Crohn's and Colitis Care in Scotland: 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
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Quality Improvement

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Introduction

More than 50,000 people in Scotland (1 in 103) live with Crohn's disease and ulcerative colitis, the two most common forms of inflammatory bowel disease (IBD). **This prevalence is the highest of any country within the UK**.[1] IBD causes gut inflammation and symptoms (e.g. diarrhoea, abdominal pain and fatigue) that can range from mild to severe, sometimes with life-threatening complications.[2]

The IBD Standards are used to guide the delivery of high-quality, personalised care across the UK.[3] To benchmark the current state of care against these standards, a UK-wide IBD Patient Survey and Service Self-Assessment were carried out in 2023, completed by 1,500 adults with IBD and 18 adult IBD services in Scotland, respectively.

Although various quality improvement initiatives have been introduced in Scotland, including 'The Endoscopy and Urology Diagnostic Recovery and Renewal Plan' and the 'National Blueprint',[4,5] when asked how they would rate the quality of their care over the past 12 months, **approximately 1 in 3 people (33%) who responded to the IBD Patient Survey selected fair or poor**. This reflects results from across the benchmarking exercise, which indicate that people with IBD in Scotland are not receiving the high quality care they require. This compromises the physical health, emotional wellbeing, quality of life and financial security of people with IBD, whilst also contributing to greater financial pressures on NHS Scotland.

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. The Scottish Government and NHS Scotland should prioritise supporting IBD services to meet the IBD Standards.[3]

Workforce

Psychologists
0% of services met standards

IBD nurse specialists
66% of services met standards

Administrators
27% of services met standards

Colorectal surgeons
27% of services met standards

Radiologists
46% of services met standards

Dieticians
13% of services met standards

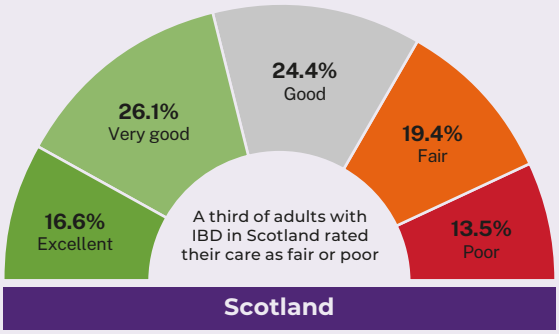
Stoma nurses
13% of services met standards

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

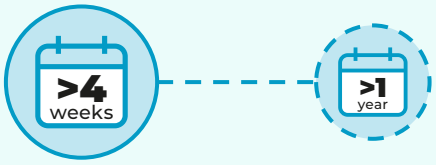
Gastroenterologists
60% of services met standards

Histopathologists
38% of services met standards

Quality of care



Diagnosis



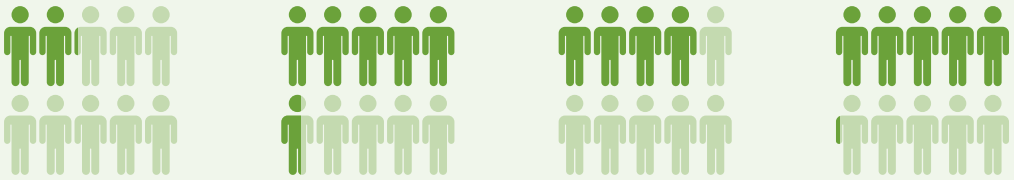
77% of people with IBD **reported seeing a primary care practitioner more than 4 weeks** after experiencing symptoms

29% of people with IBD waited over a year

65% reported **waiting more than 4 weeks** after speaking to a primary care practitioner to be referred to a specialist

22% were **diagnosed over 6 months** after being referred

Personalised care



21% of people with IBD were asked about their **mental health** by Scottish services

56% were asked about **pain**

40% were asked about **fatigue**

51% agreed care is **well organised** between primary and secondary care

Treatment

13% of adults reported **experiencing 5 or more flares in the last year**

52% waited over 1 month for investigative tests whilst in a flare

28% spent **1 (or more) nights in hospital**

of these, **84%** of admissions were **classified as an emergency**

35% of people with IBD reported **waiting 6 months or more** for their operation

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

Diagnosis

Rapid diagnosis of IBD is essential to prevent disease progression and long-term complications.[6] People may delay seeking medical assistance due to a lack of awareness of IBD symptoms, or concern about perceived stigma.[7,6,8] Almost 4 in 5 (77%) people with IBD reported waiting longer than four weeks after experiencing symptoms to see a healthcare professional, and almost 3 in 10 (29%) waited over a year. Allocating resources towards improving public awareness of IBD symptoms should be considered, to minimise avoidable delays to timely diagnosis.

Delays to diagnosis also occur in primary care. Over 3 in 5 (65%) people with IBD in Scotland reported waiting more than four weeks between their first primary care consultation to being referred to hospital, and 1 in 6 (16%) waited over a year. Reasons for these delays include appointment waiting times, delays to completing investigative tests, a lack of access to key diagnostic tools (like faecal calprotectin tests) in primary care and the changing nature of IBD symptoms. However, only around 2 in 5 (44%) respondents in Scotland agreed that their general practitioner (GP) is knowledgeable about their condition, suggesting that both guidance and enabling resources are needed to support primary care professionals to identify and prioritise people with IBD.

Once seen by a primary care professional, individuals that are referred with suspected IBD should be seen within four weeks, or more rapidly if clinically necessary.[3] However, even after referral many continue to face significant delays, with approximately 1 in 5 people (22%) waiting over six months between being referred and receiving a diagnosis. **These delays throughout the diagnosis process risk disease progression and emergency presentations, which worsen outcomes for people with IBD and are costly for NHS Scotland.**

RECOMMENDATIONS FOR ACTION

- The 'National Primary Care Diagnostic Pathway for lower GI Symptoms' should be implemented across all Health Boards in Scotland, to support primary care professionals to make appropriate, timely referrals for tests.

- High-profile public health campaigns to raise awareness of the seriousness of IBD and its symptoms, such as the Crohn's & Colitis UK initiative 'Cut the Crap' and the Scottish IBD 'awareness campaign', should be a priority for the Scottish Government to invest in, with support from dedicated experts and a focus on tackling inequalities in diagnosis.

Treatment

Treatments for people with IBD aim to induce and maintain disease remission, prevent complications and restore a normal quality of life. Flares (a period of relapse) occur in the majority of people with IBD and, if left untreated, can lead to life-threatening complications, emergency surgery and a deterioration of mental health.[9] Almost 3 in 5 (57%) people with IBD in Scotland reported experiencing a flare in the last 12 months, with more than 1 in 10 (13%) reporting more than five flares in this same time period. While flares occur for different reasons, for some, this high number in a single year could indicate poor care optimisation and/or adherence to treatment.

Timely access to specialist advice through a telephone or email advice line is essential in guiding early flare intervention.[10] The IBD Standards state that individuals requesting support from a specialist advice line should receive a response by the end of the next working day.[3] **However, roughly 1 in 4 people with IBD (23%) reported that they did not receive a response within 48 hours of contacting a medical practitioner for advice when experiencing a flare**. Furthermore, the IBD Standards recommend that people experiencing a flare should have access to review by the IBD team within a maximum of five working days, and be able to escalate or start a treatment plan within 48 hours of review.[3] However, 1 in 5 (20%) IBD services and almost 3 in 5 (58%) people with IBD reported that these recommendations were not met for reviews and treatment plans, respectively, increasing the likelihood of complications.[10]

While medical therapy and effective flare management are the main forms

of IBD treatment, surgery may be required when symptoms are severe, complications arise or if someone does not wish to escalate their medical therapy. The IBD Standards state that elective surgery should be performed as soon as a person's clinical status has been optimised and within 18 weeks of referral for surgery.[3] **Despite this, approximately 1 in 3 people with IBD (35%) waited six months or more for their operation to take place and only 3 in 5 (64%) felt their operation was completed in an appropriate timescale**. Prolonged delays to IBD surgery can lead to advanced clinical signs and complications, which can result in emergency presentations and surgery.[11] As undergoing emergency surgery is riskier and associated with increased morbidity,[12] every effort should be made to reduce emergency presentations caused by delays.

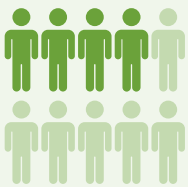
RECOMMENDATIONS FOR ACTION

- Increased support and resources must be allocated to essential IBD advice line services, to ensure responses during a flare can be received by the end of the next working day. Reviews during a flare should be conducted within five working days and treatment initiation or escalation within 48 hours of this review.
- Waiting times for surgery must be reduced to less than 18 weeks, to improve outcomes for people with IBD and reduce avoidable presentations at Accident & Emergency departments.

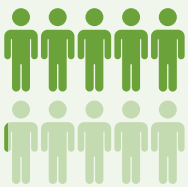
Personalised Care

21% of people with IBD were asked about their **mental health** by Scottish services

56% were asked about **pain**



40% were asked about **fatigue**



51% agreed care is **well organised** between primary and secondary care

Personalised care is a coordinated approach that addresses the complex interaction between physical symptoms, mental health, nutritional needs and social factors, and should be a guiding principle when providing care to people living with IBD. In terms of physical symptoms, up to half (50%) of people with IBD experience extraintestinal manifestations.[13] Despite this, **only 1 in 3 (36%) adults with IBD in Scotland reported being asked about conditions beyond their gut**, suggesting a narrow clinical focus that risks missing peoples' broader unmet physical needs.

Living with IBD can also have a severe impact on a person's mental health.[14] However, only half (53%) of Scottish IBD services agreed that people with IBD are routinely asked about their mental health at outpatient appointments and reviews, and **no services reported having a policy in place for investigating and treating people living with IBD who are also struggling with their mental health**. Mirroring these results, only 1 in 5 (21%) people with IBD agreed that they were asked about their mental health, and treatment options to manage this.

Finally, over 3 in 5 (65%) people with IBD living in Scotland did not agree that they have access to specialist advice or support regarding diet and nutrition, placing them at an increased risk of malnutrition.[15] **Therefore, the psychological and dietary needs of people with IBD are not being considered for a high proportion of people living with IBD in Scotland, signifying a missed opportunity to provide personalised care**.

Effective coordination between and within healthcare services is key to personalised care. This will become increasingly important across Scotland, due to a shift towards community-based healthcare, as highlighted in the Programme for Government 2024–2025: Serving Scotland.[16] However, only half (51%) of adults with IBD agreed that their care is well-organised between their GP and IBD team. To facilitate IBD services and primary care practices to deliver a cohesive and personalised service, technological innovation to support care coordination should be considered.

RECOMMENDATIONS FOR ACTION

- Mental health and nutritional support should be integrated throughout the IBD services and adequately resourced. Alongside this support, referral and signposting to mental health services and the promotion of self-management apps should be prioritised.
- IBD services should be supported to utilise technology, such as secure messaging platforms, to enhance collaboration with primary care colleagues, and ensure consistent and coordinated care for people with IBD.

Workforce

Adequate staffing of the IBD multidisciplinary team is essential to deliver high-quality care. **However, no IBD services in Scotland met the IBD Standards for whole time equivalent staffing across the team** (Table 1).[3] Furthermore, no services in Scotland currently meet the IBD Standards for staffing requirements for psychologists and only 1 in 10 (13%) services meet staffing requirements for dieticians. As psychological and dietary support have been found to decrease IBD symptoms, reduce complications and improve the overall quality of life of people with IBD,[17,18] addressing inadequate staffing in these specialisms will be essential for improving IBD care.

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

IBD Team	Meeting Standards in 2023 (%)
Gastroenterologists	60
Colorectal surgeon	27
Stoma nurse	13
Dietician	13
Psychologist	0
Radiologist	46
Histopathologist	38
Administrators	27
IBD nurse specialist	66

Footnotes: ≤25% of IBD services meeting standards indicated in red; >25%–≤75% of IBD services meeting standards indicated in orange. **Source:** Data from the Service Self-Assessment.

RECOMMENDATIONS FOR ACTION

- All IBD services should be supported so that multidisciplinary teams meet the IBD Standards for staffing, ensuring that staff are available and have the capacity to deliver high-quality care.
- The number of IBD nurse specialists should be increased and opportunities for their development should be ensured, such as Master's level qualifications.

PATIENT STORY

Mareta, diagnosed with Ulcerative Colitis in 2007

My journey to getting a stoma was a long one. I trialled **many different medication options**, and due to my bowel perforating I was then operated on and had my stoma fitted. I was very, very lucky when I first got diagnosed as my **IBD nurse was fantastic**. Unfortunately, though, **she left the NHS** (luckily for me after my first stoma operation) and the **service was moved from our local hospital to a hospital 20 miles away**. They **lost a wealth of experience** in losing her and for all intents and purposes I was lucky my bowel perforated whilst she was still there, as she was the one who recognised it. The specialism that role requires is **life saving** and there are definitely **not enough nurses** who understand the condition enough as it's been lost in budget cuts.

Conclusion

The Scottish healthcare system is facing significant challenges, including higher morbidity and mortality rates than the rest of the UK, with Edinburgh displaying some of the highest rates of IBD in the world.[19,20] Ongoing financial pressures within the Scottish NHS and legacy pressures from COVID-19 pose additional barriers to IBD care.[21] Scottish IBD services must be supported in overcoming these obstacles to ensure high-quality care and improved health outcomes for service users, and to reduce the financial burden placed on the nation's healthcare system.

Results in this summary report highlight significant challenges to the delivery of high-quality IBD care in Scotland. By following the recommendations outlined in this report, Scottish IBD services can address these barriers to care delivery and meet the IBD Standards.

The time to act is now. The Scottish Government and NHS Scotland must prioritise working with clinicians, people with IBD and charities to improve Scottish 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)**
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