



“
Joining Crohn’s & Colitis UK
for support was one of the
best things I did.”

Seema and son, Zayaan,
living with Crohn’s disease

**2024: A YEAR OF PROGRESS,
A FUTURE OF HOPE**

**CROHN’S &
COLITIS UK**



REVEALING WHAT LIFE WITH CROHN'S OR COLITIS IS REALLY LIKE



During Crohn's and Colitis Awareness Week, we asked people to 'Face the Facts' and help us combat unmet needs in care, support and understanding within the broader community and healthcare system. We highlighted key findings from the [IBD UK Report](#), shedding light on the state of Inflammatory Bowel Disease (IBD) care in the UK. This was supported by our community, who shared their personal stories, bringing the real-life impact behind the facts to light.

Over two million people saw our posts via our social media channels and an unbelievable **17 million people viewed a segment on ITV News.**

Achieving this coverage was vital, helping to ensure that more people understand the impacts of Crohn's and Colitis, and how important our work is to bring about change.

MEMBERSHIP MATTERS

BECAUSE NO ONE SHOULD FACE CROHN'S OR COLITIS ALONE



Through our growing community of over **59,000 members**, we provided support, resources and a sense of belonging. By joining us, our members gained access to a wide range of resources and a supportive community.

“

The starter pack was really helpful when I was newly diagnosed – it advised applying for a radar key, which is a godsend. ”



CONNECTING PEOPLE THROUGH VIRTUAL EVENTS



Fatigue, pain and the need to stay near a toilet make it hard for people to socialise during a Crohn's or Colitis flare-up, which can leave people feeling isolated and lonely. Our virtual social events provide opportunities to meet other people affected by Crohn's or Colitis.

Attendees value having a supportive 'safe space' to discuss their concerns and coping strategies with people who truly understand.

Hearing other people's experiences made them feel less alone, more hopeful, supported, understood and inspired.



Last year we handled **9,467** helpline enquiries



HELPING PEOPLE FEEL HEARD AND UNDERSTOOD

99%

agreed or strongly agreed that the person who replied understood their needs and responded appropriately.

97%

agreed or strongly agreed that the information received was helpful.

99%

agreed or strongly agreed that they would recommend the helpline service to others affected by Crohn's or Colitis.

“

Quick pick-up. Incredibly knowledgeable. They listened carefully to my queries and provided support in an extremely professional, calm, reassuring, caring way. Confidence was quickly built, so I felt I could ask any question, no matter how small. I felt supported beyond expectations. **”**

“

Fantastic experience as a first-time attendee... It was a feel-good session, so I came away feeling more supported and realising that there are others out there who understand deeply what it is truly like living with the condition. I'll be attending more events in the future. **”**

We held **61** virtual social events, enabling **665** people to interact with and feel connected to others who are affected by Crohn's or Colitis.

“

I've felt very alone since being diagnosed. I have so much support, but my friends and family don't understand the severity of my illness. This event made me feel like I'm not the only one struggling. **”**

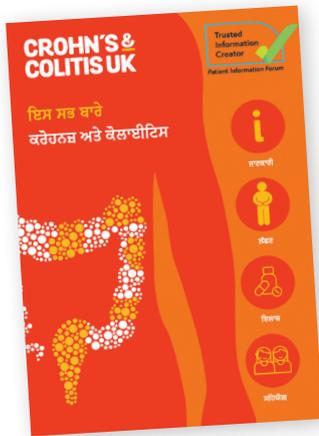
Your support means people can rely on our up-to-date, evidence-backed information.

Reliable information is fundamental in helping people make informed decisions about their treatment and care, and supporting them to self-manage their condition as well as possible. That's why we have updated our high-quality health resources and developed new ones to ensure people have the right information when they need it most.

These resources are available to inform, support and empower people living with Crohn's or Colitis. Last year there were:

2,513,625 views of our written information resources

871,554 users of our written information resources



We produced **11 new online resources**, including two videos and several **quick guides**, to help people understand symptoms and treatments, or apply for disability benefits.

There were **265 downloads** of our professionally translated **'All About Crohn's and Colitis'** PDF resource,

which is available in Polish, Gujarati, Punjabi, Urdu, Bengali and Welsh.

22,590 booklets were sent to healthcare professionals, who ordered them from 70 IBD services and NHS organisations.

“As a frightened adult of 59 years old, your website gave me hope, knowledge, understanding and peace of mind.”

OUR SYMPTOM CHECKER



We've supported thousands more people who thought they might have Crohn's or Colitis to speak to their GP about their symptoms.

More than **302,000** people have completed the symptom checker since it launched two years ago. One in two adults don't know the symptoms of Crohn's or Colitis, so this is a crucial resource.

✓ As a result **88%** were told to contact their GP.

✓ and **74%** of people told us they'd followed up with their GP.



24,191 users of our **Medicine Tool** – an accessible digital resource to help with making decisions about treatments – and our **Talking Toolkit**, which helped people find the 'right words' to talk about their condition.

Pioneering tailored information and support

Following extensive research and collaboration with people living with Crohn's or Colitis, healthcare professionals and other organisations in 2024, we are proud to launch our new Digital Learning Hub this year.

Up to 60% of patients could not correctly report the information provided by their healthcare provider 10 to 80 minutes after their consultation. We need to change that.

The Digital Learning Hub will address the key challenges people face by providing clear, accessible support, helping people better understand their condition, make informed health decisions and gain greater confidence in managing their care.

“I fully endorse the aims of the Digital Learning Hub... I will signpost my patients to it with confidence.”



Dr Christian Selinger, Consultant Gastroenterologist and Clinical Adviser to Crohn's & Colitis UK

UNCOVERING A MAJOR CAUSE OF INFLAMMATORY BOWEL DISEASE



Last summer, researchers at the Francis Crick Institute, Imperial and UCL, led by Dr James Lee (left), discovered an element of DNA that drives inflammation and increases the risk of developing Crohn's or Colitis.

 **This breakthrough brings us closer to understanding and addressing the causes of Inflammatory Bowel Disease (IBD).**

Excitingly, we will be able to target this pathway using existing drugs. This groundbreaking research was part-funded by us, thanks to our supporters.

“

Thankfully, researchers such as Dr Lee and others are helping to accelerate answers to questions about the causes of Crohn's and Colitis and will bring us closer to maximising treatment pathways. This research is an exciting step towards the possibility of a future without Crohn's and Colitis. ”

Marianne Radcliffe, our CEO

GROWING OUR RESEARCH COMMUNITY

Last year, 50 people took part in or helped shape a wide range of high-quality research studies. Making sure people living with Crohn's or Colitis can share their insights and experience to help shape and direct research ensures research is more relevant, meaningful and beneficial.



UNDERSTANDING THE NEEDS OF PEOPLE LIVING WITH CROHN'S OR COLITIS

After engaging with people living with Crohn's or Colitis – including those historically underrepresented in research – we identified the top 10 areas of people's lives that are most impacted by Crohn's or Colitis. This insight enables us to direct our efforts towards the areas that matter most to our community.

This work will inform our new strategy, which launches in 2025.

Top 10 impacts on quality of life

- 1 Fatigue and energy management
- 2 Anxiety about toilets and accessing them
- 3 Living with unpredictable symptoms and flare-ups
- 4 Living with physical symptoms
- 5 Feeling embarrassed and self-conscious
- 6 Dealing with poo
- 7 Complex emotions (e.g. frustration, worry, grief)
- 8 Always being alert to signs and symptoms
- 9 Having to plan and strategise activities and events
- 10 Sleep disruption

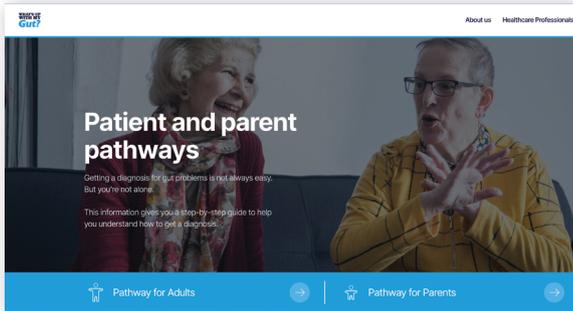
INVESTING IN RESEARCH IS A PRIORITY

In 2024 we **launched five new research projects**, made possible by the incredible generosity of our donors, legacy supporters and supportive community. This would not have been possible without your commitment. Our research spans a diverse range of areas, from studying strictures and fistulas to predicting medicine resistance and enhancing gut healing in children. We're also harnessing artificial intelligence to detect pre-cancerous changes in the bowel. Each of these projects brings us closer to improving the lives of those affected by Crohn's or Colitis – and, ultimately, to finding a cure.

You can find out more about the projects your support has helped us invest in here.



Helping GPs and other healthcare professionals make vital decisions



Early diagnosis is vital to ensure people get on the right treatment path as soon as possible. Until now, there was no single diagnostic pathway to help ensure people with lower gastrointestinal symptoms get the right test at the right time.

Working with other gut health experts, we have developed a new diagnostic pathway. This has been clinically endorsed, providing clear guidance for healthcare professionals. The new website [What's Up With My Gut?](#) can help busy GPs and health professionals make vital decisions about tests and investigations when someone presents with gut-related symptoms.

We have also developed a patient toolkit whatsupwithmygut.org.uk/patient to make the process of diagnosis less overwhelming.

Ultimately, the sooner we can ensure people are on the right path to the treatment they need, the better.

“There should be a copy on every GP’s wall.”

Medical student

Putting pressure on the Government to make the needs of people living with Crohn’s or Colitis a priority

In July 2024, we launched our Cut the Wait campaign, asking supporters to sign our open letter to the Secretary of State for Health and Social Care in England. A total of **34,496 supporters signed** the open letter asking him to prioritise the needs of people living with Crohn’s or Colitis.

STARRING ON THE *BBC* BREAKFAST SOFA!



OUR CALL TO ACTION TO IMPROVE CARE

IBD UK is a unique alliance of 17 clinical, professional and patient organisations dedicated to improving standards of care and treatment for people with IBD. We are proud to chair and provide the secretariat for this important initiative.

We launched the **IBD UK National Report** – the only audit of the state of IBD care across UK hospitals – and 17,654 people with IBD and 150 IBD hospital services took part, giving an insight into the reality of IBD care across the UK. This report will help us to call for urgent, essential improvements in NHS care.

The report was shared with all UK politicians, calling on them to help address the need for change.

Using expertise to provide rapid access to care

Our **nurse specialist programme** is driving improvements in care and health outcomes.

We funded three nurses to complete an MSc in Advanced Clinical Practice, and three nurses to join the Royal College of Nursing Advanced Nurse Practitioner credentialing programme. We now have a total of 37 nurses participating in the IBD Nurses Programme across England, Wales and Northern Ireland.

 **29 July was a landmark day for us** as we appeared on *BBC Breakfast* to highlight the urgent need to cut waiting times for diagnosis and treatment. Our interim Director of Services, Advocacy and Evidence, Fern Howard, shared how we're working to ensure people with Crohn's or Colitis are diagnosed early, receive the right treatment and can live the lives they choose.

We also received a response from the former Parliamentary Under-Secretary of State for Public Health and Prevention, Andrew Gwynne, outlining the Government's commitment to improving IBD care.

Additionally, Liberal Democrat deputy leader Daisy Cooper spoke at her party conference about her

We held four community days to enable our nurses to share best practice, hear from experts on how to improve IBD care in their services and facilitate peer support. We also delivered three advice line training sessions, providing guidance and expertise to nurses on running an IBD advice line.

We are driving improvements in care and health outcomes

IBD Nurse Gayle Martin at Ulster Hospital was refused funding from her NHS Trust to obtain a qualification in Advanced Nursing Practice to enhance her skills in IBD nursing, because she worked part-time. Fortunately, through our IBD Nurses Programme, we were able to fund her MSc. Drawing on her advanced training, Gayle has created a clinical nurse-led IBD rapid-access clinic, which has delivered faster access to treatment, helping over 500 patients a year!

Crohn's Disease diagnosis and the life-threatening challenges she faced.

In 2024, we had meetings and engaged with more than 70 parliamentarians, as well as contributing to 10 consultations, including the Scottish COVID-19 Inquiry and the Work and Pensions Committee Inquiry into Disability Employment.

With growing visibility in parliament and strong evidence to support our cause, we are committed to driving systemic change for people living with IBD.



“ I can usually see patients within 48 hours and request investigations, getting them on rapid-access scope lists, diagnosed and into treatment a lot quicker. Medical and surgical colleagues will accept referrals directly from me, trusting that I have run appropriate investigations. **Before the gastro hub and rapid-access clinics, it took at least three months to see a consultant. Now, patients can be seen within a week. ”**

Gayle Martin, IBD nurse

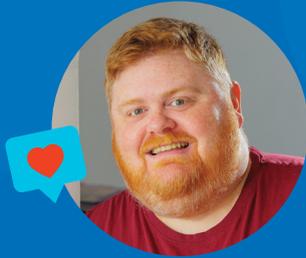


“ My IBD nurse, Lisa, is my insider, someone who has got to know me personally and fights to make sure I get the care I need. Lisa is a vital part of my care, saving me so many unnecessary trips to the GP, my consultant and A&E. Everyone with IBD deserves their own specialist nurse like mine. **”**

Hannah, who has lived with Crohn's for 17 years

INFORMING, RESPONDING, REASSURING

Thanks to the ongoing commitment and kindness of our supporters like you, we're able to support thousands of people who may have nowhere else to turn.



“

Meeting people through Crohn's & Colitis UK's social events helped me so much. I still get fatigued, but I'm in a place now where I have the mental resilience to know when I need to take a rest and stop it getting worse.”

Adam Murfet

“

This website, which was recommended by my IBD consultant and nurses, really helped in the beginning of my journey with Crohn's. The information available and updates to it keep me coming back to refresh my knowledge and learn about the new or different treatments available to me. I also really like reading stories from other sufferers – it helps me to feel connected and supported by a larger community.”



THANK YOU

This was all possible because of you.

CROHN'S & COLITIS UK

crohnsandcolitis.org.uk

