

Written evidence submitted by Crohn's & Colitis UK (DEL0251)

Key recommendations

- **The government needs to recognise and support the vital role of patient charities in supporting people during the pandemic and beyond**
- **The key concerns from people affected by Crohn's and Colitis are:**
 - **Delayed diagnosis**
 - **Delays to planned surgery**
 - **Redeployment of specialist teams**
 - **Access to medicines**
- **For patients with Crohn's and Colitis any increase in uncontrolled disease activity, delays to diagnosis or planned surgery leads to a rise in emergency surgery, more extensive surgery, life threatening complications, increased risks of cancer, mortality and disease progression**
- **When planning for a return to "ordinary" healthcare it is key that decisions about priorities are based on individual patient need rather than prioritising services based on specific conditions**
- **Better coordination between central government, NHS communications, specialist clinicians and patient charities is needed to avoid patients receiving incorrect or conflicting information**

1. Who are we?

1.1 We are Crohn's & Colitis UK – the UK's leading charity for Crohn's Disease and Ulcerative Colitis. We're working to improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's Disease and Ulcerative Colitis.

1.2 Over 300,000 people in the UK are living with Crohn's Disease or Ulcerative Colitis, collectively known as Inflammatory Bowel Disease (IBD) – that's 1 in every 210 people. But there's growing evidence the real number could be almost double that. Crohn's and Colitis are lifelong conditions. The median age of diagnosis is 29.5 yearsⁱ – but you can be diagnosed at any age.

1.3 In Crohn's and Colitis the gut becomes swollen, ulcerated and inflamed causing debilitating symptoms including acute abdominal pain, weight loss, diarrhoea (sometimes with blood and mucus), tenesmus (constant urge to have a bowel movement), and severe fatigue.

1.4 Crohn's and Colitis don't just affect the gut. They can affect almost every part of the body and every aspect of life: from digestion and joints to energy levels and mental health. People living with the conditions often face a lifetime of medication and, in many cases, major surgery. If left untreated, complications from Crohn's and Colitis can be fatal.

1.5 The lifetime costs for treating and caring for Crohn's and Colitis are estimated at £900 million per year, which is comparable to those of heart disease or cancerⁱⁱ.

2. Impact of the pandemic on people with Crohn's and Colitis

2.1 As the national charity for anyone affected by Crohn's and Colitis, we have heard directly from people about the key concerns affecting them.

2.2 Many people with Crohn's and Colitis take steroids, biologics and immunosuppressant medications which means they are at increased risk of severe illness from Covid-19.

2.3 One of their key concerns was confusion about their risk status and whether they should be "shielding". Some people with Crohn's or Colitis are classified as high risk according to expert guidance from the British Society of Gastroenterology (BSG), however many have not received letters from the government or NHS instructing them to shield. Without this proof of risk, many vulnerable people are being compelled into attending work by their employers, putting them at even greater risk.

2.4 Conversely, the NHS sent out blanket shielding letters to patients on certain medications, regardless of what condition they use the medicine for or what dosage they take. This resulted in many people with Crohn's and Colitis who are at moderate risk of complications from coronavirus (as opposed to high risk) incorrectly being told they need to shield. This has led to people unnecessarily delaying medical appointments and relying on government schemes to access food.

2.5 In order to prevent confusion we recommend that in future there should be alignment between risk grids for different conditions that use similar medications i.e. gastroenterology and rheumatology.

2.6 We have published patient friendly online decision trees, based on coronavirus risk grids for adults and children developed by the British Society of Gastroenterology (BSG) and the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN). These risk grids help patients identify their level of risk, share the results with their clinicians and understand how to protect themselves and stay safe and well.

2.7 For people affected by Crohn's and Colitis there has been a need to make decisions about risks and their lifestyle, employment and education and this will continue to be a key area of concern as the UK moves out of the lockdown stage of the pandemic.

2.8 Unlike many other long-term conditions, Crohn's and Colitis affect people of all ages and a significant number of people affected by the conditions are working. For those continuing to work there has been considerable concern about the risk to their health and their families. We have heard from many people who felt pressured to work, either by employers, because they are key workers or for financial reasons where they believed their risk level, or the risk level of someone in their household, meant they should stay at home.

2.9 Clear information and guidance to people about their risk status and the action they need to take to stay safe and well is critical. There needs to be better coordination between central government/NHS communications and patient charities and specialist clinicians to avoid the anxiety caused in people who received the wrong information.

2.10 Crohn's & Colitis UK is a member of the Prescription Charges Coalition, who are calling for an emergency suspension of prescription charges for all people with long-term conditions in England. Research shows third of people with long-term conditions skip collecting their medication because of the cost. At a time when it is critical for everyone to be taking the medication they need to stay

well; we urge the government to implement this simple measure to aid medication adherence by patients with long-term conditions.

3. How to achieve an appropriate balance between coronavirus and ‘ordinary’ health and care demand

3.1 We’ve heard directly from people affected by Crohn’s and Colitis about the impact of the changes to NHS service because of the pandemic including people reporting delays with investigations and treatment. These delays are a huge concern and we believe that increasing “ordinary” healthcare again must be a key priority for the NHS alongside the management of the pandemic to avoid unnecessary increases in the severity of illness for those patients who have been unable to access routine healthcare or who have been frightened to do so.

“My joint surgical and medical appointment has been cancelled, with no date for a new appointment. I worry there will be a large backlog when IBD services start running again and I will be forgotten about. We had plans to discuss my next elective surgery and now I feel in limbo waiting,”

Sophie, 27, living with Crohn’s Disease

3.2 It is particularly important in patients with Crohn’s and Colitis who are at risk of experiencing ‘flares’ or recurrence of symptoms. About half of patients experience a flare within a year. Flares can be avoided or reduced in number and/or severity in well managed patients. The cost of treating an outpatient in a flare is 2-3x higher than treating a stable patientⁱⁱⁱ.

3.3 Each year Ulcerative Colitis care costs^{iv}:

- £1693 per patient in remission
- £2,903 per patient in relapse with mild-to-moderate Ulcerative Colitis
- £10,760 per patient in relapse with severe Ulcerative Colitis

Each year, Crohn’s Disease care costs:

- £1,800 for patients in remission
- £10,513 for patients in relapse

Delayed diagnosis

3.4 People have contacted us with concerns about delays to diagnosis because of cancellations of routine referrals, no access to investigations including endoscopy, and no follow up appointments for those who were part way through investigations. People awaiting official diagnosis remain unsure whether they are living with Crohn’s or Colitis, and therefore do not know that they may be at higher risk of complications from coronavirus, nor where to look for support.

3.5 Some people told us that they were newly diagnosed just before lockdown, but as follow up appointments were cancelled they were left without any understanding of what their diagnosis means or any treatment which they found very frightening. For some people they described this as feeling “abandoned” by the NHS and medical teams.

3.6 Delayed diagnosis also increases the likelihood of surgery or more expensive treatments and if left untreated can cause more serious complications, which might require emergency surgery, or can be fatal. Uncontrolled disease activity also increases the risk of people with Crohn’s or Colitis developing bowel cancer.

Delays to planned surgery

3.7 Callers to our helplines have reported that their planned surgery has been cancelled or postponed and it is unclear when their surgery will be rescheduled.

3.8 This has left people with Crohn's and Colitis living with pain and difficult symptoms and the awareness that delays to planned surgery may lead to needing emergency surgery, more extensive surgery, life threatening complications or mortality.

Redeployment of specialist teams

3.9 Specialist teams have been redeployed which has resulted in patients reporting difficulties in accessing care and advice. Patients have reported being unable to contact their IBD nurse for advice on managing their symptoms or changes to their prescriptions.

3.10 People experiencing a "flare", an exacerbation of symptoms, have reported being unable to contact their IBD team and they have been left without clear information on the action to take to manage the flare, the increased risks for them with coronavirus and the action they need to take, including adjusting medication doses.

3.10 In many settings hospital advice lines are currently not operational and IBD nurses have been drafted to the frontline of critical care, so more people are depending on us for advice on managing their conditions. The NHS is referring patients to our helpline and information services as the first line of support for people with Crohn's and Colitis.

Access to medicines

3.11 Some patients are experiencing issues with access to medicines. We have heard that in some areas homecare services are not available to new patients. Homecare services are used to provide some subcutaneous medicines direct to patients in their own homes, which has resulted in some patients with Crohn's or Colitis being unable to access required medication.

3.12 Some people have reported delayed or cancelled vitamin B12 injections and iron infusions. These do not seem to have been deemed urgent or a priority by most GP surgeries and healthcare teams, but enquirers have contacted us to say that these treatments are key to managing their fatigue (a common debilitating symptom of Crohn's and Colitis).

3.13 In addition we have heard that routine drug monitoring blood tests are being delayed to avoid people coming into hospital. While we support this decision in the interests of safety, it is important to note that this could lead to side effects and adverse reactions being missed, and appropriate treatment delayed.

4. Meeting the wave of pent-up demand for health and care services that have been delayed due to the coronavirus outbreak

4.1 It is key to ensure that assessments and decisions about the priorities for dealing with pent up demand are based on the individual needs of patients rather than by prioritising based on selected conditions. For patients with Crohn's and Colitis uncontrolled disease activity, delays to planned surgery or delays to diagnosis could lead to a rise in emergency surgery, more extensive surgery, life threatening complications, increased risks of cancer and mortality.

4.2 Increased collaboration between primary and secondary care is needed to re-establish referral pathways and make sure patients don't fall through the gaps. Careful consideration needs to be given to agree the priority for catching up on GP referrals, based on individual patient need.

4.3 Specialist teams, including specialist IBD nurses, that have been redeployed need to be brought back into their roles as soon as it is safe to do so.

4.4 We believe that it is vital that IBD teams are able to deliver key services including triaging patients with urgent care needs, supporting those with uncontrolled or flaring disease and beginning treatment for people newly diagnosed with Crohn's and Colitis.

4.5 Recommencing planned surgery is also critical to avoid further pressures on the system. "Clean" areas will need to be identified so that this can take place safely. Reintroduction of elective surgery for patients with Crohn's and Colitis is key due to the increased risks of bowel cancer with uncontrolled disease.

4.6 For patients with Crohn's and Colitis it will be key to create "cold" areas so that patients can receive vital medicines safely including community-based infusion services.

4.7 Increasing access to tests and treatments at home is also required including home faecal calprotectin (FCP) testing, given many laboratories are currently not processing stool samples for FCP due to the risk of coronavirus transmission, and ensuring patients can receive subcutaneous medicines at home wherever possible.

4.8 We recently wrote to the Chief Executive of NICE to highlight the importance of expediting access to new subcutaneous medications for Crohn's and Colitis – as a response to the pausing of the appraisal process for ustekinumab to treat Crohn's Disease due to coronavirus. The appraisal process was then reopened, and a Final Approval Document issued supporting the use of ustekinumab. NICE should continue to appraise medications that can be safely delivered at home, and not just focus on appraising guidance relating to coronavirus.

5 Providing healthcare to vulnerable groups who are shielding

5.1 Many people with Crohn's and Colitis are in the vulnerable group and are currently considered to be at higher risk and advised to continue shielding.

5.2 We know from calls to our helplines that people who are shielding are very anxious when attending hospital for appointments or treatments e.g. infusions.

5.3 We believe that vulnerable groups need to be provided with more information to explain the precautions that are in place and the steps that have been taken to keep them safe. We have heard from people who have decided not to attend for vital treatment due to their concerns about the risks of exposing themselves to potential infection.

5.4 It will be important to consider how care can be provided to vulnerable people remotely wherever possible using telephone and video technology.

6. How to ensure that positive changes that have taken place in health and social care as a result of the pandemic are not lost as services normalise

6.1 We are aware that some teams have been able to offer care via virtual telephone and video clinics and we hope that this positive change will continue and become more widespread. Greater use of technology and remote care also reduces the risks of potential infection for those who are shielding.

6.2 Virtual clinics are welcomed by many patients in terms of convenience, reduced travel costs etc and this is particularly true for some patients with Crohn's and Colitis due to the nature of the disease symptoms which often make travel outside of the home difficult. We hope to see increased

options for patients on how they receive their care, including virtual clinics when appropriate for the patient, with discussion of the options available. It's important that care delivered virtually continues to be personalised and consider the whole person, and not just focussed on medical treatment.

7. Working with patient charities

7.1 We call on the government, and the NHS in all four nations, to work closely with patient charities like Crohn's & Colitis UK. The government needs to do more to recognise and support health and social care charities who are supporting people with critical services during the pandemic.

7.2 We have experienced an unprecedented increase in enquiries to our helpline during the pandemic (at the peak we experienced a four-fold increase in enquiries) and at the same time our income has dropped significantly (by 50%). We expect both these trends to continue for the rest of the year as accessing alternative funds, including government sources, is proving very difficult. A third of our staff are furloughed through the Government's job retention scheme; the remaining staff have moved to short time working for the remainder of the year.

7.3 We are providing a frontline service which has filled some of the gaps left by the redeployment of services.

7.4 We have demonstrated that we have provided a vital interface between the NHS and patients. Our information and support services have provided much needed support to patients and taken the pressure off frontline NHS services. Recognition and support from the government of the key role we play in supporting people affected by Crohn's and Colitis would be welcomed.

Other useful information

The BSG has produced guidance on [endoscopy](#) which balances risks to both health care professionals and patients and a series of [documents for service recovery planning](#) to consider planning in the short, medium, and long term.

The Association of Coloproctology of Great Britain and Ireland (ACPGBI) have produced [IBD guidance for surgery](#)

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ⁱ IBD Standards Group (2013) *IBD Standards: Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD), 2013 Update*, p.10

ⁱⁱ Lucas C, Bodger K. Economic burden of inflammatory bowel disease: a UK perspective. *Expert Review of Pharmacoeconomics & Outcomes Research*, 2006;6(4):471-82, and Cummings J F R, Keshav S, Travis SPL. The management of Crohns disease. *BMJ* 2008;336:1062-6. Cited in Royal College of Physicians (2014) *National audit report of inflammatory bowel disease service provision: adult national report*. UK IBD audit. London: RCP, 2014.

ⁱⁱⁱ Bassi A, Dodd S, Williamson P Cost of illness of inflammatory bowel disease in the UK: a single centre retrospective study. <https://www.ncbi.nlm.nih.gov/pubmed/15361497>

^{iv} Ghosh N, Premchand P. UK cost of care model for inflammatory bowel disease <https://www.ncbi.nlm.nih.gov/pubmed/28839807>