Crohn’s & Colitis UK evidence submission: Endoscopy services: follow up inquiry

[December 2022]

1. About this submission

1.1 **Crohn’s & Colitis UK**[1] is the leading charity for people affected by 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.

1.1 Over 26,000 people in Wales have Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn’s Disease and Ulcerative Colitis.[2] These are lifelong diseases of the gut, in which the gastrointestinal immune system responds inappropriately. They can affect almost every part of the body and every aspect of life: from digestion and joints to energy levels, mental health, education and the ability to work.

1.2 Crohn’s and Colitis require tight monitoring and management, often over several decades from the age of diagnosis. Care is managed across primary and secondary care, often with medications or surgery, or a combination of both. Treatments aim to control inflammation and to prevent ‘flares’, a worsening in symptoms, which may be unpredictable. There is no known cure.

1.3 Delays to diagnosing these conditions affects people’s ability to continue education and work and narrows their treatment options, while increasing their risk of being hospitalised or needing emergency surgery.

1.4 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.[3]

1.5 Endoscopy services, notably colonoscopy, flexible sigmoidoscopy and gastroscopy, are essential for the diagnosis, monitoring and surveillance of Crohn’s and Colitis. Almost all (99%) people with Colitis and 64% of people with Crohn’s disease are diagnosed at colonoscopy or flexible sigmoidoscopy.[4]

---

[1] www.crohnsandcolitis.org.uk

[2] Crohn’s & Colitis UK (2022). New research shows over 1 in 123 people in UK living with Crohn’s or Colitis (crohnsandcolitis.org.uk)

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

[4] Arms-Williams et al. Changes in Incidence and Clinical Features of Inflammatory Bowel Disease in Cardiff, UK over 50 years: an Update for 2005-2016. Paper submitted for publication)

1.6 Colonoscopies for monitoring or surveillance are recommended around 8-10 years after the start of Crohn's or Colitis symptoms, and then follow-on colonoscopies every one, three or five years. People with Crohn's or Colitis also have an increased risk of bowel cancer, particularly those with more extensive or active disease or Primary Sclerosing Cholangitis (PSC). NICE[5], BSG guidelines[6] and the IBD Standards recommend regular cancer surveillance, in line with national guidance.

1.7 This submission outlines our response to the Sixth Senedd Health and Social Care Committee follow up inquiry on endoscopy services.

2. Pre pandemic pathways and diagnostic services in Wales

2.1 The IBD Standards[7] state what high-quality care should look like at every point of a patient's journey. In regards to diagnostic technologies and pathways, the IBD Standards state that:

2.1.1 *Clear pathways and protocols for investigating children and adults with persistent lower gastrointestinal symptoms should be agreed between primary and secondary care and should include guidance on the use of faecal biomarker tests in primary care to aid rapid diagnosis* (Statement 2.1)
2.1.2 *Patients who are referred with suspected IBD should be seen within four weeks, or more rapidly if clinically necessary* (Statement 2.2).

2.2 However, even before the pandemic, people in Wales with suspected Crohn's or Colitis were waiting too long to be diagnosed. One in four (24%) wait over a year, with nearly half (44%) visiting A&E at least once. Only half (54%) of services in Wales had clear pathways and protocols in place, the lowest in the UK. Furthermore, almost seven in ten (68%) patients in Wales waited more than four weeks for investigative tests, with one in ten (11%) waiting more than six months.[8]

2.3 Sharing their experiences of diagnosis before the pandemic, people living with Crohn's and Colitis said:

"I was referred for a colonoscopy but the wait list was enormous, decided to go private and was seen within 2 weeks. I was diagnosed in February 2020 and started treatment immediately."

---

[5] NICE (2022), Overview | Colorectal cancer prevention: colonoscopic surveillance in adults with ulcerative colitis, Crohn's disease or adenomas | Guidance | NICE

[6] Brish Society of Gastroenterology (2019), Brish Society of Gastroenterology consensus guidelines on the management of inflammatory bowel disease in adults https://www.bsg.org.uk/wp-content/uploads/2019/12/BSG-IBD-Guidelines-2019.pdf

[7] IBD UK (2019), IBD Standards Core Statements, IBD-Standards-Core-Statements.pdf

[8] IBD UK (2021), Crohn's and Colitis care in the UK: The hidden cost and a vision for change, <croj8096-ibd-national-report-web-210427_-2.pdf (crohnsandcolitis.org.uk)>

"I was going weeks without going to the toilet to then weeks where I would go anything up to 40 times a day all accompanied with severe stomach cramps, blood loss and hair loss to name a few! It became so bad that I would literally not leave the house unless I was able to plan out exact toilet stops along the way. Which as a young 25 year old was pretty awful."

"I had been turned away from the hospital and doctors more times than I can count with them saying 'but you look fine it's probably just IBS'. For weeks I couldn't stop being sick and going to the doctors I was finally admitted to hospital when they carried out a CT scan and found my bowel had perforated I was rushed for emergency surgery."

3. Impact of COVID on endoscopy services

3.1 The pandemic had a significant impact on endoscopy in line with national guidance[9], with much of this cancelled during the first lockdown. Studies showed stark decreases in lower gastrointestinal endoscopy, including both diagnostic and therapeutic colonoscopy and flexible sigmoidoscopy.[10]

3.2 Many endoscopy units ran at a reduced capacity, with an 83% reduction in activity compared to pre-COVID levels in Wales [11], and slow recovery with 30%-50% of previous levels of activity taking place in January 2022 despite considerable potential to increase efficiency and activity in line with guidelines.

3.3 Crohn's & Colitis UK's Healthcare Survey 2021[12] found that 24% of those in Wales who said they had needed a colonoscopy during the previous six months reported waiting more than the recommended limit of four weeks for this, with 37% of these saying their colonoscopy had been cancelled with no new date for when this would take place. Most colonoscopies were required for diagnosis or investigation and appropriate management of flares.

3.4 Sharing their experiences of trying to get a diagnosis during the pandemic, people living with Crohn's and Colitis said:

"After months of phone appointments with my GP, blood tests, unsuccessful visits to A&E and misdiagnoses of long Covid, IBS, gastroenteritis and a fast track for suspected ovarian cancer, I was eventually rushed to hospital with sepsis, perforated bowel and a large abscess in my small intestine."

"I had to wait 16 months for my sigmoidoscopy [needed for diagnosis]."

---

[9] Bodger K, Bloom S, Dobson L, et al (2021), PMO-37 COVID-19 impact on care and prescribing for inflammatory bowel disease: Data from the IBD Registry, Gut 2021;70:A95-A96.

[10] British Society of Gastroenterology (2021), Endoscopy activity and COVID-19: BSG and JAG guidance | The British Society of Gastroenterology

[11] Rutter MD, Brookes M, Lee TJ, et al (2020), Impact of the COVID-19 pandemic on UK endoscopic activity and cancer detection: a National Endoscopy Database Analysis, Gut 2021;70:537-543.

[12] Crohn's & Colitis UK (2021), Healthcare Survey 2021 – What patients told us (crohnsandcolitis.org.uk)

> *"After my daughter was born I went into a huge flare and was admitted to hospital, where I was finally able to have a sigmoidoscopy and given a diagnosis. I still haven't had a full colonoscopy to see how far the disease goes."*

3.5 Our healthcare survey showed that many people living with Crohn's and Colitis in Wales struggled to get a diagnosis and the care and treatment they needed during the pandemic, including appropriate support while waiting for diagnostics and treatment. This resulted in flares of their condition, hospital admissions and surgery and affected their mental wellbeing, relationships, and ability to work.

3.6 The pandemic has therefore exacerbated existing issues in relation to the implementation of appropriate pathways and access to endoscopy services.

4. Post pandemic opportunities

4.1 Bowel conditions remain 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, from food poisoning to irritable bowel syndrome (IBS), coeliac disease, Crohn's or Colitis, or bowel cancer. Another challenge that GPs face is that the symptoms of Crohn's and Colitis can present atypically. For example, while diarrhoea is the most common symptom, not all adults and only a quarter of children with these conditions will experience it.[13]

4.2 The impact of the pandemic presents an opportunity to reconfigure lower gastrointestinal pathways and services and we welcome the work by Health Boards to agree a standardised referral pathway for endoscopy referrals to reduce inequalities between communities as part of the National Endoscopy Programme.

4.3 However, a Freedom of Information request put forward by Crohn's & Colitis UK on whether there was a pathway in primary care to investigate lower gastrointestinal symptoms where cancer is not suspected, which included faecal calprotectin tests[14], revealed the variation in access to the tests in primary care and in the existence of a pathway between Health Boards across Wales.

---

[13] Sandhu, B.K., Fell, J.M.E., Beattie, R.M. et al. on behalf of the IBD Working Group of the British Society of Paediatric Gastroenterology, Hepatology, and Nutrition (2010), Guidelines for the management of inflammatory bowel disease (IBD) in children in the United Kingdom. Journal of Pediatric Gastroenterology and Nutrition, 50 (Suppl 1): S1–S13. https://doi.org/10.1097/MPG.0b013e3181c92c53

[14] Faecal calprotectin diagnostic tests for inflammatory diseases of the bowel, primarily to support clinicians with the differential diagnosis of inflammatory bowel disease (IBD) or irritable bowel syndrome (IBS) are supported by NICE guidance - Overview | Faecal calprotectin diagnostic tests for inflammatory diseases of the bowel | Guidance | NICE

5. Recommendations

Recommendation 1: Develop a patient-led national diagnostic pathway for people with lower gastrointestinal symptoms

5.1 Referral and pathway reconfiguration needs to be focused not just on high-profile priorities such as cancer, but also on conditions such as Crohn's and Colitis, which are often overlooked, but carry comparable costs to the health service. Any national clinical pathway should therefore include all patients presenting with lower gastrointestinal symptoms, including those with suspected colorectal cancer and not in isolation.

5.2 As part of this pathway a consistent approach to the use of faecal calprotectin testing should be embedded as well as a clear referral pathway for patients with persistent lower gastrointestinal symptoms who do not meet the FIT threshold for referral. Calprotectin and FIT testing have comparable sensitivity and specificity for the detection of both inflammatory bowel disease and colorectal cancer.[15] These tests should be used to prioritise patients for direct colonoscopy rather than using an arbitrary designation of 'urgent suspected cancer' based on clinical suspicion alone.

5.3 The pathway should clearly set out which tests should be done, in which order, to ensure that patients get the right tests and referral at the right time. In turn this would build confidence among the public and the healthcare profession as well as reduce the burden on endoscopy services and reduce waiting times.

Recommendation 2: Prioritise endoscopies by patient need

5.4 Once people with suspected Crohn's or Colitis are appropriately referred for endoscopy, they need to be prioritised to be seen within four weeks as recommended by the IBD standards. Clinicians tell us that people end up in emergency services in excruciating pain, or they end up having unplanned emergency surgeries because they could not access a colonoscopy. We continue to hear anecdotal evidence from people who are referred to hospital for a colonoscopy but are waiting several months, and in some instances over a year.

5.5 Clinicians therefore need to be able to prioritise endoscopies based upon patient need and clinical risk. This in turn would reduce the burden of people with Crohn's or Colitis presenting at A&E services and avoid unnecessary and costly emergency surgery.

---

[15] Erik Mooiweer, MD, Herma H. Fidder, MD, PhD, Peter D. Siersema, MD, PhD, Robert J. F. Laheij, MD, PhD, Bas Oldenburg, MD, PhD, Fecal Hemoglobin and Calprotectin Are Equally Effective in Identifying Patients with Inflammatory Bowel Disease with Active Endoscopic Inflammation, *Inflammatory Bowel Diseases*, Volume 20, Issue 2, 1 February 2014, Pages 307–314, https://doi.org/10.1097/01.MIB.0000438428.30800.a6

Recommendation 3: Develop a pathway from endoscopy to treatment for people diagnosed with Crohn's or Colitis

5.6 The IBD Standards state that:

5.6.1 *After diagnosis, all outpatients with IBD should be able to start a treatment plan within 48 hours for moderate to severe symptoms and within two weeks for mild symptoms* (Statement 3.4)

5.7 To meet this standard, we recommend that all endoscopy units have a clear pathway for initial treatment immediately after endoscopy for those diagnosed with Crohn's or Colitis. Such a pathway would prevent the need for the GP to rerefer in order for treatment to be initiated.

5.8 This pathway should include endoscopists having access to an IBD specialist (such as an IBD nurse or gastroenterologist) to discuss likely IBD cases in order to minimise the time between endoscopy and confirmation of diagnosis and treatment starting. Furthermore information on the pathway should be available within endoscopy units (in written form/poster) for endoscopists who may not be familiar with treatment of Crohn's and Colitis.

For further information, please contact policy@crohnsandcolitis.org.uk