

**CROHN'S &  
COLITIS UK**

**BACK OUR  
CALL FOR  
EARLY  
DIAGNOSIS**

Reduce the burden of Crohn's and Colitis  
on patients and the NHS

# We're Crohn's & Colitis UK

We're fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. Right now, over 500,000 people in the UK are living with a lifelong disease that many people have never heard of.

Because of the stigma and misunderstanding surrounding these diseases, thousands of people are suffering in silence. But they're not alone. We're here for them. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence.

We're here for everyone affected by Crohn's and Colitis.

# Executive summary

In 2019 one in four people waited more than a year to be diagnosed<sup>i</sup>. Nearly half end up in A&E at least once before their diagnosis. Delays to treatment affects people's ability to continue education and work and narrows their treatment options while increasing their risk of being hospitalised or needing emergency surgery. Treating each patient with Crohn's and Colitis now costs the NHS as much as treating those with cancer or heart conditions<sup>ii</sup>. Yet despite clear patient need, increased clinical risk and rising costs to the NHS, improving the diagnosis of Crohn's and Colitis remains at the bottom of the health agenda.

## We need three steps to achieve early diagnosis of Crohn's & Colitis:

1

**We need urgent action to raise public awareness of lower gastrointestinal conditions and their symptoms, so that people can get checked, and take control of their health.**

Talking about our toilet habits is still taboo. But people risk ending up in A&E if they continue to ignore the symptoms of an illness that could be life-threatening.

2

**We need a national pathway for primary care to build confidence among the public and the healthcare profession so that people can be diagnosed and treated without delay.**

Bowel conditions are notoriously difficult to diagnose. This is complicated further by the fact there is no nationally agreed pathway for GPs for those presenting with lower gastrointestinal symptoms.

3

**We need clinicians to be able to prioritise endoscopies based on patient need and clinical risk.**

Too many people put their lives on hold or end up in A&E in excruciating pain, or having emergency surgery, simply because people with suspected Crohn's or Colitis could not access a colonoscopy. Diagnosis is too frequently made at a time of crisis, a crisis that could have been prevented with early diagnosis. This has significant implications for the patients and the NHS.

**Back our call for early diagnosis.**

**Reduce the burden of Crohn's & Colitis on patients and the NHS.**

Together, we can help people take control of their health, build back public confidence in primary care, and ensure people get on a treatment plan rather than on an operating table.

# Back our public health campaign

## **People do not know the symptoms of a serious illness that if left too long could be life threatening.**

There is a misconception that you must have continuous symptoms to have Crohn's or Colitis. The truth is these conditions could present with symptoms such as diarrhoea and stomach pain, which may come and go every few weeks and months. Yet, one in two adults do not know these symptoms could be signs of Crohn's or Colitis<sup>iii</sup>.

Too many people brush aside these symptoms, even if they persist for weeks and months. A recent survey we commissioned found that the equivalent of four million people across the UK would not see their GP even if they saw blood in their stools. 1 in 10 people said this was because they would not want to make a fuss.

Young adults, between the ages of 18 and 34, are the group least likely to think that their symptoms could be Crohn's or Colitis. In recent research, we found young adults are more likely to make excuses for their symptoms: from exam or work-related stress to relationship troubles, and to frequent food poisoning. Many would 'self-diagnose' themselves with various health conditions, without going to the GP.

## **People are brushing aside their symptoms simply because they are too embarrassed, too scared or because they do not have the right words to speak to a GP.**

Talking about our toilet habits is still taboo. It is not something we talk about in everyday conversations, and so when people get symptoms like diarrhoea or blood in stools, they are embarrassed to talk about it. Even to a GP. This is particularly an issue for young adults aged 18 to 34. Many hide their symptoms from friends and family, and some would even skip eating or drinking before meeting up with friends – just in case they need to rush to the loo. 1 in 6 say they would delay going to a GP because they are too embarrassed about their symptoms<sup>iv</sup>.

“ I was going to the toilet eight times a day with diarrhoea and stomach ache but felt too embarrassed to tell anyone – it got so bad I just stopped going out, seeing friends then leaving the house at all. ”

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Jonny, London

## **Unproven remedies found online may be giving false hope to people and delaying them from seeking help.**

Half of people have never heard of Crohn's or Colitis<sup>v</sup>, and even those who have, cannot list more than two symptoms<sup>vi</sup>. When people experience multiple symptoms, they put each one down to a different cause, rather than linking them together as signs of Crohn's or Colitis.

Our research shows that young adults feel these symptoms in isolation are not serious enough to see a GP about – so they try to manage their symptoms through dietary and life style changes. Many prefer to get their advice from other young people and from social media. Many self-diagnose medical conditions, assisted by online resources, or by recognising symptoms that a friend previously had. All instead of contacting their GP. In fact, 1 in 7 young adults say they would not do so, because they do not want to waste a healthcare professional's time<sup>vii</sup>.

But self-diagnosis and following remedies promoted online will not help people with Crohn's and Colitis and may be potentially dangerous. Research commissioned by Crohn's & Colitis UK found that unverified medical treatments were the most highly discussed and engaged topics among the general public and young adults discussing symptoms like stomach pain and diarrhoea on social media, while verified treatments garnered the lowest attention<sup>viii</sup>.

People living with Crohn's or Colitis tell us they had spent months, and in some instances years, making drastic changes to their diet and lifestyle prior to their diagnosis. We even heard from people eating only Bran Flakes, or gummy bears to take control of their health.

**This is a risk to people's health and we need everyone to have access to reliable health advice, wherever they look for it.**

### **We need to cut the noise, and get people checked.**

This is why we are launching our campaign – *Cut the Crap: Check for Crohn's or Colitis*. We want people to stop ignoring the key signs of what is a serious disease, stop making excuses for their symptoms, and get medical advice from reliable healthcare professionals like GPs.

This is because we know that after weeks or months of dropping out of social events, sports, dates, school, or work, as they keep having to rush to the toilet or are doubled over with stomach pain, it is a relief to know what is really going on with their bodies and take control of their own health with treatment that works.



Campaign visual

Our new campaign web pages feature our symptom checker, along with information for people who are experiencing one or more of these symptoms so they know what to do, including whether they should be contacting a GP, what they can expect from a GP appointment, what symptoms they should communicate and what tests they can ask for.

### **We can't do this alone.**

We need you to support our public health campaign so that we can reach more people living with lower gastrointestinal symptoms and encourage them to use the symptom checker. We need you to listen to people affected by these conditions in your community and help us raise awareness of these conditions in the parliaments.

# Develop a patient-led diagnostic pathway

For patients to reach the right services as quickly as possible, it is essential that primary healthcare professionals are aware of the signs and symptoms of Crohn's and Colitis and the correct tests to ask for. One of the key challenges that GPs face is that the symptoms of Crohn's and Colitis can present atypically. For example, while diarrhoea is the most common symptom, not all adults and only a quarter of children with these conditions will experience it<sup>ix</sup>.

At the same time, bowel conditions are notoriously difficult to diagnose. A patient presenting to a pharmacy or a GP surgery with diarrhoea or stomach pain or fatigue could be experiencing one of a range of conditions. From food poisoning to irritable bowel syndrome (IBS), coeliac disease, Crohn's or Colitis, or bowel cancer. Yet, there is no nationally agreed pathway for primary care professionals to make decisions on which tests should be done, in which order, for those presenting with lower gastrointestinal symptoms.

Research<sup>x</sup> commissioned by Crohn's & Colitis UK found that under 3% of people diagnosed between 2009 and 2019 had faecal calprotectin testing in their general practice record within the year before their diagnosis. A Faecal Calprotectin test can show whether you have inflammation in your gut, which would be a sign that you may have Crohn's or Colitis.

The same research found nearly a third (29%) of people diagnosed with Crohn's or Colitis had either been previously diagnosed with irritable bowel syndrome or been prescribed antispasmodic drugs prior to their diagnosis. The average time between having a diagnosis of irritable bowel syndrome (IBS) and the diagnosis of inflammatory bowel disease (IBD) was 5.5 years.

A Freedom of Information request put forward by Crohn's & Colitis UK to healthcare commissioning bodies this year revealed that only a handful of areas in the UK have a clear pathway in primary care to investigate diseases of the gut other than cancer. We need people, regardless of who they are and where they live, to have a safe and timely diagnosis journey.

Currently 1 in 10 people would delay contacting a healthcare professional with diarrhoea, stomach pain or blood in stools, because they believe their symptoms will not be taken seriously<sup>xi</sup>. Developing a pathway for tests and referrals to secondary care would build confidence among the public and the healthcare profession, that people can get the right tests and referral at the right time. We are working with other patient charities and clinicians to develop a patient-led primary care pathway for the diagnosis of lower gastrointestinal conditions.

**5.5 years**

**The average time between having a diagnosis of irritable bowel syndrome (IBS) and the diagnosis of inflammatory bowel disease (IBD) was 5.5 years.**

**1 in 10**

**Delay contacting healthcare professionals with diarrhoea, stomach pain or blood in stools, because they believe their symptoms will not be taken seriously.**

**We need your help to make this a reality across the UK.**

# Prioritise endoscopy by patient need

## Waiting lists have grown significantly during the pandemic.

We hear from people contacting our Helplines who are referred to hospital for a colonoscopy but are now waiting several months. In some instances, over a year.

The debilitating symptoms are putting people's lives on hold. They are unable to work, attend school or college, leave their house or even eat.

Clinicians tell us people end up in emergency services in excruciating pain, or they end up having unplanned surgeries resulting in emergency surgery. Simply because people with suspected Crohn's or Colitis could not access a colonoscopy.

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In June 2022<sup>xii</sup>, 61% of people waited for over 6 weeks in Scotland.

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Diagnosis is too frequently made at a time of crisis, a crisis that could have been prevented with early diagnosis. This has both significant implications to patients and the NHS.

## We need clinicians to be able to prioritise endoscopies based on patient need and clinical risk.

### References

- <sup>i</sup> Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change. IBD UK, 2021
- <sup>ii</sup> Luces, C. and Bodger, K. (2006). Economic burden of inflammatory bowel disease: A UK perspective. *Expert Review of Pharmacoeconomics & Outcomes Research*. 6, 471-482.
- <sup>iii</sup> Based on a survey of 10,000 people representative of the UK population commissioned by Crohn's & Colitis UK. Carried out by Censuswide and commissioned by Crohn's & Colitis UK in June 2022.
- <sup>iv</sup> Censuswide.
- <sup>v</sup> Censuswide.
- <sup>vi</sup> Based on a survey of 2,000 people representative of the UK population commissioned by Crohn's & Colitis UK. Carried out by Yonder, in June 2022.
- <sup>vii</sup> Censuswide.
- <sup>viii</sup> Digital listening of all conversations across social channels such as Instagram, Twitter, TikTok, Facebook, Twitch, Reddit, Forums was conducted by Pulsar in July 2022.
- <sup>ix</sup> Sandhu, B.K., Fell, J.M.E., Beattie, R.M. et al. on behalf of the IBD Working Group of the British Society of Paediatric Gastroenterology, Hepatology, and Nutrition (2010). Guidelines for the management of inflammatory bowel disease (IBD) in children in the United Kingdom. *Journal of Pediatric Gastroenterology and Nutrition*, 50 (Suppl 1): S1-S13. <https://doi.org/10.1097/MPG.0b013e3181c92c53>
- <sup>x</sup> Crohn's & Colitis UK (2022) Epidemiology Summary: Incidence and Prevalence of IBD in the United Kingdom. <https://crohnsandcolitis.org.uk/media/4e5ccomz/epidemiology-summary-final.pdf>
- <sup>xi</sup> Censuswide.
- <sup>xii</sup> Diagnostic Waiting Times (2022) <https://www.opendata.nhs.scot/dataset/diagnostic-waiting-times>

## Pledge your support



Back our public campaign and help people take control of their health.



Support our call for a national diagnostic pathway for people with lower gastrointestinal symptoms.



Prioritise endoscopies by patient need, to get people diagnosed and on a treatment plan, rather than on an operating table.

**CROHN'S &  
COLITIS UK**

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