

# Crohn's and Colitis Care in the UK

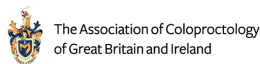
The Hidden Cost and a Vision for Change



Association of Coloproctology of Great Britain and Ireland • British Association for Parenteral and Enteral Nutrition • British Dietetic Association • British Society of Gastroenterology • British Society of Gastrointestinal and Abdominal Radiology • British Society of Paediatric Gastroenterology, Hepatology & Nutrition • CICRA (Crohn's in Childhood Research Association) • Crohn's & Colitis UK • Ileostomy & Internal Pouch Association • IBD Registry • Primary Care Society for Gastroenterology • Royal College of General Practitioners • Royal College of Nursing • Royal College of Pathologists • Royal College of Physicians • Royal Pharmaceutical Society • UK Clinical Pharmacy Association

**IBD UK was formed in 2017 as a partnership of 17 professional bodies, royal colleges and patient organisations encompassing all major stakeholders in UK IBD care delivery.**

**IBD UK's aim is for everyone with IBD to receive safe, consistent, high-quality, personalised care, whatever their age and wherever they live in the UK.**



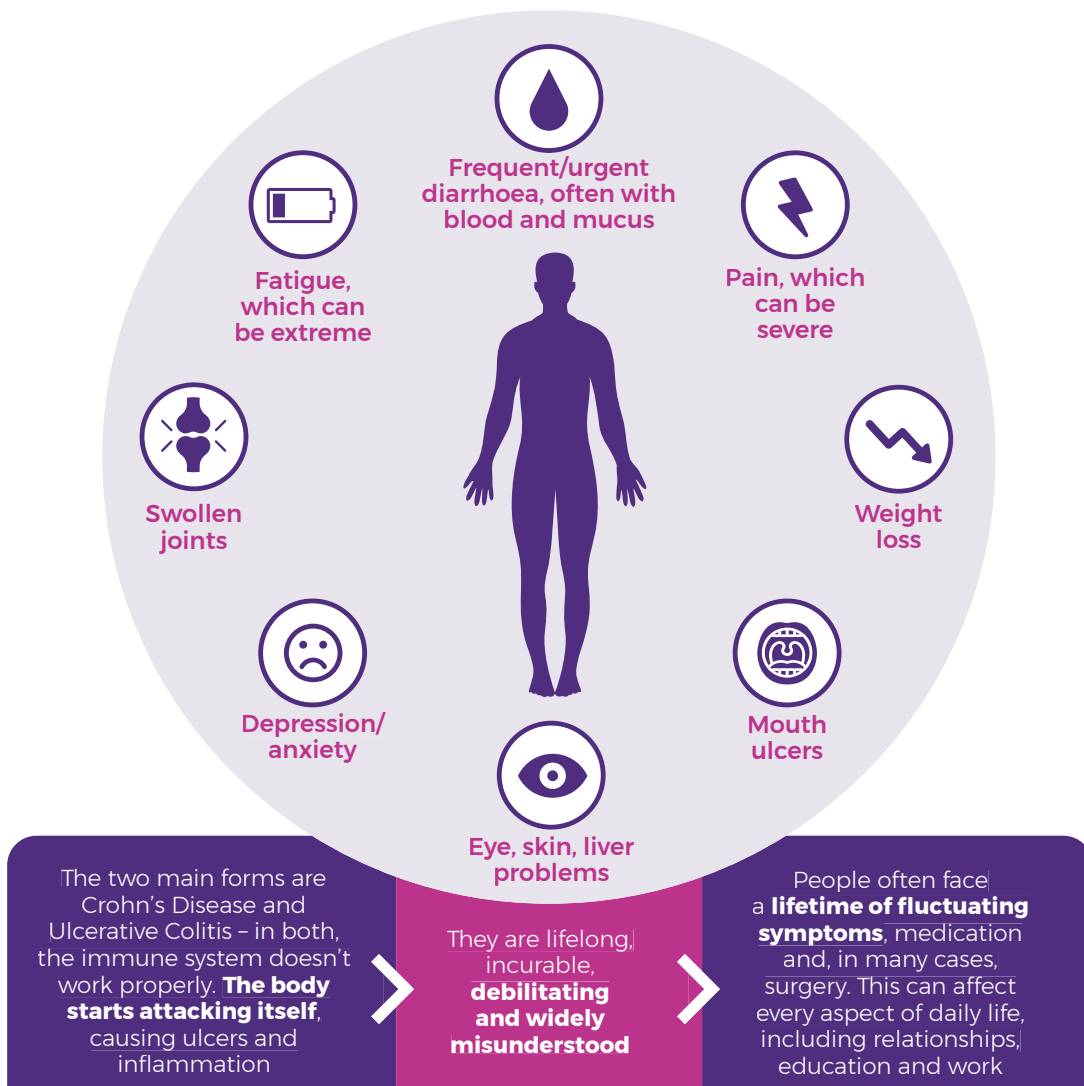
**Full report and IBD Standards available  
at [www.ibduk.org](http://www.ibduk.org)**

**Email [info@ibduk.org](mailto:info@ibduk.org) with any queries**

# Executive Summary

Ongoing research is revealing that over 500,000 people in the UK have Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn's Disease and Ulcerative Colitis. That's at least one in every 133 people. This is a considerable increase on previous estimates of around 300,000 people.

## IBD and its impact Symptoms can affect almost every part of the body



IBD can be extremely debilitating and impact on every area of a person's life. Symptoms include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue, and associated anxiety and depression. Delays to diagnosis and treatment and a lack of personalised and multidisciplinary care can lead to serious and potentially life-threatening complications for the individual, such as a perforated bowel or bowel cancer, and expensive treatment and care for the NHS.

The UK-wide IBD Patient Survey and Service Self-Assessment, carried out between July 2019 and January 2020, provide a unique picture of IBD care, benchmarked against the IBD Standards 2019.

- **10,222 adults, children and young people with IBD across the UK, supported by 99% of IBD services, took part in the Patient Survey.**
- **166 adult and paediatric IBD services (72%) across the UK completed the Service Self-Assessment.**

The results highlight key actions that are urgently needed to reduce high levels of inefficient and costly reactive care, including emergency care, which have been exacerbated by the COVID-19 pandemic.

The IBD Quality Improvement Programme, led by the Royal College of Physicians, and concerted programmes of work across the four nations, have maintained a focus on IBD service improvement since the first IBD Standards in 2009. However, it is clear that much more still needs to be done.

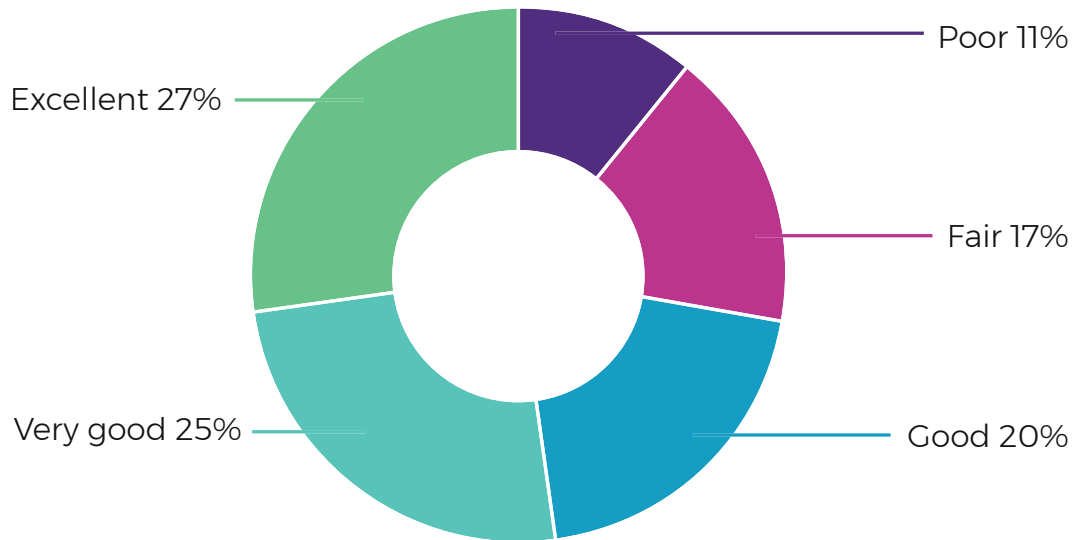
This report highlights pockets of excellent practice, but also demonstrates considerable variation in care across services. This includes some differences between paediatric and adult services and across the four nations. There are system-wide issues that need to be addressed to enable services to deliver consistent, high-quality, personalised care for people with IBD, whatever their age and wherever they live in the UK.

## How do people with IBD view their care?

Of those who responded to the Patient Survey:

- 28% rated the quality of their care as fair or poor.
- 72% rated the quality of their care as excellent, very good or good.

**Figure 1: Overall, how would you rate the quality of your Crohn's or Colitis care over the last 12 months?**



The top three factors that predicted how highly people with IBD rated their quality of care were:

- Feeling supported by a team of IBD specialists
- Having regular reviews
- Discussing wider life goals and priorities, as part of planning their care

### Four areas for change

For care and support to improve – for everyone living with IBD in the UK – we need to see:

- 1. Improvements in diagnosis and information provision**
- 2. Personalised care and support for self-management**
- 3. Faster access to specialist advice and treatment**
- 4. Effective multidisciplinary team (MDT) working**

## 1. Improvements in diagnosis and information provision

**Problem:** It is taking too long for people with IBD to be diagnosed and they are not receiving the information and support they need to cope with adjusting to their condition. This can have a huge effect on the individual's physical and mental health, education and career, and carries a significant cost for the NHS.

- 26% of those responding to the Patient Survey waited more than a year for a diagnosis.
- 41% had visited Accident and Emergency (A&E) at least once before being diagnosed, with 12% visiting three or more times.
- 32% said they were not offered any information about their condition when diagnosed.
- Only 24% of services had referral pathways in place and reported being able to see over 90% of patients with suspected IBD within four weeks of referral.



### RECOMMENDATIONS FOR ACTION

1. There should be a public health campaign to raise awareness of the symptoms of Crohn's and Colitis.
2. Healthcare professional associations, training bodies and patient organisations need to work together to upskill community healthcare professionals in recognising potential IBD.
3. Faecal calprotectin testing must be used consistently and appropriately in primary care, as part of agreed referral pathways between primary and secondary care, and emergency and specialist teams. These referral pathways should be in place in every service.
4. Governments across the four nations should ensure that services are resourced to enable people with suspected IBD to be seen, investigated, diagnosed and treated in line with the time frames set out in the IBD Standards.

## 2. Personalised care and support for self-management

**Problem:** Care is reactive and focused on medication, leaving people struggling with pain, fatigue, anxiety, extraintestinal manifestations and other issues related to their Crohn's or Colitis. This means they are unable to manage and live well with their condition.

- 89% of those responding to the Patient Survey had found it hard to cope with having Crohn's or Colitis over the previous year.
- During medical appointments:
  - 29% were not asked about pain
  - 48% were not asked about fatigue/tiredness
  - 60% were not asked about mental health
  - 47% were not asked about IBD-related complications and/or conditions outside of the gut
- 91% reported they did not have a personalised care plan
- 69% did not know when their screening colonoscopy was due



### RECOMMENDATIONS FOR ACTION

1. Everyone with IBD should have a personalised care plan from diagnosis, based on a holistic needs assessment, detailing specific multidisciplinary support and flare (relapse) management.
2. Structured self-management programmes should be co-produced with patients and commissioned for everyone with IBD.
3. Everyone with IBD should have regular reviews and monitoring that meets their individual needs, both in terms of frequency and delivery.

### **3. Faster access to specialist advice and treatment**

**Problem:** People with IBD are not able to get specialist treatment and care quickly enough. This is resulting in high numbers of emergency hospital admissions and potentially avoidable flares, where their condition is not well-controlled and serious complications can arise.

- 70% of those responding to the Patient Survey said they had experienced one or more flares in the previous 12 months, with 14% reporting more than five.
- 31% said they had received no information on flare management.
- 72% of hospital admissions were emergency admissions.
- 22% waited longer than 18 weeks for elective IBD surgery.



#### **RECOMMENDATIONS FOR ACTION**

- 1.** All IBD services should ensure that everyone with IBD:
  - (i) has a plan in place detailing steps to take in the case of a flare and
  - (ii) can receive a response from an IBD advice line by the end of the next working day.
- 2.** Commissioners and managers should ensure that rapid access clinics and prompt access to investigations are in place in every service, supported by flare pathways that are agreed between primary, secondary and emergency care.
- 3.** There should be a clear process for admission to a specialist gastroenterology/colorectal ward in every IBD service. Job plans for IBD nurse specialists should include time for inpatient visits.
- 4.** Surgery for IBD needs to be prioritised appropriately, alongside surgery for other conditions, given the significant risk to patients of delays.



## 4. Effective multidisciplinary (MDT) team working

**Problem:** People with IBD don't have access to the full range of specialist care they need, and it's not well coordinated or based on all their needs.

- No adult IBD services reported meeting the IBD Standards' recommendations for all roles across the team.
- 14% reported having enough IBD nurse specialists to meet the IBD Standards.
- 13% reported having enough pharmacists to meet the IBD Standards.
- 7% reported having enough dietitians to meet the IBD Standards.
- 2% reported have enough psychologists to meet the IBD Standards.
- Only 48% of those responding to the Patient Survey felt their care was coordinated with other specialist services.



### RECOMMENDATIONS FOR ACTION

1. Commissioners and managers should ensure that every IBD service is resourced to meet the staffing requirements for the IBD team, including gastroenterologists, IBD nurse specialists, colorectal surgeons, stoma nurses, dietitians, pharmacists, psychologists, radiologists and histopathologists. The MDT should hold regular, effective meetings, supported by an administrator.
2. Commissioners and managers should ensure that pathways are in place to deliver well-coordinated care across specialties, including joint medical/surgical clinics, and between paediatric and adult services and primary and secondary care, supported by effective data systems.
3. Every IBD service should have a leadership team in place, including a manager, to plan and develop IBD services effectively and efficiently, ensuring patient involvement and co-production.

## Conclusions

The data highlights specific areas where action needs to be taken and some common overarching themes and principles. These need to be considered alongside the recommendations to deliver high-quality, safe, consistent, personalised care for people with IBD, whatever their age and wherever they live in the UK.

**1. Care should be personalised, proactive and preventative, not reactive.**

Everyone with IBD should receive an early and accurate diagnosis and have a personalised care plan. This must include access to the full range of specialist support, including rapid response when required, and ongoing monitoring and review.

**2. Information and support are fundamental to people with IBD feeling confident and able to live well with their condition.**

Everyone with IBD should receive accessible information at all stages of their care. This must meet their individual needs, as part of shared decision-making, and signpost to patient organisations for further information and wide-ranging support.

**3. IBD nurse specialists are central to high-quality IBD care as part of the complete IBD multidisciplinary team.**

Everyone with IBD should have access to an IBD nurse specialist and all IBD services should meet the standard for IBD nursing provision.

**4. Data and IT systems should underpin patient care, service planning and audit.**

Everyone with IBD should be entered on a clinical IBD system to enable coordinated care, with data provided to support local and national audit and service improvement.

### **Further information and support**

If reading this report has raised any concerns for you then please contact the **Crohn's & Colitis UK Helpline**

0300 222 5700

helpline@crohnsandcolitis.org.uk

www.crohnsandcolitis.org.uk

If you have questions or concerns about ileostomy or internal pouch surgery, please contact the **Ileostomy & Internal**

**Pouch Association**

0800 018 4724

info@iasupport.org

www.iasupport.org

If you have questions or concerns relating to children with IBD, please contact **CICRA (Crohn's in Childhood Research Association)**

020 8949 6209

support@cicra.org

www.cicra.org



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