Written evidence submitted by Crohn's & Colitis UK (CBP0076)

Inflammatory Bowel Disease (IBD)

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. IBD is a lifelong, often debilitating condition, with no cure, which affects adults and children of all ages. The peak diagnosis period is between the ages of 15-40, with symptoms often evident for up to 10 years prior to diagnosis.[1] Symptoms include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue and weight loss, with associated anxiety and depression. These 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 part of life: from digestion, eyes and joints to energy levels and mental health. With many of these symptoms largely invisible, it can appear that someone is healthy when they are in fact incredibly unwell. Treatment requires specialist multidisciplinary care. People living with IBD face a lifetime of medication and, in many cases, major surgery. If left untreated, complications from the condition can be life-threatening. Medication includes steroids, immunosuppressants and biologic medicines. Lifetime costs are comparable to a number of major diseases, including heart disease or cancer.[2] The annual cost of treating a flare (relapse) or Ulcerative Colitis or Crohn's Disease is up to six times greater than treating a patient in remission.[3]

Crohn's & Colitis UK

Crohn's & Colitis UK is 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.

Summary of key points and recommendations

For patients with IBD, delays to diagnosis, treatment or planned surgery are associated with a rise in emergency surgery, more extensive surgery and life-threatening complications, increased risks of cancer, mortality and disease progression.[4]

- 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
    - Delayed appointments and difficulties accessing IBD specialists and GPs

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[1] Prevalence and Duration of Gastrointestinal Symptoms Before Diagnosis of Inflammatory Bowel Disease and Predictors of Timely Specialist Review: A Population-Based Study | Journal of Crohn's and Colitis | Oxford Academic (oup.com)

[2] Luces C, Bodger K (2006). Economic burden of inflammatory bowel disease: A UK perspective. *Expert Review of Pharmacoeconomics & Outcomes Research*. 6: 471-482.

[3] Ghosh N, Premchand P (2015). A UK cost of care model for inflammatory bowel disease. Frontline Gastroenterology. 6: 169-174.

[4] Inflammatory bowel disease clinical service recovery during the COVID-19 pandemic | Frontline Gastroenterology (bmj.com)

- 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
    - Expediting access to non-invasive testing, home monitoring and preventative supported self-management through digital/remote means
    - Implementing different approaches to managing care effectively, for example, introducing an IBD care coordinator role
- Opportunities to redesign care, such as remote appointments and shifts to subcutaneous treatments:
    - Need to involve patients and be based on delivering personalised care and shared decision-making
- National clinical leadership and a defined strategy for IBD is urgently needed to drive improvements in care and accelerate innovation across the system

The evidence

Our submission draws on a range of sources, including published articles, IBD Registry[5] data and surveys of healthcare professionals and people with Crohn's and Colitis, which assess the provision of IBD care before and at different stages of the coronavirus pandemic.

The interim results from Crohn's & Colitis UK's "Healthcare Survey 2021",[6] highlight challenges and opportunities in relation to healthcare provision and clearing the backlog, based on experiences over the last 6-12 months.

- One in five (19%) have experienced disruption to getting medication over the past 6 months.
- 44% have had to wait longer than usual for clinic/outpatient appointments related to their Crohn's or Colitis or have had these cancelled over the past 6 months.
- 23% of those who have needed health services over the past 6 months report having a flare of their condition due to difficulties accessing the health services and treatment.

Published in April 2021, the IBD UK report "Crohn's and Colitis Care: The Hidden Cost and a Vision for Change"[7] 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.[8]

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

- 41% of patients responding who had been diagnosed in the previous two years having 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.

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[5] UK IBD Registry - IBD Registry

[6] 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

[7] Crohn's and Colitis Care in the UK: The Hidden Cost and a… | IBD UK

[8] IBD Standards | IBD UK

- Only 14% of hospital IBD services had the number of IBD nurse specialists needed to deliver a robust service, based on caseload modelling that 2.5 whole time equivalent IBD nurse specialists are needed per 250,000 population (1:500 IBD patients).[9]
- No IBD service across the UK met the IBD Standards staffing requirements for all members of the team.

Crohn's & Colitis UK's "Life in Lockdown" survey,[10] undertaken during June and July 2020 found that IBD services were often hard to reach due to redeployment of nurse specialists, tests and procedures were badly affected and much of the planned surgery had been postponed.

- 18% reported that they had had a flare because they couldn't access the healthcare they needed.
- 89% of those who had surgery planned had had this cancelled with no new date given.
- Fewer than half (46%) of patients were accessing tests as procedures as usual.
- 26% either had to wait longer than usual to speak to an IBD specialist or were unable to do so at all.
- 67% of those who have had surgery cancelled over the past 12 months do not have a new date for this.

1. Anticipated size of the backlog and pent-up demand

1.1 Diagnosis

Delayed diagnosis of IBD can lead to reduced response to medical treatments and higher incidence of urgent and emergency intervention.[11] Children may experience delayed growth or development.

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 referring them 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%).[12]

Interim results from Crohn's & Colitis UK's "Healthcare Survey 2021" show delays in diagnosis, initial treatment and difficulties with obtaining GP care, which would be essential to identification of suspected IBD and appropriate referral to specialists.

- 28% of those who have been diagnosed with Crohn's or Colitis during the past 12 months waited longer than a year from the time they first spoke to a healthcare professional until their diagnosis was confirmed.
- 43% of those who have been diagnosed with Crohn's or Colitis during the past 12 months waited longer than 2 weeks for treatment to start.

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[9] OTU-009 Modelling caseload standards for IBD specialist nurses in the UK | Gut (bmj.com)

[10] Life in Lockdown: What patients told us about their healthcare | Crohn's & Colitis UK (crohnsandcolitis.org.uk)

[11] Mozdiak E, O'Malley J, Arasaradnam R (2015). Inflammatory bowel disease. *BMJ*. 350: h4416.

[12] 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, 8-11th November 2021.

- 43% of those who have needed care from their GP over the past 6 months said they were not able to get this.

> *"It was difficult trying to speak with my GP, but once I did and fully explained what was happening, she sorted tests. The delay in diagnosis and medication caused the symptoms to be acute, and a 6 hour stay in A&E."*
>
> *"Once I was referred to a specialist, I was told the wait list was approximately 52 weeks. I had a bleed with mucus, so was then referred on to the urgent pathway."*
>
> *"I had appointments with specialists cancelled 3 times, so it took over a year to be seen. Then I turned 16 and the first lockdown happened, and I was discharged and had to go onto a waiting list again for another specialist who dealt with over 16-year-olds. That took another 7 months of waiting."*
>
> *"Still not seen specialist since being diagnosed. Appointment in September, over 2 months since diagnosis. I'm lost, scared and have no idea what to do."*
>
> *"I had been ill for over a year before I saw a doctor and for weeks was just told to go to A&E as my GP wouldn't give me an appointment. Then after tests no doctor every bothered to contact me with results or diagnosis. I received a letter from the IBD nurse, and it was at that point I realised what I had."*

1.2 Investigations

IBD patients require endoscopy for diagnosis, monitoring, surveillance and treatment. The pandemic has had a significant impact on endoscopy in line with national guidance,[13] 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 GI endoscopy, including both diagnostic and therapeutic colonoscopy and flexible sigmoidoscopy.[14]

- 57% of those who had needed a colonoscopy over the past 6 months said this took place after a wait of more than 4 weeks or has still not taken place.

> *"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."*

Faecal calprotectin is a non-invasive and inexpensive test of inflammatory markers. Appropriately used, as part of agreed referral pathways, this can aid GPs in identifying appropriate referrals to gastroenterology specialists. However, faecal calprotectin services have been disrupted during the pandemic, with two-thirds of UK services reporting a reduction or suspension of this critical service.[15]

1.3 Treatment and monitoring

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[13] Endoscopy activity and COVID-19: BSG and JAG guidance | The British Society of Gastroenterology

[14] 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)

[15] Inflammatory bowel disease clinical service recovery during the COVID-19 pandemic | Frontline Gastroenterology (bmj.com)

Active IBD, together with oral corticosteroids, puts adult patients with IBD who contract Covid-19 at higher risk of adverse outcomes.[16] It is therefore essential that a service can start treatment quickly.

The British Society of Gastroenterology advocates that flare clinics should be delivered by senior clinical decision-makers with IBD nurse specialists, pharmacists and dietitians encompassing the steps necessary to start new biological treatment with counselling, screening and teaching of injection technique (for subcutaneous treatment). Acute drug prescriptions providing patients with a minimum of 4 weeks therapy should be provided and homecare delivery arrange for maintenance therapy. Regular review of flaring patients is necessary to ensure that they have responded to the change in treatment. Therapeutic drug monitoring for immunomodulators and biological therapies is essential to ensure patient safety and optimisation of medication to minimise disease flares. In order to maintain clinical remission, it is imperative that IBD advice lines, infusion suites, homecare services and blood monitoring continue to be delivered reliably to minimise disease flares.

A survey of IBD services carried out between April and May 2020[17] found that:

- Twenty-seven per cent (33/121) of services reported an inability to set up new homecare services for subcutaneous biologics and immune-modulatory therapy.
- In addition, 20% (25/122) also experienced disruption to the homecare delivery provision of therapies due to provider issues.
- All IBD multidisciplinary team (MDT) meetings had been cancelled in 28% (34/122) of the services, while 40% (49/122) had converted them to virtual MDTs.
- There was a significant reduction in gastroenterologists and IBD nurse specialists able to deliver the service due to redeployment (51% (64/125) and 40% (50/125), respectively), self-isolation due to Covid-19 symptoms (22% (27/125) and 17% (21/125)) and belonging to the shielding category (9% (11/125) and 14% (18/125).

Crohn's & Colitis UK's Healthcare Survey 2021 found that:

- One in five (19%) had experienced disruption to getting medication over the past 6 months.
- 44% have had to wait longer than usual for clinic/outpatient appointments related to their Crohn's or Colitis or have had these cancelled over the past 6 months.
- 16% reported having a flare and 18% said that their mental health had been affected due to difficulties accessing the health services and treatment they needed.

Difficulties accessing medication highlighted by survey respondents include delivery drivers with Covid, poor communication between GPs and the specialist team, delays in carrying out blood tests needed before a change of medication can be made safely, medicine supply issues and slow processing of prescriptions.

> *"Blood tests difficult to book, so prescription couldn't be released"*

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[16] British Society of Gastroenterology guidance for management of inflammatory bowel disease during the COVID-19 pandemic | Gut (bmj.com)

[17] Organisational changes and challenges for inflammatory bowel disease services in the UK during the COVID-19 pandemic | Frontline Gastroenterology (bmj.com)

> *"It has been so difficult to get prescriptions from the GP as they don't seem to be able to find the information from the hospital on the electronic system, so it always takes numerous phone calls for each prescription."*
>
> *"Slow service from GP, taking longer than the 48 hours they advise to process via the online app. On one occasion took 5 days for GP to process. Pharmacy not having required medications in causing further delays."*
>
> *"The delays in accessing my new medication have meant I have needed to take a course of steroids and have been unable to care for my 8-month-old at times. I have been waiting 2 months since requesting new medication and it is still not ready."*

1.4 Surgery and emergency care

At the start of the pandemic, potential elective surgery for IBD was put on hold or withheld in all IBD services surveyed.[18] Data shows large reductions in emergency and elective IBD care during the first wave of the pandemic in England. 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.[19]

It is therefore suggested that there is likely a large burden of untreated disease in the community and that IBD patients should be prioritised on surgical and endoscopic waiting lists were feasible.

Crohn's & Colitis UK's Healthcare Survey 2021, finds that:

- 66% of those who have needed elective IBD surgery over the past 12 months have waited longer than 18 weeks for this or have had surgery cancelled.
- 67% of those who have had surgery cancelled over the past 12 months do not have a new date for this.

> *"I am on the waiting list for major surgery and the hospital cannot tell me if it will be this yar or next. I am living a poor-quality life."*
>
> *"I need a stoma, but still waiting for a date. I'm down for an emergency, but I've been waiting since March."*
>
> *"I have been waiting over 13 months for a Pan proctocolectomy – my initial referral was in July 2020. I feel that I have been abandoned and am not likely to be seen for surgery anytime soon. I also have metastatic cancer that has spread to my lymph nodes and stage 4 chronic kidney disease."*

2. What capacity is available within the NHS to deal with the current backlog

IBD is a complex and fluctuating condition with both physical and emotional effects, which requires specialist multidisciplinary care. However, the IBD UK report highlights that no IBD service was meeting the staffing requirements for delivery of a robust service in 2019-20, falling well below the standard for IBD nurse specialists, pharmacists, dietitians and psychologists.

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[18] ibid

[19] 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)

This capacity issue has been challenged further by the impact of the pandemic, with specialists redeployed, sick or isolating. IBD nurse specialists are central to the delivery of safe, high-quality IBD care, yet even before the pandemic, only 14% of services had the number required for the number of IBD patients, based on caseload modelling.

Given delays to diagnosis, investigations and surgery were a pressing concern prior to the pandemic, with high levels of urgent and emergency care an indication of services under pressure, IBD services are clearly ill-equipped to deal with the backlog. Mental health, already an under-supported service for people with IBD, will be required now more than ever.

> *"I was flaring on and off since January, but not given sufficient care for it from my hospital specialists so when I was rushed to hospital as an emergency I was very, very poorly. I'd lost a lot of weight, blood, fluids, and couldn't walk unassisted because I was so weak. Luckily, once I was admitted, I was treated very quickly but it's clear that when they're unable to see you visibly or when they don't contact you sufficiently, they don't see how sick you are."*
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> *"I'm a bit concerned that my gastro team have written saying, if I don't use the service in the next 6 months, I will be discharged back to my GP's care and will need to be re-referred if I have problems subsequently. I have a condition which could flare up at any time. I'd rather things stayed as they are, and I could contact my IBD nurse whenever I needed to."*
>
> *"The care and support is non-existent. GP letters appear to be ignored. I feel abandoned and scared. I am very anxious that my health will suffer as a consequence. My mental health has already suffered."*
>
> *"I am still suffering on a daily basis with other symptoms related to my condition but have to wait to hear if I get an appointment with anyone o try and sort it. I don't feel I have a life anymore, just a miserable existence."*

3. How much financial investment will be needed to tackle the backlog over the short, medium and long-term; and how should such investment be distributed?

Investment in innovation and new models of care is needed, supported by national specialty leadership for IBD to enable a more planned and strategic approach to the delivery of IBD care across England.

The IBD UK report highlights pockets of excellent care and innovation, and some services have introduced new approaches during the pandemic, for example, regular faecal calprotectin home monitoring.[20] But without national leadership to drive strategic change, the benefits of these are not available to the majority of IBD patients.

Data and IT systems are also fundamental to ensure good communication flows, timely, responsive, and joined-up care and planning to understand and meet the needs.

> *"It has been very difficult to get the medication I need due to breakdowns in communication between the GP and the hospital, locum doctors who have struggled to override the system to*

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[20] Point-of-care faecal calprotectin testing in patients with paediatric inflammatory bowel disease during the COVID-19 pandemic | BMJ Open Gastroenterology

> *prescribe something and long queues on the telephone line to the GP surgery. I have found this all very stressful whilst trying to work full time.”*
>
> *“The hospital asked for me to get a blood test at my GP surgery to check for ferritin and haemoglobin levels due to a bad reaction after a procedure. GPs refused because they had no evidence I’d been to hospital for any procedure.”*

Investment needs to be focused not just on high-profile priorities such as cancer and heart disease, but also on serious conditions such as IBD, which are often overlooked, but carry comparable impact. Given the significant cost to the NHS of flares and emergency admissions for IBD, this should result in more cost-effective care overall as well as improved health outcomes.

> *“While I was flaring since January, I got less than minimal support and ended up being rushed to hospital in an ambulance as a bad emergency.”*
>
> *“My GP doesn’t deal with Crohn’s, but it’s so difficult to get hold of my hospital specialists so while I was flaring since January, I got less than minimal support and ended up being rushed to hospital in an ambulance as a bad emergency.”*

Given the impact of delays on both quality of life and outcomes, there is a need to focus on diagnosis, including those recently diagnosed and those who have not yet received a diagnosis. This should include clear guidance and information to GPs and community healthcare professionals, supported by national referral pathways embedded in IT systems. It is currently unclear how community diagnostic hubs will support those with potential or established IBD in terms of both diagnosis and cancer surveillance, given the higher cancer risk that is associated with IBD. Those who are flaring or waiting for surgery should also be prioritised, including a focus on mental health support.

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

4. How might the organisation and work of the NHS and care services be reformed in order to effectively deal with the backlog?

There is considerable potential to reform IBD care to deal with the backlog.

Virtual appointments offer opportunities going forward, but these should not be the only option available, and patients should be given a choice. It is also critical that whatever type of appointment is offered, personalised care is delivered, including shared decision-making and support for self-management.

- 80% of those responding to Crohn’s & Colitis UK’s Healthcare Survey 2021 said they had mostly had telephone appointments over the past 6 months.
- 60% said they were very or somewhat satisfied with this approach to their care, while 28% said they were very or somewhat dissatisfied.
- Only 12% said they were usually or always offered a choice of type of appointment, while 67% said they had never been given a choice.

These results suggest that a high proportion of people with Crohn’s or Colitis are satisfied with remote appointments. However, this is by no means universal. People told us:

> *“I have never met my consultant and would appreciate an in-person appointment. I am concerned my appointments moving forwards will only be by telephone.”*

> *"I don't feel I can explain my condition over the phone."*
>
> *"If I had had a face-to-face consultation, I would not have required emergency surgery and the doctor would have been able to examine my abdomen."*
>
> *"I don't mind a phone appointment. It is the quality of care that matters more to me."*
>
> *"Prompt telephone appointments. Very good explanations and they listened well and gave good advice."*

Clear pathways need to be established to support effective, efficient care at each stage of the patient journey. Patients should be involved in service redesign and national specialty leadership is needed to support a strategic approach to adoption.

Clear communication to and support for waiting patients is also critical, so that they understand how and when to access the service, how to manage and live well with their condition and what steps to take if they have a flare or need urgent care.[21]

An IBD coordinator role should be considered to facilitate access to tests and clinical review on a similar basis to cancer co-ordinators. This would free up capacity from IBD nurse specialists to enable them to focus on more specialist care and support.

To help triage calls to the IBD advice line, one service operates a daily huddle where cases can be discussed with the consultant on-call and directed to same day urgent assessment in the admission unit, or face-to-face flare clinic slots. Flare clinics operate as a one-stop-shops with clinical assessment, medication counselling and dietetic support, with prescriptions available on-site to minimise delays in starting therapy for oral or subcutaneous drug therapy. This is an example of a model which could be adopted across services.

More remote, non-invasive testing, including faecal calprotectin testing and patient-entered data on symptoms and quality of life could be utilised to identify priorities for review, treatment, and further investigation. It will be important to ensure that the needs of patients who are typically underserved are not neglected with this approach.

For example, some services have been able to track patients suspected of a new diagnosis with high faecal levels to ensure they receive priority access to colonoscopy slots. All new diagnoses should be discussed in weekly multidisciplinary team meetings to ensure appropriate follow up is in place. There is also to potential to align patients with a new diagnosis into clinical research and trial endoscopy and clinic slots, which may offer more efficient access to therapies.

5. What positive lessons can be learnt from how healthcare services have been redesigned during the pandemic? How could this support the future work of the NHS?

Positive lessons have included the adoption of technology, including telephone and video appointments, and virtual multidisciplinary team meetings (MDTs), which offer potential to integrate services based on other sites, including GPs. MDTs have been shown to be fundamental to good IBD care, including prompt diagnosis and effective treatment.

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[21] Patient Noun Adjective: understanding the experience of waiting for care | National Voices

The IBD Registry Covid-19 Risk Tool[22] was developed rapidly during the first wave of the pandemic, involving clinical experts and Crohn's & Colitis UK. This helped over 40,000 people with IBD to understand their risk level for Covid and take appropriate precautions at the start of the pandemic. This highlights what can be achieved through technology, combining appropriate expertise and focused effort.

Some IBD services have been using portals and apps to support more joined-up patient-centred care, including Patient Knows Best, MyChart, My IBD Care and the IBD Portal. Together with personalised care planning, including supported self-management, and faecal calprotectin home monitoring to detect and address early signs of inflammation, these offer great potential for a more effective and efficient approach to ongoing care for a proportion of patients. This should then enable greater capacity for closer multidisciplinary management of more complex patients due to reduced need for appointments.

There has been a move in some services to introduce subcutaneous treatment, in place of clinic-based infusions. The decision about which biologic drug and mode of delivery, should be shared between clinician and patient. Subcutaneous treatment does offer benefits in reducing trips to and time spent in hospital, which can be convenient for patients and reduce infection risk. However, there is a requirement for appropriate training and reliable deliveries from delivery companies.

Specialist pharmacists play a valuable role in streamlining the process of starting biologic drugs, which can otherwise take weeks and even months, with people often becoming more ill during this time. However, the IBD UK report highlights that most IBD services are not able to benefit from this due to insufficient provision.

6. How effectively has the 111 call-first system for A&E departments been? What can be done to improve this?

While praising staff in emergency services, a proportion of those responding to Crohn's & Colitis UK's Healthcare Survey 2021 reported a lack of knowledge of IBD by emergency care teams and long waits.

> *"Had to phone NHS 111 for my wife. Took 40 mins to get through. Call then disconnected, took another 45 minutes. My wife was very sick. Asked to phone GP for assistance. Did this, GP could not assist and told me only option was to take her to A&E."*
>
> *"I spent 7 hours in A&E as my Crohn's was flaring up. I was told it was a stomach infection and sent away with antibiotics."*
>
> *"I was advised to go to A&E by NHS 111 due to passing a lot of blood over 20 toilet trips in one day. At A&E, the doctor refused to physically examine me due to Covid, said it must be piles and sent me home with anusol, despite me expressing concerns that my brother has Colitis and knew it was this prior to being diagnosed."*

7. What can the Department of Health & Social Care, national bodies and local systems do to facilitate innovation as services evolve to meet emerging challenges?

Funding and support are needed to facilitate innovation across a range of condition areas and to spread the adoption of good practice across services to benefit more patients.

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[22] COVID-19 UK IBD tool for patients - IBD Registry

Clinicians need to be upskilled and supported to adopt new technology and practice and the voluntary sector and patients should be involved at all stages of development and implementation.

A strategic approach is required at a national specialty level to meet this challenge.

8. To what extent is Long-Covid contributing to the backlog of healthcare services? How can individuals suffering from Long-Covid be better supported?

Long-Covid involves many of the same symptoms experienced by people with IBD which are very difficult to treat, including pain and fatigue. Investment is needed in these areas, to support research into treatments, a systematic approach to measurement and guidelines management.

Sept 2021