

## Written evidence submitted by Crohn's & Colitis UK

### About us

1. Crohn's & Colitis UK welcomes the opportunity to respond to this inquiry on [NHS backlogs and waiting times](#).
2. Crohn's & Colitis UK is the leading charity for Crohn's and Colitis in the UK. We work to improve diagnosis, treatment and care, to fund research into a cure, to raise awareness and to provide information and support.<sup>1</sup>
3. Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn's Disease and Ulcerative Colitis, affects over 421,000 children and adults in England. They are lifelong, often debilitating conditions, with no cure.<sup>2</sup> Symptoms include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue, and weight loss, with associated anxiety and depression. They lead to time off school and work, withdrawal from social relationships and inability to carry out everyday activities, such as shopping and exercise. IBD doesn't just affect the gut. It can affect almost every part of the body and every aspect of life: from digestion, eyes and joints to energy levels and mental health. With many of these symptoms invisible, it can appear that someone looks healthy when they are in fact incredibly unwell. This creates stigma and misunderstanding, with thousands of people suffering in silence.
4. People can be diagnosed at any age, with most diagnosed between the ages of 15 and 40. IBD requires tight monitoring and management, often over several decades depending on age of diagnosis. Care is managed across primary and secondary care, often with high-cost medications or surgery, or a combination of both. Delayed diagnosis increases the likelihood of surgery or more expensive treatments and results in a poorer prognosis.<sup>3</sup> If left untreated, poorly managed or in cases of severe disease, Crohn's and Colitis can cause serious complications, which require emergency medical and/or surgical intervention. The burden of Crohn's and Colitis on the NHS is increasing year on year and per patient costs are comparable to cancer and heart disease.<sup>4</sup> The annual cost of treating a flare (relapse) is up to six times greater than for treating a patient in remission.<sup>5</sup>

### Summary of points, recommendations, and potential areas of inquiry

- IBD services are not currently appropriately resourced or supported to deliver safe and appropriate IBD care and to manage the backlog
- The coronavirus pandemic has led to:
  - A reduction in reported diagnoses of IBD
  - Cancellation of and reduced access to endoscopy and surgery for IBD
- Disrupted access to essential medication

<sup>1</sup> [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk) (last accessed 27/10/21)

<sup>2</sup> [About Inflammatory Bowel Disease | Crohn's & Colitis UK \(crohnsandcolitis.org.uk\)](#)

<sup>3</sup> Mozdiak E, O'Malley J, Arasaradnam R (2015). Inflammatory bowel disease. *BMJ*. 351: h4416. [Inflammatory bowel disease | The BMJ](#)

<sup>4</sup> Luces C, Bodger K (2006). Economic burden of inflammatory bowel disease: A UK perspective. *Expert Review of Pharmacoeconomics & Outcomes Research*. 6: 471-482.

<sup>5</sup> Ghosh N, Premchand P (2015). A UK cost of care model for inflammatory bowel disease. *Frontline Gastroenterology*. 6: 169-174. doi:10.1136/flgastro-2014-100514.

- Delayed appointments and difficulties accessing IBD specialists and GPs
- This has impacted the ability of people with Crohn's and Colitis to stay well and has led to:
  - Flares, which may cause further bowel damage and increase cancer risk
  - High need for mental health support
  - Likely increased need for more high-cost drug treatment and complex surgery
- Priorities for clearing the backlog should include:
  - Ensuring that IBD endoscopy and surgery is appropriately prioritised according to clinical need
  - Publishing clearer data to monitor how urgent and serious non-cancer surgery is being carried out and lengths of waitlists
  - Clearly communicating to patients about lengths of waits and decisions about their care and treatment
  - Expediting access to non-invasive testing, home monitoring and preventative supported self-management through digital/remote means
  - Implementing different approaches to managing care effectively between specialist hospital care services and primary/community care, for example, introducing an IBD care coordinator role.
- Opportunities to redesign care, such as remote appointments and shifts to subcutaneous treatments must involve patients and be based on delivering personalised care and shared decision-making.
- A defined strategy for managing chronic long-term conditions like IBD which require highly complex MDT care is urgently needed to drive improvements in care and accelerate innovation across the system

### Possible questions:

- How is Federation of Surgical Specialty Associations (FSSA) guidance being applied?
- Is urgent and serious non-cancer surgery and endoscopy - for example, for Crohn's Disease and Ulcerative Colitis - being prioritised appropriately?
- How will programmes such as GIRFT and Rightcare be funded to drive quality improvement and reduce unwarranted variation in care to support elective recovery?
- What actions will be taken for those people whose surgery has been cancelled but who have not been contacted since and/or offered a new date?
- Is NHS England doing enough to give people with long-term conditions the skills and confidence to manage their condition to reduce pressures on NHS? Are there plans to optimise or centralise digital approaches to patient education/supported self-management for long-term conditions to aid rollout?
- Has adequate focus been given to young people and adults with dependents, who are waiting for elective surgery and for whom delays can impact their employment and livelihoods?

## 1. Current position of NHS backlogs and waiting times following the COVID-pandemic, including the points at which patients wait for NHS treatments

Our submission draws on a range of sources, including published articles, existing guidance, IBD Registry<sup>6</sup> data, and surveys of healthcare professionals and people with Crohn's and Colitis, which assess the provision of IBD care before and during the coronavirus pandemic.

The results from Crohn's & Colitis UK's "Healthcare Survey 2021",<sup>7</sup> highlight challenges and opportunities in relation to healthcare provision and clearing the backlog, based on experiences during the previous 6-12 months.

### Decisions about prioritisation

The Federation of Surgical Specialty Associations (FSSA) has developed a [Clinical Guide to Surgical Prioritisation in the recovery from the Coronavirus Pandemic](#). This guide should be *"used for reference to changing national priorities and to assess when local arrangements, therefore, need to be revised."* The guide states that patients should be pre-assessed and prehabilitated prior to surgery and that patients on a waiting list should be regularly reviewed.

The [British Society of Gastroenterology's guidelines for colonoscopy for high-risk surveillance patients during COVID-19](#) say that it is *'imperative that senior clinicians continue to triage patients according to clinical need and target the resources available to those at highest clinical risk of serious disease and where further delay risks adverse outcomes'*. The guidance states that those people with IBD at high risk of cancer should be prioritised for cancer surveillance. They also recommend that:

- For patients due surveillance colonoscopy at an interval of less than 3 years, we recommend that this is performed within 6 months of the original due date
- For patients due surveillance colonoscopy at an interval of 3 or more years, we recommend that a colorectal surveillance procedure be performed within 12 months of their original due date (i.e. this may include surveillance modalities other than colonoscopy, where deemed clinically appropriate)
- Stool faecal immunochemical testing FIT can be considered for patients on surveillance waiting lists who are overdue, to prioritise those for expedited or urgent colonoscopy, in line with existing guidance.

[Timely access to care: Principles for recovery](#) sets out from the perspective of National Voices, which represents a range of health and social care charities, recommendations for system leaders and government, those planning services and voluntary, community and social enterprise organisations to follow. We are supportive of these recommendations, in particular:

- Clear communications to patients about lengths of waits and decisions about their care and treatment

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<sup>6</sup> UK IBD Registry - IBD Registry

<sup>7</sup> Based on over 3,700 responses received to date from people living with Crohn's or Colitis and parents/carers of children with Crohn's or Colitis

- Clear communications to patients to continue to seek help and how to access the right care, at the right time and in the right place
- NHS England (NHSE) publishing a wider range of statistics to monitor the elective recovery, including data on chronic condition management such as Crohn's and Colitis
- A focus on supporting self-management and patient education to empower patients to keep themselves as well as possible and avoid hospital admission or emergency surgery (where possible)

## The emerging threat of missed and delayed diagnosis

IBD is not well understood either by the public or by general practitioners (GPs), who see a high proportion of patients with lower gastrointestinal symptoms. This creates delays in people recognising they have symptoms that should be investigated and in GPs carrying out the relevant tests and making the necessary referrals to secondary care. There are often further delays before a specialist can be seen and then before treatment is initiated. The pandemic has created additional challenges at each of these stages, due to difficulties accessing appointments, tests and investigations.

IBD Registry data from April to June 2020, compared with the same period in 2019, shows that the rate of new diagnoses of IBD recorded fell from 49 to 13 per 1,000 events (-74%).<sup>8</sup> Diagnosis is also taking longer than before the pandemic:

- 29% who had been recently diagnosed said this had taken more than a year
- 41% said it had taken more than two weeks for treatment to start after diagnosis (up from 24% in 2019)

*“I was an inpatient when I got diagnosed so needed rescue treatment. I do believe my late diagnosis caused me to end up in hospital.”*

*“Never actually saw a 'human' - I still have only spoken to my GP and consultant over the phone. The only time I have physically seen someone was to have my colonoscopy.”*

*“No face-to-face appointments and no real explanation or support.”*

## Access to IBD advice lines and GPs

As a chronic, fluctuating condition with the potential for complications to be serious and potentially life-threatening, rapid access to specialists is essential for people with Crohn's or Colitis.

The IBD Standards state that people should get a response from their IBD advice line by the end of the next working day.

- More than one in four (27%) of those who had tried to contact their IBD advice line said they did not usually or always get a response by the end of the next working day

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<sup>8</sup> Bodger K *et al* on behalf of the UK IBD Registry Collaboration. **COVID-19 impact on care and prescribing for inflammatory bowel disease: Data from the IBD Registry.** Abstract to be presented at British Society of Gastroenterology Annual Meeting, 8-11<sup>th</sup> November 2021.

- 41% of those who had needed care from their GP during the previous six months said they had been unable to get the care they needed

Some of the issues highlighted were related to difficulties getting appointments or tests, while others were caused by limitations of telephone appointments and lack of joined-up care.

*“It has been very difficult to get appointments and blood tests for monitoring.”*

*“GP didn't know what to do, ended up in A&E as I couldn't access IBD flare line.”*

*“Most appointments were over the phone. I had to send photos of Crohns-related skin issues to my surgery.”*

*“Always difficult! Shared care agreement with GP to prescribe azathioprine. However, he was unaware our son was in biologics- adalimumab - because this is prescribed by hospital. Lack of joined-up care.”*

## Colonoscopy

IBD patients require endoscopy for diagnosis, monitoring, surveillance and treatment. The pandemic has had a significant impact on endoscopy in line with national guidance,<sup>9</sup> with much of this cancelled during the first lockdown. Enhanced safety procedures present challenges in terms of managing the backlog. Studies have shown stark decreases in lower gastrointestinal endoscopy, including both diagnostic and therapeutic colonoscopy and flexible sigmoidoscopy.<sup>10</sup>

Nearly one quarter of those who needed a colonoscopy during the previous six months said this had been cancelled, with fewer than half of these being given a new date.

People with IBD have an increased risk of bowel cancer, particularly those with more extensive or active disease or Primary Sclerosing Cholangitis (PSC). [NICE](#) and [BSG guidelines](#) and the IBD Standards recommend regular cancer surveillance, in line with national guidance. However, only 18% of those responding to the (pre-pandemic) IBD UK patient survey reported that they knew when their screening colonoscopy was due and would receive a reminder. 52% of services said there was a clear, documented process for colorectal cancer surveillance which is communicated to patients. NHSE's quality improvement programme Getting It Right First Time (GIRFT) found post-colonoscopy colorectal cancer rates varied between trusts from 3.31% to 12.05%, with rates being much higher among patients with IBD.

These findings underline the importance of urgently reviewing surveillance for people with IBD who are at increased risk of cancer, and whose surveillance has been affected by COVID-19, to ensure that early detection in this high-risk group is not missed. This is reinforced by the [British Society of Gastroenterology's guidelines for colonoscopy for high-risk surveillance patients during COVID-19](#).

<sup>9</sup> [Endoscopy activity and COVID-19: BSG and JAG guidance | The British Society of Gastroenterology](#)

<sup>10</sup> M Deputy, O Faiz et al The provision of, and outcomes for, inflammatory bowel disease services during the Covid-19 pandemic: a nationwide observational study (unpublished, journal submission pending, based on analysis of Hospital Episode Statistic data)

*“The delay in colonoscopy was very stressful as I was having a flare and really needed a colonoscopy.”*

*“CT showed definite stricture and obstruction - Consultant said I need urgent colonoscopy with dilation to widen the stricture - was told 4 - 6 week wait - but now told I have no date but on the waiting list.”*

*“I had to wait a long time to get the colonoscopy which has meant that the change of treatment has also been held up and my health has deteriorated over the waiting time.”*

## **Urgent care**

Many people with Crohn’s or Colitis may require urgent or emergency care if they experience a severe flare and are unable to contact anyone in the specialist team quickly. Flares that are untreated can allow inflammation to progress leading to malnutrition, bowel obstruction, fistulas, and intestinal rupture or perforation.

- 29% of those who needed urgent care during the previous six months said they were not able to get the help they needed.

*“Waiting times at A&E have been up to 10 hours, particularly recently. I have been sent home from A&E to come back to ambulatory care units in 2 days’ time with a fistula leaking faeces with no short-term care in place to manage this- because of a lack of capacity in the system”*

*“Urgently admitted under general surgery and told that Gastro surgeons were unavailable to me.”*

## **Surgery**

21% of people with Crohn’s will have resection surgery within five years of diagnosis and 26% within 10 years. 10-15% of people with Ulcerative Colitis are likely to require surgery at five to 10 years. People with extensive disease are at risk of potentially life-threatening complications - such as a complete blockage or perforation of the bowel - if surgery is not considered in a timely fashion.

FSSA [guidance](#) states that:

- Colectomy for acute severe ulcerative colitis - not responding to conservative Rx should be priority 1b and the procedures to be performed in <72 hours
- Crohn’s disease stricture/fistula not responsive to endoscopic/medical Rx should be prioritised at a P2 and procedure to be performed < 1 month
- (Paediatric general and urological surgery) Crohn’s Disease - stricture/fistula/ optimise medication/ nutrition should be prioritised at a P2 and procedure to be performed < 1 month
- Seton insertion - symptomatic anal fistulae (incl. perianal Crohn’s) should be a priority 3 and the procedure to be performed < 3 months
- Colectomy/ proctectomy for colitis refractory to medical Rx (excluding acute, severe colitis treated urgently should be prioritised as a priority 3 and a procedure to be performed < 3 months
- (Paediatric general and urological surgery) Laparotomy - Colectomy for colitis (Ulcerative Colitis/ Hirschsprung’s) not responding to conservative Rx should be priority 1b and the procedures to be performed in <72 hours

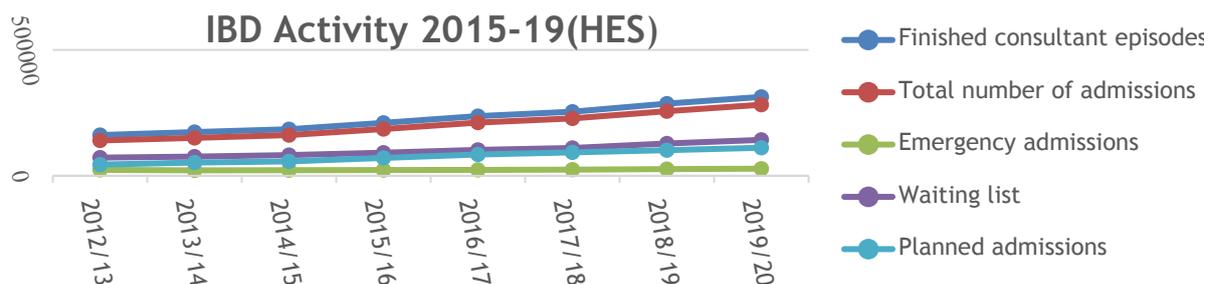
Emergency medical admissions for acute Ulcerative Colitis and acute Crohn’s Disease were greatly reduced (16.4% and 8.7% respectively). Reductions were observed for all IBD procedures with the largest deficits in lower gastrointestinal endoscopy, reversal of ileostomy and surgery for ileal Crohn’s Disease.<sup>11</sup> Crohn’s & Colitis UK’s Healthcare Survey found that:

- 29% of those who needed surgery during the previous 12 months had had this cancelled, and over half of these still did not have a new date for the surgery to take place
- More than one third of the operations needed were for unplanned emergency surgery, which might have been avoided had appropriate treatment been possible at an earlier stage

*“Need rectum removal and fitted with permanent stoma. Been waiting for nearly a year for this surgery after failing all medications and having a severe reaction to the last one. Currently on meds to manage some symptoms but continue to struggle daily.”*

*“Panproctocolectomy, priority 2. Initial referral July 2021 (have been waiting over 13 months). I also have metastatic cancer and Stage 4 chronic kidney disease.”*

## 2. How trends in waiting times changed before the emergence of COVID-19.



We had seen a gradual improvement in standards of care in IBD, supported by the creation of the IBD Standards and IBD Audit from 2009-14. However, there were concerns that the gains seen over years bought through increased focus would be lost when the Healthcare Quality Improvement Partnership IBD Audit, led by the Royal College of Physicians, ended in 2014.

Published in April 2021, the IBD UK report [“Crohn’s and Colitis Care: the Hidden Cost and a Vision for Change”](#)<sup>12</sup> was based on the most comprehensive assessment of IBD care ever undertaken from 166 (72%) of IBD services and over 10,000 adults and children with IBD against the IBD Standards, which define good quality care.<sup>13</sup>

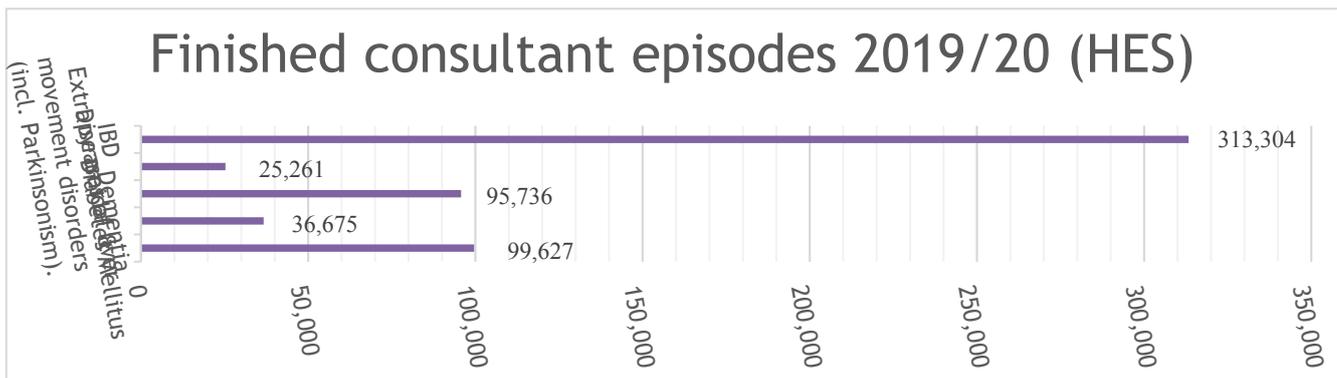
Data collected in 2019/2020 revealed high levels of urgent and emergency care, the result of services under strain. This manifested in delays in diagnosis, investigations and surgery and a lack of personalised, proactive care.

<sup>11</sup> M Deputy, O Faiz et al The provision of, and outcomes for, inflammatory bowel disease services during the Covid-19 pandemic: a nationwide observational study (unpublished, journal submission pending, based on analysis of Hospital Episode Statistic data)

<sup>12</sup> [Crohn’s and Colitis Care in the UK: The Hidden Cost and a... | IBD UK](#)

<sup>13</sup> [IBD Standards | IBD UK](#)

- 41% of patients responding who had been diagnosed in the previous two years had visited A&E at least once before diagnosis, with 12% visiting three or more times
- Of those who had received hospital inpatient treatment during the previous year, 72% had been admitted as emergencies
- Only 14% of hospital IBD services had the number of IBD nurse specialists needed to deliver a robust service - based on caseload modelling, 2.5 whole time equivalent IBD nurse specialists are needed per 250,000 population (1:500 IBD patients).<sup>14</sup>
- No IBD service across the UK met the IBD Standards staffing requirements for all members of the team.



### 3. The effect that COVID-19 has had on waiting times.

Our recent healthcare survey shows that many people living with Crohn's and Colitis have been struggling to get a diagnosis and the care and treatment they need over the past 12 months. This has resulted in flares of their condition, hospital admissions and surgery and affected their mental wellbeing, relationships, and ability to work and do everyday tasks.

- 22% of those who have needed health services or treatment during the previous six months said that difficulties accessing this had resulted in a flare of their condition
- 24% reported that their mental health had been affected
- This has led to time off work, affected relationships and the ability to do everyday tasks

While people are waiting for a diagnosis, the impact of symptoms can be profound, leading to time off school and work, withdrawal from social relationships, and inability to carry out everyday activities such as shopping and exercise. Children may experience delayed growth and development. Delayed diagnosis can lead to reduced response to medical treatments and a higher incidence of urgent and emergency surgical intervention. For example, those who experience symptoms for more than six months prior to their diagnosis of Ulcerative Colitis are more likely to need a colectomy.

*"I struggle to look after my young baby because I am so unwell."*

*"I have found the difficulty in accessing care emotionally exhausting and it meant my flare wasn't treated for the first 5 weeks, which caused it to be the worst flare ever."*

*"Newly diagnosed so understanding and dealing with this condition has been tough."*

December 2021

<sup>14</sup> [OTU-009 Modelling caseload standards for IBD specialist nurses in the UK | Gut \(bmj.com\)](#)