

Crohn's and Colitis UK evidence submission: Supporting people with chronic conditions

[May 2023]

1. About this submission

- 1.1 Crohn's & Colitis UK¹ 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.
- 1.2 Crohn's and Colitis, the two main forms of Inflammatory Bowel Disease (IBD), are lifelong chronic diseases of the gut. They follow a relapsing and remitting disease course. Relapses (or 'flare-ups') often occur suddenly and unpredictably throughout a person's lifetime. There is also significant variation in the pattern and complexity of the symptoms both between people and in the individual at different times in their life.^{2,3} 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. There is no known cure.
- 1.3 Over 26,000 people in Wales have IBD, increasing from 1 in every 123 people to 1 in every 67 people in those aged over 70 across the UK, posing a substantial social and economic burden on governments and health systems in the coming years.⁴
- 1.4 Symptoms include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue, and weight loss. IBD does not 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.
- 1.5 IBD requires ongoing monitoring and management, often over several decades from the age of diagnosis. If left untreated, poorly managed or in cases of severe disease, IBD can cause serious complications, which require emergency medical and/or surgical intervention. The burden of IBD on the NHS is increasing year on year and, per patient life-time costs are comparable to cancer and heart disease.⁵
- 1.6 The IBD Standards, developed in 2019 by IBD UK, a partnership of professional bodies, royal colleges, and patient organisations, set out what good care should look like for people with IBD. There is currently no quality statement nor delivery plan driving improvement in Wales for lower gastrointestinal conditions.
- 1.7 This submission sets out the variation in access to services across Wales, the importance of self-management, and highlights areas of consideration for the Committee in the next stages of this inquiry.

¹ Crohn's & Colitis UK, www.crohnsandcolitis.org.uk

² Solberg *et al* (2009). Clinical course during the first 10 years of ulcerative colitis: results from a population-based inception cohort (IBSEN Study). *Scand J Gastroenterol*, 44(4):431-40.

³ Solberg *et al* (2007). Clinical course in Crohn's disease: results of a Norwegian population-based ten-year follow-up study. *Clin Gastroenterol Hepatol*, 5(12):1430-8.

⁴ Crohn's & Colitis UK (2022). [New research shows over 1 in 123 people in UK living with Crohn's or Colitis \(crohnsandcolitis.org.uk\)](http://www.crohnsandcolitis.org.uk)

⁵ Luces C, Bodger K (2006). Economic burden of inflammatory bowel disease: A UK perspective. *Expert Review of Pharmacoeconomics & Outcomes Research*. 6: 471-482.

2. Summary of Recommendations

2.1 In the next stages of this inquiry, we would encourage the Committee to consider:

2.1.1 To address the variation in care between health boards at a condition level, such as embedding the IBD Standards.

2.1.2 To improve collaboration among patients and patient organisations, Welsh Government and Health Boards to reduce delays to diagnosis through:

2.1.2.1 Increasing public awareness

2.1.2.2 Improving awareness of symptoms and the effective use of tests amongst healthcare professionals

2.1.3 How symptom led, opposed to condition specific, pathways could bring benefits to patients and reduce pressure on services such as endoscopy.

2.1.4 The need for workforce planning and funding that takes account of the need for multidisciplinary teams and is informed by disease populations estimates, and how this is achieved equitably across health boards.

2.1.5 How prescribing data can be appropriately shared in order to support quality improvement activity that covers all stages of a patients journey.

2.1.6 To consider how best practices in self-management can effectively be rolled out across Wales and systems for meaningful patient involvement

2.1.7 How to ensure that the mental health needs of people with long term conditions are met, including access to psychological support.

2.1.8 The needs of people with relapsing and remitting conditions, such as Crohn's and Colitis

3. Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds, and disabled people

3.1 As a chronic, fluctuating condition with the potential for complications to be serious and potentially life-threatening, rapid access to specialist care is essential for people with Crohn's or Colitis for effective condition management, treatment and monitoring. The majority of this takes place in secondary care.

3.2 A new global study has found that patients who wait longest to be diagnosed with Crohn's or Colitis are between 2 and 4 times more likely to develop adverse and costly clinical outcomes, including bowel surgery.⁶ Timely access to diagnostics and early treatment are essential.

⁶ Jayasooriya, N., Baillie, S, Blackwell, J. et al., (2023). Systematic review with meta-analysis: Time to diagnosis and the impact of delayed diagnosis on clinical outcomes in inflammatory bowel disease. *Aliment Pharmacol Ther.* Doi: 10.1111/apt.17370.

- 3.3 IBD care in Wales remains understaffed and under-resourced, with no service in Wales meeting the IBD Standards. The IBD UK audit in 2019/2020⁷ revealed high levels of urgent and emergency care for people with IBD, the result of services under strain.
- 3.3.1 47% of the patients in Wales who responded to the 2019 IBD UK Patient Survey, and had been diagnosed in the previous two years, had visited A&E at least once before diagnosis
 - 3.3.2 90% had found it hard to cope with having IBD during the previous year
 - 3.3.3 No IBD service in Wales met the IBD Standards staffing requirements for all members of the team
- 3.4 This manifests in delays in diagnosis, investigations and surgery and a lack of personalised, proactive care, with significant variation in care and patients experience between health boards but also between hospitals in the same health board.
- 3.5 There is currently vast variation in the implementation of IBD Standards across Health Boards in Wales, as shown in Table 1. Regional approaches alone will not result in preventing delayed diagnosis, treatment, and increasing emergency surgeries. We recommend the full implementation of the IBD Standards, clear national targets, and commitments to invest in digital tools to monitor patient outcomes across health boards to ensure equity in care.
- 3.6 We urge the Committee to address unwarranted variation at a condition level by embedding the IBD Standards.**

Diagnosis

- 3.7 Before the pandemic, people in Wales with suspected IBD were waiting too long to be diagnosed.
- 3.7.1 One in four (24%) wait over a year, with nearly half (44%) visiting A&E at least once.
 - 3.7.2 Only half (54%) of services in Wales had clear pathways and protocols in place, the lowest in the UK.
 - 3.7.3 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
- 3.8 Bowel conditions are particularly difficult to diagnose with low awareness of symptoms amongst the general public and health care professionals. Symptoms, such as stomach pain, diarrhoea, and weight loss, can be associated with a range of other conditions. These include irritable bowel syndrome (IBS), bowel cancer, coeliac disease, endometriosis, and ovarian cancer.

⁷ IBD UK (2021), Crohn's and Colitis care in the UK: The hidden cost and a vision for change, [Crohn's and Colitis Care: The Hidden Cost and a Vision for Change, IBD UK, 2021](#)

⁸ Ibid

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

"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."

- 3.10 There are systemic barriers for patients to come forward, as revealed by a recent independent survey⁹ commissioned by Crohn's & Colitis UK:

- 3.10.1 1 in 3 report difficulties in getting a GP appointment
- 3.10.2 1 in 7 report difficulties in discussing sensitive symptom information with receptionists
- 3.10.3 1 in 7 worry the key symptoms (diarrhoea, weight loss and abdominal pain) would not be taken seriously.

- 3.11 The availability of key tests, including qFIT and faecal calprotectin tests in primary care are also crucial in ensuring appropriate referrals are made for people living with IBD. Faecal calprotectin has only recently been rolled out to primary care providers across Wales and research conducted by Crohn's & Colitis UK and the Royal College of General Practitioners¹⁰ highlighted a lack of confidence in the use of these tests.

- 3.12 We would urge the Committee to consider how Welsh Government and Health Boards can best collaborate with patient organisations to reduce delays to diagnosis through:**

- 3.12.1 Increasing public awareness of Crohn's and Colitis**
- 3.12.2 Improving awareness of symptoms and the effective use of tests amongst health care professionals**

Diagnostic pathways

- 3.13 Access to endoscopy, particularly colonoscopy and flexible sigmoidoscopy, is key for the diagnosis of IBD. Almost all (99%) people with colitis and almost two thirds (64%) of people with Crohn's Disease are diagnosed following endoscopy.¹¹

⁹ UK wide with a sample size of 2,026 participants.

¹⁰ RCGP and Crohn's & Colitis UK Inflammatory Bowel Disease Spotlight Project 2017-2020, www.crohnsandcolitis.org.uk/improving-care-services/health-services

¹¹ 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.

- 3.14 Diagnostic pathways and referrals onto diagnostic endoscopies should consider IBD, as delays have been shown to significantly increase adverse patient outcomes such as emergency surgeries, bowel complications and fistulas; and increase the burden on the health service.¹²
- 3.15 As part of this pathway a consistent approach to the use of faecal calprotectin testing (FCP) should be embedded as well as the 'Faecal calprotectin use in primary care in Wales' pathways for patients with persistent lower gastrointestinal symptoms who do not meet the FIT (Faecal Immunochemical Testing) threshold for referral. FCP and FIT testing have comparable sensitivity and specificity for the detection of both IBD and colorectal cancer.¹³ 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.
- 3.16 There should be investment in a patient led diagnostic pathway which 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
- 3.17 **We encourage the Committee to consider how symptom led, opposed to condition specific, pathways could bring benefits to patients and reduce pressure on services such as endoscopy.**

Secondary care

- 3.18 Following initial referral from primary care, the vast majority of care for people with IBD takes place in secondary care. This includes treatment, ongoing care and monitoring, flare management, and surgery.
- 3.19 For people 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.
- 3.20 A treatment plan should be put in place as soon as possible following a diagnosis of IBD, to get symptoms under control, improving outcomes and quality of life. Periods of relapse, often known as flares, are experienced at least once every year, when the condition is active, by 50% of people with IBD.¹⁴ They can last from weeks to months and impact on all aspects of life.

¹² Jayasooriya, N., Baillie, S, Blackwell, J. et al., (2023). Systematic review with meta-analysis: Time to diagnosis and the impact of delayed diagnosis on clinical outcomes in inflammatory bowel disease. *Aliment Pharmacol Ther.* Doi: 10.1111/apt.17370.

¹³ 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>

¹⁴ Molodecky MA, Soon IS, Rabi DM, et al. (2012), Increasing incidence and prevalence of inflammatory bowel disease with time, based on systematic review, *Gastroenterology* 142(1): 46-54. <https://doi.org/10.1053/j.gastro.2011.10.001>

- 3.21 Only 58% of services said they had processes in place which enabled them to start a treatment plan within 48 hours and 24% of patients responding to the 2019 IBD UK Patient Survey who had been diagnosed within the previous 2 years reported that it had taken longer than 2 weeks to start diagnosis.¹⁵ Delays to treatment are resulting in high numbers of emergency hospital admissions and potentially avoidable flares, where the condition is not well-controlled and serious complications can arise.
- 3.22 In response to the 2019 IBD UK Patient Survey:
- 3.22.1 70% of those responding to the said they had experienced one or more flares in the previous 12 months, with 14% reporting more than five.
 - 3.22.2 31% said they had received no information on flare management.
 - 3.22.3 72% of hospital admissions were emergency admissions.
 - 3.22.4 22% waited longer than 18 weeks for elective IBD surgery.
- 3.23 Prior to the Covid-19 pandemic, waits for elective IBD surgery in Wales were the longest of all four UK nations, with only 46% of services reporting that this took place within 18 weeks of referral. A third (30%) of patients reported waiting longer than 18 weeks for elective IBD surgery.¹⁶
- 3.24 Referral to a gastroenterologist is essential for the diagnosis and ongoing care of people living with IBD, but patients are waiting on average 20 weeks for an appointment.¹⁷ One contributing factor to these delays, which could be avoided, is the lack of digital support in some health boards. Electronic referral systems for GPs which enable consultants to respond rapidly with advice through the Welsh Clinical Portal have had a positive impact, resulting in a reduction rate in routine waiting lists for gastroenterology clinics of over 40%. Despite this clear benefit, electronic referrals remain unavailable for gastroenterology in Aneurin Bevan, Betsi Cadwaladr, and Cwm Taf Morgannwg.
- 3.25 Furthermore, people with IBD are at greater risk of several comorbidities including diabetes, bowel cancer, hypertension, atrial fibrillation, angina, stroke, rheumatoid arthritis, asthma, chronic obstructive pulmonary disorder, and chronic liver disease.^{18 19 20}
- 3.26 A well-resourced IBD Service is essential for improved patient outcomes and to better respond to comorbidities and deliver personalised care. For example, people

¹⁵ 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](https://www.crohnsandcolitis.org.uk/wp-content/uploads/2021/08/CROJ8096-IBD-National-Report-WEB-210427-2.pdf)

¹⁶ Ibid

¹⁷ [Median waiting time for referral to treatment, by local health board, September 2011 onwards](#)

¹⁸ Irving, P., Barrett, K., Nijher, M., & de Lusignan, S. (2021). Prevalence of depression and anxiety in people with inflammatory bowel disease and associated healthcare use: population-based cohort study. *Evidence-based mental health*, 24(3), 102-109. Advance online publication. <https://doi.org/10.1136/ebmental-2020-300223>.

¹⁹ Tindell A, Johnsson H, McInnes IB. Arthritis, Arthropathy, and Osteoporosis in Inflammatory Bowel Disease. In: *Crohn's Disease and Ulcerative Colitis* [Internet]. Cham: Springer International Publishing; 2017 [cited 2018 Aug 20]. p. 571-83.

²⁰ The British Society of Gastroenterology (2019) British Society of Gastroenterology consensus guidelines on the management of inflammatory bowel disease in adults. <https://www.bsg.org.uk/resource/bsg-consensus-guidelines-ibd-in-adults.html>

who were more likely to have contact with an IBD nurse specialist and have regular reviews for their Crohn's or Colitis reported having fewer flares.

3.27 IBD Clinical Nurse Specialists are an essential part of services, with their roles often including provision of patient education, disease management and therapy monitoring, patient support, continuity of care, audit and rapid access for advice and review during flares.²¹ However no service in Wales fully meets the recommended staffing ratio of 2.5 whole time equivalent (WTE) Clinical Nurse Specialists with a special interest and competency in IBD nor 1.5 WTE Clinical Nurse Specialist with a special interest and competency in stoma therapy and ileoanal pouch surgery per catchment population of 250,000.²² Furthermore there is variation in the roles and responsibilities of IBD Clinical Nurse Specialists across health boards.

3.28 There should be clearly defined career pathways for all grades of nurses working within IBD care, with sufficient resourcing for all IBD Clinical Nurse Specialists to hold, or work towards, Masters level nursing qualifications, to retain high calibre nurses and encourage more into the profession.

3.29 The IBD Standards state that: *Patients should be cared for by a defined IBD multidisciplinary team led by a named consultant adult or paediatric gastroenterologist (Statement 1.1)*. For a catchment population of 250,000 people, the IBD multidisciplinary team should include:

- 2 WTE Consultant Gastroenterologists
- WTE Colorectal Surgeons
- 2.5 WTE Clinical Nurse Specialists with a special interest and a competency in IBD
- 1.5 WTE Clinical Nurse Specialist with a special interest and competency in stoma therapy and ileoanal pouch surgery
- 1 WTE Dietitian allocated to gastroenterology
- 0.6 WTE Expert Pharmacist in IBD
- 0.5 WTE Psychologist
- 0.5 WTE Administrator to provide support for IBD meetings, IBD database recording and audit
- 0.5 WTE Radiologist with a special interest in gastroenterology
- 1 named Histopathologist with a special interest in gastroenterology

3.30 The team should work alongside healthcare professionals with an interest in IBD who provide essential supporting services including:

- A Rheumatologist
- An Ophthalmologist
- A Dermatologist
- An Obstetrician
- A Hepatologist
- A Social Worker
- A Nutrition Support Team

²¹ Ibid

²² IBD UK (2019) *IBD Standards 2019*. [Homepage](#) | IBD UK

- A Consultant Paediatrician²³

- 3.31 However, the 2019 IBD UK Benchmarking found that no service in Wales had adequate staffing in place. Furthermore, only 39% of services in Wales reported multidisciplinary team meetings taking place weekly or fortnightly, the lowest across the UK.
- 3.32 Most Health Boards reported using an estimate of 1 person in every 250 when planning services for people who had Crohn's or Colitis. However, new figures show the number of people living with these conditions is over double that, with 1 in 121 people in Wales living with the conditions.²⁴
- 3.33 We encourage the Committee to consider the need for workforce planning and funding that takes account of the need for multidisciplinary teams and is informed by accurate data on disease populations.**

Access to medicines

- 3.34 IBD requires ongoing clinical monitoring and management, often over several decades from the age of diagnosis. There is currently no medical or surgical cure and available treatments aim to address disease symptoms and maintain remission. Treatment management depends on clinical severity, extent of disease and the person's preference, and may include aminosalicylates, corticosteroids and biologics. An immunosuppressant may be considered to maintain remission if aminosalicylates fail to do so. The range of available treatment options remains far from optimal a substantial number of people with IBD experience lack of response and/or adverse reactions to biologic as well as conventional therapies.
- 3.35 Consequently, around 1 in 5 people with Crohn's Disease and 7 in 100 people with Ulcerative Colitis will need major surgery in the first five years after diagnosis.²⁵ For many patients, the prospect of surgery is one they face with considerable anxiety, and it can bring with it a range of potential complications, which may require further treatment and ongoing management. There can also be an associated profound psychological and social impact, for example, in terms of body image and self-esteem. For those who are facing this at an age when they have just begun to form relationships and do not yet have a family, this can be especially difficult, as it can for those of some religious faiths and cultures.
- 3.36 Therefore, being able to access the widest and most advanced range of evidence-based medicines and treatments is critical to treating and managing the condition and facilitating patient choice and personalised care. We welcome the One Wales Medicines process, which enables medicines approved by the All-Wales Therapeutics and Toxicology Centre to be made available across Wales, reducing inequalities to treatment access.

²³ Ibid

²⁴ IBD UK (2021), Crohn's and Colitis care in the UK: The hidden cost and a vision for change, Crohn's and Colitis Care: The Hidden Cost and a Vision for Change, IBD UK, 2021

²⁵ Tsai L *et al.*, Contemporary Risk of Surgery in Patients With Ulcerative Colitis and Crohn's Disease: A Meta-Analysis of Population-Based Cohorts. *Clin Gastroenterol Hepatol.* 2021 Oct;19(10):2031-2045.

3.37 As well as ensuring patient choice and access to a wide choice of medicines, data regarding their use should be essential for quality improvement. The IBD Dashboard²⁶ provides an overview of data at condition level to provide insights into good practice and unwarranted variation between health boards. It includes data across a patient's journey from waiting times and referral to treatment to investigative tests such as faecal calprotectin tests and surgical procedures. However, data regarding the use of biologics is not included despite being collected by health boards as the data is not available to Digital Health and Care Wales.

3.38 We encourage the committee to consider the way in which prescribing data can be appropriately shared in order to support quality improvement that covers all stages of a patient's journey.

4. Support available to enable effective self-management where appropriate, including mental health support

4.1 Care for IBD predominantly focuses on controlling gastrointestinal symptoms leaving people struggling with pain, fatigue, anxiety, and other associated issues. Self-management can enable people to live fuller, freer lives by empowering them to take more control of their condition.

“For me, self-management means that I am able to live my life as normal, or almost as normal, despite my disease. It means that my options and opportunities are not limited because of my disease.”

4.2 People with IBD want to be able to self-manage and take more control, but need better support to do so as most services do not currently support self-management. Research from Crohn's and Colitis UK with patients and health care professionals highlighted that misconceptions, terminology, and definitions of self-management vary widely among people living with IBD and healthcare professionals.

4.3 The IBD Standard 7.2 identifies the need for supported self-management, stating that: “Patients should be supported in self-management, as appropriate, through referral or signposting to education, groups and support.”²⁷

4.4 An example of good practice in Wales has been a recent online Wales-wide patient education event and the production of a video providing advice on diet and IBD, led by the All-Wales Clinical Lead for IBD. These have been positively welcomed by patients and would benefit from more opportunities for system wide promotion to patients, in addition to more resources for patient education.

4.5 Good self-management for IBD means treating the person as a whole. Taking into account a person's emotional and psychological wellbeing as well as the management of their symptoms and treatments is a vital component of self-management. We believe that the vital components of self-management for IBD are:

4.5.1 A responsive IBD service that is easy to access when needed

4.5.2 IBD services with resources to support self-management

²⁶ IBD Dashboard, [Value Based Healthcare - Digital Health and Care Wales \(nhs.wales\)](#)

²⁷ IBD UK (2019) *IBD Standards 2019*. [Homepage](#) | IBD UK

- 4.5.3 IBD Health Care Professionals who are confident and knowledgeable about self-management
 - 4.5.4 Good relationships between people with IBD and Health Care Professionals
 - 4.5.5 Good quality information and support for people with IBD to feel empowered and in control
 - 4.5.6 Access to tools, plans and support to manage treatments, symptoms, and flare-ups
 - 4.5.7 Access to emotional and psychological support
 - 4.5.8 Access to e-health and technology resources
- 4.6 Personalised care, when delivered well, has positive effects on patients' decision-making, confidence and ability to manage a health condition and has been shown to reduce admissions and contact with the NHS.²⁸ However, the IBD UK 2019 Patient Survey showed variation across Wales on whether patients' wider life and priorities were discussed as part of planning their care, with responses ranging from 12% to 60% across Welsh services.²⁹
- 4.7 To enable people living with IBD to effectively self-manage their condition there needs to be a shared understanding of what self-management means, for current organisational culture and working practices to change by embedding a personalised, structured and consistent approach to care, that supports and empowers patients to self-manage their condition, while allowing ongoing clinical monitoring and direct access to specialist care.
- 4.8 Giving people living with IBD a voice and active role in the planning, development, delivery, and review of their healthcare services will support and empower them to live well with their condition. It will create improved services and better patient outcomes.
- 4.9 While conditions such as cancer and asthma have seen investment and commitment to meet these needs,³⁰ there has not been the same recognition, urgency, or proliferation of holistic or person-centred interventions in IBD. Structured self-management programmes, such as those available for other chronic conditions, should be provided on the same basis for people with IBD.
- 4.10 We encourage the Committee to consider how best practice can effectively be resourced and rolled out across Wales and systems for meaningful patient involvement.**

5. Interactions between mental health conditions and long-term physical health conditions

²⁸ NHS England. Personalised care: Evidence and case studies.
www.england.nhs.uk/personalisedcare/evidence-and-case-studies

²⁹ IBD UK (2020), Local Service Reports Map, [Local Service Reports Map | IBD UK](#)

³⁰ Welsh Government and Wales Cancer Network, Cancer Delivery Plan for Wales 2016-2020, <https://www.gov.wales/sites/default/files/publications/2018-12/cancer-delivery-plan-2016-to-2020.pdf>

- 5.1 The symptoms of IBD and their unpredictable nature, can have a profound and devastating impact on all aspects of a person's life. The frequent and urgent need for the toilet, together with loss of sleep and the invisible symptoms of pain and continual or profound fatigue, can severely affect self-esteem and social functioning, particularly among the young and newly diagnosed. Emotional wellbeing can therefore be significantly affected by difficulty in coping with personal lives and feelings of embarrassment, frustration, sadness, and fears of needing surgery or developing cancer. Stigma and lack of wider understanding of the conditions exacerbates the impact.
- 5.2 Consequently, research suggests that anxiety, depressive episodes, depressive disorders, suicidal ideation, and self-harm are higher in people with IBD compared to the general population.^{31 32} Emerging evidence shows that not only do these psychiatric comorbidities affect an individual patient's quality of life, these disorders are also associated with a more severe disease course and increased healthcare resource utilisation.³³
- 5.3 Psychological support is essential for people living with IBD, and is required from diagnosis, throughout ongoing care and during both medical and surgical treatments. The following nationally recognised guidelines and Standards highlight this necessity:
- 5.3.1 British Society of Gastroenterology (BSG) IBD Guidelines:³⁴
- 5.3.1.1 Statement 118 - We suggest that in patients with IBD, Psychological therapies including CBT, hypnotherapy and mindfulness meditation be offered to interested patients, particularly those with psychological symptoms as adjunctive therapy to improve symptom control and Quality of Life.
 - 5.3.1.2 Good practice recommendation 25 - IBD patients experiencing fatigue should be investigated for psychological symptoms.
 - 5.3.1.3 Statement 119 - We suggest that psychological interventions may be useful for IBD patients with pain where no physical cause can be found and may be offered as adjunctive therapy.
 - 5.3.1.4 Statement 120 - We suggest that patients with disabling fatigue in whom no correctable metabolic deficiency is found may be directed to supportive psychotherapy, stress management or graded exercise.
- 5.3.2 IBD UK Standards 2019:³⁵
- 5.3.2.1 Statement 3.1 - All newly diagnosed IBD patients should be seen by an IBD specialist and enabled to see an adult or paediatric gastroenterologist, IBD nurse specialist, specialist gastroenterology

³¹ Neuendorf R, J. *et al.*, (2016). Depression and anxiety in patients with Inflammatory Bowel Disease: A systematic review. *Psychosom Res*, 87, p.70-80.

³²Lamb CA, Kennedy NA, Raine T, *et al.* British Society of Gastroenterology consensus guidelines on the management of inflammatory bowel disease in adults *Gut* 2019;**68**:s1-s106.

³³ Hill, E., Nguyen, N.H., Qian, A.S. *et al.* (2022). Impact of Comorbid Psychiatric Disorders on Healthcare Utilization in Patients with Inflammatory Bowel Disease: A Nationally Representative Cohort Study. *Dig Dis Sci*, 67, 4373-4381.

³⁴ The British Society of Gastroenterology (2019) British Society of Gastroenterology consensus guidelines on the management of inflammatory bowel disease in adults. <https://www.bsg.org.uk/resource/bsg-consensus-guidelines-ibd-in-adults.html>

³⁵ IBD UK (2019) *IBD Standards 2019*. <https://www.ibduk.org>

dietitian, surgeon, psychologist, and expert pharmacist in IBD, as necessary.

- 5.3.2.2 Statement 3.2 - After diagnosis, all patients should have full assessment of their disease, nutritional status, bone health and mental health, with baseline infection screen, in order to develop a personalized care plan.
- 5.3.2.3 Statement 5.4 - Patients with IBD being considered for surgery should be provided with information in a format and language they can easily understand to support shared decision making and informed consent and offered psychological support.
- 5.3.2.4 Statement 6.8 - On admission, patients with IBD should have an assessment of nutritional status, mental health and pain management using validated tools and be referred to services and support as appropriate.
- 5.3.2.5 Statement 7.4 - Pain and fatigue are common symptoms for IBD patients and should be investigated and managed using a multidisciplinary approach including pharmacological, non-pharmacological and psychological interventions where appropriate.

- 5.4 Despite clear recommendations from research findings, national clinical guidance and the IBD Standards there is a lack of psychological and wellbeing support for people with IBD. Currently no health board in Wales has appropriate staffing for adults with IBD for psychological support. Most have no service at all, with very long waiting lists where provision does exist.
- 5.5 Six in 10 (60%) of patients responding to the 2019 IBD UK Patient Survey³⁶ reported that they were not asked about their mental health during medical appointments. Of those recently diagnosed only 10% of respondents reported that how well they were coping emotionally had been assessed.

“[My] Mental health has massively affected me since diagnosis, and I am still struggling. This has never been discussed in all the appointments and admissions I've had, and it needs to improve or young people with the disease are just going to struggle even more”

“I have suffered with anxiety for most of my adult life. However, after my diagnosis I quickly suffered a mental breakdown. I feel more immediate aftercare would have helped me. Someone to talk to about Crohn's & to help process a diagnosis of a life-long condition. I was sign posted to the Crohn's & Colitis UK website however at a time of crisis looking at a website for information is very overwhelming & impersonal”

“The lack of support and information and feeling like I was then taking up someone's time unnecessarily also impacted my mental health. When I have been able to access some support, I mentioned several times about severe tiredness and mental health, with no options discussed and medication focused on the bleeding and diarrhoea. Treatment has been reactive rather than ways to proactively manage my condition and learn how I can best live with it.”

³⁶ IBD UK (2021). *Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change*. Crohn's and Colitis Care in the UK: The Hidden Cost and a... | IBD UK

- 5.6 Intervention has been shown to work. An evaluation of integrated psychological support for patients with IBD found that the most common reason for referral into the service was for support adjusting to IBD and its symptoms. The study concluded that for every £1 spent on the pilot project³⁷:
- 5.6.1 The number of bed days reduced by more than 60%
 - 5.6.2 Inpatient admissions reduced by over 70%
 - 5.6.3 IBD follow up appointments reduced by 60%
 - 5.6.4 Number of scans reduced by 75%
- 5.7 We would urge the committee to consider how to ensure that the mental health needs of people with long term conditions are met, including access to psychological support.

6. Impact of the pandemic

- 6.1 COVID 19 had a severe impact on IBD care, from diagnosis to treatment and surgery, exacerbating the existing constraints on IBD care across Wales. Our 2021 Healthcare Survey³⁸ showed that many people living with IBD 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.
- 6.2 The lack of understanding of IBD by the public or by GPs, who see a high proportion of patients with lower gastrointestinal symptoms, leads to delays in people recognising symptoms that should be investigated, and in the relevant tests and 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 including endoscopy.
- 6.3 Sharing their experiences, people living with Crohn's or Colitis said:
- "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."*
- "Doctors refused to see me due to Covid, ended up in hospital and having blood transfusions after becoming severely anaemic with a BMI lower than 17"*
- 6.4 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%).³⁹ Diagnosis is also taking longer than before the pandemic.

³⁷ Eccles, J. A., Ascott, A., McGeer, R., *et al* (2021). Inflammatory bowel disease psychological support pilot reduces inflammatory bowel disease symptoms and improves psychological wellbeing. *Frontline Gastroenterology*, 12, p. 154-157.

³⁸ Crohn's & Colitis UK, [Healthcare Survey 2021 - What patients told us \(crohnsandcolitis.org.uk\)](https://www.crohnsandcolitis.org.uk)

³⁹ 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. [PMO-37 COVID-19 impact on care and prescribing for inflammatory bowel disease: Data from the IBD Registry | Gut \(bmj.com\)](https://www.gut.bmj.com/)

- 6.5 The pandemic has also had a significant impact on endoscopy in line with national guidance⁴⁰, 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.⁴¹
- 6.6 Many endoscopy units ran at a reduced capacity, with an 83% reduction in activity compared to pre-COVID levels in Wales⁴², 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.
- 6.7 Waiting times for endoscopy remain high, with more than 1 in 5 of those on the waiting list (5,708 out of 24,673) waiting 40 weeks or more for a diagnostic endoscopy at the end of February 2023, higher than any other category.⁴³ We welcome the focus on this through the endoscopy services follow up-inquiry.

7. Conclusion

- 7.1 We strongly welcome this focus by the Health and Social Care Committee on supporting people with chronic conditions.
- 7.2 Where you live should not determine the quality of care you experience, however there remains variation across services. This has been exacerbated by the pandemic.
- 7.3 Giving people living with IBD a voice and active role in the planning, development, delivery, and review of their healthcare services will support and empower them to live well with their condition. It will create improved services and better patient outcomes.
- 7.4 In the next stages of this inquiry, we would welcome a focus on the needs of people with relapsing and remitting conditions, such as Crohn's and Colitis, and how system wide change and reducing variation can most effectively be driven through national strategies and pathways, workforce development and planning, and patient involvement.

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

⁴⁰ Ibid

⁴¹ British Society of Gastroenterology (2021), [Endoscopy activity and COVID-19: BSG and JAG guidance](#) | [The British Society of Gastroenterology](#)

⁴² 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.

⁴³ [Diagnostic and Therapy Services Waiting Times by week, November 2019 onwards \(gov.wales\)](#)

Table 1. Results for a selection indicators from the 2019 IBD Patient Survey and Service Self-Assessment for the hospitals in Wales who responded. Red indicates where the indicator has not yet been achieved, green indicates where it has been achieved.

Hospital	Population Coverage	No. IBD Patients Supported	No. Patient Survey Respondents	Quality of care (good, very good and excellent)	Patients with IBD are seen within 4 weeks from their first referral	All elective IBD surgery takes place within 18 weeks	All IBD patients have a personalised care plan based on a holistic needs assessment	All patients have access to non-acute endoscopy and imaging within 4 weeks and within 24 hours for patients who are acutely unwell or require admission to hospital	All patients with confirmed IBD are recorded in an electronic clinical management system
Ysbyty Gwynedd	194,139	1,300	40	59%	Red	Red	Red	Red	
Glan Clwyd	225,000	700	33	43%	Red	Red	Red	Red	
Wrexham Maelor	387,000	1,824	58	76%	Red	Green	Red	Red	
Withybush	125,055	450	34	91%	Red	Red	Green	Red	
Morrison (Paediatric)	500,000	51	N/A	N/A	Red	Green	Red	Green	
Neath Port Talbot	142,906	750	15	92%	Red	Red	Green	Red	
Princess Of Wales	150,000	1,500	8	57%	Red	Green	Green	Red	
Royal Glamorgan	150,000	600	31	55%	Red	Green	Red	Red	
Prince Charles	200,000	700	17	50%	Red	Green	Green	Red	
University Hospital of Wales and University Hospital Llandough	650,000	3,000	99	83%	Red	Red	Red	Red	
Royal Gwent, Nevill Hall and Ysbyty Ystrad Fawr	750,000	3,513	95	61%	Red	Red	Green	Red	
Total (Achieved)					0	5	4	5	1