The State of IBD Care in the UK

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

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Executive Summary

Background

Inflammatory bowel disease (IBD) is a chronic condition: the two main forms are Crohn's disease and ulcerative colitis. Both cause gut inflammation and symptoms including diarrhoea, abdominal pain and fatigue. These symptoms can range from mild to severe, with life-threatening complications. Over 500,000 people in the United Kingdom (UK) are affected, impacting their daily lives and mental health.[1]

The IBD Standards are used to guide the delivery of high-quality and personalised care across the UK.[2] To benchmark current care against these standards, a UK-wide IBD Patient Survey and a Service Self-Assessment were carried out in 2023. These surveys are an update to similar surveys carried out in 2019, which provide a useful point of comparison.[3]

Overview

To provide an overall assessment of IBD care in 2023, people with IBD were asked how they would rate the quality of their care over the past 12 months, what aspects of IBD care are most important to them and what areas of care require significant improvement. Roughly one in three adults (35%) rated their care as ‘fair’ or ‘poor’, a higher proportion than in 2019. A higher proportion of children and adolescents with IBD rated their care quality more favourably compared with adults, but one in seven (14%) still rated it as ‘fair’ or ‘poor’.

Results indicated that people want to be seen quickly and for it to be simple and convenient for them to contact their IBD service. People with IBD also value care that considers their wider wellbeing and wish to see changes that ensure that their wellbeing is being considered.

Diagnosis

Rapid diagnosis of IBD is crucial to prevent worsening of symptoms and long-term complications. However, people experiencing symptoms often wait months before seeing a primary care professional and for a referral to see a specialist. Current waiting times to see a specialist and undergo diagnostic tests, including lower gastrointestinal (GI) endoscopies, are also not meeting IBD Standards at a high proportion of IBD services. These delays can have a considerable effect on peoples' physical health, mental health, education and career.

Delays to diagnosis can also result in significant extra costs for the NHS, with one in seven adults (14%) with IBD currently diagnosed during emergency hospital admission.

RECOMMENDATIONS FOR ACTION

- Faecal calprotectin tests should be available across primary care.
- The 'National Primary Care Diagnostic Pathway for lower GI Symptoms' should be implemented across the UK, to support primary care professionals to make appropriate, timely referrals for tests.
- A nationally agreed waiting time for lower GI endoscopies should be implemented across the UK when IBD is suspected.
- IBD services must be resourced to ensure people with newly diagnosed IBD are initiated onto a treatment plan as soon as possible. This should be within one week for moderate-to-severe disease and two weeks for mild disease.
- High-profile public health campaigns to raise awareness of IBD symptoms, such as the Crohn's & Colitis UK initiative 'Cut the Crap', need multi-stakeholder endorsement, support for wide dissemination and investment from governments across all four nations.

Treatment

People with IBD are not able to access rapid specialist advice and are not starting treatment quickly enough, resulting in potentially avoidable “flares” (a period of relapse where their condition is not well controlled) and risking serious complications. One in six adults (17%) reported experiencing more than five flares in the previous 12 months, while 70% of hospitalisations in the past two years were emergency inpatient stays without surgery. Extended waiting times for planned IBD surgeries are also putting individuals immediate and long-term health at risk.

RECOMMENDATIONS FOR ACTION

- Advice lines need to be resourced to ensure that those experiencing symptoms of a flare receive a response by the end of the next working day, to guide early flare intervention. Reviews during a flare should be conducted within five working days and individuals should have their therapy escalated, or be on a treatment plan, within 48 hours of review.
- Nationally agreed waiting times for planned IBD surgery should be implemented across the UK. Elective IBD operations should be performed as soon as a person is clinically optimised for surgery, which must be within 18 weeks from initial referral.
- IBD services should define and optimise their strategies and policies for patient reviews. IBD services should consider implementing a flexible review system, whereby those judged to be suitable can initiate reviews as needed, rather than following a routine schedule.

Personalised Care

Despite calls for greater personalisation of IBD care,[3] evidence that this is how care is experienced by people with IBD in the UK is limited. The need for effective personalised care approaches is particularly acute in the adult population, with 53% of adults not asked about wider life goals and 37% reporting that their care was not well organised. Mental health support across both adults and young people is also poor, with only 20% of adults and 49% of children and adolescents reporting that they were asked about their mental health during their care.

RECOMMENDATIONS FOR ACTION

- To promote integrated mental health support throughout the diagnosis and treatment process for IBD. Alongside the need for integrated specialist psychological support, this should include referral and signposting to mental health services and the promotion of self-management.
- A personalised care plan template should be developed and nationally endorsed. This is an important step towards ensuring that everyone with IBD has a personalised care plan detailing specific multidisciplinary support and flare management.
- Structured self-management programmes, focused on wellbeing support, should be co-produced with service users and commissioned for people with IBD who are suitable.[a]
- Greater utilisation of technology should be encouraged to enable IBD services to strengthen their collaboration with primary care colleagues and to ensure that people with IBD receive consistent and coordinated care.
- A national review of the transition from paediatric to adult IBD services should be undertaken, to identify and address the discrepancies between what IBD services report providing and peoples' experiences.

[a]Note that clinical self-management is limited to those with ulcerative colitis taking oral and topical 5-aminosalicylic acids.

Workforce

The workforce crisis across the NHS is reflected in UK IBD services. None of the 126 adult IBD services met the IBD Standards for multi disciplinary team (MDT) staffing across all roles. Opportunities to improve the IBD services through feedback and audits are also inadequate.

RECOMMENDATIONS FOR ACTION

- MDTs within all IBD services should be resourced to meet the IBD Standards for staffing, to ensure that staff are available and have the capacity to deliver high-quality care.
- Opportunities for feedback should be available and encouraged by IBD services across the UK. Engagement from people with IBD and IBD services with IBD UK's benchmarking process provides an opportunity for a nationwide audit of services and therefore should be encouraged by healthcare decision makers.

Conclusions

Challenges facing the UK health system are reflected in UK IBD services and the experiences of people who use them. These include high demand, long waiting times, strained budgets and a workforce under pressure. The 2023 IBD UK benchmarking demonstrates that delays to diagnosis and treatment, combined with limitations to personalised care and a workforce in crisis, are placing additional strain on Accident & Emergency departments and lead to avoidable hospital admissions. This comes at a cost, not only to the NHS, but also to the financial security, physical health, emotional wellbeing and quality of life of people with IBD.

While undoubtedly best practices are being followed, and many IBD services are delivering high-quality care, **significant work is still required to ensure IBD Standards are consistently met by all UK IBD services** and that these actions are reflected in the experiences of service users. Recommendations outlined in this report therefore build on those proposed in 2021 and reinforce the call for greater recognition of the healthcare needs of the over 500,000 people with IBD estimated to be living across the UK.

This round of IBD benchmarking also revealed common themes. These themes need to be considered alongside the recommendations, to ensure the delivery of consistent, high-quality and personalised care for people with IBD:

Theme 1: Quick access reduces risk of deterioration

- Long waiting times for referral, diagnosis and treatment for people with IBD must be addressed, providing dividends for all by enhancing peoples' wellbeing, improving clinical outcomes and minimising unnecessary costs.

Theme 2: Clear communication is crucial

- Communication between IBD services and people with IBD, as well as within IBD services and between primary and secondary care, remains a crucial area for improvement.

Theme 3: Care should be personalised, proactive and centred around wellbeing

- People with IBD identified wellbeing support as a crucial area for improvement. Once an endorsed template for a personalised care plan has been developed, everyone with IBD should receive a plan, giving them the opportunity to ensure care delivery is tailored to their unique needs.
- Everyone with IBD should feel part of the decision-making process regarding their care and should be given the resources to understand their condition.
- IBD has ramifications beyond the gut. Key symptoms, such as pain, fatigue and poor mental health, must be recognised, managed and treated.

Theme 4: Discrepancies between service provision and peoples' experience require further exploration

- Throughout this report, IBD services and people living with IBD report different experiences when it comes to care provision. In many circumstances this signals different expectations in terms of care delivery. However, in other situations the cause of this discrepancy is unclear and requires further exploration.

As we look to the future, results from this second round of IBD benchmarking underscore the urgent need for increased resources for IBD services across the UK, to bridge the gap between current practice and the IBD Standards. **The time to act is now. The UK and devolved Governments, health leaders and policymakers must prioritise working closely with clinicians, IBD charities, and people living with IBD to address the considerable challenges across diagnosis and treatment, while ensuring a fully resourced workforce is in place to deliver personalised care that is available to everyone living with IBD across the UK.**