networks organise social events, awareness raising and education talks for their local communities. They also fundraise to support the ongoing work of the charity. The events are open to everyone, and where volunteers have sought to provide family focused events, especially for young people under the age of 18, we have previously supported them in managing the additional aspects around safeguarding of children and young people at these events.

[CICRA](#) run in-person Family Days and have started to return to running them this year following the COVID pandemic. They also run an [e-PALS scheme](#).

How are we going to assess patients for targeted treatments? Are we going to need a very complex computer system to assess and provide individual treatments?

Targeted or personalised treatments are still a new idea, so practical ways of implementing this in clinic will need to be developed. You might like to read about [a study we are currently funding](#), for Dr Matthias Friedrich at the University of Oxford to look at how this could be done for Ulcerative Colitis. Dr Friedrich told us more about it in a blog post recently which you can [read here](#).

We find that we have to move out of our city and are wondering which hospitals are centres of excellence for IBD in the UK as this will factor in our decision on where we move to.

You may like to search for local hospitals on the [IBD UK website](#) to see how they did in the 2019 Benchmarking survey where IBD services reviewed how they were doing against the IBD Standards. Please note that not all hospitals took part, and an updated version of the survey was carried out in 2023, with the results expected later in the year. You may also like to use the Crohn's & Colitis UK ['Find a Nurse' map](#) to see whether services in the areas you are considering have an IBD Nurse Specialist.

Both my father, myself and my daughter all suffer from IBD, I believe my grandfather suffered too. Can you provide me details of any research into a genetic (familial) link?

Crohn's and Colitis happen when the body's immune system goes wrong. Usually, the immune system protects the body. In Crohn's and Colitis, the immune system starts attacking the body. We don't know why the immune system attacks the body. It is probably caused by a mix of genes and the environment (like germs, diet, smoking and stress). Researchers have identified hundreds of genetic changes that affect your risk of developing Crohn's or Colitis. Many of these changes are in genes that control the immune system. Changes in these genes may alter the immune system's response to bacteria in the gut. This can lead to ongoing inflammation. You can read more about this [here](#).

Genetic variations are a major focus of Crohn's and Colitis research, as they can affect your chance of developing these conditions. If scientists could identify the particular genetic variations that contribute to Crohn's and Colitis, they could learn more about what causes these conditions to develop and discover better treatments. More than 200 genetic variations have been found that affect your risk of developing Crohn's or Colitis - but scientists do not know what all of these variations do, or how they contribute to someone developing the conditions.

You can read more about some of the studies into genetics that we have helped to fund [here](#) and [here](#).

I'm interested in Dr Lees mention of future work on Fistulas & Stricture Therapy. What is this looking at please?

Professor Shaji Sebastian is current leading a study called GONDOMAR - Goals, Needs and Determinants of Multimodal Therapy in Perianal Crohn's Fistula. This study will

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recruit and follow over 4,000 patients with perianal fistulas from over 80 hospitals across the UK. GONDOMAR will be developed into a research platform to help hospitals share their knowledge of perianal fistula to help develop best practice and improve outcomes for patients. You can read more about it [here](#).

Should any new or worsening symptoms, such as increased joint pain or possible gastro infections be managed by my IBD team, or should I go to the GP?

Your IBD team should provide support for you if you are experiencing symptoms of a flare-up such as increased pain. The [IBD Standards](#) state that rapid access to specialist advice should be available to patients to address a potential flare-up early, including access to a telephone/email advice line with response by the end of the next working day. There should also be good communication between your IBD team and your GP. IBD UK carried out a benchmarking survey in 2019 and again in 2023 to assess how IBD services across the UK were doing against the national IBD Standards. The results of the 2023 surveys will be available by early 2024 and will help inform the work of IBD UK and the charity in encouraging improvement in the areas that need it most.

Fatigue and pain both increase even in remission, when tasked to do too much (a lower baseline to deal with activity stresses) - is this included in the studies?

The IBD-BOOST study looked fatigue, pain and urgency across a large group of people with IBD, including those who reported being in remission. We know that symptoms like fatigue and pain often do persist even when someone with Crohn's or Colitis is in remission. You may find our [information pages on Fatigue](#) helpful.

How do we avoid too narrow a focus of complications being solely intestinal rather than taking a broader view of the many extra intestinal manifestations and correlating inflammatory diseases that IBD patients are vulnerable to developing when their IBD is undertreated?

We are currently developing resources to support healthcare professionals treating people with Crohn's or Colitis. One of the areas we want to provide education in is extra-intestinal manifestations (EIMs) and we recently collaborated with NB Medical to create a webinar about EIMs aimed at healthcare professionals.

Is there any link between age and pain?

We don't currently have any information about this, but we are always looking for ways to improve and we regularly review our information. We will consider including information about this when we produce future resources.

When will AWARE-IBD personalised care plan template be available?

You can download the AWARE-IBD personalised care plan template and accompanying information sheet [here](#). Please note this is currently only in use in Sheffield, but we will share any news on the charity website if this is adopted in other areas of the country.

I developed Crohn's later in life following multiple admissions for IV antibiotics to treat infection & sepsis. My dog was recently prescribed antibiotics along with probiotics. Have we got things to learn from vets?

Some small studies have found that certain high-potency probiotics may help people with Colitis stay in remission. But it is currently not recommended because other more effective options are available. As yet, there is no clear evidence that probiotics can help induce or maintain remission in people with Crohn's.

There is some evidence that people receiving certain types of antibiotics are at greater risk of developing infections and symptoms like diarrhoea. As a result, some doctors do prescribe probiotics for patients who are considered at high risk of developing these complications, to take alongside their course of antibiotics.

Can you please add microscopic colitis patients to your research projects. There is so little attention given to this.

We are happy to advertise studies from across the spectrum of IBD research and this would include microscopic colitis. We are also reviewing our research strategy in 2024 and hope to ensure the topics our own grants cover are those of most importance to people living with all forms of IBD.

Is there a link after having ALL cancer then getting Colitis?

Acute Lymphocytic Leukaemia (ALL) is a type of cancer of the blood and bone marrow – the spongy tissue inside bones where blood cells are made. We don't currently have any information about this type of cancer in relation to Crohn's and Colitis, but we are always looking for ways to improve and we regularly review our information. We will consider including information about this when we produce future resources. In the meantime, you may find the Cancer Research UK pages useful: [Acute lymphoblastic leukaemia \(ALL\) resources and support | Cancer Research UK](#)

Will new evidence on UPFs (Ultra Processed Foods) inform guidance on low residue diet? It is hard to eat healthily with strictures. Advice is white bread etc

Research is currently being done to find out whether ultra-processed foods can increase gut inflammation; one of these studies is taking place at King's College London and is called the ADDapt Trial which you can read about [here](#). This work is in its early stages but it is possible that in the future it may influence dietary advice for people with Crohn's and Colitis, once a body of evidence has been built up. You may find some of our [information pages about Food](#) helpful. You could also watch the talk about UPFs which Professor Kevin Whelan gave at our AGM this year and read the Q&A from the event, which can be found [here](#).

Are we more at risk because of food preservatives chemicals and medicine given to the animals we eat?

Research is currently being done to find out whether food additives can increase gut inflammation; one of these studies is taking place at King's College London and is called the ADDapt Trial which you can read about [here](#).

Is anyone looking at additives in medications, such as titanium dioxide and other formulation fillers/coatings and their effect on IBD and/or the microbiome? Polypharmacy is a problem if there is additional conditions to treat alongside IBD (or because of treatment side-effects) - and increases with age.

We don't currently have any information about this, but we are always looking for ways to improve and we regularly review our information. We will consider including information about this when we produce future resources.

Can we check if there is inflammation travelling to the brain neurological from the gut the brain gut axis. And leaky gut is known to affect the brain and increase anxiety because of the disease is affecting the brain?

We don't currently have any information about this, but we are always looking for ways to improve and we regularly review our information. We will consider including information about this when we produce future resources.

Re: Sexual health study, is there any evidence that Chronic IBD can cause impotency?

You may find our information pages on [Sex and Relationships](#) helpful.

Is there going to be any research into hyperbaric oxygen therapy for IBD, in particular for healing and fatigue?

We don't currently have any information about this, but we are always looking for ways to improve and we regularly review our information. We will consider including information about this when we produce future resources.

Is there a link with eye colour?

We don't currently have any information or evidence about a link between eye colour and Crohn's and Colitis.