Crohn's and Colitis Care in Wales: A Vision for Change

Association of Coloproctology of Great Britain and Ireland · British Association for Parenteral and Enteral Nutrition · British Dietetic Association · British Society of Gastroenterology · British Society of Gastrointestinal and Abdominal Radiology · British Society of Paediatric Gastroenterology, Hepatology and Nutrition · CICRA (Crohn's in Childhood Research Association) · Crohn's & Colitis UK · Ileostomy & Internal Pouch Association · Primary Care Society for Gastroenterology · Royal College of General Practitioners · Royal College of Nursing · Royal College of Pathologists · Royal College of Physicians · Royal Pharmaceutical Society · UK Clinical Pharmacy Association

IBD UK
Strategy
Partnership
Quality Improvement

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Introduction

More than 26,000 people (1 in 127 people) in Wales live with Crohn's disease and ulcerative colitis, the two most common forms of inflammatory bowel disease (IBD). This is nearly double previous estimates.[1] These chronic conditions cause gut inflammation and symptoms (e.g. diarrhoea, abdominal pain and fatigue) that range from mild to severe, with life threatening complications.[2]

The IBD Standards set out what high-quality care should look like at every point of a person with IBD's journey – from first symptoms, to diagnosis, treatment and ongoing care.[3] These have been developed by IBD UK, a coalition of 16 patient organisations and professional bodies with an interest in IBD. To benchmark current care against these standards, a Service Self-Assessment and IBD Patient Survey were carried out in 2023, completed by 851 adults living with IBD and 9 adult IBD services in Wales.[a]

Over a third (36%) of Welsh respondents rated their care over the past 12 months as fair or poor.

Too many people living with IBD in Wales are waiting too long to be diagnosed and receive treatment. This wait comes at a cost, not only to the NHS in Wales, but also to the physical health, emotional wellbeing, financial security and quality of life of people living with IBD.

Everyone living with IBD should have access to high-quality care at every stage of their journey, regardless of who they are and where they live. To drive much needed change, the Welsh Government and the NHS in Wales should commit to supporting IBD services meet the IBD Standards.[3]

[a]3 in 4 services in Wales.

Workforce

IBD nurse specialists
0% of services met standards

Psychologists
0% of services met standards

Gastroenterologists
33% of services met standards

Colorectal surgeons
50% of services met standards

Stoma nurses
88% of services met standards

Radiologists
88% of services met standards

Dieticians
13% of services met standards

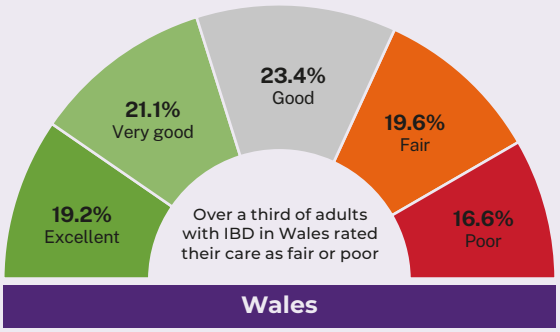
Pharmacists
25% of services met standards

Multidisciplinary team
No IBD service in Wales meets the IBD Standards for multidisciplinary team staffing

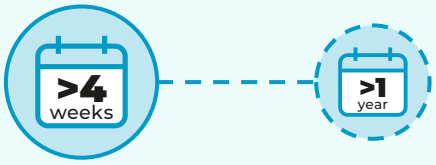
Administrators
67% of services met standards

Histopathologists
88% of services met standards

Quality of care



Diagnosis



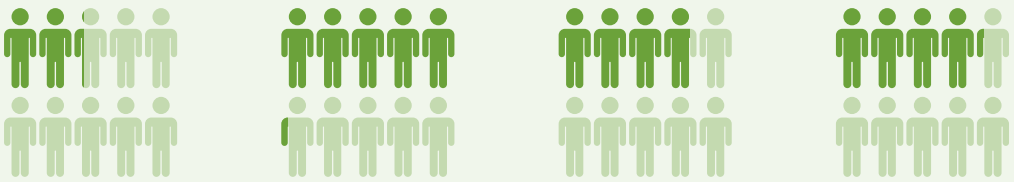
82% of people with IBD **reported seeing a primary care practitioner more than 4 weeks** after experiencing symptoms

33% of people with IBD waited over a year

72% reported **waiting more than 4** weeks after speaking to a primary care practitioner to be referred to a specialist

21% were **diagnosed over 6 months** after being referred

Personalised care



23% of people with IBD were asked about their **mental health** by Welsh services

52% were asked about **pain**

38% were asked about **fatigue**

42% agreed care is **well organised** between primary and secondary care

Treatment

19% of adults reported **experiencing 5 or more flares in the last year**

60% waited over 1 month for investigative tests whilst in a flare

26% spent **1 (or more) nights in hospital**

of these, **80%** of admissions were **classified as an emergency**

50% of IBD services reported **surgery waiting times >18 weeks**

Sources: Data from the Service Self-Assessment and IBD Patient Survey.

Diagnosis

Rapid diagnosis of IBD is crucial to prevent worsening symptoms, increased morbidity and serious long-term complications, including colorectal cancer.[4,5] However, people living with IBD report delays at multiple stages, often enduring symptoms of a serious illness for extended periods of time. This includes delays to seeking medical assistance, repeated visits to their general practitioner (GP), and waiting for appointments, test results and a diagnosis.

More than 4 in 5 (82%) people living with IBD reported waiting more than four weeks to see a healthcare professional about their symptoms, and 1 in 3 (33%) reported waiting over a year. Improved awareness of IBD symptoms amongst the public and healthcare professionals is important in reducing delays to diagnosis. However, only 2 in 5 (42%) people with IBD agreed that their GP is knowledgeable about their IBD type and 3 in 5 (62%) reported being offered a stool test as part of their diagnostic journey.

The IBD Standards set out that people referred to a specialist with suspected IBD should be seen within four weeks, or more rapidly if clinically necessary.[3] However, nearly three quarters of respondents (72%) reported waiting more than four weeks to be referred to a specialist, and 1 in 6 (16%) reported waiting over a year. Many continue to face significant delays after referral, with over 1 in 5 (21%) people waiting over six months between referral and a diagnosis being made.

As lower gastrointestinal (GI) endoscopy is the primary method of diagnosis, it is essential that waiting lists for this procedure are reduced in Wales. Welsh Government policy and funding decisions for endoscopy should therefore adequately reflect the needs of people living with IBD.[6]

RECOMMENDATIONS FOR ACTION

- Invest in public health campaigns to raise awareness of IBD symptoms, such as the Crohn's & Colitis UK 'Cut the Crap' campaign and symptom checker, with a focus on tackling inequalities in diagnosis.
- Implement the 'National Primary Care Diagnostic Pathway for lower GI Symptoms' across Wales, ensuring access to faecal calprotectin tests, to provide clarity for primary care professionals, reduce pressure on endoscopy departments and ensure people living with gut related symptoms get the right tests at the right time.

Treatment

When a person is diagnosed with IBD, treatments focus on controlling inflammation, inducing remission and preventing flares (a period of disease relapse).[7,8] Uncontrolled symptoms risk complications that may require hospitalisation and/or lifechanging surgery.

In Wales, over half (55%) of adults living with IBD reported experiencing a flare in the last 12 months. Out of these, half (50%) reported three or more flares and, concerningly, almost 1 in 5 (19%) reported more than five flares, which could indicate poor care optimisation and/or adherence to treatment. Rapid access to specialist advice is necessary in the event of a suspected flare, to guide early flare intervention and reduce the likelihood of complications.[9] However, almost 1 in 3 (30%) people did not receive a response from an advice line within 48 hours.

Furthermore, 3 in 5 (60%) reported waiting over one month for an investigative test whilst experiencing a flare, potentially delaying treatment and risking complications.

Over 1 in 4 (26%) adults living with IBD reported spending one or more nights in hospital because of their IBD over the past two years. Of these, almost half (47%) reported they were admitted multiple times and **4 in 5 (80%) reported that their most recent admission was classed as an emergency.** Many of these emergency admissions may have been avoidable through earlier diagnosis, effective flare management or access to IBD Hot Clinics providing rapid assessments from IBD nurse specialists.[10]

Prolonged delays to IBD surgery can lead to advanced clinical signs and complications, which can result in emergency presentations and higher-risk surgery.[11] Despite the 18-week referral-to-surgery target,[3] half of Welsh IBD services (including all larger services) reported waiting times over 18 weeks for elective surgery.

RECOMMENDATIONS FOR ACTION

- Improve access to specialist support in the event of a flare, through investments in best practice, such as IBD Hot Clinics.
- Introduce dedicated resources and targets for non-cancerous conditions, to ensure all IBD operations are performed as soon as a person is clinically optimised and within 18 weeks from initial referral.

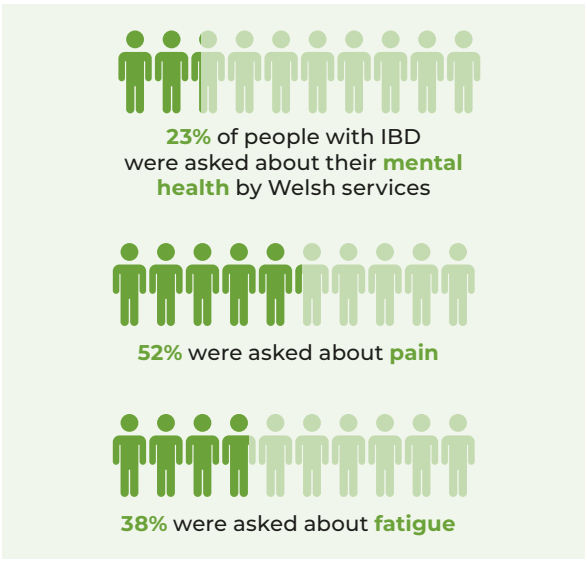
PATIENT STORY

Abby, diagnosed with ulcerative colitis in 2002

After over 10 years of relatively good health, this **started to deteriorate** in 2015 and I was put on various immunosuppressants. These worked for a while, but my last two colonoscopies showed low grade dysplasia and after a number of years of my consultant suggesting surgery, I finally decided it needed to be done as I was also having frequent accidents. Sadly, **my local hospital does not carry out planned ileostomy surgeries, so I had to travel two hours** away at the end of April 2024 to have my permanent ileostomy surgery. **This was extremely hard for me** as I had to be away from my two children and family for a week. Thankfully, **the care I received was outstanding**. I also had amazing support from my wonderful local gastro nurse. My only worry after the surgery was the two-hour journey home, over mountains and windy roads. I was trying to find public toilets that were open, so I was able to empty my bag, which is **not easy when you live in a rural area.**

Personalised Care

Personalised care is a coordinated approach that addresses the complex interaction between physical symptoms, mental health, and social factors, and should be a guiding principle when providing care to people living with IBD. However, despite personalised care being at the heart of optimal IBD management, fewer than 1 in 4 (23%) adult respondents agreed that they were asked about their mental health or emotional wellbeing.



No adult IBD service in Wales has a psychologist as part of their multidisciplinary team, with young adults transitioning from paediatric care facing a cliff edge in support. No adults undergoing surgery reported that they were offered the opportunity to speak to a counsellor or psychologist before their operation, and only one IBD service agreed that individuals undergoing surgery are offered specialised psychological support.

Similarly, **no service in Wales reported having a locally agreed policy to investigate or treat mental health problems**. The lack of resources to support the mental health of people living with IBD in Wales is concerning, as evidence suggests that depression and anxiety are more common in people with IBD.[12]

Good communication between primary and secondary care services is crucial for personalised care, reducing risk and avoiding harm. However, **only 2 in 5 (42%) adults living with IBD agreed that their care is well-organised between their GP and IBD team**.

The lack of IT capability and implementation, including electronic health records, is one of the main reasons for poor GP integration and communication with people with IBD.[13] This limits opportunities for individuals to take an active role in managing their IBD and can increase demand for services such as IBD nurse specialist advice lines.

RECOMMENDATIONS FOR ACTION

- Integrate mental health support throughout the diagnostic and treatment stages of IBD care, ensuring access to specialist psychological support.
- Improve IT capabilities to support greater collaboration between IBD services and primary care, ensuring that people with IBD receive consistent and coordinated care.

Workforce

Multidisciplinary team working is essential for the delivery of high-quality care. However, data from the Service Self-Assessment suggests that **no service in Wales meets the IBD Standards for whole time equivalent staffing across the team (Table 1)**.[3]

IBD nurse specialists are central to IBD care delivery and are the most frequent first contact for specialist advice for people living with IBD.[14] However, no service in Wales currently meets the IBD Standards for staffing numbers for this critical role and, concerningly, several services rely on just one IBD nurse specialist, creating challenges in delivering high-quality care in periods of absence.

Nearly twice as many people are living with Crohn's disease and ulcerative colitis than previously thought, with numbers expected to continue to increase.[1] However, most Welsh services (88%) reported that the data they used for the IBD population size, provided in the Service Self-Assessment, was estimated. This underscores the need to enhance digital systems to ensure that services can be appropriately resourced, based on accurate IBD population figures.

RECOMMENDATIONS FOR ACTION

- Improve digital systems and introduce a condition specific registry to ensure accurate data on the number of staff and people with IBD are available, to inform service planning.
- Increase the number of IBD nurse specialists and ensure opportunities for development, such as a Master's level qualification.
- Support all IBD services to meet the IBD Standards on staffing for all members of the multidisciplinary team, to ensure that staff are available and have the capacity to deliver high-quality care.

Table 1. The percentage of Welsh adult IBD services meeting IBD Standards whole time equivalent staffing recommendations

IBD team	Number of Welsh IBD services responding	Meeting Standards in 2019 (%)	Meeting Standards in 2023 (%)
Gastroenterologists	9	36	33
Colorectal surgeon	8	0	50
Stoma nurse	8	27	88
Dietician	8	9	13
Psychologist	8	0	0
Radiologist	8	18	88
Histopathologist	8	18	88
Administrators	9	9	67
IBD nurse specialist	9	0	0
Pharmacists	4	-[a]	25

Footnotes: ≤25% of IBD services meeting standards indicated in red, >25%–≤75% of IBD services meeting standards indicated in orange and ≥75% of IBD services meeting standards indicated with green. [a]Data from 2023 relates specifically to pharmacists that have IBD-linked funding and are therefore not comparable with 2019 data. **Source:** Data from the Service Self-Assessment.

Conclusion

Everyone living with Crohn's disease or ulcerative colitis should have access to high-quality care at every stage of their journey, regardless of who they are and where they live. However, no service in Wales meets the IBD Standards.

Healthcare in Wales is facing significant challenges, with an older population, ongoing financial pressures and legacy pressures from COVID-19.[1,15] Supporting Welsh IBD services to overcome these challenges and deliver high-quality care will ensure better health outcomes and reduce economic constraints, delivering longer-term benefits to society as a whole.

Results in this report highlight significant challenges to the delivery of high-quality IBD care in Wales. However, these challenges can be addressed through the outlined recommendations for meeting the IBD Standards.

The time to act is now. The Welsh Government and NHS Wales must prioritise working with clinicians, people living with IBD and charities to improve Welsh IBD care now and in the future.

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Further information and support

If reading this report has raised any concerns for you then please contact the **Crohn's & Colitis UK Helpline**
0300 222 5700
helpline@crohnsandcolitis.org.uk
www.crohnsandcolitis.org.uk

If you have questions or concerns about ileostomy or internal pouch surgery, please contact the **Ileostomy & Internal Pouch Association**
0800 018 4724
info@iasupport.org
www.iasupport.org

If you have questions or concerns relating to children with IBD, please contact **CICRA (Crohn's in Childhood Research Association)**
020 8949 6209
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