The State of IBD Care in the UK

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IBD UK board members and key contributors

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Writing and graphic design support
Costello Medical

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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.**

Background

Inflammatory Bowel Disease (IBD)

IBD is a painful, debilitating and lifelong condition, with periods of relapse (called "flares") and remission. The cause is not fully understood, but is thought to be a mix of genetic susceptibility, abnormal gut microbiome, environmental factors and a dysregulated immune response. The two main forms of IBD are Crohn's disease and ulcerative colitis. Over 500,000 people in the United Kingdom (UK) have IBD. That's at least one in every 123 people.[1]

Crohn's disease causes inflammation in the gut, anywhere from the mouth to the anus, but is most common in the small bowel and colon (the large bowel). The inflammation can affect every layer of the bowel wall. Ulcerative colitis causes inflammation and ulceration of the inner lining of the rectum and colon. Symptoms of IBD can include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue and weight loss, with associated anxiety and depression. These conditions can lead to time off school and work, withdrawal from social relationships and an inability to carry out everyday activities, such as shopping and exercise. However, IBD does not just affect the gut. It can affect almost every part of the body and every aspect of life: from digestion, eyes and joints to energy levels and mental health.

With many of these symptoms invisible, it can appear that someone looks healthy when they are in fact incredibly unwell. This creates stigma and misunderstanding around IBD, leaving many to suffer in silence. You can develop IBD at any age, but most people are diagnosed between the ages of 15 and 30, meaning it has a significant impact on their working life. In a pan-European survey, over 40% of people with IBD reported being unable to work for 10 or more days in the previous year due to their IBD. In addition, 43% had to make an adjustment to their working life (e.g. home working or flexible hours) because of their condition.[4] As the UK population ages, the number of older people with IBD and a range of co-morbidities is set to increase.[5]

There is currently no cure for IBD. Treatment aims to induce and maintain remission, manage and reduce the number of flares, prevent complications and enhance quality of life.[6] People living with IBD may face a lifetime of medication and, in many cases, major surgery. Twenty one percent of people with Crohn's disease will have resection surgery within five years of diagnosis and 26% within 10 years.[7] For those with ulcerative colitis, 10–15% are likely to require surgery after 5–10 years.[8] People with extensive or severe disease are at risk of potentially life-threatening complications, such as a

complete blockage or perforation of the bowel, if surgery is not performed in a timely fashion.

If left untreated, complications from IBD can be life-threatening. Medical treatment includes steroids, traditional immunosuppressants, novel small molecules, biologic medicines and surgery to remove damaged bowel.[9] Lifetime costs for IBD are comparable to a number of major diseases, including heart disease and cancer.[10]

Setting the Standard for IBD Care

The first UK nationwide audit of IBD services in 2006 identified large variation in standards of care and highlighted the need for authoritative published standards defining what a good IBD service should look like.[11] In 2009, the Standards for the Healthcare of People who have Inflammatory Bowel Disease were published by the IBD Standards Group. These were updated in 2013 and underpin the National Institute for Health and Care Excellence (NICE) quality standards for IBD, published in 2015[12] and Scotland Leading the Way – the National Blueprint for Inflammatory Bowel Disease, published in 2016.[13] The IBD Quality Improvement Programme, which was led by the Royal College of Physicians,[14] and concerted programmes of work across the four nations, have previously maintained a focus on IBD service improvement.

IBD UK

The aim of enhancing care for people with IBD was further advanced by the formation of IBD UK in 2017. IBD UK is a partnership of 16 professional bodies, Royal Colleges and patient organisations encompassing all major stakeholders in UK IBD care delivery. IBD UK's aim is for everyone with IBD to receive safe, consistent, high-quality and personalised care, whatever their age and wherever they live in the UK.

IBD UK worked with over 150 healthcare professionals and 700 people living with IBD to develop the 2019 IBD Standards, which set out what high-quality, personalised care should look like for a person with IBD at every point of their journey, from first symptoms to treatment and ongoing care, and how IBD services need to be organised to deliver this.[15] These standards were developed in alignment with the British Society of Gastroenterology consensus guidelines on the management of IBD in adults[16] and Association of Coloproctology of Great Britain and Ireland consensus guidelines in surgery for IBD.[17] Please note that the 2019 IBD Standards are now being updated, to reflect the evolving nature of clinical practice; where IBD Standards no longer reflect current best practice, this has been highlighted in this report.

IBD Benchmarking

IBD UK has since developed the IBD Benchmarking Tool, which is designed to assess how well services are performing against the IBD Standards, highlighting excellent care and helping services to plan improvements. This unique initiative includes a **Service Self-Assessment**, completed by individual IBD services, and the **IBD Patient Survey**, completed by people with IBD. The data help IBD UK to understand the different perceptions of care between those providing and those receiving it.

The first round of IBD benchmarking took place between July 2019 and January 2020. Local reports showing how individual services were performing against the IBD Standards were released in March 2020. A full report was subsequently released in April 2021, highlighting four areas for change:

1. Improvements in diagnosis and information provision
2. Personalised care and support for self-management
3. Faster access to specialist advice and treatment
4. Effective multidisciplinary team (MDT) working

This report brings together new results from the second round of IBD benchmarking, combining comprehensive feedback from both people with IBD and IBD services in England, Wales, Scotland and Northern Ireland, to discover how IBD services are performing following the COVID-19 pandemic, both relative to the 2019/20 benchmarking and the IBD Standards.[2] Local reports showing how individual services are performing against the IBD Standards were published in April 2024 and are available from IBD UK.

With 150 adult (126) and paediatric (24) IBD services (64% of all UK services) and 17,654 people with IBD, parents and carers taking part, we have the evidence to comprehensively assess the state of care following the COVID-19 pandemic and a vital opportunity to make recommendations to improve care for everyone with IBD.

REPORT STRUCTURE

This report is structured into several sections. It begins with an overview, presenting key findings from the IBD Patient Survey. Following this, there are four core results chapters that outline various aspects of IBD service performance: 1) Diagnosis; 2) Treatment; 3) Personalised Care; 4) Workforce. Each chapter examines specific metrics related to these critical areas of IBD care. The report ends with a short conclusion, tying together the findings from the results chapters.

Details of the methods and respondents involved in both the IBD Patient Survey and Service Self-Assessment are available in Appendix A.

1 Overview

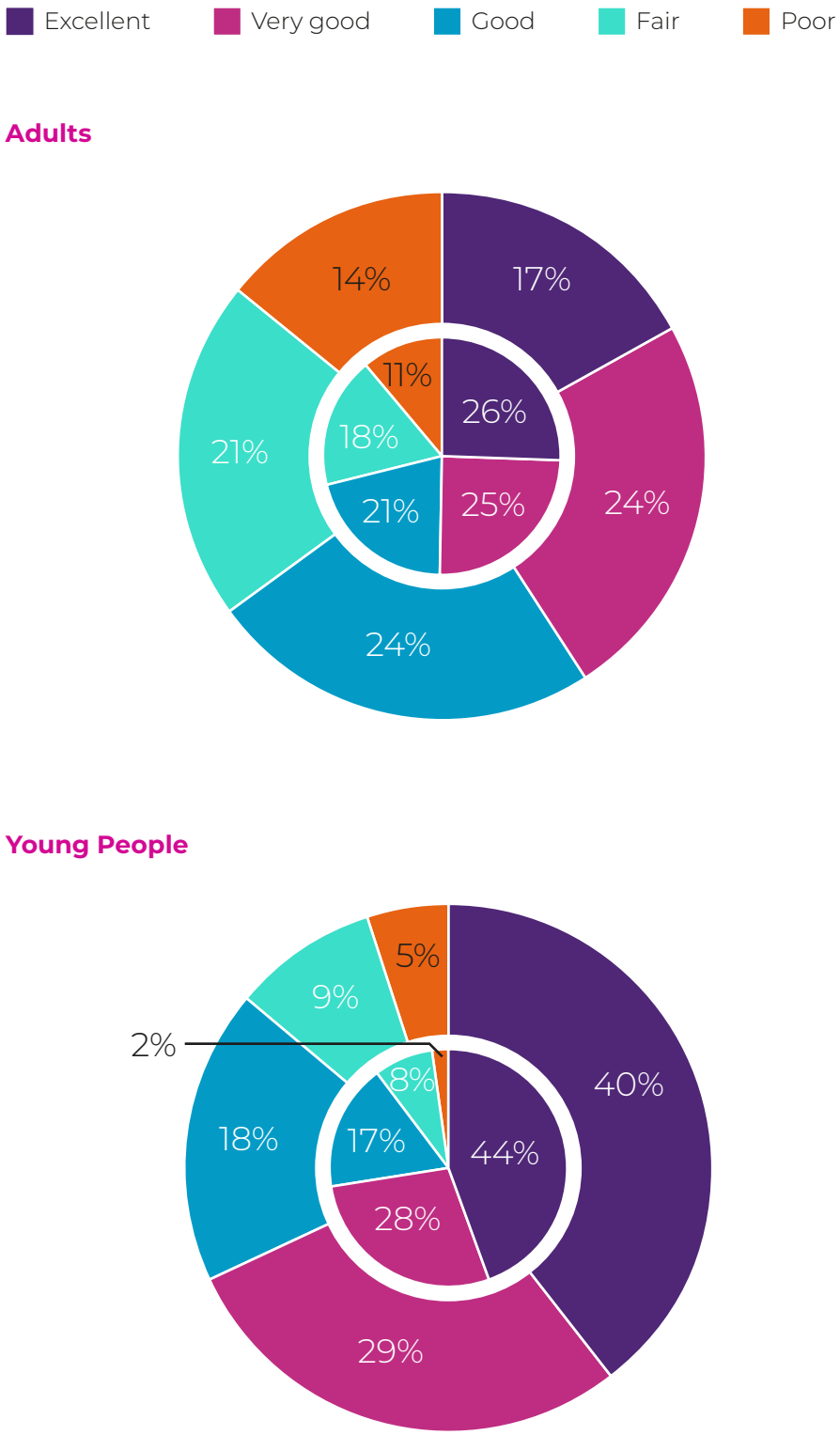
The IBD UK 2021 report shone a spotlight on the hidden impact of IBD in the UK and highlighted key areas for change.[3] Since this report was published, the UK has continued to face significant healthcare challenges, placing strain on IBD services across the country.[18] Now, as UK healthcare services grapple with insufficient funding, staff shortages, increasing demand and a backlog of appointments and procedures, this report outlines data from the largest comprehensive survey of people with IBD across the UK and explores the current state of IBD care.

Quality of Care in 2023

Ensuring high quality care is central to NHS plans across the UK and is a key indication of an effective healthcare service.[19] The IBD Patient Survey asked respondents to rate the overall quality of their care over the past 12 months. Responses indicated a significantly reduced perception of care quality between 2019 and 2023 for adults and young people with IBD across England, Scotland, Wales and Northern Ireland (Figure 1). Mirroring a trend throughout this report, a higher proportion of children and adolescents with IBD rated their care quality more favourably than adults.

However, one in seven children and adolescents (14%) still rated the quality of their care 'fair' or 'poor'. While disappointing, these results highlight the need for healthcare decision makers to refocus on IBD care in the UK and support IBD services to meet the IBD Standards and the expectations of people with IBD.

Figure 1: Quality of care rating for the past 12 months in 2019 (inner) and 2023 (outer) for adults (A) and young people (B) with IBD



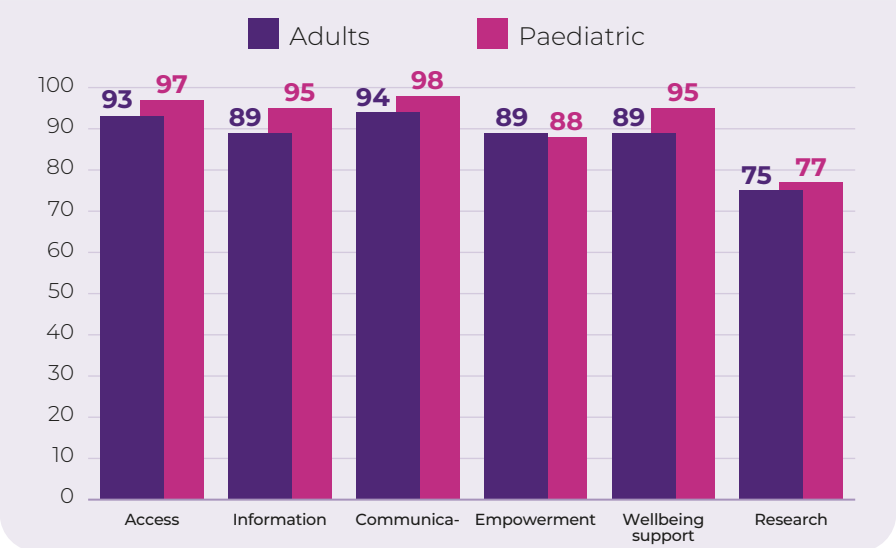
Source: Data from the IBD Patient Survey. **Footnote:** Please note some results do not sum to 100%, due to rounding.

Care Preferences

The practice of evidence-based medicine calls for peoples' values and preferences to be considered and integrated into their care, alongside the best available research and clinical expertise.[20] Between 2019 and 2023, several amendments to the IBD Patient Survey were made, to generate insights into peoples' care preferences. These changes included an assessment of: a) the importance placed on different aspects of IBD care by service users and b) what aspects of IBD care service users believe require improvements. Respondents were asked to provide a rating out of 100, with 100 representing an element of care that is perceived to be highly important.

All aspects of IBD care were rated highly by adults (median range 75–94) and young people (median range 77–98) with IBD (Figure 2). Communication and access were assigned the highest median scores by both groups, emphasising that people with IBD want to be seen quickly, for it to be simple and convenient for them to contact their IBD service and that they value communication that is rapid and easy to understand. Whilst rated as relatively lower in importance, research was also scored highly across both groups. This might reflect a tendency for people with IBD to place greater importance on immediate requirements for their care, due to the direct impact that these considerations have on their quality of life.

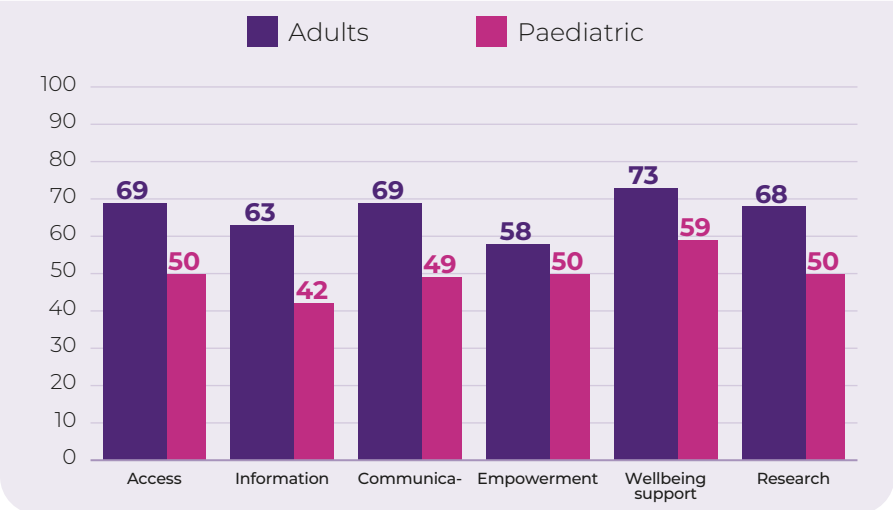
Figure 2: Importance scores assigned to different aspects of IBD care by adults and young people with IBD[a,b]



Footnotes: [a]All aspects of care rated out of 100 on importance and median scores are reported; [b]Definitions provided to respondents for different aspects of care are outlined in Appendix B of this report. **Source:** Data from the IBD Patient Survey.

When asked about aspects of care most in need of significant improvement, adults assigned higher scores across all aspects of their care when compared with children and adolescents (Figure 3). This further supports the idea that UK adults with IBD are generally less satisfied with their care. Wellbeing support, defined as support from the IBD team for a person's overall physical and mental health, was the highest scoring aspect of care across both groups. With the NHS facing a chronic workforce crisis, elements of care that support wellbeing may risk being deprioritised.[21] **These results emphasise that people with IBD across the UK value care that considers their wider wellbeing and wish to see changes that ensure that their wellbeing is being considered as part of their health care.**

Figure 3: Importance scores assigned to different aspects of IBD care, based on their need for significant improvement, by adults and young people with IBD[a,b]



Footnotes: [a]All aspects of care rated out of 100 on importance and median scores are reported; [b]Definitions provided to respondents for different aspects of care are outlined in Appendix B of this report. **Source:** Data from the IBD Patient Survey.

These overview results mirror insights from the survey across the four core results chapters (Diagnosis, Treatment, Personalised Care and Workforce) and provide a snapshot of peoples' experiences of, and preferences for, their care. **They suggest a stagnation in terms of perceived care quality since the 2019 benchmarking exercise and highlight an urgent need for health leaders, policy makers and commissioners to prioritise supporting IBD services to meet IBD Standards.** By supporting IBD services to deliver high-quality care, we can ensure better health outcomes and quality of life for people with IBD, while reducing healthcare costs and productivity losses, benefiting society as a whole.

2 Diagnosis

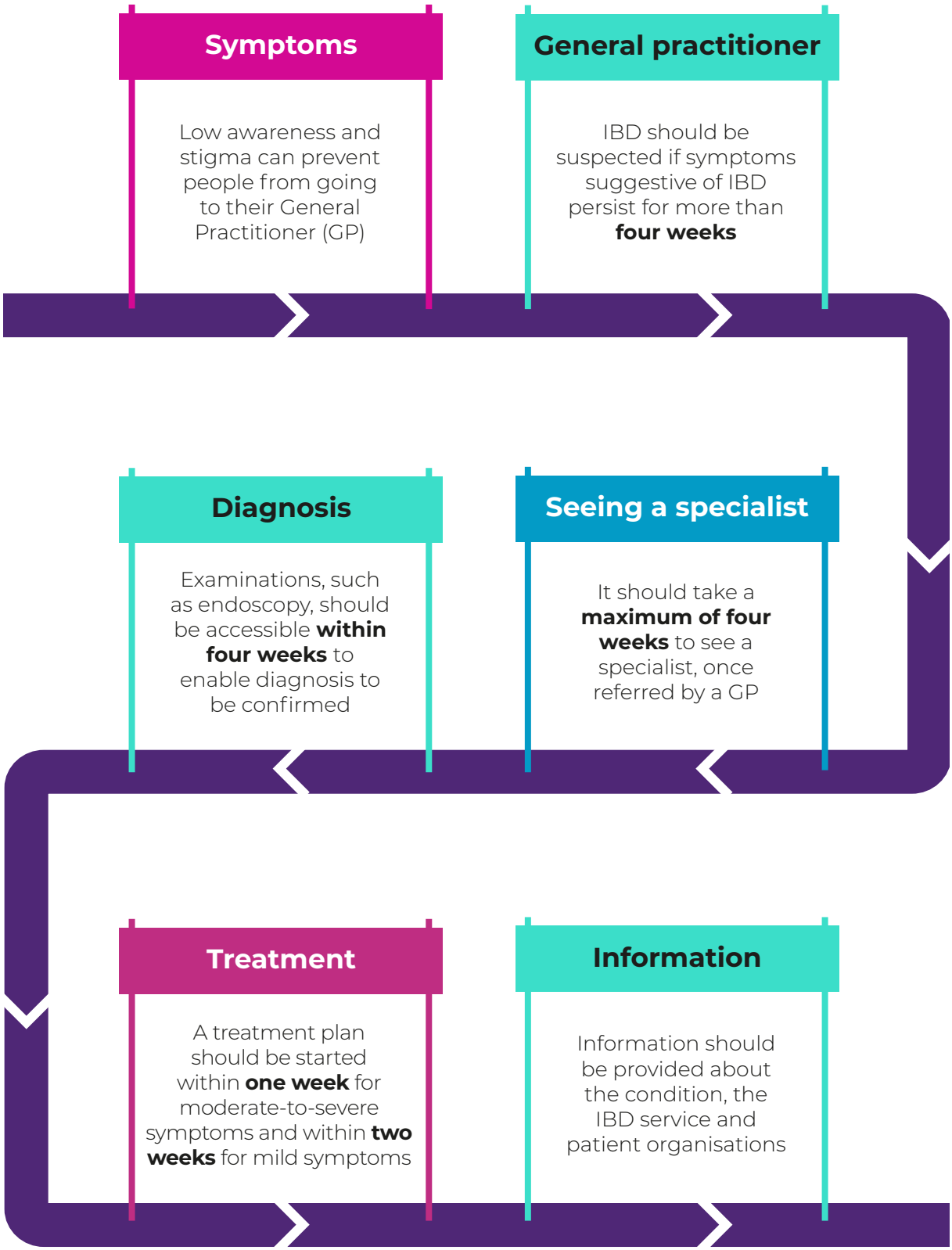
The Diagnostic Journey for IBD

The journey for people with IBD starts with symptoms. These symptoms may be mild initially, and either evolve to be intermittent, stay the same or gradually get worse. For others, acute symptoms may arise suddenly, leaving the individual struggling to cope and in severe pain.[22] While those with more severe symptoms are likely to seek help quickly, and may end-up attending Accident & Emergency (A&E), those with milder symptoms may not seek help, due to a low awareness of IBD symptoms and overlap of these with more benign conditions, like food poisoning, irritable bowel syndrome (IBS) and stress.[22,23] Stigma associated with IBD symptoms may also prevent people from visiting their primary care or community practitioners.[23]

Once contact has been established, a primary care or community practitioner should assess the individual and may perform faecal biomarker tests if they present with symptoms like abdominal pain, diarrhoea, blood in their stool, weight loss or extraintestinal manifestations. Referral should take place if symptoms are indicative of IBD and persist for more than four weeks, while those presenting with acute severe colitis should be admitted to a centre with medical and surgical expertise in managing IBD.[2] For those with milder symptoms, it should take a maximum of four weeks to see a specialist once referred by a primary care or community practitioner, with examinations occurring within four weeks, or more rapidly if clinically necessary, to enable a diagnosis to be confirmed.

The 2019 IBD Standards recommend that a treatment plan should be started for all outpatients with IBD within 48 hours for moderate-to-severe symptoms and within two weeks for mild symptoms.[2] However, the use of immediate start steroids is no longer considered best practice. Instead, biologic therapies are preferred, but require screening tests in order to be initiated. IBD services should therefore aim to initiate newly diagnosed people with IBD who have moderate-to-severe disease onto a treatment plan within one week (Figure 4).

Figure 4: The journey to diagnosis and treatment[a,b]



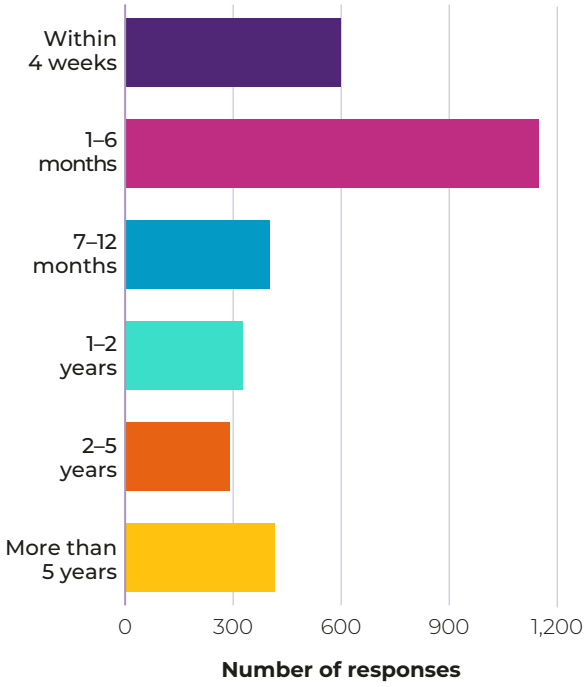
Footnotes: [a]Timeframes taken from the NICE quality standard for IBD and IBD Standards 2019.[2,12] Urgent and emergency referral should take place sooner if symptoms are severe or red flags are indicated; [b]Please note that the recommended time to initiate a treatment plan no longer aligns with the 2019 IBD Standards. **Source:** IBD UK 2021.[3]

The Current Experience of IBD Diagnosis

Engaging with Healthcare

Delayed diagnosis has been associated with disease progression in Crohn's disease and surgery in IBD,[22] while the onset of symptoms can have a profound impact on peoples' social, physical and psychological wellbeing. Despite this, a large number of adults with IBD reported extended periods of time from the onset of symptoms to the point at which they engaged with a healthcare professional (Figure 5).

Figure 5: Self-reported time from onset of symptoms to appointment with a healthcare professional[a]



Footnotes: [a]Healthcare professional defined as a doctor, nurse, pharmacist or dietitian. **Source:** Data from the IBD Patient Survey.

Results highlight that over a third (36%) of adults experiencing symptoms of IBD did not seek help from a healthcare professional for up to 6 months (Figure 5). It is therefore evident that delayed engagement with healthcare professionals following symptom onset is one factor that contributes significantly to overall delays in diagnosis. Public awareness of IBD symptoms needs to be heightened across the UK.[22] Campaigns like the Crohn's & Colitis UK initiative 'Cut the Crap', which raises awareness of IBD symptoms and recorded 250,000 people using its symptom checker (as of Spring 2024), are vital and need to be supported widely by government agencies, healthcare providers, media outlets, industry and advocacy groups.[24]

Referral and Diagnosis

Delays prior to diagnosis also occur in primary care. Roughly one in seven (14%) adults reported that they waited more than a year to be referred to a hospital after speaking with a healthcare professional (Figure 6). In addition, almost a third of adults (32%) responding to the IBD Patient Survey did not receive a stool test for inflammation (i.e. a faecal calprotectin test) prior to hospital referral. There are a multitude of different reasons why adults with IBD might experience delays to referral from primary care. These include appointment waiting times, delays to completing investigative tests, restrictions on which tests primary care or community practitioners can use and the non-specificity, as well as changing nature, of IBD symptoms.

However, only roughly one in three adults (37%) surveyed agreed that their 'GP was knowledgeable about their IBD and is helpful'. While efforts to raise awareness of IBD amongst primary care teams are needed, this likely also reflects the unprecedented pressures currently placed on primary care services across the UK.[25]

It is important that primary care and community teams are enabled to identify IBD by providing them access to faecal calprotectin tests, which have been emphasised as superior for identifying IBD in NICE DG56 guidance.[26] Where possible, IBD services should work with primary care to implement the National Primary Care Diagnostic Pathway for lower gastrointestinal (GI) symptoms, to ensure the identification and prioritisation of those with IBD in urgent need.

NATIONAL PRIMARY CARE DIAGNOSTIC PATHWAY FOR LOWER GI SYMPTOMS

The National Primary Care Diagnostic Pathway for lower GI symptoms was launched in June 2024 to give guidance to primary care healthcare professionals on screening and testing of lower GI symptoms across the UK. The pathway was developed in partnership with the British Society of Gastroenterology, the British Society of Paediatric Gastroenterology, Hepatology and Nutrition, the Association of Coloproctology of Great Britain and Ireland, Coeliac UK, The Crohn's in Childhood Research Association, Crohn's & Colitis UK, Guts UK, and The Irritable Bowel Syndrome Network. Crucially, a range of primary care healthcare professionals (including GPs and nurses) and people with lived experience were involved in the development.

Delayed diagnosis for lower GI conditions has significant impact on the NHS. Before the pathway, there were other diagnostic tools that looked at individual lower GI conditions – though these were often unhelpful for someone presenting with symptoms, rather than a diagnosed condition. There were also difficulties surrounding the need to consult multiple separate documents. It was agreed that the only way to make a real impact going forward was to develop a nationally agreed pathway for the diagnosis of people presenting with lower GI symptoms.

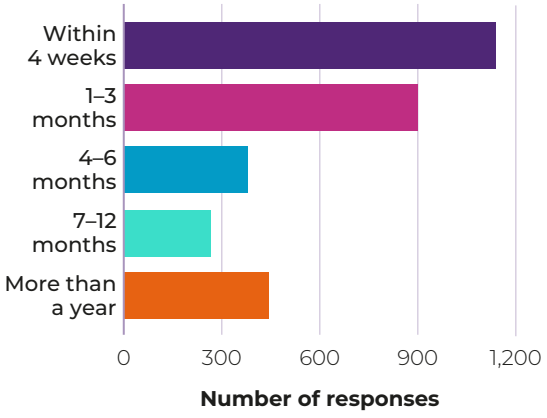
For more information, including paediatric and adult pathways, and endorsements, visit the dedicated website: https://www.whatsupwithmygut.org.uk/healthcare.

If you are interested in learning more or have any questions, please contact the Health Services team at Crohn's & Colitis UK.

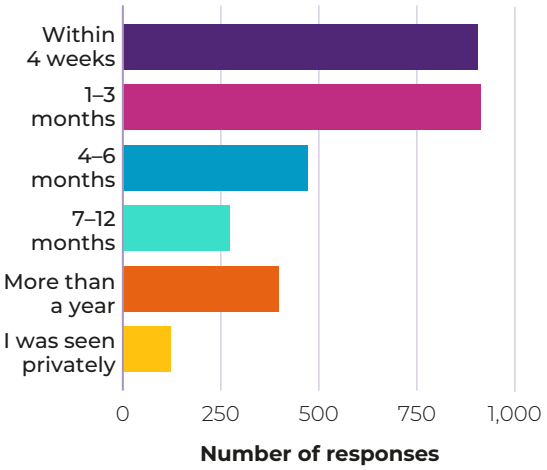
Once a referral has been received, three quarters of IBD services (75%) report adults with suspected IBD waiting for more than four weeks to be seen by a specialist, with one in ten (10%) reporting waiting times between 7–12 months. In terms of diagnosis, 67% of adults reported waiting for more than four weeks between being referred to hospital and a diagnosis being made, with 13% waiting for more than a year and 4% opting to be seen privately (Figure 6). **Therefore, once adults with suspected IBD are referred for specialist assessment, they can still face significant delays prior to diagnosis.**

Figure 6: Time from first speaking to a healthcare professional about symptoms to referral (A) and time from referral to diagnosis (B)

A



B



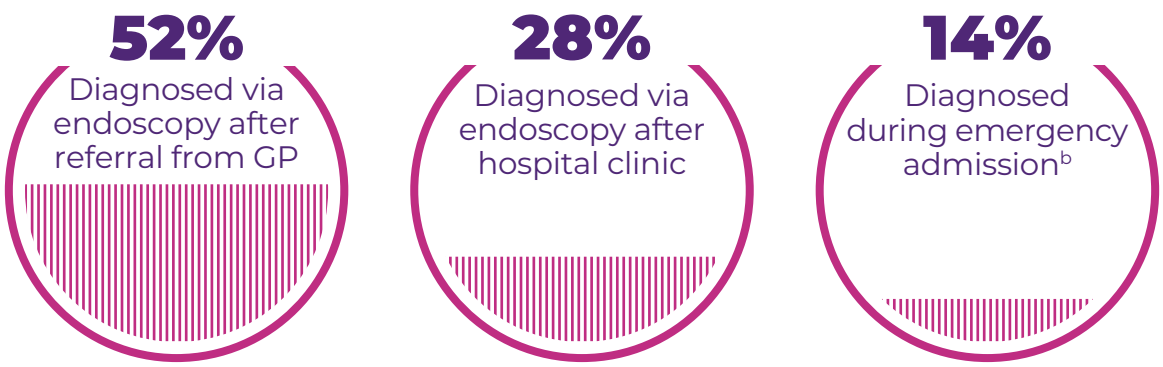
Source: Data from the IBD Patient Survey.

Responses to the IBD Patient Survey indicate that the majority of adults with IBD (80%) were diagnosed via lower GI endoscopies, either after referral from a GP or after a hospital clinic (Figure 7). Seventy percent of services responding to the Service Self-Assessment reported waiting times for outpatient colonoscopy or flexible sigmoidoscopy to be greater than four weeks. Furthermore, 22% of services reported waiting times to receive histology results that were greater than four weeks, highlighting the importance of resource for histopathology as well as endoscopy. **Waiting times for lower GI endoscopies and their results should therefore be considered a key contributor to delays between referral and diagnosis experienced by many adults with IBD across the UK.**

These delays reflect a year-on-year rising demand for diagnostic and therapeutic lower GI endoscopies, inappropriate referrals, workforce vacancies and the prioritisation of cancer-related investigations.[27] The COVID-19 pandemic also led to a substantial reduction in GI endoscopies, creating a significant backlog that further exacerbated these challenges.[28]

One in seven adults with IBD (14%) also reported being diagnosed during an emergency hospital admission (Figure 7). It is crucial that individuals showing symptoms, that could be managed via standard primary and secondary care diagnostic procedures, are not delayed. This delay can lead to disease progression and avoidable emergency admissions that place unnecessary pressure on already overstretched A&E departments.

Figure 7: Self-reported diagnostic process[a]



Footnotes: [a]3.7% diagnosed via radiology and 2.4% diagnosed via an operation; [b]Diagnosed via lower GI endoscopies or radiology. **Source:** Data from the IBD Patient Survey.

PATIENT STORY

Kirsty, diagnosed with Crohn's disease in 2022

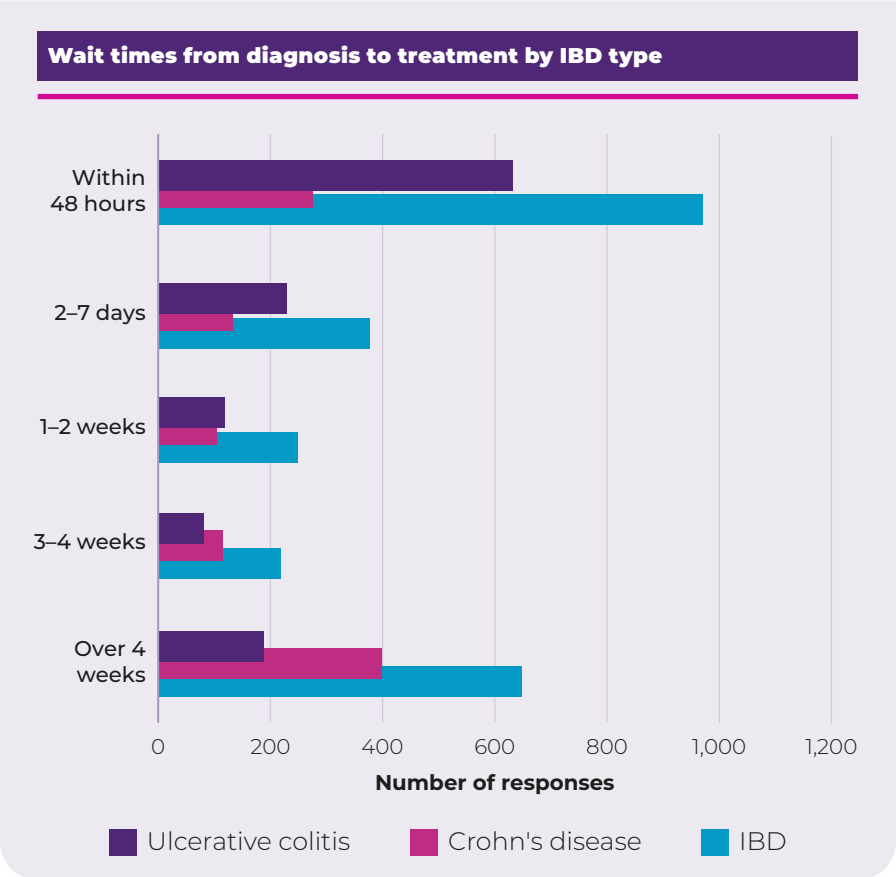
My symptoms started during the pandemic. I had mouth ulcers and consulted my dentist, but I was also experiencing recurring abdominal pain. The dentist referred me to a specialist, but my appointment wasn't until the following year. My GP told me I would need to have more tests when my gums weren't inflamed from the ulcers. I had a second GP phone appointment where I was told it was probably IBS. My symptoms continued, and I experienced urgency to go to the toilet as well as constipation. In 2022, I had a face-to-face appointment with the GP and was again diagnosed with IBS.

It was only when I received results from the biopsy of my gums that I found out I had Crohn's disease. Before I was referred to the IBD team, I ended up in A&E with a kidney infection. I was sent home with antibiotics and liquid morphine. Two days later, I couldn't move because of the pain. I called NHS 111 and went to A&E again. After a computed tomography (CT) scan, I was told I needed to have surgery. Within 24 hours, I was having parts of my intestines removed and a stoma bag fitted. If I had been taken seriously and had my symptoms investigated fully, maybe I could have avoided a life-changing operation.

Treatment

The majority of adults with IBD reported treatment initiation within 48 hours of diagnosis. **However, one in three adults (33%) reported initiating treatment three or more weeks after their diagnosis** (Figure 8). A subgroup analysis of this data shows that those diagnosed with Crohn's disease wait significantly longer to initiate treatment on average than individuals diagnosed with ulcerative colitis, with 39% and 15% waiting over four weeks, respectively.

Figure 8: Time from diagnosis to treatment initiation for people with IBD



Source: Data from the IBD Patient Survey.

While the increasing complexity of treatments for IBD mean that patient safety should determine the timing of treatment initiation, it is important that IBD services reduce clinically unnecessary delays, such as those arising from capacity issues. Results suggest there remains a significant number of adults experiencing long delays to treatment initiation.

This can cause severe impacts to their quality of life and worse longer term outcomes as they await treatment.[22] Therefore, all adult IBD services should initiate newly diagnosed people with IBD onto a treatment plan within one week for moderate-to-severe disease and two-weeks for mild disease, to safely facilitate the beginning of treatment as soon as is clinically feasible.

DIAGNOSIS IN CHILDREN AND ADOLESCENTS

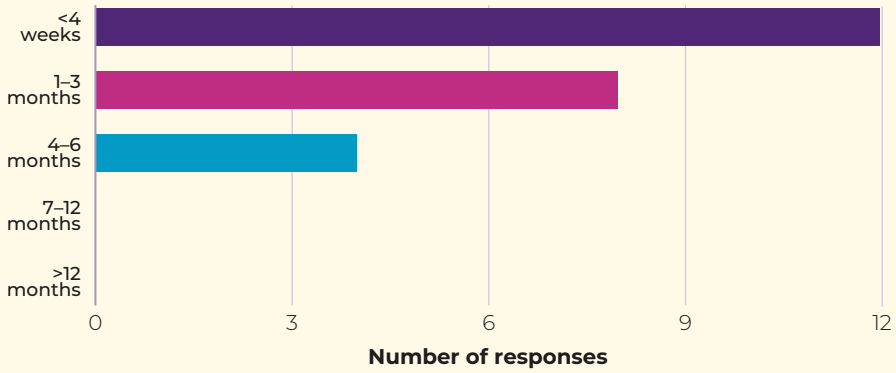
Half of the paediatric services (50%) responding to the Service Self-Assessment estimated seeing children and adolescents with suspected IBD in a paediatric gastroenterology service within four weeks after first presentation to any healthcare professional. The equivalent data for the patient experience was not available from the IBD Patient Survey.

However, only 37% of children and adolescents reported having a lower GI endoscopy within four weeks of seeing a hospital-based doctor, with 6% waiting more than a year. As with the adult population, these data indicate that waiting times for lower GI endoscopies, caused by NHS pressures and exacerbated by the COVID-19 pandemic, are significantly delaying diagnosis in the UK paediatric population.[28]

Sixteen percent of children and adolescents with IBD also reported having to wait three weeks or more to initiate treatment following diagnosis. While this is a smaller proportion compared to adults, it is critical that all children and adolescents with active IBD start treatment in a timeframe that is appropriate for their disease severity, to maximise the clinical benefits of treatment and minimise the impact of untreated, but treatable, disease on quality of life.

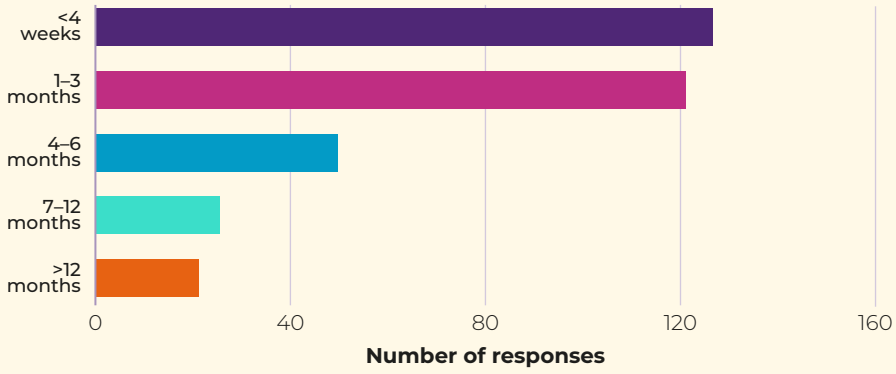
DIAGNOSIS IN CHILDREN AND ADOLESCENTS

"How quickly are patients with suspected IBD usually seen in the paediatric gastroenterology service after first presentation to any healthcare professional?"



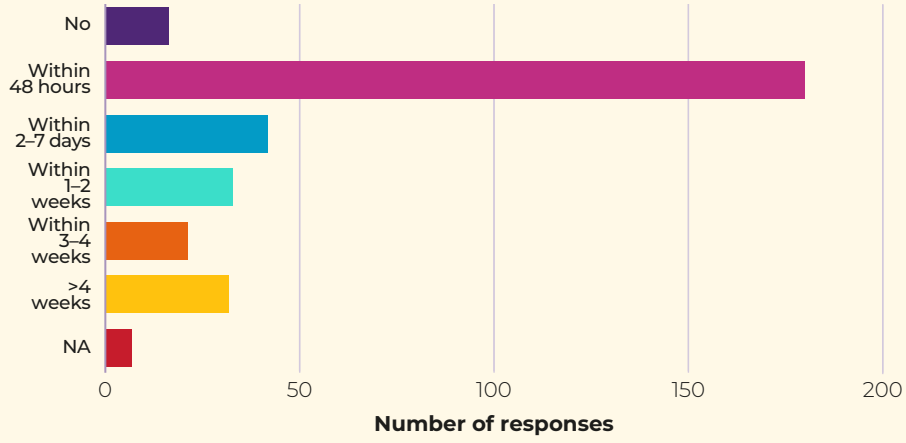
Source: Data from the Service Self-Assessment.

"How long did it take from seeing a hospital-based doctor to the time you have had your first endoscopy?"



Source: Data from the IBD Patient Survey.

"After your endoscopy did you start treatment? Treatment in this situation could have been drug or dietary therapy (e.g. exclusive enteral nutrition). If you did not need any specific treatment, or an operation, please answer "Not applicable"."



Source: Data from the IBD Patient Survey.

RECOMMENDATIONS FOR ACTION

IBD Standards for diagnosis are not being met by a significant number of UK IBD services, particularly for adults. The accumulation of delays in the initial presentation of symptoms to a healthcare professional, followed by significant delays in health service referral times and access to lower GI endoscopies, are anxiety inducing, resource intensive and may impact clinical prognosis. Key recommendations for action therefore include:

- Faecal calprotectin tests should be available across primary care. It is crucial that primary care practitioners are enabled to identify IBD by removing restrictions on their use of faecal calprotectin tests.

- Professional associations, training bodies and patient organisations should continue to raise awareness of IBD amongst primary care practitioners. The implementation of the National Primary Care Diagnostic Pathway for lower GI symptoms across England, Scotland, Wales and Northern Ireland would support primary care professionals to make appropriate, timely referrals for tests.

- Endoscopies play a fundamental role in the diagnosis and management of IBD. Focus needs to be placed on reducing waiting times for lower GI endoscopies, by prioritising this diagnostic procedure when IBD is suspected. A nationally agreed waiting time for lower GI endoscopies must be implemented.

- IBD services across the UK need to consistently initiate people newly diagnosed with IBD onto a treatment plan within one week for moderate-to-severe disease and within two weeks for those with mild symptoms, to minimise the impact of untreated, but treatable, disease on peoples' quality of life and to improve long term clinical outcomes.

- High-profile public health campaigns to raise awareness of the symptoms of Crohn's disease and ulcerative colitis need multi-stakeholder endorsement, support for wide dissemination and investment from governments across all four nations. Examples include the Crohn's & Colitis UK initiative 'Cut the Crap' and the IBD awareness campaign that ran in Scotland.

3 Treatment

Treatment for IBD

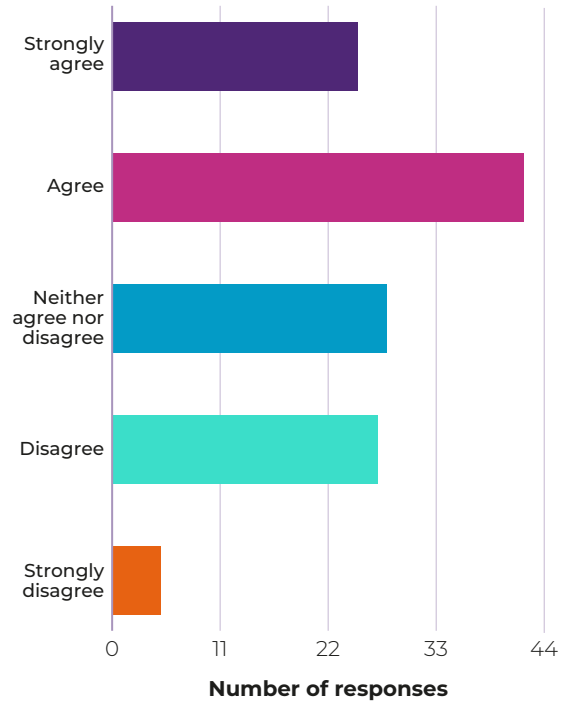
Treatment for IBD depends on the severity of symptoms and how much of the gut is affected.[29] It may involve medication and/or surgical intervention. The primary goals of IBD treatment are to induce and maintain remission, prevent complications and enhance the quality of life of people living with IBD.

When someone is diagnosed with IBD, initial treatments focus on controlling inflammation and inducing remission using effective medications administered as an injection, orally or rectally. The choice of therapy depends on the disease type, disease severity and the person's overall health. After achieving remission, the treatment goal shifts to restoring normal quality of life and preventing a flare.[30] Throughout the treatment process, the IBD Standards emphasise that people should be supplied with adequate information on the risks and benefits associated with medical and surgical interventions, to contribute to shared decision making.[2]

Remission Maintenance

IBD is experienced in a variety of different ways and necessitates a diverse set of clinical and care approaches. IBD services should therefore develop policies to ensure care is safe, standardised and comprehensive. A high proportion of services (89%) responding to the Service Self-Assessment reported that they had a locally agreed policy for immunomodulatory and biological therapy in place. However, approximately half (53%) of IBD services agreed that there was a locally agreed policy for steroid use (Figure 9). This is concerning, as long-term steroid use has been associated with an increased risk of adverse events.[31,32] Therefore, the IBD Standards emphasise that steroid treatment should be managed in accordance with guidelines and audited on an ongoing basis, which requires collaboration between IBD services and Integrated Care Boards/GPs.[2]

Figure 9: Services' agreement that there is a locally agreed policy for steroid use for IBD



Source: Data from the Service Self-Assessment.

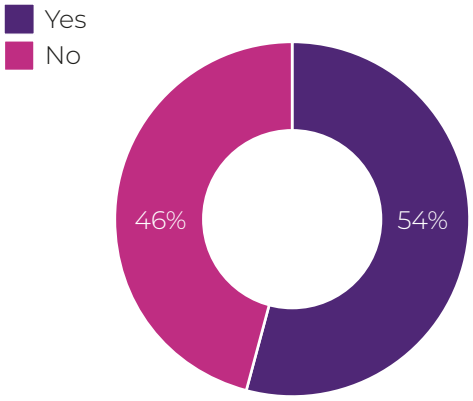
People with IBD in remission should also be reviewed at agreed intervals by an appropriate healthcare professional, to assess disease activity, response to treatment and wellbeing.[2] A little over half of services (54%) reported having locally agreed policies in place for determining how frequently review and monitoring of people living with stable IBD should take place. Similarly, only four in ten services (41%) reported having a process in place to ensure that all relevant information is discussed with individuals and recorded at each review. These results mirror insights from the IBD Patient Survey, with three in ten adults (31%) reporting that they do not have reviews, either in the clinic, online or via the phone, as often as they would like and roughly one in seven (15%) stating that they have never had a review (Figure 10).

Reviews present an opportunity to monitor disease and treatment response, as well as provide education and lifestyle counselling, which can empower people with IBD to manage their condition effectively. However, considering the challenges facing the NHS in terms of rising demand and inadequate staffing, ensuring that reviews are proportionate and do not unnecessarily burden IBD services is critical, so that these services can focus on delivering priority care. **These results indicate a missed opportunity for a proportion of IBD services to both define and optimise their strategies for patient review, through the implementation of agreed policies.** By communicating these policies with their adult service users, IBD services may be able to minimise the numbers who feel that their reviews are not frequent enough.

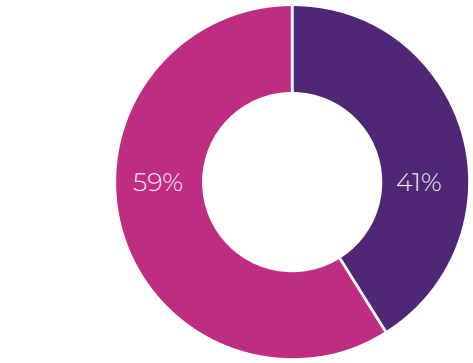
Figure 10: Review provision for adults with IBD

Service Self-Assessment Survey

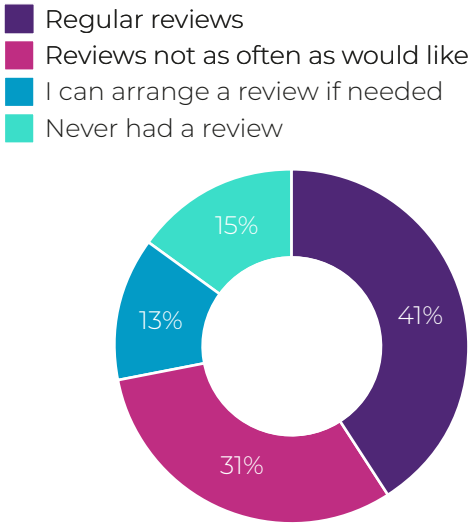
54% reported having policies in place to determine how frequently review and monitoring of people with IBD should take place



41% reported having a policy in place to ensure that all relevant information is discussed and recorded



IBD Patient Survey

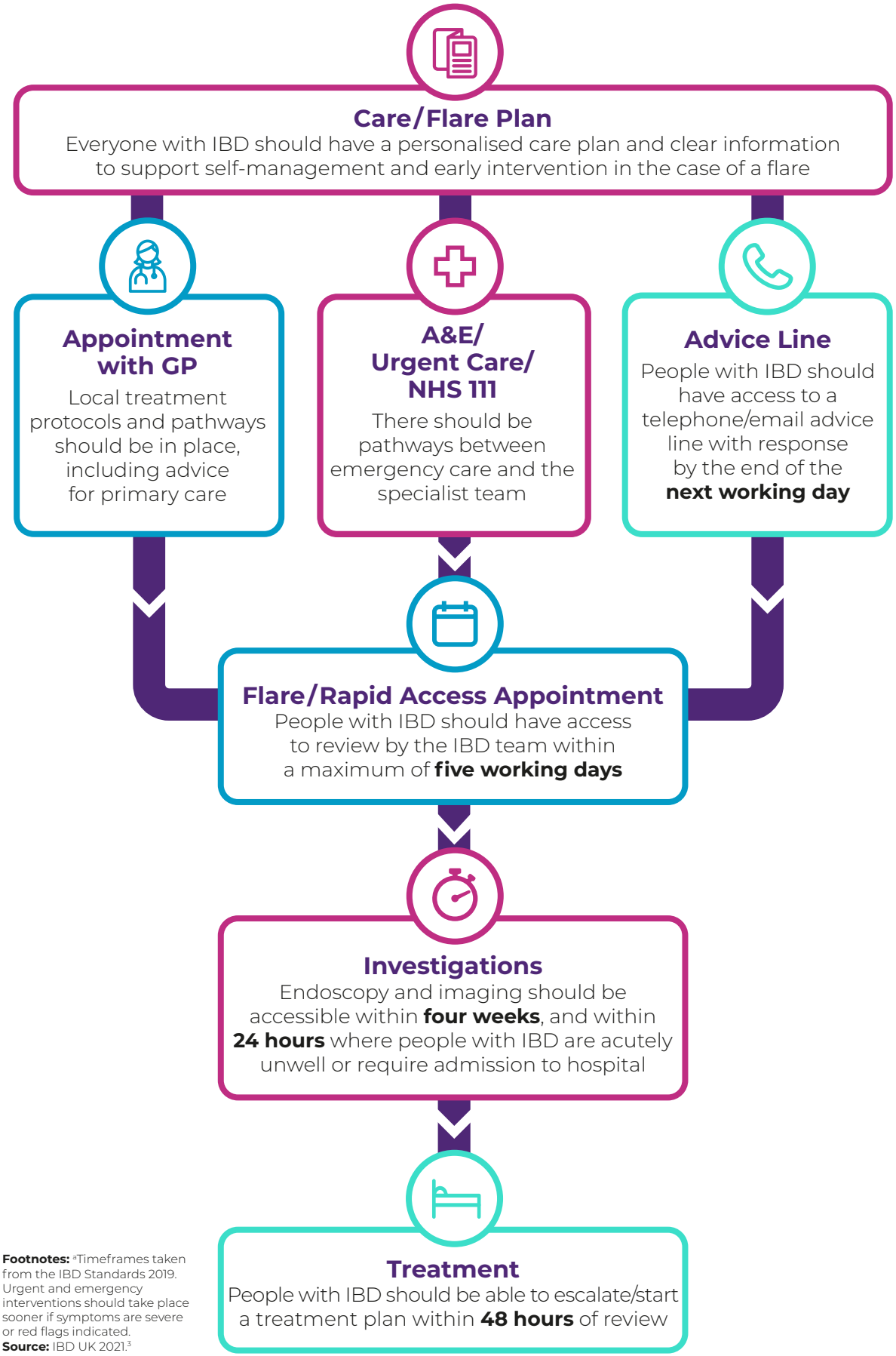


Sources: Data from the Service Self-Assessment and IBD Patient Survey.

Flare Management

Flares occur in the majority of people with IBD. If left untreated, complications can be life threatening, including dehydration, malnutrition, obstructions, intestinal ruptures and deterioration of mental health.[3] Rapid access to specialist advice should be available to people with IBD to guide early flare intervention. This should include access to a telephone or email advice line that provides a response by the end of the next working day. Furthermore, people with IBD should have access to a review by an IBD team within five working days and be able to escalate, or start a treatment plan, within 48 hours of review (Figure 11).[2]

Figure 11: Different routes to access IBD specialists[a]

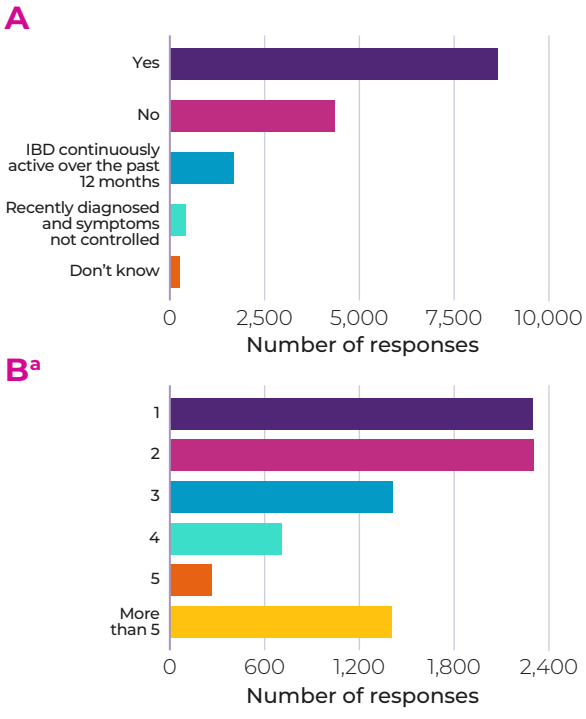


Footnotes: [a]Timeframes taken from the IBD Standards 2019. Urgent and emergency interventions should take place sooner if symptoms are severe or red flags indicated.
Source: IBD UK 2021.[3]

Prevalence of Flares

Amongst adults with IBD responding to the IBD Patient Survey, **over half (56%) reported experiencing one or more flares in the past 12 months.** Of these individuals, 45% reported experiencing three or more flares. **Concerningly, roughly one in six adults (17%) reported experiencing more than five flares in the previous 12 months** (Figure 12). While flares can occur for a variety of different reasons, for some this high volume in a single year might reflect poor care optimisation and/or adherence to treatment. This can be highly detrimental to the person's quality of life, as flares may reduce their ability to complete daily activities, such as attending school, college or work.

Figure 12: Self-reported flares (A) overall frequency of adults with IBD experiencing one or more flares in the past 12 months and (B) the number of flares they have experienced



Footnotes: [a]Data from a sub-population of respondents who all confirmed experiencing at least one flare in the past 12 months.
Source: Data from the IBD Patient Survey.

Access to Specialist Advice

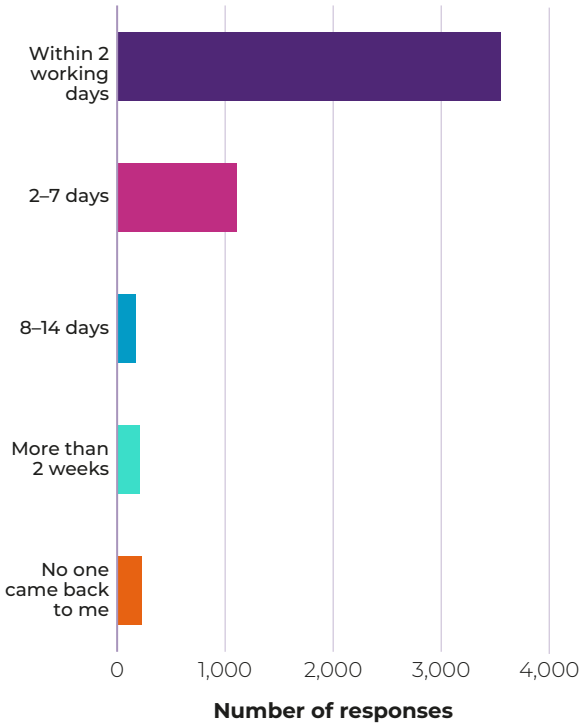
Having access to specialist advice during a flare is essential, to ensure that people with IBD receive effective and timely care. Ninety-nine percent of services reported that an agreed process was in place for adults with IBD to contact the IBD team using telephone and/or email during a flare. In addition, 96% agreed that this advice line was available five days per week, while 74% agreed that adults with IBD received a response by the end of the next working day, in line with IBD Standards.[2]

26%

This highlights that a little over one quarter of UK IBD services still do not have provisions in place to ensure advice is highly accessible for adults experiencing a suspected flare.

The majority of adults with IBD also reported receiving a response from their IBD advice line within two working days, aligning with the data provided by IBD services (Figure 13). However, roughly one in three adults (32%) reported waiting two or more working days to receive a response and one in nine (11%) reported waiting over a week. These delays inhibit opportunities to support self-management, reduce anxieties and promote quality of life during the critical early stages of a flare. Furthermore, delays in flare management can lead to more severe clinical signs and an increased likelihood of major interventions, such as emergency surgery. Therefore, while the majority of UK IBD services report offering a highly accessible service for IBD flares, support is needed for those IBD services who are delayed in responding to adults experiencing a suspected flare.

Figure 13: Waiting times to receive a response from the IBD advice line



Source: Data from the IBD Patient Survey.

Flare Management

Eighty-five percent of services agreed that a process is in place for discussion and communication of a management plan for optimisation of IBD care, following a flare, within five working days. This suggests that the majority of IBD MDTs across the UK are able to respond, review and develop a care plan rapidly for adults experiencing a flare.

However, implementation of this care plan can be delayed for a variety of factors. Less than one third (28%) of adults with IBD, who required an investigative test for a flare in the past 12 months, reported this test taking place within 4 weeks. Eighteen percent reported waiting 1–3 months and 2% of adults reported waiting over a year. While a range of different investigative tests might be required in the event of a flare (e.g. faecal calprotectin, stool culture, blood test, lower GI endoscopies and/or radiological tests) it is possible that issues with access to lower GI endoscopies, which are currently affecting IBD diagnosis, may also be impacting flare management.[25]

In addition, only a quarter of adults with IBD reported that their treatment escalation, or initiation of a treatment plan, following a flare occurred within 48 hours of review, in line with IBD Standards.[2] Instead, 21% reported treatment escalation or initiation taking 2–7 days, 6% reported 8–14 days, 11% reported more than two weeks and 6% reported that nobody responded to them. The causes of delays to treatment initiation or escalation require further investigation. Therefore, while results indicate that most UK MDTs are developing rapid management plans, implementation of investigative tests and treatment is still delayed for a high proportion of adults with IBD experiencing a flare.

Hospitalisation

People with IBD may require hospitalisation if their IBD symptoms are severe, or for an emergency or planned operation.

22%

Of those adults responding to the IBD Patient Survey, roughly one in five reported spending time in an NHS hospital because of their IBD in the past two years.

Of these individuals, nearly half were admitted to hospital more than once. The reason for hospitalisation was predominantly an emergency inpatient stay without surgery (Table 1).

Unnecessary admissions could be reduced through earlier diagnosis, timely and proportionate reviews and effective flare management procedures. This improves clinical outcomes and quality of life for people with IBD, as well as reducing unnecessary costs to the NHS.

Table 1: Reasons for hospitalisation in the past two years

Reason for most recent hospitalisation	Percentage of adults with IBD (%)
A planned operation	**14**
An emergency operation	**12**
A planned inpatient stay (no surgery)	**5**
An emergency inpatient stay (no surgery)	**70**

Source: Data from the IBD Patient Survey.

Infrastructure

Infrastructure is also an important consideration for IBD inpatient care. As IBD symptoms can include more frequent and urgent diarrhoea, IBD Standards state that if ensuite bathrooms are not available on wards, three beds per toilet are recommended to ensure individuals can access a bathroom when needed.[2] However, 16% of adults with IBD reported they did not have an easily accessible toilet during their hospital stay. IBD services also reported four beds per toilet on average. This may be a reflection of the current shortage of hospital beds and out-dated infrastructure across the NHS. Nevertheless, a lack of convenient access to a toilet for someone with IBD may severely increase anxiety. Healthcare decision makers should therefore ensure that every person with IBD has easy access to a toilet during their inpatient stay.

Access to Specialist Care

Due to the complexity of treating IBD, certain requirements are outlined in the IBD Standards for inpatient care. These include that people with IBD be transferred to a designated specialist ward within 24–48 hours of hospital admission and that they have access to an IBD nurse specialist.[2] However, a significant number of adults with IBD (42%) reported that they did not stay on a specialist IBD ward. An additional 20% reported that they were moved to a specialist ward after more than 24 hours on

another ward, potentially limiting their access to specialist care.

While the 2019 IBD Standards state that all IBD inpatients should have access to an IBD nurse specialist, in reality not all those admitted to hospital will need to see an IBD nurse during their admission.[2] Nevertheless, IBD nurse specialists can play a vital role in the education, coordination and support of ward teams and are central to the delivery of effective IBD care more broadly. Campaigns such as 'More IBD Nurses, Better Care' have been instrumental in increasing the workforce.[33] Efforts are also underway to address challenges with the IBD nurse specialist role, including undefined career progression pathways and stress caused by the 'unseen workload' of advice lines.[33] The recent publication of a framework for professional practice for IBD nurses by the Royal College of Nursing is a positive development in this area.

Surgery

When IBD symptoms are severe or complications arise, surgery may be required; people living with IBD may also elect to have surgery if they do not want to escalate their medical therapy. Emergency and elective surgeries can range from procedures to fix GI perforations, draining abscesses or bowel resection with or without formation of a stoma. The decision to form a stoma depends on the presenting issue and the individual's condition at the time of surgery.

The IBD Standards emphasise that those being considered for surgery should be provided with information in a format and language that they can easily understand, to support shared decision making and ensure informed consent has been acquired.[2] The majority (81%) of adults undergoing surgery reported that they were given sufficient information to help them understand their surgery and the benefits and risks of the procedure. This aligns with a high proportion (91%) of IBD services reporting that they give or direct adults with IBD to information leaflets, decision aids or other media to support decision making.

However, the IBD Standards also emphasise that those being considered for surgery should be offered psychological support.[2] Other opportunities, such as speaking to someone who has undergone a similar operation, can also be invaluable to aid peoples' decision making. While the majority of adults with IBD undergoing surgery reported being given sufficient information, it was much rarer for individuals to be given these other learning and support opportunities before their surgery (Table 2). Opportunities to speak to peers, counsellors and psychologists are critical for enhancing wellbeing and should therefore be viewed as a core part of peri-surgical care by IBD services.

Table 2: Opportunities offered to people with IBD before their operation

Opportunity	Percentage of adults given this opportunity (%)
Speak to someone who had the same or similar operation	5
Speak to a counsellor or psychologist	3
Understand results from the surgeon's previous operations and be able to choose another surgeon should you wish to	14
Consider the option of laparoscopic (keyhole) surgery[a]	32

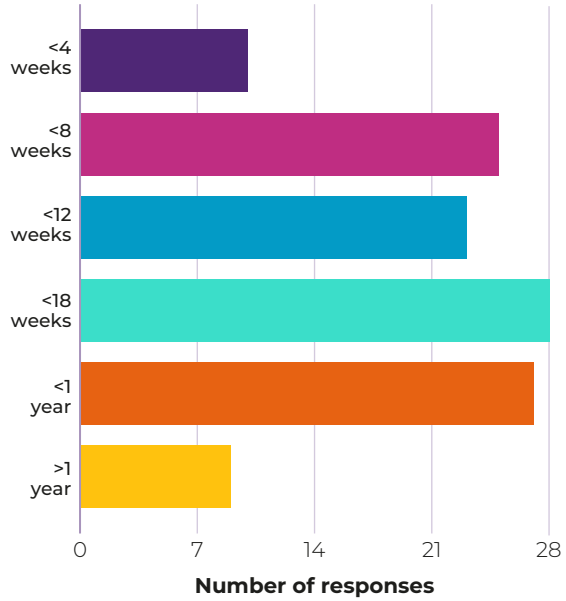
Footnotes: [a]This statement was chosen by participants of the IBD Patient Survey and does not reflect their suitability for laparoscopic surgery based on their physician's expert opinion. **Source:** Data from the IBD Patient Survey.

Waiting significant amounts of time for elective surgeries can increase the risk of complications. 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.[2]

However, adults with IBD reported waiting a median of four (interquartile range: 2–8) months for their operation to take place, with roughly one in three adults (36%) not agreeing that their operation was completed in an appropriate timescale. Similarly, more than a quarter of adult IBD services (30%) reported that waiting times were ≥18 weeks for IBD surgery (Figure 14).

Prolonged delays for IBD surgery may lead to worsening symptoms, increased risk of complications (including changes to the bowel that increase the risk of cancer and that make future surgeries more dangerous) and decreased quality of life.

Figure 14: Waiting times for elective IBD surgery after adults with IBD have been optimised



Source: Data from the Service Self-Assessment.

The IBD Standards highlight that people with IBD should have access to coordinated surgical and medical expertise.[2] One way this can be achieved is through 'joint clinics' with a colorectal surgeon and IBD gastroenterologist. Research suggests that joint clinics are preferred by people with IBD, as they reduce anxiety, provide consistent messaging and minimise trips to hospital.[34] However, only 27% of IBD services reported that regular joint clinics are available, while 52% relied on ad-hoc appointments and 21% reported no provision for joint clinics.

Finally, appropriate staffing before, during and after a surgical procedure is imperative to ensure that people with IBD receive the quality of care they require.[2] Nurses in particular play an important role in the pre- and post-surgical period. Encouragingly, data from the Service Self-Assessment indicated that 98% of services have a dedicated stoma nurse responsible for counselling before and after people with IBD undergo surgery (Table 3). However, access to an IBD nurse to support individuals undergoing surgery was only reported by 20% of adult IBD services. Furthermore, only 45% of adult IBD services reported having nurse specialist support available for those receiving an ileo-anal pouch (Table 3).

Table 3: Staffing for IBD surgeries

Resource	Percentage of services (%)
IBD nurse available for surgery	**20**
Nurse specialist support for ileo-anal pouch	**45**
Dedicated stoma nurse for pre and post-operative counselling	**98**

Source: Data from the Service Self-Assessment.

PATIENT STORY

Nishil, diagnosed with ulcerative colitis around 20 years ago

I've found my journey with finding the right treatment very difficult. As symptoms are so individual and can literally change from day to day, it's virtually impossible to get help for it all. A lot of the treatments, I find, are there to stop the symptoms, not get to the underlying issue or find the root of the problem. I get that it's difficult, but I don't want to be on 15 tablets a day for the rest of my life. There's also the issue of trying to treat everything else that comes along with colitis, such as the chronic fatigue, low iron, migraines – to name a few! My consultant isn't a specialist in those areas, he knows about gut health, so finds it difficult to prescribe me what I need for the other issues (even though they're caused by my colitis). This means chasing other doctors, who think my IBD consultant should be looking at it more holistically. When this isn't the case, you end up on a cocktail of meds, which have their own side effects! Although I was quite quickly diagnosed, finding the right medication and changing them once my symptoms changed has been an ever-increasing battle.

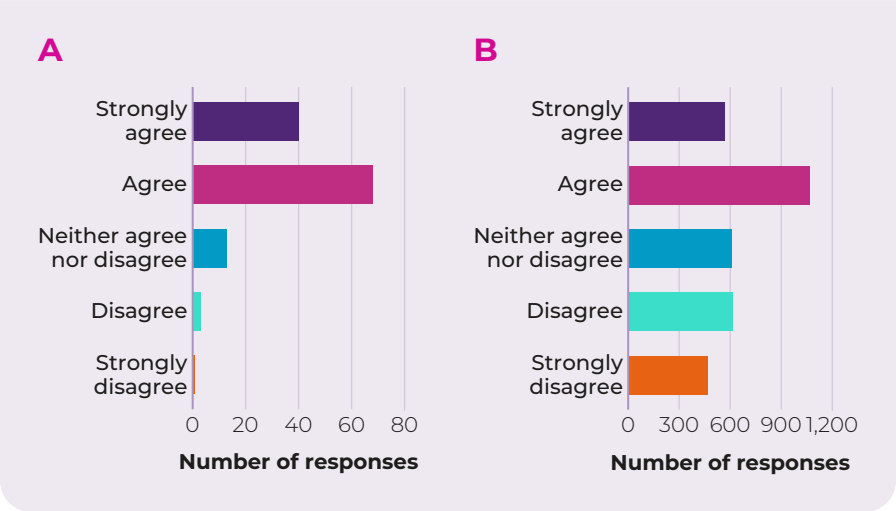
Discharge

Once a person with IBD is ready to be discharged, the IBD Standards emphasise the need for clear written information outlining follow-up care and prescribed medication, as well as coordination of care.[2] Eighty six percent of IBD services across the UK reported that adults with IBD are routinely counselled on discharge medications, including IBD specialist medicines (Figure 15a). However, less than half of adults reported that they were offered clear discharge information (Figure 15b), with 42% reporting that they were not given clear explanations for prescribed medications, including side effects. Furthermore, 31% of adults reported not knowing who to contact if they had concerns following discharge.

These results suggest a discrepancy in the discharge advice IBD services believe they are providing and how well this information is received and understood by adults with IBD.

Further work is required to explore this discrepancy. Nevertheless, if people are confused about their discharge information and who is responsible for elements of their care, this may lead to them experiencing further complications relating to their IBD and potentially needing to have more hospital visits.[35]

Figure 15: Number of IBD services reporting routine counselling on discharge medications (A) and adult respondents reporting that they were given clear information to help manage their care after discharge from hospital (B)



Source: (A) Data from the Service Self-Assessment; (B) Data from the IBD Patient Survey.

IBD RIGHTCARE SCENARIO: HANNAH'S STORY

NHS England RightCare scenarios use fictional patients to show the difference between a suboptimal, but realistic, pathway of care compared to an optimal one. RightCare, in partnership with Crohn's & Colitis UK, has published a new scenario on IBD that highlights the key elements of optimal care across the patient pathway. For the purposes of this scenario, the fictional patient is Hannah.

Throughout the pathway, key themes of optimal care that are supported by national guidance and standards are highlighted. In Hannah's story, these are:

- Monitoring the effectiveness of treatment and shared care
- Timely identification and referral
- Importance of personalised care and self-management
- Rapid access to specialist advice and treatment
- Effective multidisciplinary working
- Addressing delays to surgery and driving up quality

These themes highlight where along the care pathway often requires improvement.

As the table below shows, the optimal journey is also cheaper than the suboptimal journey, but the main difference is the quality of care and improved outcomes for Hannah, and the reduced burden on the wider NHS.

Section	Optimal (£)	Suboptimal (£)
Primary care	**31**	**126**
Secondary care	**9,198**	**20,488**
Medicines	**10,267**	**1,386**
Total	**19,496**	**22,000**

To see how Hannah experiences two very different journeys and outcomes in more detail, view her story at NHS England.

TREATMENT DELIVERY IN THE PAEDIATRIC POPULATION

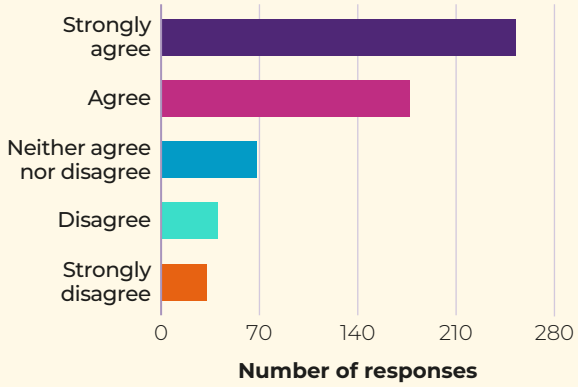
In comparison to adult respondents, data from the paediatric survey suggested a more positive experience regarding the treatment of IBD across key performance metrics. For example, a higher proportion of children and adolescents with IBD agreed that they have access to sufficient support (80% vs. 55% for adults) from very knowledgeable IBD teams and were given enough information to make informed decisions about their care options (75% vs. 58% for adults). A higher proportion also reported receiving regular reviews versus adults (70% vs. 41%) and receiving a response within two working days in the event of a flare (74% vs. 68% for adults).

However, paediatric services still have unmet needs in terms of treatment delivery. For instance, while the majority of children and adolescents with IBD did receive a response within two working days when contacting their IBD service about a flare, 3% waited for more than two weeks and 6% reported nobody responding to them. Similarly, 41% reported waiting for more than four weeks for investigative tests when experiencing a flare and only 27% reported starting treatment within two working days after a flare.

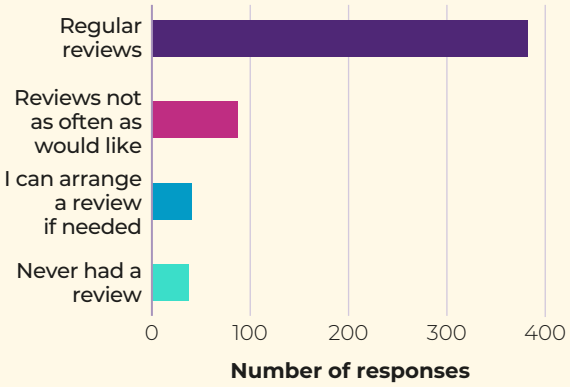
Therefore, while a higher proportion of children and adolescents may be receiving treatment in line with best practice recommendations, potentially due to smaller patient numbers on average, work is still required to understand why certain individuals do not receive this standard and develop strategies to ensure consistent service delivery for all.

TREATMENT DELIVERY IN THE PAEDIATRIC POPULATION

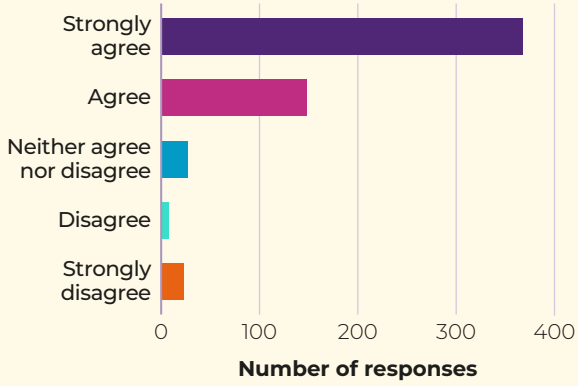
"I am given enough information about treatment and care options to let me make an informed decision. This includes information about possible benefits and side effects."



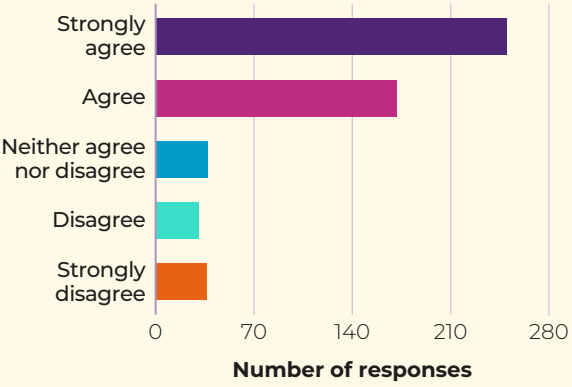
"How often is your IBD reviewed, when your condition is stable? This is about your usual reviews (follow up appointments, in clinic, by phone or online) when you are well, and not about appointments when you have flares."



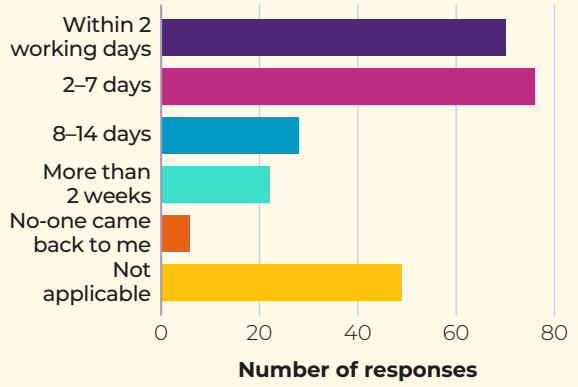
"In my opinion, the specialist team who treat me are knowledgeable about my IBD and how to treat the condition."



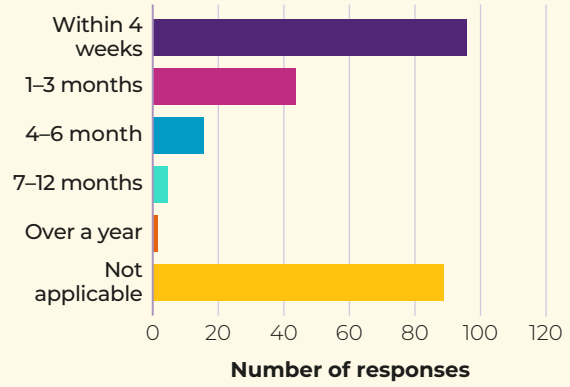
"When I contact the IBD advice line, I get a response within 2 working days."



"How long after [receiving a response about their flare] were you able to start treatment if required?"



"If you had an investigative test in the last 12 months for assessment of your flare, how long did you wait for the test?"



Source: Data from the IBD Patient Survey.

RECOMMENDATIONS FOR ACTION

When IBD services fail to meet key treatment standards, the impact on people with IBD can be significant and detrimental. Data from the 2023 benchmarking exercise indicates that a high proportion of adult and paediatric IBD services are not meeting key IBD Standards across a range of different treatment elements.[2] Many of these areas for improvement were previously identified in the 2021 benchmarking report.[3] Not optimising the delivery of treatment can increase disease activity, lead to more frequent flares, result in emergency or planned surgery and produce higher rates of complications. Moreover, failure to provide best practice care can contribute to emotional distress, reduced quality of life and heightened anxiety for people living with IBD, while also increasing costs to national healthcare services.

Key recommendations for action include:

- Rapid access to specialist advice lines is crucial to ensure people with IBD can receive support to manage their condition effectively and in a timely manner during a flare. All IBD services should be resourced to ensure that people with IBD can receive a response from a telephone or email advice line by the end of the next working day, to guide early flare intervention. In addition, people with IBD should have access to review by the IBD team within a maximum of five working days in the event of a flare and individuals should have their therapy escalated, or be on a treatment plan, within 48 hours of review.

- Current waiting times for elective and semi-elective surgery for IBD must be reduced. Elective operations for IBD need to be performed as soon as a person is clinically optimised for surgery, which must be within 18 weeks from initial referral. Nationally agreed waiting times for planned IBD surgery should be implemented across the UK to meet this goal.

- IBD services should define and optimise their strategies and policies for patient reviews. Services should consider implementing a flexible review system, whereby those judged to be suitable based on their disease stability, understanding of their condition and ability to self-manage can initiate reviews as needed, rather than following a routine schedule.[a]

- All IBD services across the UK should implement a clear process so that people with IBD have access to specialist gastroenterology and colorectal care while they are an inpatient. All inpatients should be reviewed in person by the IBD team.

[a]Implementation of a flexible review system has previously been shown to significantly reduce pressure on waiting lists. For instance, the East Surrey Hospital has utilised the 'Patients Know Best' portal allowing people with IBD to record symptoms and remotely communicate with the IBD team, reducing access to specialist care from 6 weeks to 1 week.[36]

4

Personalised Care

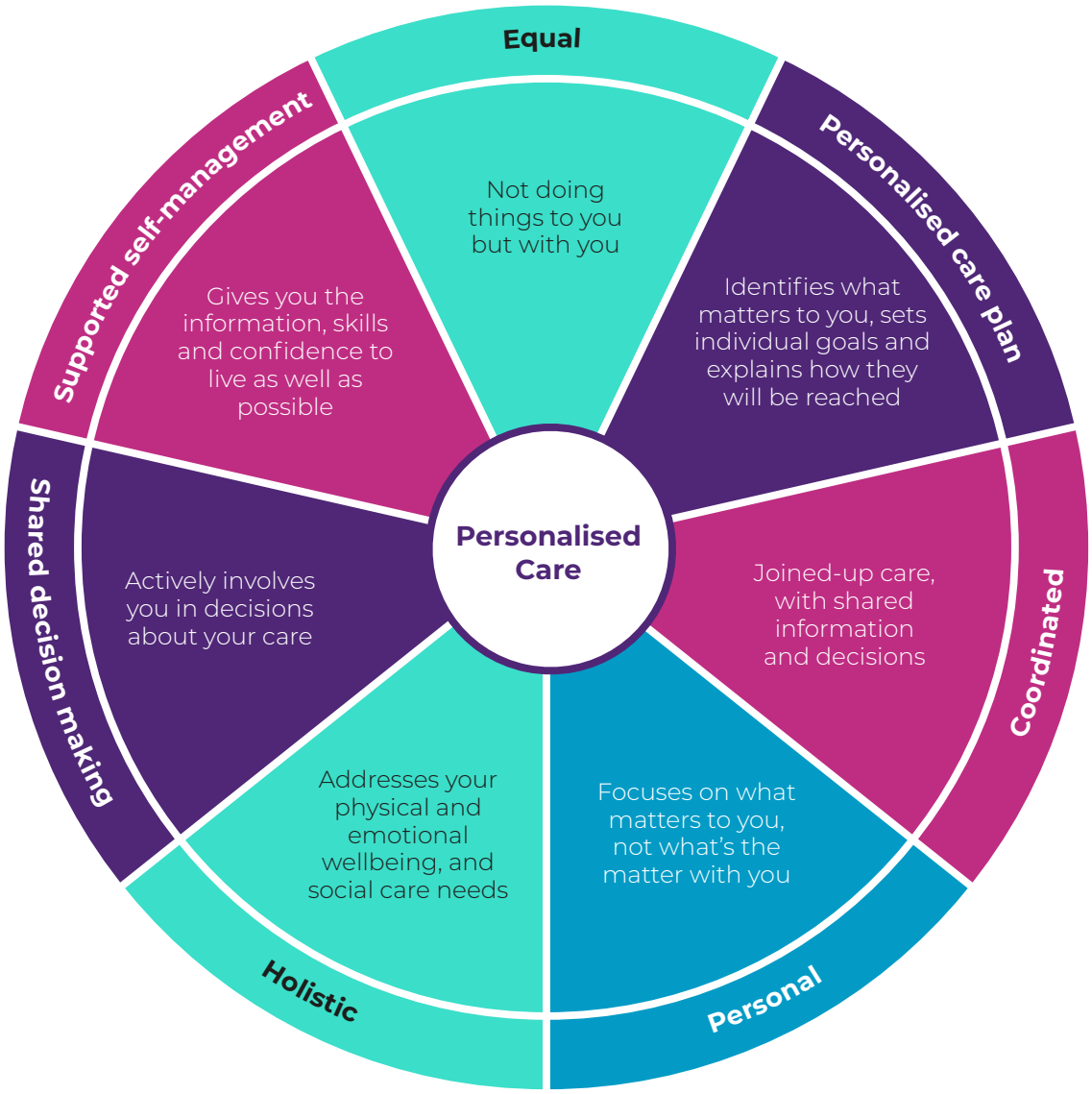
Personalised Care for IBD

Past surveys of healthcare professionals and people living with IBD suggest that the understanding of what personalised care planning means can vary significantly. For people with IBD, personalised care can be thought of as something that arises from the following features of care (Figure 16):[3]

- **Personal:** care that focuses on 'What matters to you?' rather than just 'What's the matter with you?'.
- **Holistic:** care that recognises people are more than just a diagnosis, and instead addresses their physical wellbeing, emotional wellbeing and social care needs together as one.
- **Shared decision making:** an approach that actively involves people in decisions about their care. For example, in decisions about medications or surgical interventions.
- **Self-management:** an approach that empowers people to take an active role in their care, by giving them the information, skills and confidence to self-manage and live as well as possible.
- **Equal:** care that treats people as equal partners in decisions (i.e. not doing things 'to' them but 'with' them).
- **Coordinated:** an approach that delivers integrated services, where information and decisions are shared in a timely manner and include everyone involved in their care.

When delivered well, personalised care has positive effects on peoples' decision making, levels of confidence and their ability to manage their health conditions. Personalised care approaches have also been shown to reduce admissions and contact with the NHS.[36] Therefore, personalised care is fundamental to sustaining the NHS as the population ages. This has been reflected in strategic policy, including NHS England's Long-Term Plan,[19] NHS A Healthier Wales[37] and NHS Scotland's 2020 Vision for Health and Social Care.[38]

Figure 16: Dimensions of personalised care



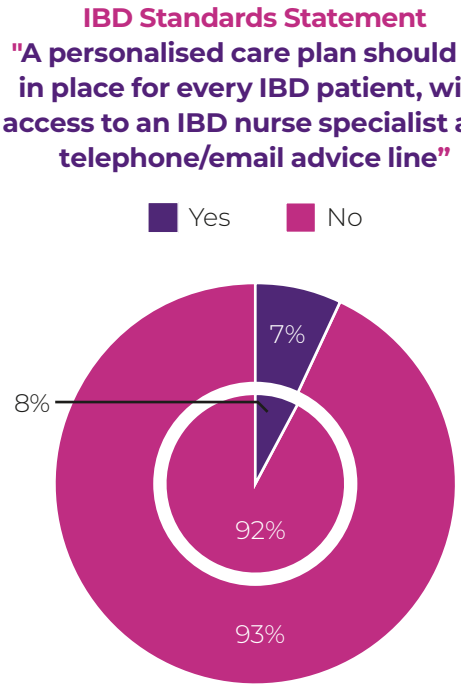
Source: IBD UK 2021.[3]

Personalised Care Plans

The IBD Standards state that a personalised care plan should be in place for everyone with IBD.[2] These plans should be developed following a holistic needs assessment, which addresses physical, social, emotional and mental wellbeing needs and preferences.[39] Personalised care plans are produced in partnership with people with IBD and shared with, and updated by, the wider MDT and their GP. They set out what matters to the person, identify personal goals and describe how these will be achieved.

Despite the potential utility of personalised care plans, **only 7% of adults with IBD that responded to the IBD Patient Survey reported having one**, with little change since 2019 (Figure 17). This occurred despite a quarter of services participating in the Service Self-Assessment reporting that they offered all adults with IBD a written personalised care plan. This discrepancy could arise due to the lack of an agreed definition or understanding of what a personalised care plan should include, and also indicates potential differences between what people with IBD feel they have in place and what services believe they are providing; this discrepancy was also identified in 2019.[3]

Figure 17: Self-reported access to a personalised written care plan for adults in 2019 (inner) and 2023 (outer)



Source: Data from the IBD Patient Survey.

IBD UK have created the Personalised Care Toolkit to support services to provide personalised care. As part of this initiative they have co-produced an Individual Care Plan, which is designed to help people with IBD prepare for their clinical appointments, by giving prompts and questions that focus on what matters most to them, and assist clinicians to initiate person-centred conversations.[40] Integration of this tool into standard operating procedures across IBD services may help to better embed personalised care into IBD clinical practice. However, it is critical that clear guidance on what a personalised care plan should include is developed, so that IBD services are enabled to more effectively provide this resource.

Coordinated Care

Personalised care is the responsibility of the whole IBD team. The 2021 IBD UK report called for an overhaul of the traditional ways in which people with IBD, doctors and nurses behave, act and communicate to ensure that all members of the IBD MDT are trained in, and are regularly using, personalised care approaches.[3] While COVID-19 inhibited the implementation of this recommendation, as typical healthcare practices return post-pandemic, now is an opportune time to develop and implement engagement initiatives aimed at onboarding the whole MDT into delivering personalised care.

However, to ensure healthcare services are tailored to the needs of individuals, primary care staff also need to be updated on peoples' care requirements, which is reflected in several of the IBD Standards.[2,3] While 99% of adult IBD services agreed that treatment changes in secondary care are communicated to primary care, with the majority stating that it takes <1 week for these changes to be communicated, 37% of adults with IBD did not think that their care was well organised between their GP and IBD

team. Furthermore, while the majority (87%) of adults felt that their IBD nurse specialist was knowledgeable, only 37% felt that their GP was knowledgeable about their condition, as highlighted in the Diagnosis section of this report.

Failure to coordinate between primary and secondary care limits the degree to which personalised care can truly be implemented. Ensuring greater integration of primary and secondary care when it comes to service delivery is essential. Coordination could be enhanced by utilising electronic methods of communication (e.g. emails rather than letters) and technological innovation (e.g. linked databases). Initiatives, such as the Personalised Care Toolkit, also provide guidance that can help to bridge the gap between primary and secondary care.[41]

AWARE-IBD, SHEFFIELD

Crohn's & Colitis UK have worked with Sheffield Teaching Hospitals NHS Foundation Trust, the University of Sheffield, epiGenesys, Sheffield Microsystems Coaching Academy and VoiceAbility to deliver a three-year project under a new Health Foundation programme called Common Ambition. The project aimed to redesign IBD services, guided by Patient Coach Sam McCormick, so that services were shaped by those who use them, their families and carers.

As a result, the AWARE-IBD team co-designed and used a novel measure of patient experience, a toolkit to support patients in consultations, a personalised care plan, an education programme, and made changes to nurse and consultant clinics. The project evaluation concluded that putting patients in control of their care improved patient experience significantly overall.

The top five recommendations from the project for other IBD services across the UK are:

- Aim to understand what matters to people with IBD and ensure personalised care, good communication and access.
- Measure and embed patient experience.
- Listen to underserved patient groups in a meaningful way that acknowledges needs, preferences and values, and addresses barriers.
- Form partnership with relevant stakeholders with a shared goal of improvement.
- Co-design service changes with people with lived experience, led by patient priorities.

If you are interested in learning more or have any questions, please contact IBD UK.

Person-Centred Conversations

Person-centred conversations are vital, as they place the individual at the heart of decision making and care planning. By engaging people with IBD in meaningful dialogue that considers their unique values, preferences and circumstances, healthcare providers can better understand their needs and goals. While clinical communication can affect satisfaction with care, treatment adherence, quality of life and self-management,[42] person-centred approaches may foster trust, promote shared decision-making and enhance satisfaction.[3]

However, despite 81% of adult IBD services reporting that they ask people about wider life goals and aims with respect to treatment decisions, just under a quarter (24%) of people with IBD agreed or strongly agreed with the statement 'We discuss my wider life goals and priorities, as part of planning my care' (Figure 18). Again, this discrepancy indicates potential differences between what people with IBD feel they have in place and what adult IBD services believe they are providing.

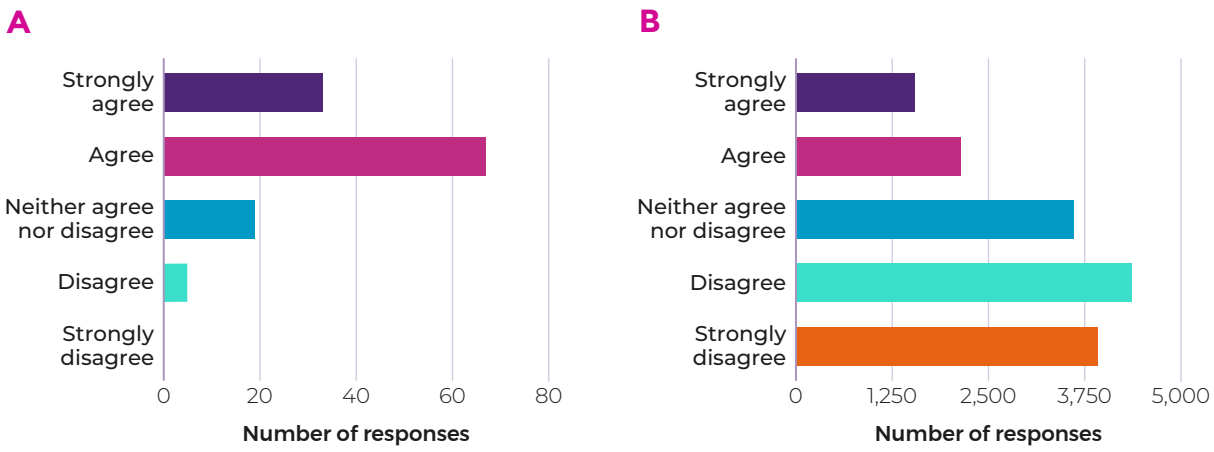
Holistic Care

Holistic care is important for people with IBD, because it addresses the complex interplay between physical symptoms, mental wellbeing, nutritional needs and social factors. People with IBD are affected by symptoms unrelated to their bowel, with up to 50% experiencing extraintestinal manifestations, involving different parts of their body: commonly joints, skin, bones, eyes, kidneys and liver.[43]

However, despite these clinical manifestations, only 31% of adults with IBD reported being asked about conditions beyond their gut (Figure 19).

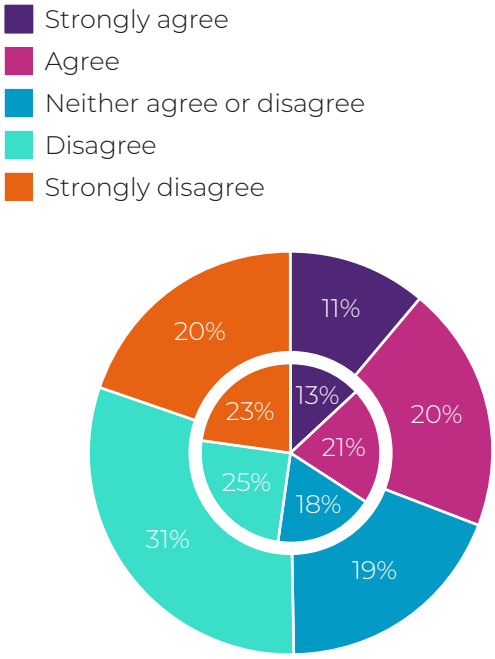
This proportion dropped from 2019, where 34% agreed to this question, indicating limited progress in providing this critical element of holistic care. Providing holistic care through inexpensive changes, such as improving access to dermatology, rheumatology and ophthalmology could be considered. This type of MDT working could be facilitated with virtual video consultations.

Figure 18: Discussion of wider life goals and priorities, as part of care, according to IBD services (A) and people with IBD (B)



Sources: (A) Data from the Service Self-Assessment; (B) Data from the IBD Patient Survey.

Figure 19: The proportion of people with IBD reporting that they were asked about conditions beyond their gut in 2019 (inner) versus 2023 (outer)



Source: Data from the IBD Patient Survey.

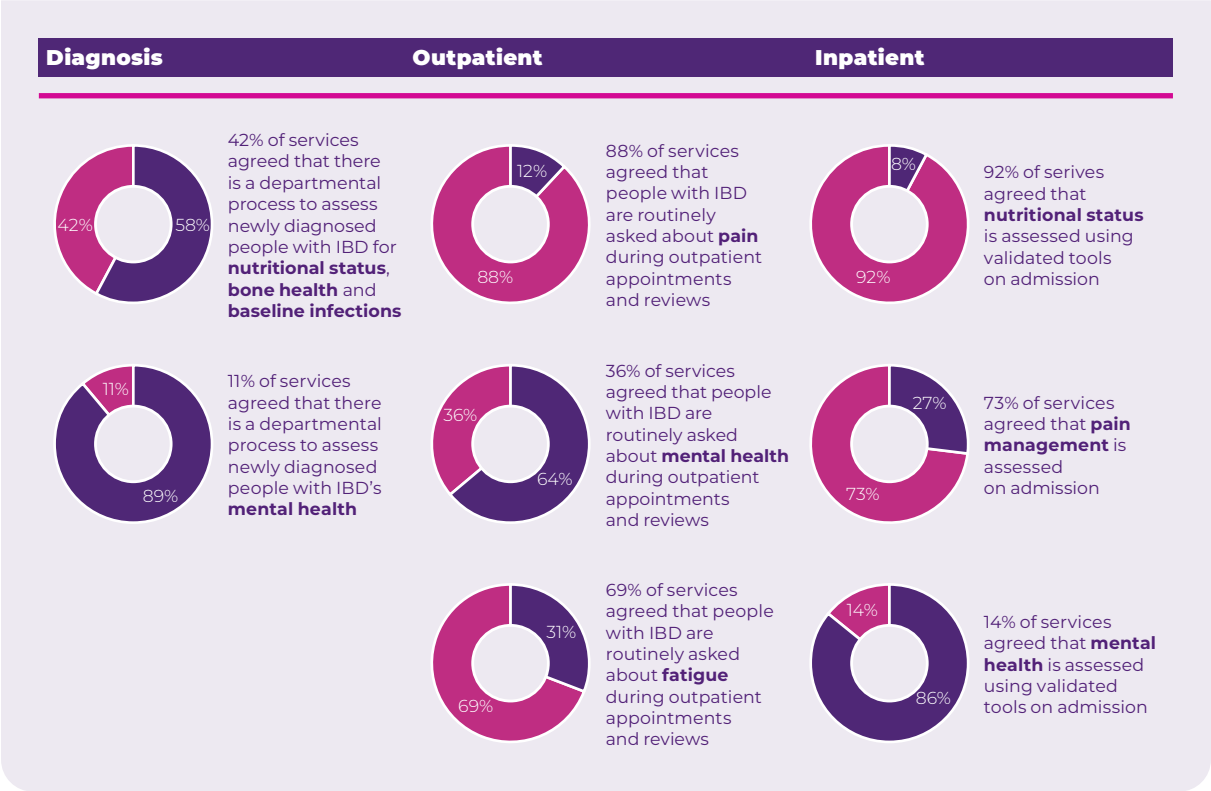
Holistic Assessments

When people with IBD engage with healthcare services, this offers a vital opportunity to assess other clinical and social impacts that arise from having IBD. Research completed in Germany, Canada, Norway and Spain has indicated a high prevalence of fatigue in people with active IBD and for those in remission.[44-47] Similarly, pain can affect people with active and inactive IBD and has been found to be highly prevalent.[48,49] IBD can also affect people's wellbeing due to malnutrition, having to come to terms with having a lifelong and often debilitating condition, sleep disturbances, the unpredictable nature of the symptoms or loss of self-esteem related to body changes or surgery.[3]

As a result, IBD Standards state that:[2]

- **After diagnosis, everyone with IBD should have a full assessment of their disease, nutritional status, bone health and mental health, in order to develop a personalised care plan.**
- **Pain and fatigue should be investigated and managed using a multidisciplinary approach.**
- **People with IBD should have an assessment of their nutritional status, mental health and pain management on admission.**

Figure 20: Service self-assessment of holistic care measures at diagnosis, outpatient and inpatient appointments[a]



Footnotes: [a]'Strongly agree'/'agree' responses indicated in pink; 'neither agree nor disagree'/'disagree'/'strongly disagree' responses indicated in purple. **Source:** Data from Service Self-Assessment.

Despite this guidance, less than half of adult IBD services agreed that they had a process to assess newly diagnosed people with IBD for their nutritional status, bone health and baseline infections (Figure 20). Even fewer services (11%) agreed that there was a departmental process to assess newly diagnosed people's mental health. This represents a significant missed opportunity to complete a holistic assessment at diagnosis, to support the establishment of personalised care.

While the majority of services reported asking people with IBD about their pain and fatigue during outpatient appointments and reviews (88% and 69%, respectively), 64% either provided a neutral or disagree response when asked whether people with IBD are asked about their mental health. Similarly, during admission to hospital, the majority of services reported that nutritional status and pain management were assessed (92% and 73%, respectively), but only 14% agreed that mental health was assessed using validated tools (Figure 20). A high proportion of IBD services are therefore missing critical opportunities to deliver holistic care.

Holistic Care: The Experience of Adults with IBD

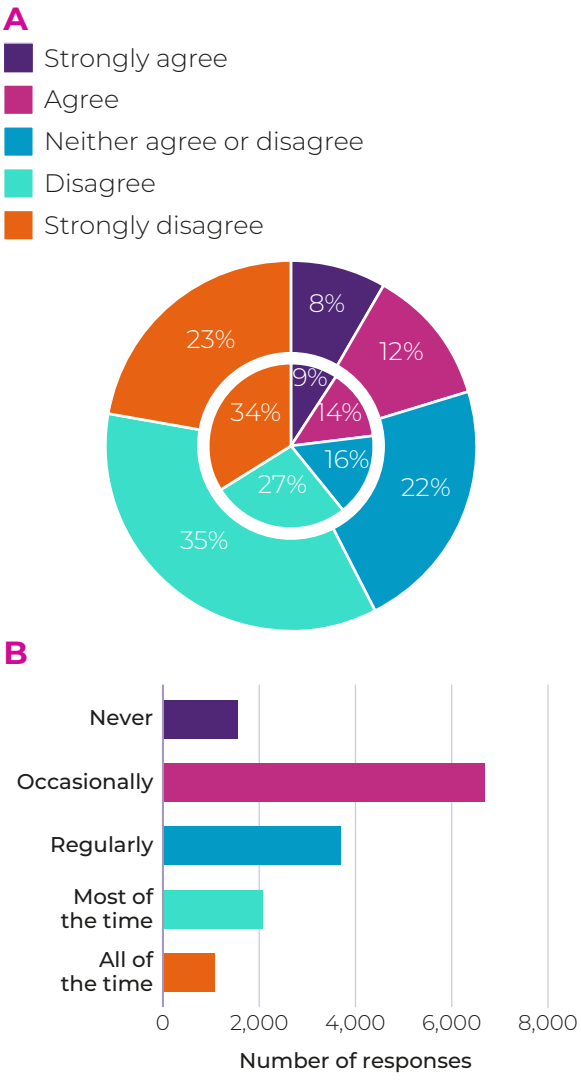
Adult respondents were asked about their access to nutritional advice and whether they were asked about pain, fatigue and mental health in the IBD Patient Survey. The majority (67%) of respondents did not agree that they have access to specialist advice or support with diet and nutrition. Access to this support is essential to ensure diets can be tailored to minimise symptoms and address nutritional deficiencies. Furthermore, an assessment of nutritional status on admission to hospital is important, to ensure that this can be taken into account when developing care plans, to ensure malnutrition does not inhibit recovery from a flare or surgery.

Only half (53%) of adult respondents agreed that they were asked about pain, while less than half (37%) reported being asked about fatigue. These results broadly mirror information provided by the IBD services in the Service Self-Assessment. Nevertheless, it is surprising, given how prevalent these clinical signs are, and the significant impact that both pain and fatigue can have on the wellbeing of people with IBD.[50] It is crucial that UK IBD services assess their adult service users for these symptoms and develop care plans that mitigate their severity and impact on peoples' quality of life.

Finally, only 20% of people with IBD agreed that they were asked about their mental health.

While people with IBD reported being more likely to be asked about their mental health in 2023 versus 2019, this incremental gain was small and the clinical significance of it uncertain (Figure 21). Furthermore, 24% of adult respondents reported finding it hard to cope regularly, while 14% reported finding it hard to cope most of the time and 7% all of the time.

Figure 21: The proportion of people with IBD reporting that they were asked about their mental health in 2019 (inner) versus 2023 (outer) (A) and the number finding it hard to cope with their condition over the past 12 months (B)



Source: Data from the IBD Patient Survey.

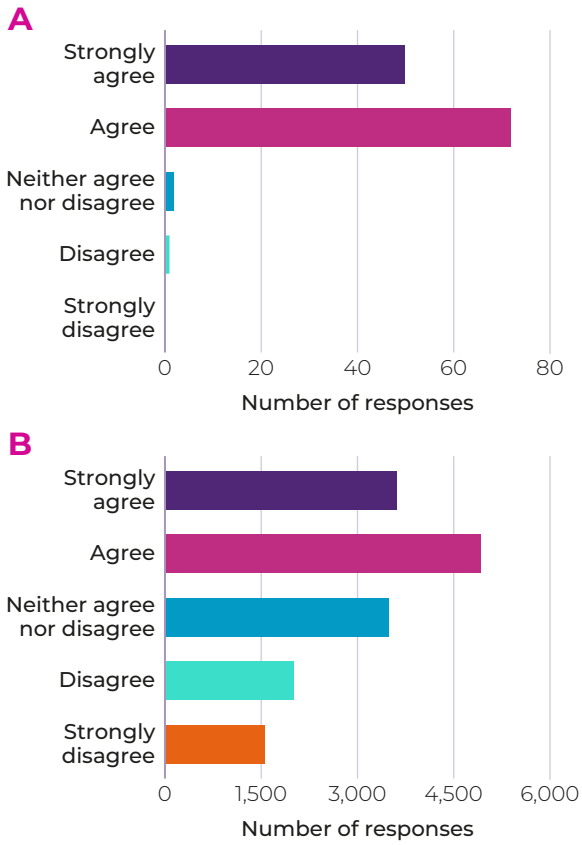
Results therefore indicate a substantial unmet need in terms of the assessment and treatment of people with IBD's mental health. Psychological support needs to be offered throughout a person's IBD journey, as set out in the IBD Standards.[2] Alongside the need for integrated specialist psychological support as part of the MDT, this should include referral and signposting to community services, such as the NHS Talking Therapies programme in England. While self-referral for talking therapies is not routinely available in Scotland, Wales or Northern Ireland, initiatives like Living Life, SilverCloud, NHS 111 Press 2 and Contact provide access to psychological support in the devolved nations.

Shared Decision-Making

The IBD Standards state that people with IBD should be supported to make informed, shared decisions about their treatment and care, to ensure these take their preferences and goals fully into account.[2] While the desire to be involved in shared decision-making will vary, evidence indicates that those who have more knowledge, skills and confidence in managing their own health and care are more interested in decisions about their care. This has a positive effect overall. People need to be supported to access and make use of the full range of resources that exist to support shared decision-making, including written information, peer support, counselling, decision-making aids and education opportunities.[51]

Almost all IBD services responding to the Service Self-Assessment agreed that people with IBD are supported to be actively involved in management decisions about their care; however, only 55% of people with IBD agreed that they were involved as much as they would like, while 23% actively disagreed with this statement (Figure 22). These findings raise questions about how services can improve shared decision-making. To address this, IBD services could consider enhancing access to information and ensuring it is available in comprehensive and accessible formats. For example, Crohn's & Colitis UK has created a Medicine Tool to help people with IBD understand more about the medicine options that suit their needs. Building strong relationships with service users and encouraging them to be open and honest is also vital.

Figure 22: Involvement in care and treatment decisions, according to IBD services (A) and people with IBD (B)



Sources: (A) Data from the Service Self-Assessment; (B) Data from the IBD Patient Survey.

Information and Self-Management

When people with IBD have difficulties self-managing their condition, this can lead to complications, and poorer mental and physical health outcomes.[52] The evidence shows that good self-management means fewer symptoms and hospitalisations and less need for treatment escalation.[53] Self-management in IBD enables people to have more control over their lives, by giving them the knowledge and skills to develop life goals, make healthy choices and manage their condition.

A core component of self-management is information, as this helps ensure that people with IBD understand their condition and can manage everyday symptoms. Ninety-one percent of services reported that IBD information is made available to all those newly diagnosed with IBD. Similarly, 70% of services reported that people with IBD in remission are offered self-management and patient-initiated follow-up, with support and education to enable them to do this. The majority (64%) of adults with IBD responding to the IBD Patient Survey agreed that they had the information and skills to confidently manage everyday symptoms and live as well as possible. While this is positive, focus needs to now be placed on understanding why 17% disagreed and what information or support services these individuals require in order to feel confident to manage their symptoms.

The IBD Standards also state that people with IBD should be supported in self-management through referral or signposting to education, groups and support.[2] However, the majority of services reported that a group education programme for IBD was not available (73%). The findings indicate a clear need for greater provision of opportunities for education and information about patient organisations to support self-management. Structured self-management programmes are available for other chronic conditions such as cancer and diabetes and should be provided on the same basis for people with IBD. A new education programme from Crohn's & Colitis UK, currently under development, will be invaluable for helping to address these challenges.

Finally, research participation plays a critical role in empowering people with IBD to access essential information and develop necessary skills for self-management. By actively engaging in research studies related to IBD, individuals contribute to the generation of knowledge about the disease, while staying informed about cutting-edge developments and evidence-based practices.[54] Moreover, research participation often involves educational components that equip individuals with practical skills for self-management, such as dietary modifications, symptom tracking and medication adherence. However, despite 76% of services agreeing that people with IBD are recruited to observational, registry and/or UK Clinical Research network clinical trials at their site, the proportion of adults reporting participation in research was minimal (Figure 23).

Figure 23: Adult self-reported participation in research

IBD Standards Statement
"IBD services should encourage and facilitate involvement in multidisciplinary research through national or international IBD research projects and registries"

Source: Data from the IBD Patient Survey.

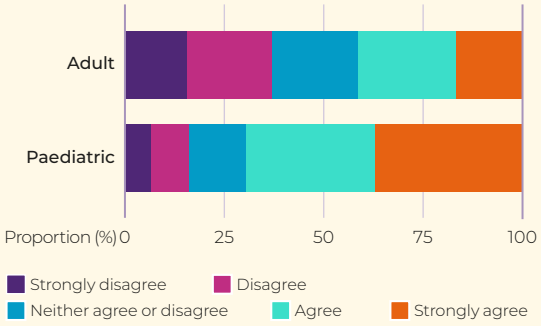
The low participation of adults with IBD in research across the UK means studies are unlikely to include participants representative of the whole IBD community, particularly as barriers to engagement disproportionately impact minority ethnic groups.[55] While it appears that many services are offering research opportunities, further work is required to ensure that people with IBD are aware of this research, understand the potential benefits of participation to them, and that research is carried out in a way that accommodates the needs of people with IBD and incentivises participation. Ensuring the highest quality care is delivered across UK IBD services could also help improve research participation, as individuals are less likely to prioritise research when feeling unwell.

PERSONALISED CARE: THE PAEDIATRIC EXPERIENCE

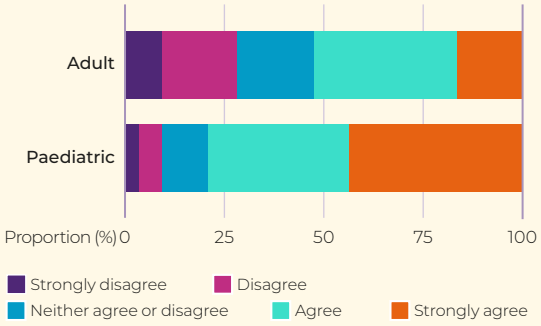
Key data on personalised care in the paediatric IBD population are outlined below. These data show that children and adolescents with IBD report a more personalised care experience than adults across key metrics. For example, a higher proportion of paediatric respondents indicated that they were asked about wider life goals (54% vs. 24%), pain (79% vs. 53%), fatigue (70% vs. 37%), their mental health (49% vs. 20%) and conditions outside of their gut (61% vs. 31%) versus adults. The lowest proportion of children and adolescents with IBD reported being asked about their mental health, suggesting that this unmet need affects both populations.

While it is positive to see higher proportions of children and adolescents with IBD reporting to receive personalised care, work is still evidently required to ensure consistency in experience for all. In addition, while structural differences inhibit a true like-for-like comparison between adult and paediatric services (for example paediatric services are often smaller and delivering care to a smaller population) there might nevertheless be learnings from paediatric services in terms of care delivery that could be imported into the adult setting to enhance personalised care.

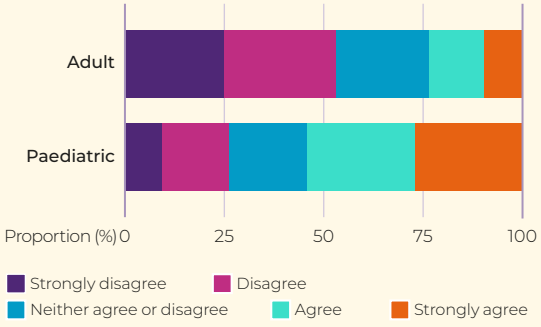
Organisation of care across teams



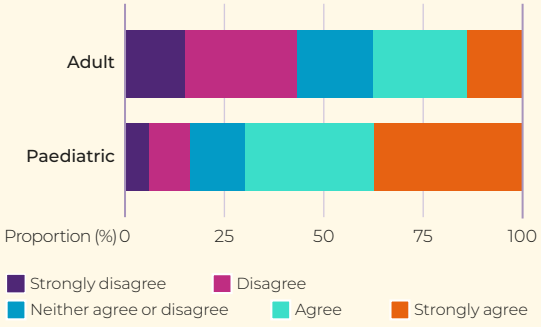
Asked about pain and treatment options



Asked about life goals

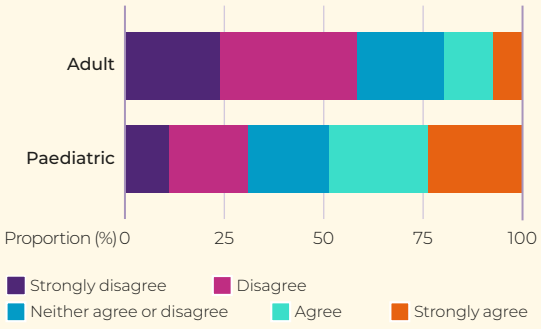


Asked about fatigue and its treatment

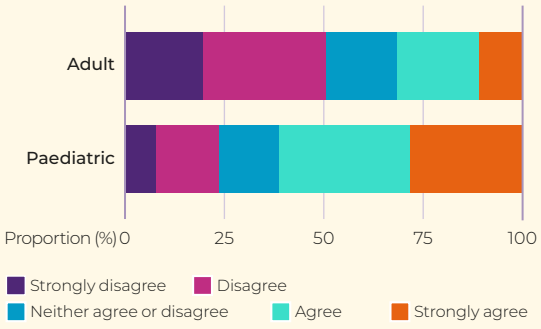


PERSONALISED CARE: THE PAEDIATRIC EXPERIENCE

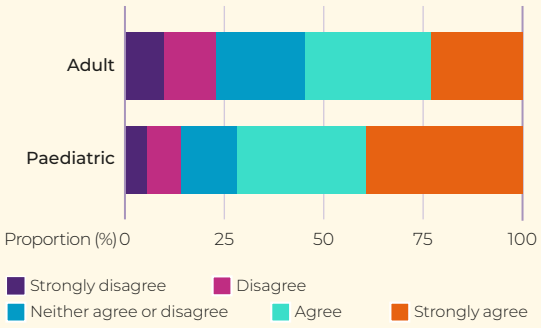
Asked about mental health



Asked about complications/conditions beyond the gut



Feeling involved with decisions



Between the ages of 16 and 18, children and adolescents with IBD will typically move from paediatric to adult care ("transition"). This transitional period can pose unique challenges both in terms of the delivery of care and in terms of maintaining personalised care approaches. However, by planning for transition, and using joint clinics, healthcare professionals can improve the way they manage this critical time for young people with IBD.[56,57]

All paediatric services that responded to the Service Self-Assessment confirmed that there is a structured transition programme in place for children and adolescents with IBD. These programmes are reportedly well resourced, with 96% and 75% of services reporting that they have a named transition lead and transition coordinator, respectively. Furthermore, most paediatric services (96%) also reported hosting joint clinics between paediatric IBD and adult IBD services and 83% reported that teenagers are routinely prepared for transition. This represents a significant improvement from 2019, where only 78% of paediatric services reported having a transition protocol in place.

Source: Data from the IBD Patient Survey.

PERSONALISED CARE: THE PAEDIATRIC EXPERIENCE

However, according to those who transitioned from paediatric services within the last two years, only 11% reported having a named coordinator, 12% reported having an individual transition plan, 38% reported having joint clinics between the paediatric team and members of the adult IBD services, and 42% were given information about what to expect from their transition. Almost four in ten (38%) recently transitioned adults reported receiving none of this information.

Effective transitions from paediatric care to adult services has been associated with a variety of benefits in several chronic diseases. Studies suggest that effective transition is associated with increased satisfaction with adult services and can help support individuals to independently manage their condition.[58] Furthermore, clinical outcomes can be enhanced through improvements in clinic attendance and physical growth.[58, 59] While it is encouraging that IBD services report providing a comprehensive transition service, the discrepancy between this and the experience of those recently transitioning into adult care requires further exploration.

PATIENT STORY

Scarlett, diagnosed with Crohn's disease in 2009

When I was 15 years old, doctors told me I had Crohn's disease. Being 29, and receiving adult care for some time, I would say the treatment as a child and as an adult is completely different. The biggest things being the time scales and wait times. Any tests were promptly booked and then happened within 1–2 months maximum with a follow-up appointment if required when I was a child. Right now, I am due to see my consultant and that should have been in February this year. It's now June and I don't have an appointment at all. I'd also say the sense of urgency was greater when I was experiencing a flare-up as a child. They would instantly start investigating or book me a check-up. As an adult, I'll contact my IBD team but most of the time they suggest going to my GP, sending off for bloods or going to A&E if it's bad enough. The support feels different. It's hard to say as the NHS is obviously struggling far greater right now than 14 years ago. I am extremely grateful to all the doctors and nurses who provide care as best as they can.

RECOMMENDATIONS FOR ACTION

Despite the current challenges faced by the NHS, it is crucial that the 'care' in healthcare is retained. While the 2021 report made several recommendations for action related to personalised care, evidence that these have been widely put into practice is limited.[3] The need for personalised care approaches is particularly acute in the adult population, whilst mental health support across both adults and young people is limited. While it is understandable that IBD services have struggled to implement the 2021 recommendations for personalised care during the COVID-19 pandemic, it is nevertheless vital that IBD services are supported to develop their personalised care practices, in order to enhance both their clinical practice and the health and wellbeing of their service users.

Key recommendations for action include:

- Mental health support should be provided throughout the diagnosis and treatment process for IBD. Psychological stress can contribute to increased IBD activity, worsening clinical signs and decreased quality of life. Evidence suggests that this can be improved through mental health support services.[60] Alongside the need for integrated specialist psychological support as part of the MDT, this should include referral and signposting to mental health services and promotion of self-management apps.

- A personalised care plan template, similar to the one developed by the AWARE-IBD project, should be introduced and nationally endorsed. Everyone with IBD should have a personalised care plan from diagnosis, based on a holistic needs assessment, detailing specific multidisciplinary support and flare management. Therefore, the development of endorsed national guidance on how a personalised care plan is defined, and what it should contain, is critical to support this.

- Structured self-management programmes focussed on wellbeing support should be co-produced with service users and commissioned for people with IBD who are suitable. These programmes can empower people with IBD to self-manage elements of their condition, can enhance clinical outcomes, improve mental health and reduce pressures on the NHS.[a]

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

- Greater utilisation of technology should be encouraged, to enable IBD services to strengthen their collaboration with primary care colleagues, to ensure that people with IBD receive consistent and coordinated care. This could include secure messaging platforms and ensuring the interoperability of electronic health records, to facilitate quick and effective cross service communication.

- The provision of effective transition to adult IBD services for children and adolescents with IBD should be reviewed nationally. While IBD services report well-resourced transition programmes, this is not reflected in the experience of people who recently transitioned from paediatric to adult services. Further work is required to identify and address the causes of this discrepancy.

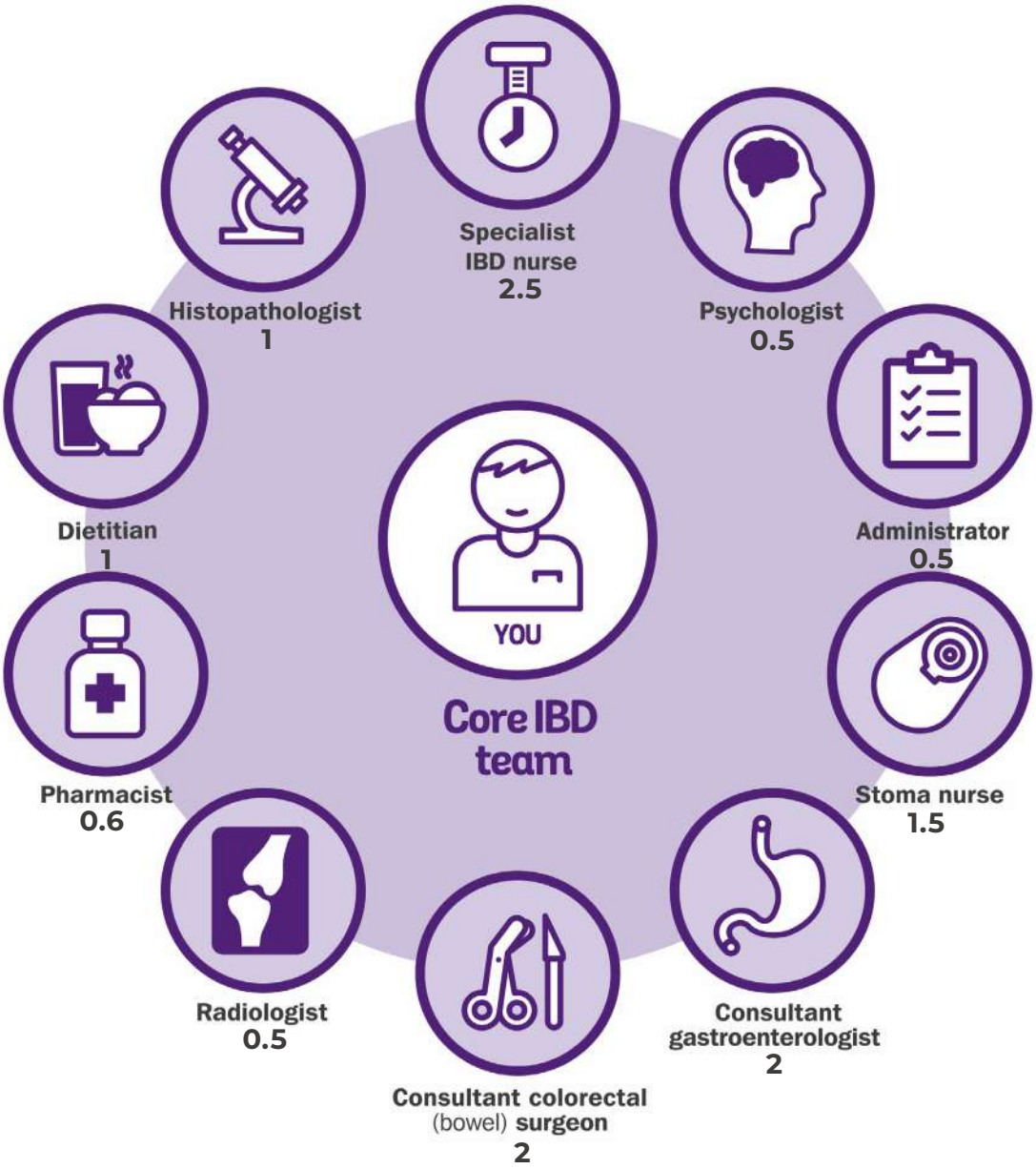
5 Workforce

MDT Team

IBD is complex and fluctuating, and its physical and emotional effects can vary hugely from one person to another. This means that good coordination is essential to deliver high-quality and personalised care. This needs to happen between specialities in secondary care, between paediatric and adult services, between primary and secondary care and within IBD teams via MDT working.

MDT meetings involve all key professional groups required to support consideration of complex cases and/or diagnostic dilemmas to create a clear care plan. The range of professionals that should be involved in an IBD MDT, according to the IBD Standards, is outlined in Figure 24. For adult services, the number of staff indicated in Figure 24 represents those required per 250,000 catchment population.[3]

Figure 24: Recommended IBD MDT team



Source: IBD UK 2021.[3]

MDT-driven care has been shown to improve care quality across various conditions. Responses to the Service Self-Assessment indicate that 98% of responding services held some form of MDT meeting for people with IBD, with 95% reporting that these meetings occur monthly or more frequently, allowing for regular coordination and more rapid decision-making. Mirroring other results in this report, despite the comprehensive coverage of MDT-orientated care reported by the majority of IBD services, roughly **a quarter of adults with IBD (26%) reported that they did not feel that they were supported by a team of IBD specialists**. This indicates that the comprehensive coverage reported by services is not necessarily experienced in that way by people with IBD who require access to an MDT.

Staffing

The IBD Standards state that services should have a leadership team in place, which includes a senior clinician, IBD nurse specialist and manager, who have responsibility for managing, monitoring and developing the service.[2] Eighty two percent of services that responded to the Service Self-Assessment reported having a leadership team, an increase from 78% in 2019.[3]

The IBD Standards also define the required composition of an IBD team in an adult IBD service.[2] The proportion of adult services meeting the IBD Standards whole time equivalent (WTE) staffing recommendations in 2019 and 2023 are presented in Table 4. **None of the 126 adult IBD services that completed the Service Self-Assessment met the IBD Standards for all roles across the team.**

Table 4: The percentage of adult IBD services meeting IBD Standards WTE staffing recommendations[a]

IBD team	Number of IBD services responding	Percentage (%) of IBD services meeting standards in 2019	Percentage (%) of IBD services meeting standards in 2023
Gastroenterologists	118	31	50
Colorectal surgeon	117	18	22
Stoma nurse	118	34	47
Dietician	117	9	21
Psychologist	117	18	6
Radiologist	115	44	77
Histopathologist	114	12	32
Administrators	118	47	41
IBD nurse specialist	118	14	20
Pharmacists	127	-[b]	17

Footnotes: [a]≤25% of IBD services meeting standards indicated in red, ≤50% of IBD services meeting standards indicated in orange and ≥75% of IBD services meeting standards indicated in green; [b]Comparison with 2019 not possible due to differences in question wording. Data from 2023 relate specifically to pharmacists that have IBD-linked funding. **Source:** Data from the Service Self-Assessment.

Whilst there has been an increase in MDT staffing since 2019, the percentage of services meeting recommendations remains low. Less than 25% of adult IBD services met resourcing recommendations for colorectal surgeons, dieticians, psychologists, IBD nurse specialists and pharmacists (Table 4). These are critical functions that are required for the delivery of timely, safe and person-centred care. In addition, these calculations relied

on outdated population estimates, with recent epidemiological studies suggesting that there are nearly twice as many people with IBD in the UK than previously thought; these prevalence figures are expected to continue to rise over the coming years.[61]

The proportion of IBD services meeting IBD Standards for administrators and psychologists is particularly low (Table 4). This is significant, given that results throughout this report highlight the unmet need for psychological support for people with IBD. In addition, with 59% of adult IBD services not meeting recommendations for administrative support, it is often over-stretched IBD nurse specialists who are responsible for completing administrative tasks, increasing the burden on these vital members of the MDT team, and increasing the likelihood of job dissatisfaction and burnout.[62]

There therefore remains a clear need for targeted support, to ensure that those IBD services not meeting WTE staffing recommendations are able to enhance their MDT resource. This should include insights generation, to understand why certain IBD services are struggling with MDT staffing, combined with interventions that address these causes. Interventions could include training, mentoring and incentive programmes, as well as ensuring MDT support is included within job descriptions.

PATIENT STORY

Joe, diagnosed with ulcerative colitis in 2017

For the last two years after my surgery, I haven't really had much contact with my IBD nurses since I've been fully healthy, and instead been supported by stoma nurses. I've had some small issues recently so contacted the IBD nurses and noticed that it took a lot longer to get help than before my surgery. I don't blame them since I know how overwhelmed the NHS is at the moment (I went to A&E recently and got told it would take 13 hours to get seen!), but they've been very helpful. I had an issue with the skin around my stoma and my stoma nurses were extremely helpful and we eventually found a treatment that worked, and I'm grateful for how amazing they were despite the amount of stress the NHS is currently under. IBD nurses are very important for me but there isn't enough of them. I've noticed longer call backs and waiting times for appointments over the years. They're amazing though, same goes for my stoma nurse who I am able to text for advice.

Offering opportunities to enhance the knowledge and skills of those participating in IBD MDTs can be a simple retention strategy, which also plays an important role in enhancing clinical capacity. Notably, the Crohn's & Colitis UK Nurse Specialist Programme, which promotes learning and develops expertise by funding IBD nurse specialists to complete either an MSc in Advanced Clinical Practice or join the Royal College of Nursing Advanced Nurse Practitioner credentialing programme, has upskilled 34 nurses as of 2023. These nurses are able to carry out advanced assessments, prescribe medication and monitor people with IBD independently. Investing in the ongoing professional development of our IBD healthcare workforce is therefore a critical step for retention, capacity building and ultimately enabling efficient and high-quality care.[63]

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.

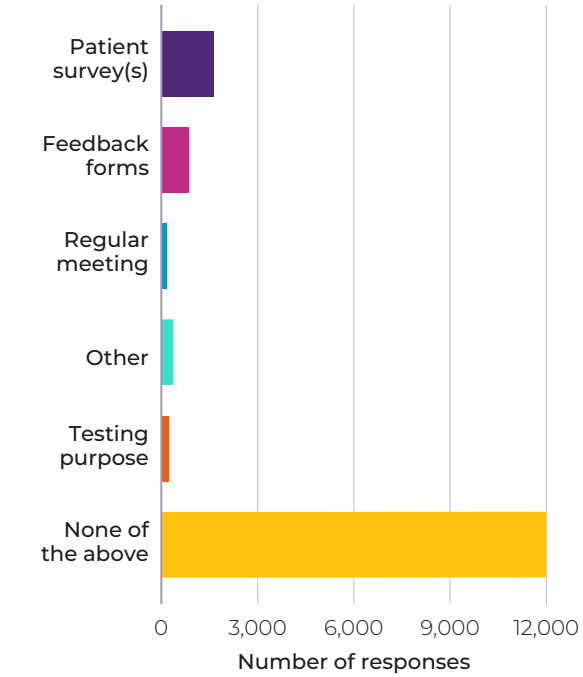
For more information about the Crohn's & Colitis UK Nurse Specialist Programme, please visit the Crohn's & Colitis UK website.

Monitoring and Improvement

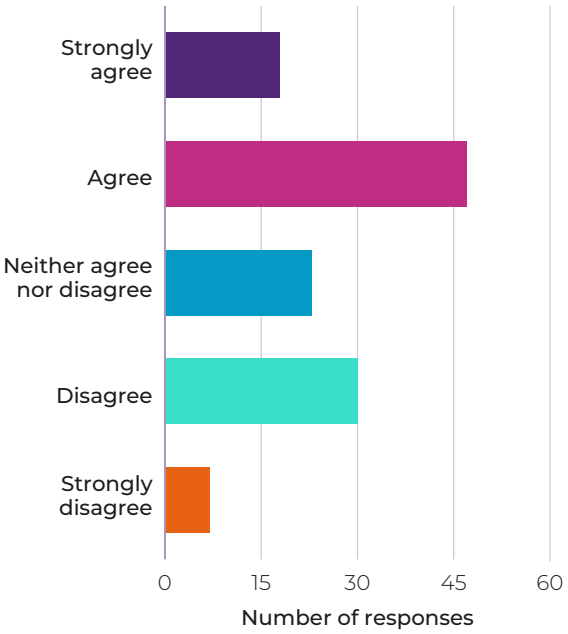
Regular audits, feedback mechanisms and ongoing monitoring and improvement activities are essential components of quality assurance in clinical care settings. The 2021 report described the involvement of people with IBD as the 'final piece of the MDT puzzle'.[3] However, 82% of adults with IBD reported not having the opportunity to give feedback about their care in the last 12 months (Figure 25a). Similarly, 30% of adult IBD services reported relying only on comments cards/feedback forms and the friends & family test to gather input from people with IBD (Figure 25b). This represents a significant missed opportunity for these IBD services to better understand the needs of those under their care.

Figure 25: Feedback opportunities from people with IBD (A) and the level of agreement from adult IBD services that patient feedback is gathered using methods other than comment cards/feedback forms and the 'friends and family test' (B)

A



B



Sources: (A) Data from the IBD Patient Survey; (B) Data from the Service Self-Assessment.

Furthermore, audits are important, as they allow healthcare providers to assess adherence to clinical guidelines and identify areas for improvement in processes and outcomes. However, 41% of services disagreed that audits of different aspects of the IBD service were carried out at least annually. Over half (52%) also disagreed that there was an audit plan and cycle in operation, with formal reporting of outcomes and service improvement actions. Likely reasons for these shortcomings include overstretched teams, minimal administrative support and reliance on paper-based audit processes. Therefore, further work is required to ensure all adult IBD services across the UK embed appropriate monitoring and improvement initiatives, to ensure that they are able to optimise their service delivery.

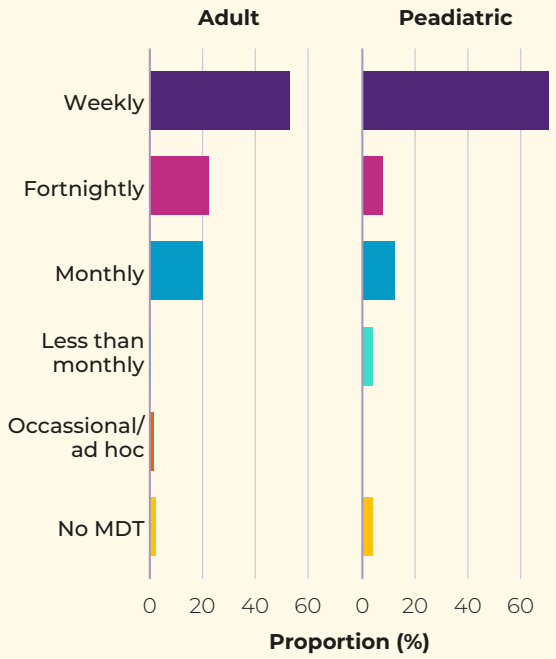
THE PAEDIATRIC MDT

Data from the paediatric Service Self-Assessment suggests that paediatric MDTs take place more regularly than adult MDTs, with 71% of paediatric MDT meetings taking place weekly, versus 53% of adult MDTs. There was a slight difference between the proportion of paediatric and adult IBD services reporting that core staff (including [paediatric] gastroenterologists, surgeons, IBD nurse specialists and radiologists) regularly attend IBD MDTs (77% vs. 71% in paediatric and adult IBD services, respectively). A similar result was identified for stoma nurses (9% vs. 7%). However, notably more paediatric IBD services reported dieticians (73% vs. 49%) and psychologists (50% vs. 8%) attending MDTs compared with adult services, whereas a marginally higher proportion of adult IBD services reported pathologists and pharmacists attending MDTs (46% vs. 53% and 50% vs. 56%, respectively).

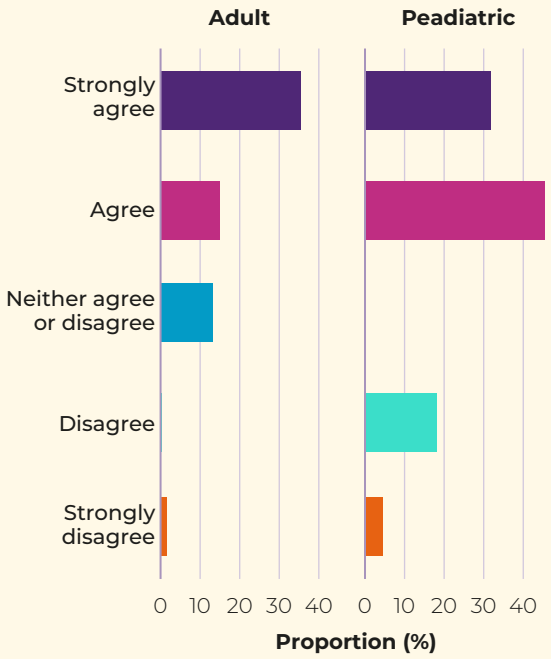
The data therefore suggests a more frequent occurrence of MDT meetings in paediatric IBD services, compared to adult services, with notable differences in the presence of certain specialities (particularly dieticians and psychologists). These results suggest tailoring in MDT composition to address the unique needs of paediatrics and adults with IBD. Enhancing the capacity of IBD MDTs across the paediatric and adult populations is however desirable, to facilitate the delivery of high-quality, coordinated and multidisciplinary care.

THE PAEDIATRIC MDT

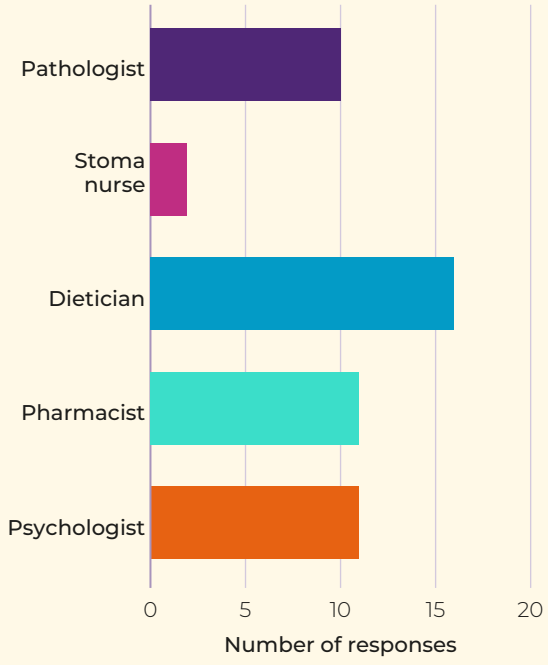
Frequency of paediatric and adult IBD MDT meetings



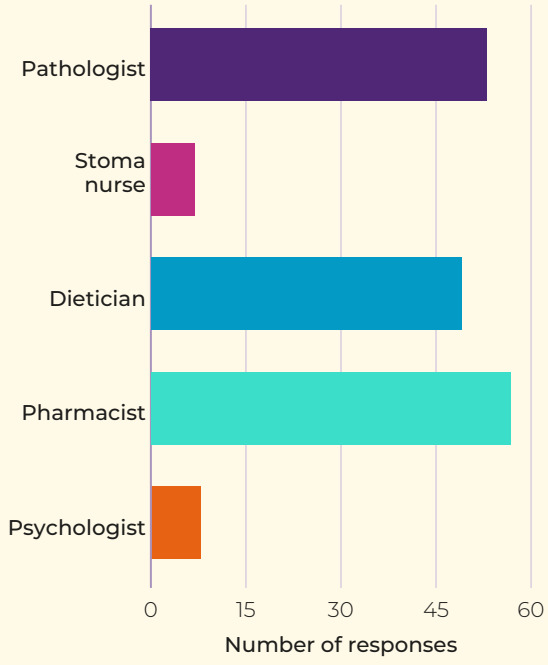
Paediatric and adult MDT meetings attended by all core staff members



Paediatric MDT meetings attended by additional staff members



Adult MDT meetings attended by additional staff members



Source: Data from the Service Self-Assessment.

RECOMMENDATIONS FOR ACTION

The workforce crisis across the NHS is reflected in the current workforce capacity of UK IBD services.[21] None of the 126 adult IBD services that completed the Service Self-Assessment met the IBD Standards for MDT staffing across all roles. The proportion of adult IBD MDTs meeting requirements for psychologists is particularly low and has decreased since 2019. Opportunities to improve the IBD services through feedback and audits are also inadequate in a high proportion of UK IBD services and this needs consideration.

Key recommendations for action therefore include:

- Enhancing the capacity of the IBD workforce is critical to enabling IBD services to deliver a standard of care that meets the IBD Standards and the other recommendations outlined in this report. All IBD services should be resourced to meet the IBD Standards for MDT staffing to ensure that staff are available and have the capacity to deliver coordinated and high-quality multidisciplinary care. This includes capacity to undertake relevant continuing professional development opportunities. Focus needs to be placed on psychologists and pharmacists in adult IBD services. Participation in IBD MDTs should be reflected in job roles for all MDT members, whose involvement is recommended in the IBD Standards.

- Opportunities for feedback should be available and encouraged by IBD services across the UK, in order to help people with IBD feel engaged with their health care, whilst informing the service of areas for improvement. 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

The UK is facing a range of challenges to its healthcare system, brought about by the combination of an ageing population, the rising number of people living with comorbidities and financial pressures within the NHS. This increasing demand, combined with insufficient funding, has left healthcare services struggling to deliver high-quality care. With the addition of COVID-19, which further disrupted the delivery of health care across the UK, pressures placed on healthcare services have now become unsustainable. With this backdrop, it is perhaps unsurprising that results from the second round of IBD benchmarking suggest that IBD Standards are still not being met by a significant proportion of IBD services across many key areas of IBD care and that little progress appears to have been made against the recommendations outlined in the 2021 report.[3]

While undoubtedly best practices are being followed by some services, 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 revealed common themes, which cut across the four chapters. These themes need to be considered alongside the recommendations to deliver consistent, high-quality, personalised care for people with IBD wherever they live in the UK:

Theme 1: Quick access reduces risk of deterioration

- Long waiting times for referral, diagnosis and treatment for people with IBD must be addressed. Survey results highlight the importance placed on rapid access to care by service users, which is also emphasised by the IBD Standards. This is because delays can worsen clinical prognosis, negatively impact quality of life and present a greater economic burden for the NHS. Delivering rapid access to care therefore offers 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. IBD services that can communicate effectively with service users can enhance people's understanding and confidence with managing their condition, empowering them to make informed healthcare decisions. Similarly, efficient intra-service communication is a core enabler of personalised care.

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. This must include access to the full range of specialist support.
- Everyone with IBD should feel part of the decision-making process regarding their care and should be given the resources to understand their condition. There should be ample opportunities for feedback and this feedback should be used to improve the IBD services going forwards.
- IBD has ramifications beyond the gut. Key symptoms, such as pain, fatigue and declining mental health are still not being adequately recognised, managed or treated. Psychological and specialist support should be available to all people with IBD and healthcare professionals need to be trained to offer this or refer people to the appropriate services.

Theme 4: Discrepancies between service provision and patient 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 for this discrepancy is unclear. While it is possible that those responding to the IBD Patient Survey may disproportionately represent individuals with more negative care experiences, while those IBD services responding to the Service Self-Assessment may overrepresent higher performing services, these discrepancies warrant further investigation.

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. This report presents actionable recommendations that healthcare decision-makers must take forward, in order to end the stagnation (and in places deterioration) of IBD care quality. By prioritising investment in IBD care and staffing, committing to implement the IBD Standards and reducing waiting times for IBD diagnosis, treatment and surgery, healthcare decision-makers across the UK can significantly improve outcomes for people with IBD and generate downstream cost savings for health services across the four nations.

The time to act is now. The UK and devolved Governments, health leaders and policymakers must prioritise working closely with clinicians, patients and the charities that represent people with IBD to improve IBD care now and in the future.

Appendix A

When did the IBD Patient Survey take place and how was it promoted?

The IBD Patient Survey was open from April 2023 to June 2023 and was widely promoted via printed flyers and digital methods, including emails and social media. Most people completed the survey online, but translation was available on request via the Crohn's & Colitis UK helpline.

Who responded to the IBD Patient Survey?

There were 17,654 people with IBD across the UK that completed the IBD Patient Survey: 17,003 adult responses and 651 paediatric responses. Those under 18 were asked to complete the survey with a parent, carer or guardian. Seventy-eight percent of respondents were diagnosed more than two years ago. More adult responses were from females than males (72% vs. 28%); the gender of paediatric respondents was not collected.

The proportion of responses from each UK country closely matched that expected from their population size: England represented 84% (paediatrics 78%) of responses; Scotland 9% (paediatrics 11%); Wales 5% (paediatrics 8%); and Northern Ireland 3% (paediatrics 3%). Forty-eight percent of respondents (paediatrics 60%) had Crohn's disease; 46% (paediatrics 32%) had ulcerative colitis; 4% (paediatrics 8%) had Inflammatory Bowel Disease Unspecified; and 2% (paediatrics 0.2%) had microscopic colitis. A breakdown of these data is displayed in Table 5. In terms of the severity of their condition over the last 3 months, 11% reported “I have no symptoms and not been affected by the disease”; 25% agreed that “My symptoms have not got in the way of everyday activities”; 40% stated “My symptoms have got in the way of some everyday activities”; 19% described “My symptoms have significantly got in the way of everyday activities”; and 6% reported “I have been unable to perform everyday activities”. Children and adolescents with IBD also reported that their condition affects their everyday life. When asked whether they have found it hard to cope with having IBD only 6% stated “Never” whereas 46% reported “Occasionally”; 24% “Regularly”; 16% “Most of the time”; and 8% answered “All of the time”.

Table 5: Type of IBD of those participating in the IBD Patient Survey

IBD Type	Adults		Paediatric	
	n	%	n	%
Crohn's disease	8,192	48	388	60
IBD unclassified	725	4	49	8
Ulcerative colitis	7,740	46	211	32
Microscopic colitis	317	1.9	1	0.2
Other	24	0.1	2	0.3

Source: Data based on the IBD Patient Survey.

When did the Service Self-Assessment take place and how was it promoted?

The Service Self-Assessment was open from June 2023 to August 2023. Promotion was through IBD UK member organisations via digital channels and relevant events. IBD services were encouraged to register via a lead benchmarking contact and to complete the Service Self-Assessment online as a team.

Who responded to the Service Self-Assessment?

150 IBD services across the UK (64% of all IBD services) completed the Service Self-Assessment. This includes 126 adult and 24 paediatric IBD services. For the adult population, 81% of IBD services that completed the Service Self-Assessment were based in England, 11% in Scotland, 7.5% in Wales and 0% in Northern Ireland. Paediatric services also contributed, with 91% of IBD services based in England, 6% in Scotland, 3% in Wales and 0% in Northern Ireland.

Appendix B

Definitions of Aspects of Care

- **Access:** Defined as being seen quickly/easy to make contact/convenient for respondent in terms of location and timing of appointments.
- **Information:** Defined as information to help respondents understand their condition and treatment options.
- **Communication:** Defined as communication between the respondent and their team and also how their healthcare teams work together.
- **Empowerment:** Defined as empowerment to enable the respondent to make a choice and manage their condition.
- **Wellbeing support:** Defined as support from the IBD team for the respondent's overall physcial and mental health and ability to manage.
- **Research:** Defined as involvement or information about IBD research/trials/surveys/collection of data going on locally or nationally.

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Further information and support

If reading this report has raised any concerns for you, 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

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