Crohn's and Colitis Care in Northern Ireland: 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

Published December 2024
www.ibduk.org

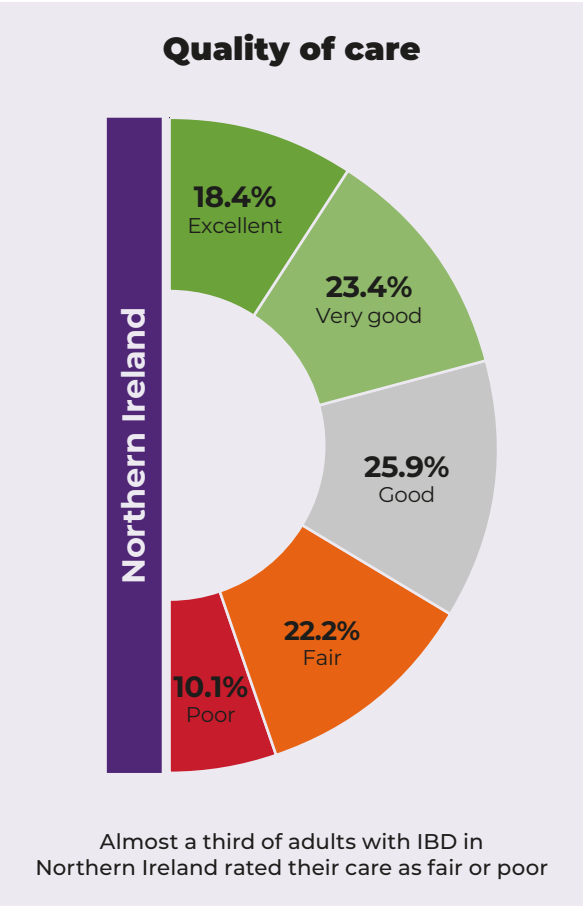
Introduction

Over 17,000 people (1 in 114) in Northern Ireland live with Crohn's disease or ulcerative colitis, the two most common forms of inflammatory bowel disease (IBD). This is nearly double previous estimates, and Northern Ireland is now displaying some of the highest incidence rates of Crohn's disease in the UK.[1] IBD causes gut inflammation, symptoms (e.g. diarrhoea, abdominal pain and fatigue) that can range from mild to severe and disease activity that can have life-threatening complications.[2]

The IBD Standards are used to guide the delivery of high-quality, personalised care across the UK.[3] To benchmark current care against these standards, a UK-wide IBD Patient Survey and Service Self-Assessment were carried out in 2023. In total, 454 adults with IBD in Northern Ireland completed the IBD Patient Survey. Due to the low Service Self-Assessment response rate, this report will only focus on IBD Patient Survey responses.

Various initiatives have been implemented to improve access to IBD care, such as 'My Waiting Times NI' and 'encompass'. However, these initiatives have fallen short in driving service improvement and ensuring efficient access to healthcare services.[4,5] **Almost 1 in 3 (32%) IBD survey respondents rated their quality of care as fair or poor**, suggesting that people are not receiving the high-quality care they require. This is problematic, as substandard care compromises the physical health, emotional wellbeing, quality of life and financial security of people with IBD, whilst contributing to greater financial pressures on the Department of Health (DoH) and the public healthcare system (Health and Social Care [HSC]) in Northern Ireland.

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 Northern Ireland Executive and HSC must prioritise supporting and adequately resourcing IBD services to meet the IBD Standards.[3]



Almost a third of adults with IBD in Northern Ireland rated their care as fair or poor

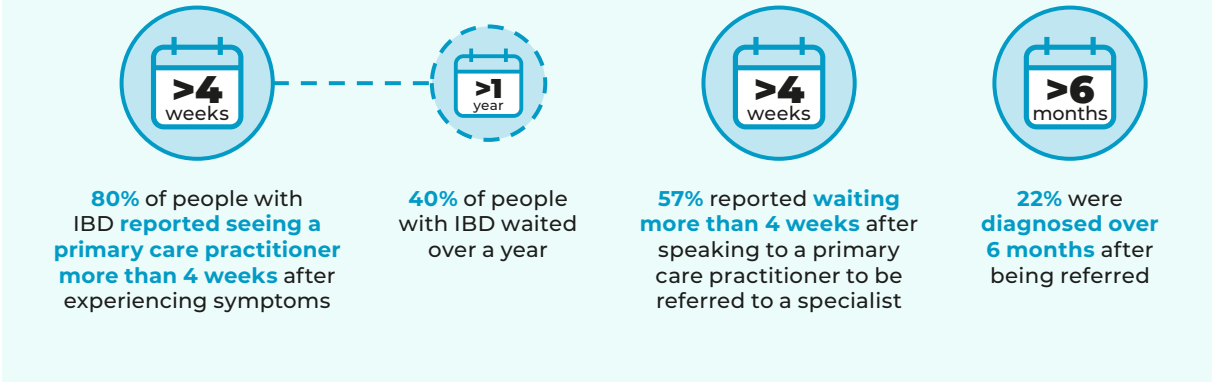
Source: IBD Patient Survey.

Diagnosis

Rapid diagnosis of IBD is vital to prevent progression of symptoms and to avoid long-term complications, while also reducing costs for HSC Trusts in Northern Ireland.[6] However, fewer than 1 in 5 (19%) adults with IBD reported seeing a healthcare professional within four weeks of experiencing symptoms, with 2 in 5 (40%) waiting over a year to seek help. These delays indicate that there may be a lack of public knowledge on the symptoms of IBD in Northern Ireland, as well as concerns about stigma.[6–8] Initiatives to improve public awareness of IBD symptoms should be considered, to minimise avoidable delays and ensure timely diagnoses.

Delays to diagnosis also occur following primary care assessment. Almost 3 in 5 (57%) people with IBD reported waiting more than the four-week period recommended by the IBD Standards for referrals,[3] and roughly 1 in 10 (13%) reported waiting over a year. Reasons for these delays include a lack of awareness amongst primary care staff on the appropriate use of faecal calprotectin tests when assessing lower gastrointestinal (GI) symptoms in primary care, leading to delays in issuing of these tests. Delays to completing other investigative tests, and the changing nature of IBD symptoms, can also postpone referrals. Furthermore, only half (52%) of people with IBD in Northern Ireland agreed that their general practitioner (GP) is knowledgeable about their IBD type. These data therefore suggest that both guidance and education are needed to support primary care professionals to identify and prioritise those with IBD.

Finally, nearly 1 in 4 (22%) respondents reported waiting over six months between being referred to a specialist and receiving a diagnosis. **Delays throughout the diagnosis process risk disease progression and emergency presentations, which worsen clinical outcomes and are costly to HSC.**



Source: IBD Patient Survey.

RECOMMENDATIONS FOR ACTION

- The 'National Primary Care Diagnostic Pathway for lower GI Symptoms' should be implemented across all HSC Trusts, to provide clarity for primary care professionals and ensure people living with gut-related symptoms get the right tests at the right time.
- The Northern Ireland Executive should invest in high-profile public health campaigns to raise awareness of the seriousness of IBD and its symptoms, such as the Crohn's & Colitis UK 'Cut the Crap' initiative, with support from dedicated experts and a focus on tackling inequalities in diagnosis.

Treatment

Treatment for IBD aims to control inflammation, induce remission and prevent flares (a period of relapse), all of which are essential to restoring a normal quality of life for people with IBD.[9] Flares occur in most people with IBD, with almost two thirds (63%) of IBD Patient Survey respondents reporting experiencing a flare in the last 12 months, and almost 1 in 5 (18%) experiencing more than five flares in this same period. For some, this high frequency of flares in a single year might reflect poor care optimisation and/or adherence to treatment.

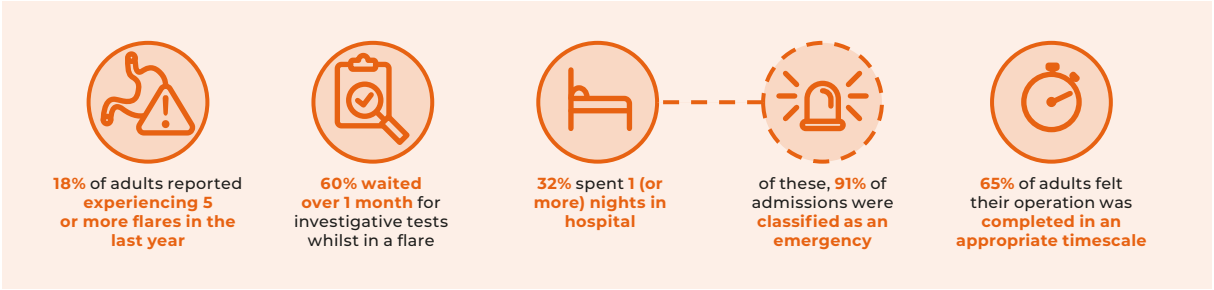
Rapid access to specialist advice from trained team members, such as IBD nurse specialists, is also essential for guiding early flare intervention for people with IBD. This should include access to a telephone or email advice line that provides a response by the end of the next working day.[3] Whilst initiatives, such as the 'Northern Ireland Flare Card',[10] have been introduced to improve flare management, and can be seen as an example of best practice, people across Northern Ireland are still facing delays in receiving advice and treatment during a flare.

Nearly 1 in 4 people with IBD (22%) reported that they did not receive a response from a medical practitioner within 48 hours of experiencing a flare. This could negatively impact how these individuals manage their flare and lead to poorer quality of life. Furthermore, the IBD Standards recommend that people experiencing a flare should be able to escalate or start a treatment plan within 48 hours of review.[3] Unfortunately, around 3 in 5 (61%) respondents reported that this recommendation was not met.

This is cause for concern, as delays in initiating treatment for flares increase the likelihood of complications for people with IBD.[11]

Finally, long wait times for elective surgeries can increase the risk of complications.[12] 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, more than 1 in 6 people with IBD (18%) reported waiting six months or more for their operation to take place and less than 7 in 10 (65%) felt that their operation was completed in an appropriate timescale**.

Prolonged delays to IBD surgery can lead to advanced clinical signs and complications, which often result in emergency presentations and surgery.[13] As undergoing emergency surgery is riskier and associated with increased morbidity,[14] every effort should be made to reduce emergency presentations caused by delays.



Source: IBD Patient Survey.

RECOMMENDATIONS FOR ACTION

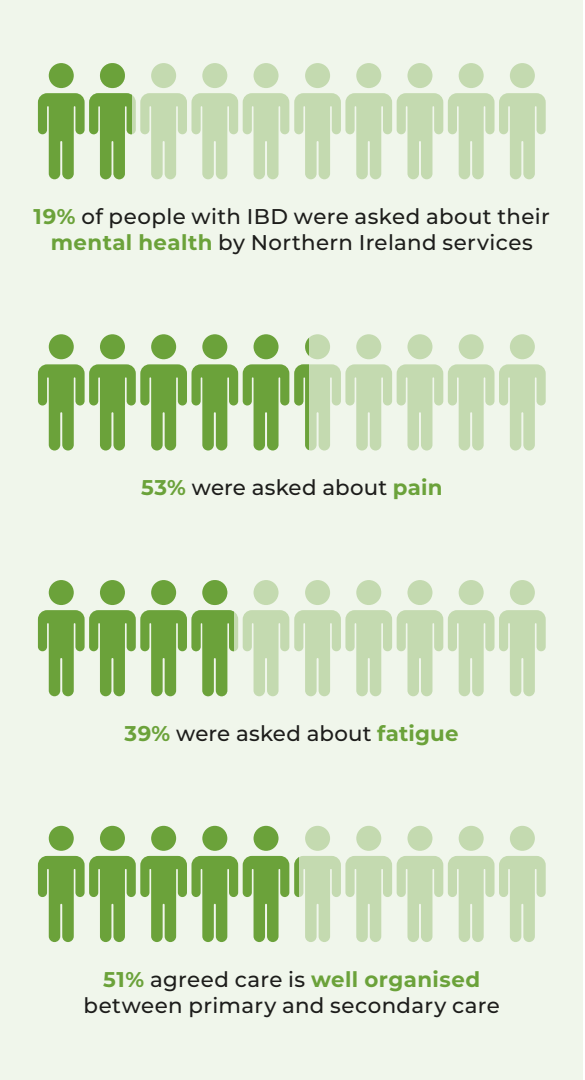
- Increased support and resources must be allocated to essential IBD advice line services, to ensure responses during a flare are received by the end of the next working day. Treatment initiation or escalation should be available within 48 hours of review during a flare.
- Every person living with IBD in Northern Ireland should have access to a suitably trained IBD nurse specialist, to ensure responsive health services and improved clinical outcomes.
- Action should be taken to reduce waiting times for surgery. Elective IBD surgeries should be performed as soon as a person is clinically optimised, which must be within 18 weeks from initial referral, to improve outcomes for people with IBD, and reduce the burden of emergency presentations and surgery on Accident & Emergency departments.

Personalised Care

Personalised care is a coordinated approach that addresses the complex interaction between physical symptoms, mental health, nutritional needs and social factors. This is particularly important for people living with IBD, as up to half (50%) report experiencing extraintestinal clinical signs affecting their joints, skin, bones, eyes, kidneys and liver.[15] Furthermore, nutrition plays a vital role in managing symptoms and promoting gut health, while the chronic nature of IBD can lead to stress, anxiety and depression, which in turn can exacerbate physical symptoms.[16]

Despite personalised care being foundational to optimal IBD management, **almost 3 in 4 (72%) adults with IBD in Northern Ireland reported that they were not asked about conditions beyond their gut, and over 4 in 5 (81%) reported they were not asked about their mental health. Additionally, almost two thirds (60%) of respondents did not agree that they have access to specialist advice or support with diet and nutrition**, representing a significant missed opportunity to provide holistic and personalised care.

Personalised care also requires coordination between IBD services and primary care. This may become increasingly important across Northern Ireland as the Executive supports a move to improving health through primary and community care, as detailed in the Draft Programme for Government 2024–2027. **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.



Source: IBD Patient Survey.

RECOMMENDATIONS FOR ACTION

- Mental health and nutritional support should be integrated throughout the diagnosis and treatment process for IBD within inpatient and outpatient care, including referral and signposting to mental health services, and the promotion of self-management.

- IBD services should aim to strengthen their collaboration with primary care colleagues and utilise technology to ensure that people with IBD receive consistent care across services. To achieve this, primary care must be offered training and support to adopt new systems (e.g. encompass)[5] that facilitate coordinated care.

Workforce

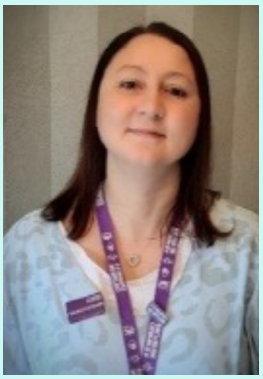
Expansion of the medical workforce has generally stagnated in Northern Ireland.[17] Offering opportunities to enhance the knowledge and skills of those in IBD multidisciplinary teams could be a simple recruitment and retention strategy, and may enhance clinical capacity. The Crohn's & Colitis UK 'Nurse Specialist Programme' promotes learning and develops expertise, empowering nurses to carry out advanced assessments, prescribe medication and monitor people with IBD independently.

This expertise is valued by service users, with **almost 9 in 10 (89%) IBD Patient Survey respondents agreeing that the IBD nurse specialists who treat them are knowledgeable about their IBD and treatment**. Investing in the ongoing professional development of the IBD healthcare workforce is therefore a critical step for recruitment, retention, capacity building and ultimately enabling efficient and high-quality care.[18]

RECOMMENDATIONS FOR ACTION

- All IBD services should be supported so that multidisciplinary teams meet the IBD Standards for staffing to ensure that staff are available and have the capacity to deliver high-quality care.
- The DoH should conduct a comprehensive workforce census, including all HSC Trusts across Northern Ireland. This regional IBD strategy will ensure improvements through a better understanding of local requirements and facilitate the provision of targeted support.
- The number of IBD nurse specialists should be increased and opportunities for their development should be ensured, such as Master's level qualifications.

GAYLE MARTIN, CROHN'S & COLITIS UK NURSE SPECIALIST PROGRAMME



We have a 'gastro hub' where we take referrals from GPs, emergency care settings, and other specialties within the hospital for patients with suspected IBD. They used to see a consultant first and were sent through to the IBD nurse once diagnosed. Now, referrals for patients with suspected IBD are also being sent directly to me, to be seen in the IBD clinical nurse specialist rapid access clinic. I can usually see patients within 48 hours and request investigations, getting them on to rapid access scope lists, diagnosed and onto treatment a lot quicker. Medical and surgical colleagues will accept referrals directly from me now, trusting that I have assessed the patient and run appropriate investigations. Prior to the development of the gastro hub and rapid access clinics, it took at least three months to see a consultant, whereas now patients can be seen within a week.

Conclusion

The healthcare system in Northern Ireland is facing significant challenges, including a capacity crisis, ongoing financial pressures within HSC and legacy pressures from COVID-19.[7] By following the recommendations outlined in this summary report, IBD services in Northern Ireland can overcome these challenges and deliver high-quality care, ensuring better health outcomes for people with IBD and reducing economic pressures.

The time to act is now. The Northern Ireland Executive and HSC must prioritise working with clinicians, people with IBD and IBD charities to improve IBD care in Northern Ireland now and in the future.

References

1. Pasvol TJ, Horsfall L, Bloom S, et al. Incidence and prevalence of inflammatory bowel disease in UK primary care: a population-based cohort study. BMJ Open 2020;10:e036584.

2. National Health Service. Inflammatory bowel disease. Available at: https://www.nhs.uk/conditions/inflammatory-bowel-disease/. Last accessed: September 2024.

3. IBD UK 2019. IBD Standards. Available at: https://ibduk.org/ibd-standards. Last accessed: April 2024.

4. Health and Social Care Trust. My Waiting Times NI. Available at: https://online.hscni.net/my-waiting-times-ni/. Last accessed: September 2024.

5. Digital Health and Care Northern Ireland. Encompass. Available at: https://dhcni.hscni.net/digital-portfolio/encompass/. Last accessed: September 2024.

6. Jayasooriya N, Baillie S, Blackwell J, et al. Systematic review with meta-analysis: Time to diagnosis and the impact of delayed diagnosis on clinical outcomes in inflammatory bowel disease. Aliment Pharm Ther 2023;57:635–652.

7. British Medical Association 2022. From bad to worse: Northern Ireland's care crisis. Available at: https://www.bma.org.uk/news-and-opinion/from-bad-to-worse-northern-irelands-care-crisis#:~:text=On%20almost%20every%20measure%2C%20Northern,to%20get%20an%20outpatient%20appointment. Last accessed: September 2024.

8. Cross E, Prior JA, Farmer AD, et al. Patients' views and experiences of delayed diagnosis of inflammatory bowel disease: a qualitative study. BJGP Open 2023;7:1–10.

9. Crohn's & Colitis UK. Treatments. Available at: https://crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/all-information-about-crohns-and-colitis/understanding-crohns-and-colitis/treatments. Last accessed: September 2024.

10. Health and Social Care 2021. Helping patients own their IBD step by step. Available at: https://www.niibdflarecard.co.uk/. Last accessed: November 2024.

11. IBD UK. Rapid access to specialist review. Available at: https://ibduk.org/ibd-standards/flare-management/rapid-access-to-specialist-advice. Last accessed: September 2024.

12. Crohn's & Colitis UK 2022. Surgery for Ulcerative Colitis. Available at: https://crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/all-information-about-crohns-and-colitis/surgery-and-complications/surgery-for-ulcerative-colitis#:~:text=The%20risks%20of%20delaying%20or,effects%20or%20complications%20from%20medicines. Last accessed: September 2024.

13. Kaur M, Dalal RL, Shaffer S, et al. Inpatient management of inflammatory bowel disease-related complications. Clin Gastroenterol Hepatol 2020;18:1346–1355.

14. Alvarez-Bautista FE, Hoyos-Torres A, Ruiz-Muñoz EA, et al. Abdominal emergency surgery in inflammatory bowel disease: postoperative outcomes and risk factors for adverse events and prolonged hospitalization. Indian J Surg 2022;85:809–816.

15. Harbord M, Annese V, Vavricka SR, et al. The first European evidence-based consensus on extra-intestinal manifestations in inflammatory bowel disease. J Crohns Colitis 2016;10:239–254.

16. McGeer R AA, Smith M, et al. IBD psychological support pilot reduces IBD symptoms and improves psychological wellbeing. Gut 2018;67:A224–A226.

17. British Medical Association 2024. NHS under pressure - Northern Ireland. Available at: https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/nhs-under-pressure-northern-ireland. Last accessed: September 2024.

18. Crohn's & Colitis UK 2023. Nurse Specialist Programme. Available at: https://crohnsandcolitis.org.uk/our-work/healthcare-professionals/ibd-nurse-specialists/ibd-nurse-specialist-programme. Last accessed: May 2024.

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
support@cicra.org
www.cicra.org

designbysoapbox.com

Writing and graphic design support
Costello Medical