

TRANSFORMING UNDERSTANDING OF CROHN'S & COLITIS

OUR STRATEGIC AMBITION 2026-36

CROHN'S &
COLITIS UK

6699

THE GIRLS
ARE GOING
OUT FOR
DINNER, AND
THE BLOOD
IN THE TOILET
BOWL KEEPS
ME AT HOME.

Priscilla



INTRODUCTION

CROHN'S AND COLITIS ARE LIFELONG INCURABLE DISEASES THAT ARE ON THE RISE

There are currently more than half a million people in the UK living with these conditions: that's around one in every 120. Your family, my friends, our colleagues, struggling to navigate life with an unpredictable condition that could flare up at any time.

And numbers are increasing, both in the UK and across the globe. Especially amongst young people. But despite the statistics, Crohn's and Colitis simply don't get the attention given to other lifelong, chronic conditions.

One of the major challenges is that, to others, Crohn's and Colitis can seem invisible. But the pain is real, the fatigue debilitating, and the spectre of having to rush to the toilet, urgently and frequently, looms large. Combined, the effect on emotional wellbeing can be profound.

In our recent research, nearly 90 per cent of people told us that living with unpredictable symptoms and flares affects their quality of life. Around half said the unpredictability interferes greatly with their social life; forty-five per cent with their education or career.

Yet, to the outside world, many patients might appear to be in perfectly good health. As one person I met recently put it: "I look fine, but internally, a war is raging every day."

There is currently no cure for Crohn's or Colitis. People are waiting too long to be diagnosed and to access treatment. The NHS is under resourced and under pressure. It's time for change. People with Crohn's and Colitis deserve more.

That's why we've developed this strategy. It's our ten-year ambition to transform the world for everyone affected by Crohn's and Colitis. It's our blueprint to increase understanding of the

conditions, so that people are diagnosed quickly and live well. And it contains our ambitious plan to unite our community - researchers, patients and healthcare professionals, here and around the world - to set out the roadmap to a cure.

To deliver this transformation, we also need to change the way we work as an organisation. We must reach more people and deliver even greater impact. So, alongside delivering the four pillars of this strategy, we'll be building strong foundations to underpin everything we do - to get us match fit and ready to face the future with confidence.

This is a bold, new vision for the future, with everyone affected by Crohn's and Colitis at its heart. Amplifying their voices, reshaping how the world sees these conditions, 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. Join us on this journey.

Marianne

Marianne Radcliffe,
Chief Executive Officer

**CROHN'S &
COLITIS UK**



This year, 25,000 people will be told they have Crohn's or Colitis.

That's enough to fill the Royal Albert Hall, four times over. For many, that diagnosis will have taken far too long.

Many will be under 30.

People are most likely to be diagnosed when they are young, and delays to diagnosis, treatment and care are holding them back in their formative years. Too many school days, graduations and celebrations will be lost.

For one in four, diagnosis takes more than a year.

These delays aren't just distressing, they're also clinically harmful. Late diagnosis often results in more severe disease, longer hospital stays and higher rates of surgery. People wait months for colonoscopies, MRIs and specialist gastroenterology appointments, then too often end up needing life-saving emergency operations.

Around one in seven people with Inflammatory Bowel Disease get the news after an emergency hospital admission.

Without treatment, symptoms get worse. Delayed diagnosis often means debilitating pain, emotional trauma and countless trips to A&E. That means lives on hold and wasted NHS resources.

Once diagnosed, the obstacles continue.

Despite the incredible work of doctors and nurses, accessing care is often frustrating. And it's getting worse. The latest snapshot of Crohn's and Colitis care in the UK found that no specialist IBD service meets the official standards for care or staffing. Only one in five has enough specialist IBD nurses and there are huge variations, depending on where you live.

Today there is no cure.

Treatment options have improved rapidly in recent years but accessing them can feel like another huge hurdle. Researchers are working tirelessly to piece together the puzzle of what causes these conditions and evidence is starting to emerge. We are getting somewhere, but without greater investment in that research we may never find the answers or a cure.

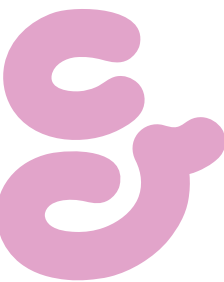
People simply don't understand these conditions.

Managing unpredictable, debilitating symptoms while everyone else gets on with life as normal can leave people feeling isolated, anxious and uncertain. Despite their growing prevalence and lifelong impact, society in general doesn't understand enough about Crohn's or Colitis. Hundreds of thousands of people face daily pain, fatigue, and emotional distress, often without recognition or understanding from those around them.

So, we have listened.

Over the past year we've been engaging with people from across the Crohn's and Colitis community. From patients to clinicians, partners to policy makers, friends, family and everyone else affected by these conditions. We've been unearthing insights and listening to the challenging truths. That is what has informed this strategy and guided our way ahead; to help us take the best decisions about where we can make the greatest difference.

IT'S TIME FOR CHANGE



WE ARE LEADING THE WAY

TRANSFORMING UNDERSTANDING OF CROHN'S & COLITIS: OUR STRATEGIC AMBITION 2026-36

OUR VISION:

A world without Crohn's and Colitis.





OUR PURPOSE:

We inform, empower and unite our community so people living with Crohn's and Colitis can lead better lives.

OUR VALUES:

Ambitious. Compassionate. Stronger together.

THE FOUR PILLARS OF OUR STRATEGY

- 1** Transform understanding of Crohn's and Colitis 
- 2** Unite researchers, patients and healthcare professionals to set out a roadmap to a cure 
- 3** Drive improvements in diagnosis, treatment and care 
- 4** Support people to live well 

1



WE WILL TRANSFORM UNDERSTANDING OF CROHN'S AND COLITIS BY:

- Educating the public and healthcare professionals to spot - and act on - the signs and symptoms.
- Driving awareness of the full impact Crohn's and Colitis have on people's lives.
- Campaigning to make the UK more Crohn's and Colitis inclusive.

So that, by 2036, Crohn's and Colitis will no longer be invisible conditions.

People won't be left isolated, wondering what's wrong. Symptoms will be recognised and responded to quickly. Everyday life will be easier - shopping, dating, travelling, playing sport, finding a clean, safe loo.

A teenager struggling with fatigue or stomach pain will not be dismissed; they'll be taken seriously and tested quickly. Employers will make small changes that make a big difference. People won't feel they need to hide their condition.

KISHAN'S STORY

Kishan Gill was diagnosed with Ulcerative Colitis just before his 15th birthday. Now 23 and living in Birmingham, he's studying immunology and immunotherapy and hopes to one day be part of the effort that helps find a cure.

"I want more people to understand just what a massive impact seemingly small things – like toilet access – can have when you're living with Inflammatory Bowel Disease.

"Colitis ruled my life for a long time: I was frustrated, exhausted and demoralised, waiting for a treatment that would actually work for me. I was rushing to the toilet up to 15 times a day, meaning I was terrified to leave the house in case I couldn't find a loo in time and had an accident. Even the things most people take for granted, like the journey to school, began to feel almost impossible. I remember my dad and I decided the only way to get through it was to find checkpoints along the way: restaurants and shops I knew had toilets. My Crohn's & Colitis UK Can't Wait Card really helped with that.

"Luckily, my Colitis is now in remission. There are good days and bad and sometimes it can feel like a real uphill struggle. But the more society knows about Crohn's and Colitis, and the more support there is for those of us living with these conditions, the better."



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Belle

2



WE WILL UNITE RESEARCHERS, PATIENTS AND HEALTHCARE PROFESSIONALS TO SET OUT A ROADMAP TO A CURE:

- Championing - and funding - research that redefines how we understand and treat Crohn's and Colitis.
- Strengthening global networks and sharing knowledge so we find answers faster, together.
- Translating the latest findings into what they mean for people living with Crohn's and Colitis, to improve lives and drive change.

So that, by 2036, we make progress faster, together.

The research landscape will be transformed with people living with Crohn's and Colitis at the forefront. We'll work with researchers, patients and healthcare professionals to shape and answer the big questions.

This collaboration across the globe will radically change the pace and scale of progress. Better tests, new treatments and a cure within sight.

DR NOOR'S STORY

Dr Nurulamin Noor is a specialist gastroenterologist based at the University of Cambridge. He has won awards for his groundbreaking research into Inflammatory Bowel Disease.

"For me, medicine has always been about people. From the very start of my career, I was struck by the profound impact Crohn's and Colitis have on people's lives. It's not only about physical symptoms, but also about independence, confidence, and quality of life. That's why I believe patient involvement in research is crucial, right from the beginning of any potential project.

"I am hugely grateful to Crohn's & Colitis UK for supporting me early in my career. The charity's funding allowed me to begin investigating why some people respond to certain treatments while others do not: a question that remains central to improving care.

"That opportunity helped lay the foundations for my research journey, and I continue to be inspired by the charity's commitment to fostering ideas that make a real difference.

"We have to speed up diagnosis and treatment. We also need to broaden our view of what research can achieve. We all know medications are vital, but we must also invest in areas such as diet, sleep, exercise, and psychological support. They may hold the key to addressing debilitating symptoms like fatigue and pain where current treatments fall short.

"Looking back, I am encouraged by the progress we've made. Treatments have advanced, outcomes have improved, and patients have more choice than ever before. But, like everyone in my field, I want us to go further, faster. We don't have all the answers and there is a lot of work still to do."



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IT'S NOT
ONLY ABOUT
PHYSICAL
SYMPTOMS.

Dr Noor



WE WILL DRIVE IMPROVEMENTS IN DIAGNOSIS, TREATMENT, AND CARE BY:

- Accelerating innovations in the diagnosis and treatment of Crohn's and Colitis.
- Amplifying patients' voices to influence decision-makers and drive change across the UK.
- Delivering expert training, support and guidance to healthcare professionals.

So that, by 2036, a diagnosis of Crohn's or Colitis takes weeks not years and is followed quickly by the right care.

Healthcare professionals and patients will have quick access to clear, helpful information, no matter who they are and where they live. Treatments will be personalised and holistic. As well as new medications, support with diet, emotional wellbeing and managing fatigue will all be the norm.

No one will be left fighting for the right treatment and care.

IMALI'S STORY

Imali Chislett from Dorset spent a long time waiting to get on the right treatment for Ulcerative Colitis. Now she advocates for faster diagnosis and better care so others don't have to go through the ordeal she did.

"Showing up at the GP's surgery or A&E to talk about blood and mucus in your poo is not easy. That's why it's so important that when people present with those symptoms, they get taken seriously not dismissed for wasting medical professionals' time. I pushed for a CT colonoscopy and it turned out I had severe Ulcerative Colitis. To be honest, I felt relieved to finally know what was going on with my body and validated to know my instincts were right.

"But, like a lot of people, I soon found out that the challenges don't stop when you get a diagnosis. The next obstacle was trying to get on the right treatment. In the end, I had a very close call when my bowel perforated and I needed an emergency ileostomy. I'm only in my mid-20s and I've had to get used to life with a permanent stoma. Things could have turned out very differently.

"I wish I'd been listened to and been more appropriately treated with tailored care. Medical professionals and the public need to understand more about Crohn's and Colitis, to give us the support we need to deal with everything from symptoms and diagnosis to treatment and side effects. It's vital to listen to patients because we are the experts.

"Crohn's & Colitis UK has a really important role to play. I see the charity as the backbone of Inflammatory Bowel Disease information. Kind people, friendly support and an informative website. That's what you really need when you're feeling at your absolute worst: expertise you can trust."



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Imali

4



WE WILL SUPPORT PEOPLE TO LIVE WELL BY:

- Providing information and guidance on the issues that matter most to people affected by Crohn's and Colitis.
- Breaking down barriers to accessing our information and services.
- Uniting people so that our community can tackle Crohn's and Colitis together.

So that, by 2036, life with Crohn's or Colitis will no longer mean living in fear.

People will feel confident and empowered to live full lives: to study, to work, to travel or start relationships. Support will be easy to find and access, online at midnight or in a local group on a Saturday morning.

Wider understanding across society will instil greater compassion and inclusivity. Our community will be strong, connected, and no one will feel they have to go through it alone.

DAVID'S STORY

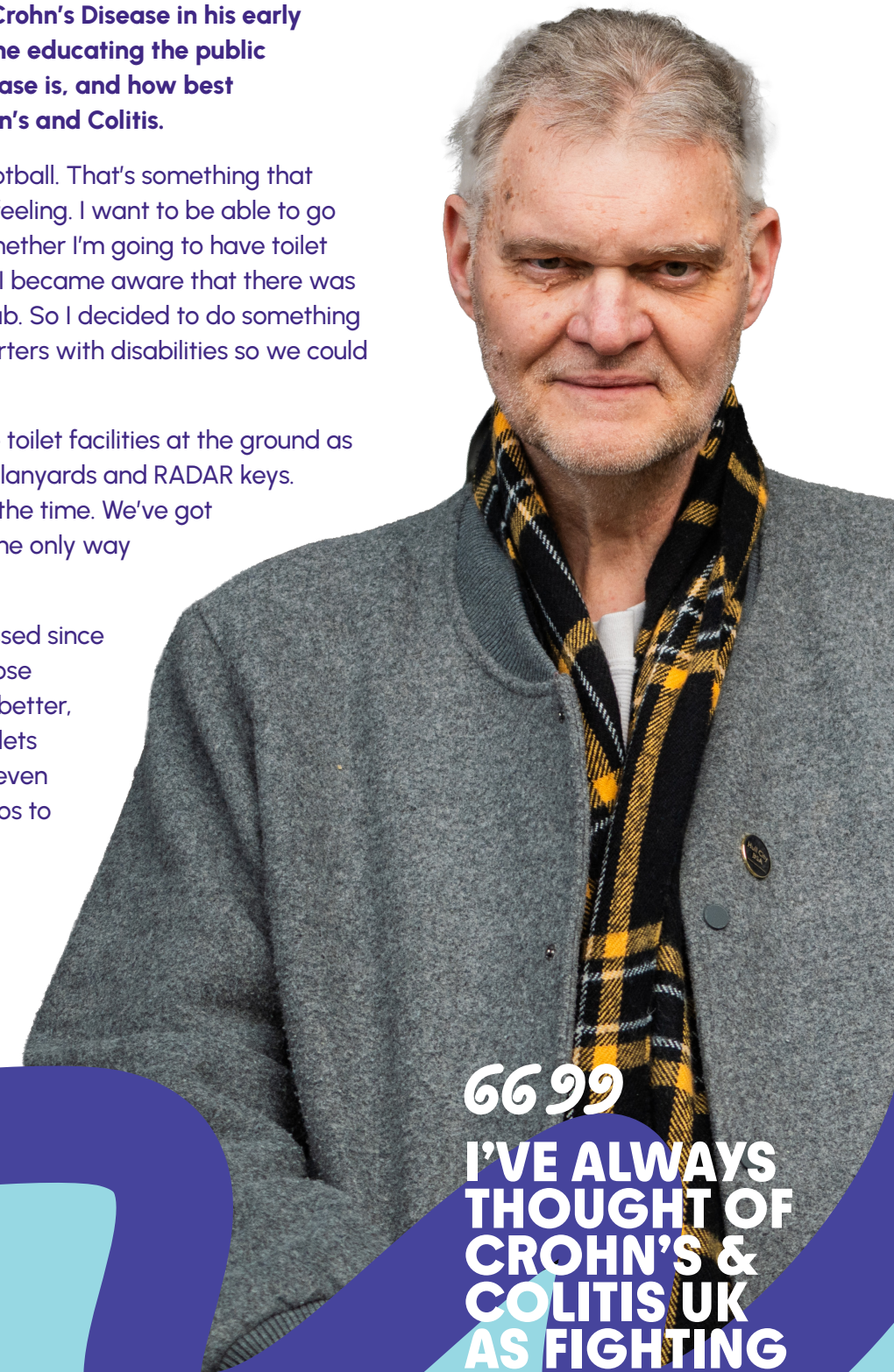
David Batte was diagnosed with Crohn's Disease in his early 20s. Now 59, he spends a lot of time educating the public on what Inflammatory Bowel Disease is, and how best to support people living with Crohn's and Colitis.

"One of my big passions in life is football. That's something that never changes, no matter how I'm feeling. I want to be able to go to a match and not worry about whether I'm going to have toilet access. I support Hull City AFC and I became aware that there was no voice for disabled fans at the club. So I decided to do something about it and recruited fellow supporters with disabilities so we could get a formal group going.

"Together we have helped improve toilet facilities at the ground as well as bringing in hidden disability lanyards and RADAR keys. We're getting bigger and better all the time. We've got to educate people because that's the only way things are going to change.

"How do I think things have progressed since I was diagnosed with Crohn's all those years ago? Well, things are getting better, albeit slowly. Colostomy friendly toilets are becoming more prevalent. I've even noticed stickers in service station loos to raise awareness.

"I've always thought of Crohn's & Colitis UK as fighting my corner. Things are definitely going in the right direction and I'm optimistic about the future."



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David

CROHN'S & COLITIS UK

**WE MUST
MAKE
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TOGETHER.**

We can't do it without you.

Get in touch: fundraising@crohnsandcolitis.org.uk



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