

# WEEKS NOT YEARS

DIAGNOSIS SHOULD HAPPEN IN WEEKS NOT YEARS,  
REGARDLESS OF WHO YOU ARE AND WHERE YOU LIVE.  
FAILURE TO DO SO DAMAGES PATIENTS' LIVES AND  
INCREASES THE BURDEN ON THE NHS.

## PEOPLE SPEND YEARS IN A MAZE OF DELAYS, MISDIRECTION AND DEAD ENDS

This brief brings together case studies that were collected as part of research commissioned by Crohn's & Colitis UK and carried out by the University of Sheffield.

It found stark differences in how people with Crohn's and Colitis experience their diagnosis, revealing journeys to diagnosis lasting between 11 months and 47 years. This is a deep inequity that needs addressing urgently<sup>1</sup>.

The research highlighted three types of delays that lead to people coping for years with symptoms of a serious illness, going back and forth between primary and secondary care and waiting for appointments, test results and an answer.



**LONG DELAYS MAKE  
SURGERY 2–4 TIMES  
MORE LIKELY**

## WHY THERE'S NO TIME TO WASTE

A new global study, the largest of its kind<sup>2</sup>, has found that patients who wait longest to be diagnosed with Crohn's or Colitis are between 2 and 4 times more likely to develop adverse and costly clinical outcomes, including bowel surgery<sup>3</sup>.

## PATIENT DELAYS

6 WEEKS

9 YEARS

### MELISSA\*

Melissa is a 20 year-old woman with Crohn's. She experienced severe abdominal pain, diarrhoea and fatigue for a month before seeing a pharmacist, who recommended paracetamol. When her symptoms didn't improve she made an appointment with her GP.

“I was very tired, and I kept going to the toilet and I was feeling like nothing was working...so I just wanted to find out... what it was.”

### MEERA\*

Meera is a 30 year old woman with Crohn's. For nine years she experienced diarrhoea and abdominal pain that would come and go. She put her symptoms down to a food intolerance and took paracetamol for the pain.

She finally made a GP appointment when she had to turn down a job interview because she was too ill to attend.

“I just thought that what happened to me was pretty normal – going to the toilet like four times in the morning and another three times in the evening, I didn't for a minute think this will be some sort of chronic disease.”

Meera's story is one we hear time and again. People do not know the symptoms of a serious illness that if left too long could be life threatening. Too many people brush aside their symptoms or seek out unproven remedies found online.

**WE NEED EVERYONE TO HAVE ACCESS TO RELIABLE HEALTH ADVICE, WHEREVER THEY LOOK FOR IT. BACK OUR PUBLIC CAMPAIGN AND HELP PEOPLE TAKE CONTROL OF THEIR HEALTH.**

## PRIMARY CARE DELAYS

2 WEEKS

5 YEARS

### AMIR\*

Amir is a 36 year old man with Colitis. When he went to his GP with diarrhoea and blood in his poo, his GP ordered the relevant tests and referred him to a gastroenterologist.

“I felt really positive because I wasn't being dismissed...the doctor didn't just say, 'oh try not to be as stressed or we'll change your diet a little bit, or exercise a bit more', she was quite concerned, and...made me feel like she's trying to get to the bottom of this.”

### HARRY\*

Harry is a 37 year old man with Colitis. When he presented to his GP with abdominal pain and diarrhoea, his GP initially diagnosed him with Irritable Bowel Syndrome (IBS), which he managed for five years. When his symptoms progressed to blood in his poo, his GP referred him for endoscopy.

“I'd probably say dismissive yeah. I was saying what do I do about this and they were like, well nothing, we don't do anything about IBS, that's just you now.”

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.

**WE NEED A NATIONALLY AGREED DIAGNOSTIC PATHWAY FOR HEALTHCARE PROFESSIONALS TO MAKE DECISIONS ON WHICH TESTS SHOULD BE DONE, IN WHICH ORDER, FOR THOSE PRESENTING WITH LOWER GASTROINTESTINAL SYMPTOMS.**

## SECONDARY CARE DELAYS

8 WEEKS

11 MONTHS

### JOAN\*

Joan is a 77 year old woman with Crohn's. After two years of repeatedly presenting to her GP with diarrhoea and abdominal pain she was referred to a gastroenterologist and for a colonoscopy. She received her appointment and tests within 8 weeks and was diagnosed with Crohn's.

“I was...relieved but also quite sad... knowing something that you can't cure, get rid of completely, that was the sad thing. But I was quite happy knowing that there are further steps... I felt relieved that all the symptoms weren't in my head.”

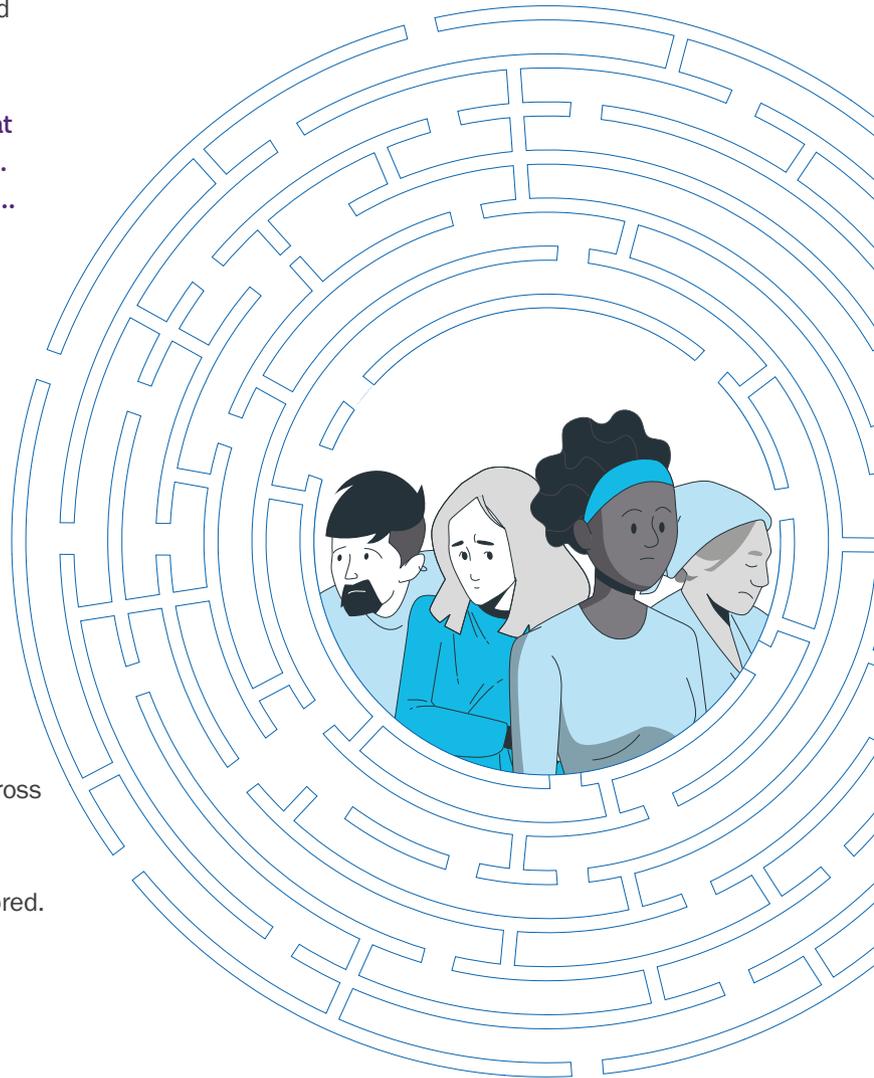
### EMILY\*

Emily is a 39 year old woman with Crohn's. She waited six months for a gastroenterology appointment and a further five months for endoscopy.

“The whole process just took so long... at one point I got an appointment for a phone call, [an] appointment to book another appointment. Which I found absolutely ridiculous...I get that there's massive waiting lists and everything, it feels to me like it [didn't] get addressed as seriously as it should.”

A Freedom of Information request to all Integrated Care Boards, Health Boards, Health and Social Care Trusts across the UK has revealed that data on the number of people with suspected Crohn's or Colitis waiting for endoscopy appointments is not being routinely collected and monitored.

WE NEED PATIENTS TO BE ABLE TO ACCESS ENDOSCOPIES BASED ON NEED AND CLINICAL RISK. WE NEED ROBUST AND REGULAR DATA COLLECTION TO MONITOR HOW MANY PEOPLE WITH SUSPECTED CROHN'S OR COLITIS ARE WAITING.



\*All names have been changed.

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WHO YOU ARE AND WHERE YOU LIVE.**

**[BACK OUR CALL #WEEKSNOTYEARS](#)  
HELP US BREAK THROUGH THE MAZE**

Write to us:

[policy@crohnsandcolitis.org.uk](mailto:policy@crohnsandcolitis.org.uk)



#### ENDNOTES

- 1 Hind, D., Sheldon, E and Ezaydi, N. (2022). Qualitative primary research on the patient experience of the journey to diagnosis with Crohn's and Colitis. Unpublished.
- 2 Researchers from St George's University of London, Imperial College London, and University College London analysed 101 studies representing over 100,000 people with Crohn's Disease and Ulcerative Colitis.
- 3 Jayasooriya, N., Baillie, S, Blackwell, J. et al., (2023). Systematic review with meta-analysis: Time to diagnosis and the impact of delayed diagnosis on clinical outcomes in inflammatory bowel disease. *Aliment Pharmacol Ther.* Doi: 10.1111/apt.17370.