CROHN’S & COLITIS UK: THE FUTURE OF GENERAL PRACTICE IN WALES

March 2025

1. About us

1.1 Crohn’s & Colitis UK is the leading UK charity dedicated to supporting people living with Crohn’s and Colitis. 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. 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][2]

1.3 More than 26,000 people in Wales live with IBD, with most diagnosed between the ages of 15 and 40. Across the UK, 1 in 67 people over the age of 70 live with IBD, posing a substantial social and economic burden on governments and health systems in the coming years. The number of people living with Crohn’s and Colitis in Wales is expected to increase.[3][4]

1.4 Symptoms include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue, and weight loss. IBD affects not only the gut but also the joints, eyes, energy levels, and mental health, significantly impacting quality of life.

1.5 IBD requires tight monitoring and management, often over several decades depending on age of diagnosis. Care is managed across primary and secondary care, often with high-cost medications or surgery, or a combination of both.

1.6 Delayed diagnosis increases the likelihood of surgery or more expensive treatments and results in a poorer prognosis. 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 IBD on the NHS is increasing year on year and, per patient life-time costs are comparable to cancer and heart disease.[5]

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[1] 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.

[2] 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.

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

[4] Welsh Government, NHS in 10+ years: an examination of the projected impact of Long-Term Conditions and Risk Factors in Wales

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

1.7 This submission highlights the challenges faced by people living with Crohn's and Colitis in receiving an early diagnosis, and ongoing support and symptom management, and how more joined up and patient centred care could be delivered by general practice in the community through improved support and access to specialist advice for GPs and improvements to digital systems.

2. Summary of key points and recommendations:

2.1 General practice plays an important role in improving patient experiences and outcomes in diagnosis and ongoing care and monitoring for Crohn's and Colitis, however this is hampered by low levels of awareness and confidence, inadequate digital systems and staffing challenges in secondary care.

2.2 To improve current experiences of general practice and allow a more preventative approach to care, we recommend:

2.2.1 **Wider implementation of symptom-led pathways and patient toolkits, such as the 'National Primary Care Pathway for Lower Gastrointestinal (GI) symptoms'[6], to help reduce delays to diagnosis, simplify guidance for primary care practitioners, and ensure that people get the right test at the right time. To support their implementation, GPs should have time to engage with CPD.**

2.2.2 **Integration of NHS Wales digital systems across primary and secondary care allowing information flow, with patient consent, with regards to diagnosis and treatment. Patients on immunosuppressants should be prioritised in the Shared Medicines Record rollout.**

2.2.3 **Longer appointment times to support the better delivery of personalised care for people living with complex long-term conditions, such as Crohn's or Colitis.**

2.2.4 **Improving access to specialist advice for GPs to enable them to better support those living with chronic conditions in the community.**

2.2.5 **NHS Wales develop data structures to support personalised care planning and data sharing across multidisciplinary teams consisting of secondary care, primary care and allied health professionals.**

3. Patient experiences of diagnosis

3.1 Delays in diagnosis and treatment limit options, increase disease progression, and result in avoidable emergency admissions, adding pressure to overstretched A&E departments. This not only has a negative impact on patient outcomes, but can affect people's ability to continue in education and work.

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[6] What's Up With My Gut? https://whatsupwithmygut.org.uk/

3.2 People living with Crohn's or Colitis face delays at all stages of diagnosis, from patient led delays, delays in primary care, and then in secondary care. Responses from Welsh patients to the IBD UK Patient Survey in 2023 revealed that:

3.2.1 More than 4 in 5 (82%) people living with IBD in Wales diagnosed in the last year reported waiting more than four weeks to see a healthcare professional about their symptoms, and 1 in 3 (33%) reported waiting over a year

3.2.2 Almost 3 in 4 (72%) people living with IBD in Wales reported waiting more than 4 weeks to be referred to a specialist, and 1 in 6 (16%) reported waiting over a year[7]

3.2.3 1 in 7 (14%) reported being diagnosed in an emergency hospital admission.[8]

3.3 When presenting in primary care with lower gastrointestinal symptoms such as abdominal pain and diarrhoea, the appropriate tests including a faecal calprotectin test (FCP), a full blood count, urea and electrolytes, and C-reactive protein should be carried out, with timely referral on to endoscopy to confirm diagnosis if IBD is suspected.[9]

3.4 However, for many this is not the case, with only 3 in 5 (62%) reporting being offered a stool test as part of their diagnostic journey, despite the test being available to primary care practitioners in every health board since 2022.[10]

3.5 Furthermore, many struggle to get a GP appointment and there are systemic barriers for patients to come forward, as revealed by a recent independent survey[11] commissioned by Crohn's & Colitis UK. In Wales:

3.5.1 1 in 5 (19.8%) report difficulties in getting a GP appointment

3.5.2 More than 1 in 10 (11.6%) reported they did not want to waste a healthcare professional's time

3.5.3 1 in 10 (10.6%) report reported they would be too embarrassed to talk about their symptoms

3.6 People living with IBD often report that their symptoms were dismissed, contributing to delays to diagnosis:

"I had been having several episodes of a discharge of fluid from my rectum and I went to see my GP. However, my GP was completely dismissive of these symptoms. He asked me if I had worms! So because of his attitude, I ignored the symptoms and dismissed them as harmless. This was a mistake. A number

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[7] IBD UK (2024), *Crohn's and Colitis in Wales: A Vision for Change*, 2024 Devolved Nations Reports | IBD UK.

[8] IBD UK (2024), *The State of IBD Care in the UK*, 2024 IBD UK Report: The State of IBD Care in the UK | IBD UK

[9] NHS England (2024), *RightCare scenario: Inflammatory Bowel Disease*, RightCare-IBD-scenario-June-2024.pdf

[10] IBD UK (2024), *Crohn's and Colitis in Wales: A Vision for Change*, 2024 Devolved Nations Reports | IBD UK.

[11] UK wide with a sample size of 3,107 participants, including 151 in Wales.

of years later, I had an episode of faecal incontinence while out for a walk. After two weeks of diarrhoea, I was admitted to hospital and diagnosed with ulcerative colitis"

"My diagnosis was a battle in itself. I began experiencing small cramps in my stomach during my GCSE's and overtime it just became worse. I was turned away from many doctors as they didn't believe I was in pain, but after a year of trying to understand my symptoms, we discovered my Crohn's. It was so frustrating because I knew something serious was going on but I felt so helpless. It took for me to be in agonising pain in hospital before any doctor actually took it seriously."

3.7 Others reported only receiving a diagnosis after switching to a GP who had a greater knowledge of the conditions:

"I was diagnosed in 2017 but have suffered for many years prior, the reason why it hadn't been picked up earlier is because I suffered severe constipation. I had recently moved to a new area meaning I had a new GP who luckily for me had good knowledge of the disease and asked all the right questions."

"The first GP I saw told me to stop taking anti-diarrhoea tablets and go away. A second GP referred immediately and a colonoscopy revealed ulcerative colitis."

3.8 Whilst NICE provides guidance on the diagnosis of individual conditions, it does not provide pathways across conditions that present with overlapping symptoms. For example, a patient presenting with diarrhoea, stomach pain and fatigue could be experiencing one of a range of conditions from food poisoning, to IBD, to bowel cancer.

3.9 Combining professional and lived experience, the 'National Primary Care Pathway for Lower Gastrointestinal (GI) symptoms' has been developed by charities supporting people living with lower gastrointestinal conditions.

3.10 The pathway, hosted on the 'What's Up With My Gut website, provides guidance for healthcare professionals, including which conditions and tests to consider, and step by step guides to support and empower parents and people trying to get a diagnosis, shorten the time to diagnosis, reduce variation among healthcare professionals and improve patients' experiences of care.[12]

3.11 **Symptom led pathways and patient toolkits, such as the 'National Primary Care Pathway for Lower Gastrointestinal (GI) symptoms', could help to reduce delays to diagnosis, simplifying guidance for primary care practitioners, and ensuring that people get the right test at the right time. To support their implementation, GPs should have time to engage with CPD.**

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[12] What's Up With My Gut? https://whatsupwithmygut.org.uk/

4. Experiences of ongoing care

4.1 Crohn's and Colitis are lifelong conditions that require continuous care and monitoring by a multidisciplinary team across both primary and secondary care. In general practice, this can include treatment to manage a flare (often with steroids), and support with managing symptoms, such as pain and fatigue. In addition to this, IBD and some treatments can impact on other areas of healthcare.

4.2 Almost half of IBD patients have at least one flare a year, with 1 in 5 (19%) responding to the 2023 IBD UK Patients Survey reporting five or more flares in the last year. The prompt recognition and treatment of flares is essential to improve the quality of life of patients and to avoid adverse outcomes.[13]

4.3 Greater support is needed to deliver co-ordinated and holistic care, with access to specialist advice for both patients and general practitioners.

4.4 Co-ordination of care

4.4.1 Well-coordinated care with GPs, for people living with long-term conditions managed in specialist services in secondary care, can increase opportunities for prevention and early intervention, reduce anxiety for patients and limit unnecessary pressure on healthcare providers through increased admin and the need for multiple appointments.

4.4.2 However, this is not the reality for many patients. Responding to the 2023 IBD UK Patient Survey, only 2 in 5 (42%) people in Wales reported that care between their IBD team and GP is well-coordinated, ranging from 0-66% depending on where people live and receive their care.[14][15]

4.4.3 Furthermore, approaches to the use of personalised care plans remain inconsistent and there are differences in understanding between patients and healthcare providers. Fewer than 1 in 10 (7%) adults with IBD that responded to the 2023 IBD UK Survey reported having a personalised care plan in place.

4.4.4 This limits the degree to which personalised care can be delivered, and may lead to patients having to repeat their experience with each new care provider, wasting valuable clinic time and increasing the risk of information or opportunities for intervention being missed.

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[13] IBD UK (2024), *Crohn's and Colitis in Wales: A Vision for Change*, 2024 Devolved Nations Reports | IBD UK.

[14] Ibid

[15] IBD UK, Local Service Reports, Local Service Reports Map | IBD UK (analysis of Welsh reports by Crohn's & Colitis UK)

4.4.5 Advice such as ‘flare-pathways’ help to provide primary care practitioners with accessible guidance on steroid intervention, dose escalation and when to refer to secondary care for those who have not had surgery or being treated with an immunomodulator.[16]

4.4.6 Remission for Crohn’s and Colitis can be achieved through a variety of medical interventions, including immunomodulatory and biological therapy, or steroids. Whilst protocols are in place, their prescription is not always communicated effectively to primary care due to the lack of shared patient records. This disconnect can also impact on patient access to vaccinations, when those on immunosuppressant medication are eligible, or impact on health issues that are not related to Crohn’s or Colitis.

4.4.7 This lack of IT capability and implementation of digital projects, including electronic Prescribing and Medicines Administration and the Shared Medicines Record, is one of the main reasons for poor GP integration and communication with people living with IBD.

4.4.8 This was most evident during the pandemic with the rollout of the shielding programme, and later vaccinations, for those on immunosuppressant medication, prescribed in secondary care. When shielding was introduced, patients receiving biologic treatments were not on any shielding list, or known to public health teams, due to these treatments being ‘Hospital Only’, resulting in almost 1 in 5 (17%) people living with Crohn’s and Colitis reporting that they received incorrect shielding information.[17]

4.4.9 **NHS Wales digital systems should clearly capture diagnosis and treatments made in secondary care, and, with patient consent, be accessible across healthcare settings. People undergoing immunosuppressant treatment should be prioritised in the roll-out of the Shared Medicines Record.**

4.5 Delivering personalised and holistic care

4.5.1 For people living with long-term conditions, especially those managing multiple conditions, personalised care plans offer improved opportunities to deliver continuity of care across multidisciplinary teams, GPs and allied health professionals and support better self-management of conditions and changes in health behaviour. Personalised care approaches have also been shown to reduce admissions and contact with the NHS.[18]

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[16] IBD UK, IBD Standards: Section 4: Flare management, Flare pathways | IBD UK

[17] Crohn's & Colitis UK Life in lockdown survey

[18] NHS England. Personalised care: Evidence and case studies, www.england.nhs.uk/personalisedcare/ evidence-and-case-studies

4.5.2 IBD care is often reactive and focused on managing gut related symptoms, despite the debilitating impact symptoms outside the gut, can have on people's lives. Common extraintestinal manifestations include joint pain, affecting more than 2 in 5 (46%) people living with IBD, and fatigue, affecting around 4 in 10 people when their IBD is in remission, rising to 7 in 10 for those with active inflammation (in a flare-up).

4.5.3 The link between poor mental health and chronic conditions is also well-established and consistently demonstrates that people with long-term conditions are two to three times more likely to experience mental health problems than the general population.[19]

4.5.4 Responding to research by Crohn's & Colitis UK, people living with IBD tell us that fatigue has one of the biggest impacts on their life.

"Fatigue is arguably the most difficult intangible part of IBD. The invisible battle that the body is fighting with IBD and medications is deeply frustrating. This can overwhelm plans, exercise regimes, working output and is incredibly difficult to articulate to others."

4.5.5 However opportunities to deliver personalised care are being missed in Wales. Responses from patients in Wales to the IBD Patient Survey in 2023[20] show that:
  4.5.5.1 Only half of respondents (52%) report they were asked about pain
  4.5.5.2 Only 2 in 5 (38%) report they were asked about fatigue
  4.5.5.3 Only 1 in 4 (23%) report they were asked about their mental health.

4.5.6 People living with multiple chronic conditions often have more complex needs, which might not be covered fully in shorter consultations, especially when patients have to repeat their experiences. The OECD Patient Reported Indicator Surveys report found that less than 6% of people living with two or more chronic conditions in Wales are managed in primary care practices scheduling regular consultations of more than 15 minutes.[21]

4.5.7 **For people living with complex long-term conditions, such as Crohn's or Colitis, longer appointment times could support the better delivery of personalised care.**

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[19] Naylor, C., Parsonage, M., McDaid et al., (2012). Long-term conditions and mental health: The cost of co-morbidities. Long-term condition and mental health Chris Naylor February 2012 (kingsfund.org.uk)

[20] IBD UK (2024), *Crohn's and Colitis in Wales: A Vision for Change*, 2024 Devolved Nations Reports | IBD UK.

[21] OECD (2025), *Does Healthcare Deliver?: Results from the Patient-Reported Indicator Surveys (PaRIS)*, OECD Publishing, Paris, https://doi.org/10.1787/c8af05a5-en.

4.6 Access to specialists

4.6.1 People living with different long-term conditions, such as IBD, may only make up a small proportion of patients GPs will see. Therefore it is not practical for GPs to have a high awareness of every condition.

4.6.2 The RCGP Spotlight Project found that 52% of GPs stated that they were 'less than confident' or 'not confident' in dealing with patients whose were experiencing a 'flare-up' of Crohn's or Colitis.[22] This lack of awareness and confidence is reflected in the 2023 IBD UK Patient Survey, in which only 2 in 5 (42%) people living with IBD in Wales agreed that their GP is knowledgeable of their condition.[23]

4.6.3 This often results in missed opportunities in managing flares, and patients being referred to their IBD team for issues that could be managed in primary care. This increases pressure on IBD teams and can contribute to delays to achieving remission allowing people to get on with their lives and a feeling of disjointed care for patients.

4.6.4 Due to long-waiting lists and pressure on secondary care, GPs also play an important role in supporting those who have been unable to register with their new IBD service when moving their care across borders or to a different health board. However, due to the complexity of treatment, interventions are limited.

"My GP in Wales has made several requests/referrals to my local hospital IBD service, but despite flare ups I am still waiting some 9 months later for my first appointment. I recently had a bad flare up only to be told when visiting my GP that the only option was attend A&E."

4.6.5 **Access to specialist support and advice for GPs is needed to help ensure that there is no wrong door approach** for those seeking support and supporting delivery of more personalised care to patients living with chronic conditions, such as Crohn's and Colitis. However this is challenged by staffing shortages in specialist teams.

4.6.6 Currently GPs access specialist advice and guidance about potential hospital referrals through a myriad of formal and informal email addresses and telephone numbers, as well as the national e-referral system. Most channels tend to be standalone, do not provide any auditable data and, in most cases, they are disconnected from core patient administration or referral systems, which are run in the absence of agreed and consistent processes or response times. All of this can mean additional work and time wasted for GPs and hospital clinicians,

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

[23] IBD UK (2024), *Crohn's and Colitis in Wales: A Vision for Change*, 2024 Devolved Nations Reports | IBD UK.

as well as delays for patients in getting access to the most appropriate care.

4.6.7 **NHS Wales must develop data structures to support personalised care planning and data sharing across multidisciplinary teams consisting of secondary care, primary care and allied health professionals.**

5. Conclusion

5.1 General practice plays a key role in the diagnosis and treatment of Crohn's and Colitis, helping to ensure early interventions and deliver care closer to home.

5.2 However the delivery of well-co-ordinated, holistic, patient-centred care is limited by low levels of condition awareness, workforce challenges in specialist teams and the lack of integrated digital systems.

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