

# Crohn's and Colitis Care in the UK

The Hidden Cost and a Vision for Change



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

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# Foreword

“High levels of emergency care and a lack of proactive, preventative care signal an urgent need for a different approach to the delivery of services.”



**Sarah Sleet**  
Chair, IBD UK  
Chief Executive,  
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This report is the culmination of significant input from hundreds of healthcare professionals and thousands of people across the UK who are living with Inflammatory Bowel Disease (IBD), of which Crohn's Disease and Ulcerative Colitis are the two main forms. The surveys and report have been led by IBD UK – an alliance of 17 professional bodies, royal colleges and patient organisations, which Crohn's & Colitis UK is privileged to chair. We believe that patients and clinicians, working together as equals in formulating and assessing service standards, is a unique approach in UK healthcare. This could provide a blueprint for other service areas to truly put the patient at the heart of the NHS.

Despite improvements in care in recent years, combined with pockets of excellent practice, the surveys portray a national picture of IBD care which was stark prior to the COVID-19 (coronavirus) pandemic. High levels of emergency care and a lack of proactive, preventative care signal an urgent need for a different approach to the delivery of services.

The impact of the pandemic has been extraordinarily challenging for the NHS and for people living with Crohn's and Colitis. Despite the positive work of staff and services throughout, the COVID-19 pandemic has exacerbated pre-existing issues such as delays in diagnosis, access to investigations and surgery and a lack of holistic multidisciplinary care. The backlog created will take considerable time to clear.

As this is tackled, it will be critical that people with IBD are appropriately prioritised, based on clinical need, and not pushed to the back of the queue. The consequences of a failure to do so would be profound for those facing potential life-changing complications.

As services adapt to delivering more care remotely, we must ensure that people with IBD receive high-quality personalised care, enabling them to live their lives to the fullest. It is fundamental that people with IBD are fully involved both in their own care, and in service development and redesign, to make sure services truly meet their needs.

This report provides clear calls to action for political decision-makers across the four UK nations, for NHS commissioners, managers and IBD services and for health professional bodies and patient organisations. If acted upon, these will transform IBD care for the future, offering far greater value and sustainability for the NHS and vastly improved experience and outcomes for people with IBD. Given that many of those affected are of working age, this will enable greater productivity and bring wider societal benefits.

Together with the [local service reports](#), released in March 2020, these calls to action offer a practical approach to service redesign and vital recognition of the specific needs of the estimated 500,000 people living with IBD across the UK.

I would like to take this opportunity to thank IBD teams across the UK, who are continuing to support and advocate for their patients in very difficult circumstances, and to everyone who has been involved in this project.

This report reveals a hidden burden of ill-health and unmet need and sets out a vision for change.

*Sarah Fleet*



# Executive Summary

Ongoing research is revealing that over 500,000 people in the UK have Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn's Disease and Ulcerative Colitis. That's at least one in every 133 people.<sup>1</sup> This is a considerable increase on previous estimates of around 300,000 people.

IBD can be extremely debilitating and impact on every area of a person's life. Symptoms include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue, and associated anxiety and depression. Delays to diagnosis and treatment and a lack of personalised and multidisciplinary care can lead to serious and potentially life-threatening complications for the individual, such as a perforated bowel or bowel cancer, and expensive treatment and care for the NHS.

The UK-wide IBD Patient Survey and Service Self-Assessment, carried out between July 2019 and January 2020, provide a unique picture of IBD care, benchmarked against the [IBD Standards](#).

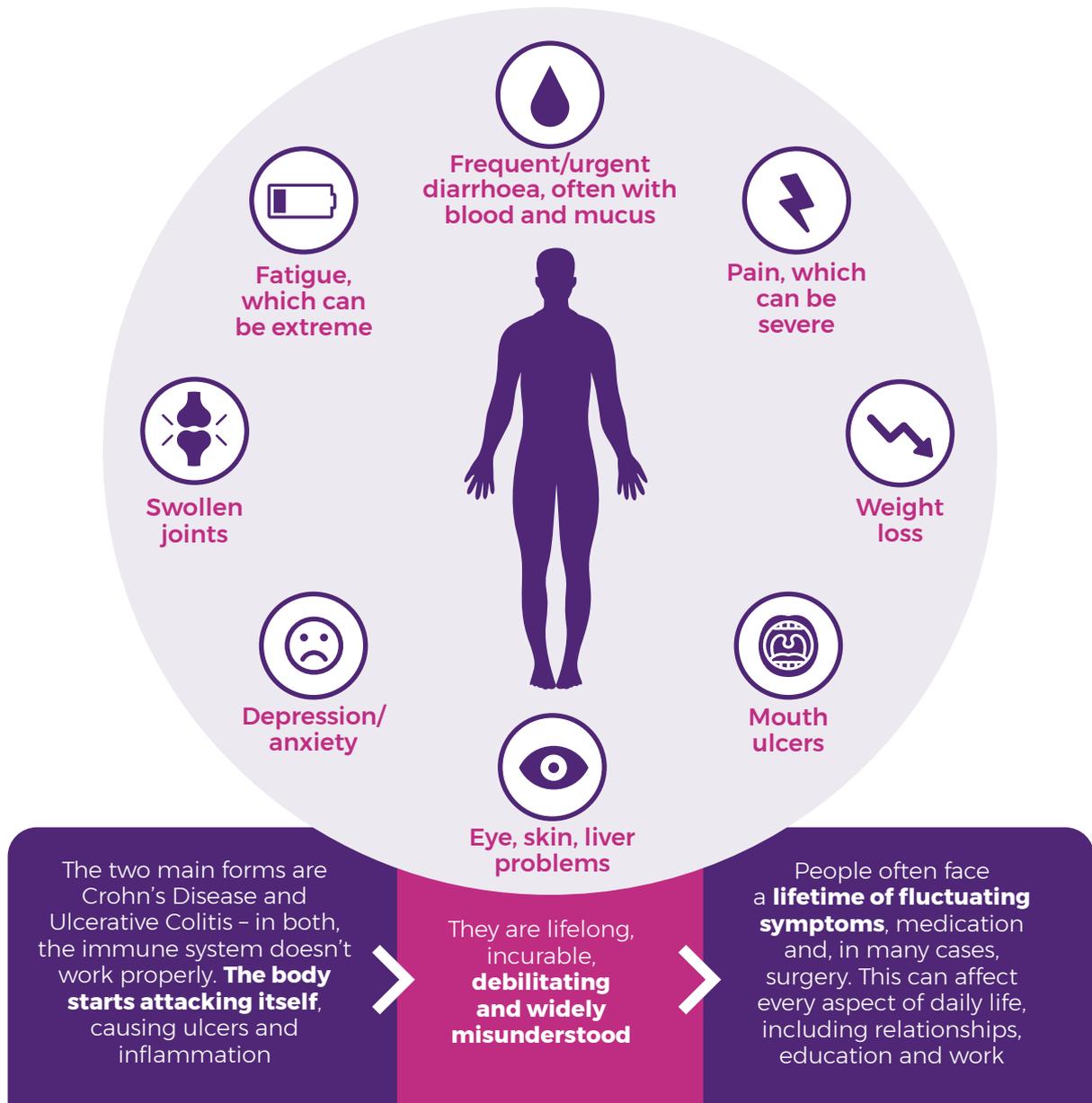
- 10,222 adults, children and young people with IBD across the UK, supported by 99% of IBD services, took part in the Patient Survey.
- 166 adult and paediatric IBD services (72%) across the UK completed the Service Self-Assessment.

The results highlight key actions that are urgently needed to reduce high levels of inefficient and costly reactive care, including emergency care.

The IBD Quality Improvement Programme, led by the Royal College of Physicians,<sup>2</sup> and concerted programmes of work across the four nations, have maintained a focus on IBD service improvement since the first IBD Standards in 2009. However, it is clear that much more still needs to be done.

## IBD and its impact

### Symptoms can affect almost every part of the body



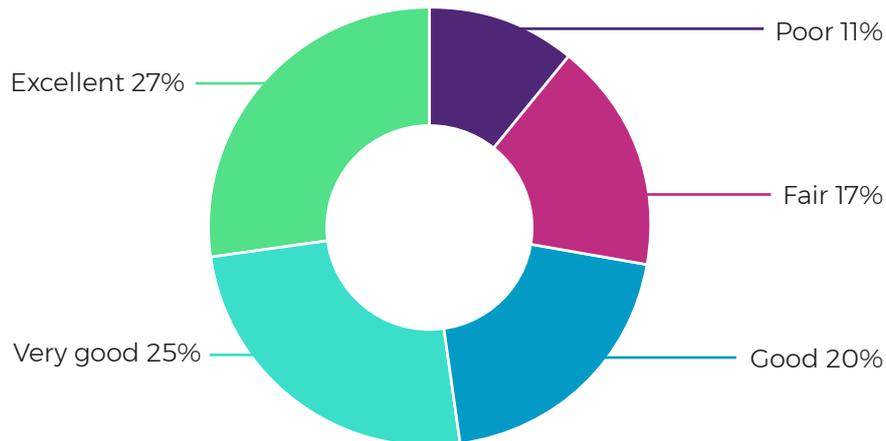
This report highlights pockets of excellent practice, but also demonstrates considerable variation in care across services. This includes some differences between paediatric and adult services and across the four nations. There are system-wide issues that need to be addressed to enable services to deliver consistent, high-quality, personalised care for people with IBD, whatever their age and wherever they live in the UK.

## How do people with IBD view their care?

Of those who responded to the Patient Survey:

- 28% rated the quality of their care as fair or poor.
- 72% rated the quality of their care as excellent, very good or good.

**Figure 1: Overall, how would you rate the quality of your Crohn's or Colitis care over the last 12 months?**



The top three factors that predicted how highly people with IBD rated their quality of care were:

- Feeling supported by a team of IBD specialists
- Having regular reviews
- Discussing wider life goals and priorities, as part of planning their care

## Four areas for change

For care and support to improve – for everyone living with IBD in the UK – we need to see:

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

## **1. Improvements in diagnosis and information provision**

**Problem:** It is taking too long for people with IBD to be diagnosed and they are not receiving the information and support they need to cope with adjusting to their condition. This can have a huge effect on the individual's physical and mental health, education and career, and carries a significant cost for the NHS.

- 26% of those responding to the Patient Survey waited more than a year for a diagnosis.
- 41% had visited Accident and Emergency (A&E) at least once before being diagnosed, with 12% visiting three or more times.
- 32% said they were not offered any information about their condition when diagnosed.
- Only 24% of services had referral pathways in place and reported being able to see over 90% of patients with suspected IBD within four weeks of referral.



### **RECOMMENDATIONS FOR ACTION**

- 1.** There should be a public health campaign to raise awareness of the symptoms of Crohn's and Colitis.
- 2.** Healthcare professional associations, training bodies and patient organisations need to work together to upskill community healthcare professionals in recognising potential IBD.
- 3.** Faecal calprotectin testing must be used consistently and appropriately in primary care, as part of agreed referral pathways between primary and secondary care, and emergency and specialist teams. These referral pathways should be in place in every service.
- 4.** Governments across the four nations should ensure that services are resourced to enable people with suspected IBD to be seen, investigated, diagnosed and treated in line with the time frames set out in the IBD Standards.

## 2. Personalised care and support for self-management

**Problem:** Care is reactive and focused on medication, leaving people struggling with pain, fatigue, anxiety, extraintestinal manifestations and other issues related to their Crohn's or Colitis. This means they are unable to manage and live well with their condition.

- 89% of those responding to the Patient Survey had found it hard to cope with having Crohn's or Colitis over the previous year.
- During medical appointments:
  - 29% were not asked about pain
  - 48% were not asked about fatigue/tiredness
  - 60% were not asked about mental health
  - 47% were not asked about IBD-related complications and/or conditions outside of the gut
- 91% reported they did not have a personalised care plan
- 69% did not know when their screening colonoscopy was due



### RECOMMENDATIONS FOR ACTION

1. Everyone with IBD should have a personalised care plan from diagnosis, based on a holistic needs assessment, detailing specific multidisciplinary support and flare (relapse) management.
2. Structured self-management programmes should be co-produced with patients and commissioned for everyone with IBD.
3. Everyone with IBD should have regular reviews and monitoring that meets their individual needs, both in terms of frequency and delivery.

### **3. Faster access to specialist advice and treatment**

**Problem:** People with IBD are not able to get specialist treatment and care quickly enough. This is resulting in high numbers of emergency hospital admissions and potentially avoidable flares, where their condition is not well-controlled and serious complications can arise.

- 70% of those responding to the Patient Survey said they had experienced one or more flares in the previous 12 months, with 14% reporting more than five.
- 31% said they had received no information on flare management.
- 72% of hospital admissions were emergency admissions.
- 22% waited longer than 18 weeks for elective IBD surgery.



#### **RECOMMENDATIONS FOR ACTION**

- 1.** All IBD services should ensure that everyone with IBD:
  - (i) has a plan in place detailing steps to take in the case of a flare and
  - (ii) can receive a response from an IBD advice line by the end of the next working day.
- 2.** Commissioners and managers should ensure that rapid access clinics and prompt access to investigations are in place in every service, supported by flare pathways that are agreed between primary, secondary and emergency care.
- 3.** There should be a clear process for admission to a specialist gastroenterology/colorectal ward in every IBD service. Job plans for IBD nurse specialists should include time for inpatient visits.
- 4.** Surgery for IBD needs to be prioritised appropriately, alongside surgery for other conditions, given the significant risk to patients of delays.

## 4. Effective multidisciplinary (MDT) team working

**Problem:** People with IBD don't have access to the full range of specialist care they need, and it's not well coordinated or based on all their needs.

- No adult IBD services reported meeting the IBD Standards' recommendations for all roles across the team.<sup>3</sup>
- 14% reported having enough IBD nurse specialists to meet the IBD Standards.
- 13% reported having enough pharmacists to meet the IBD Standards.
- 7% reported having enough dietitians to meet the IBD Standards.
- 2% reported have enough psychologists to meet the IBD Standards.
- Only 48% of those responding to the Patient Survey felt their care was coordinated with other specialist services.



### RECOMMENDATIONS FOR ACTION

1. Commissioners and managers should ensure that every IBD service is resourced to meet the staffing requirements for the IBD team, including gastroenterologists, IBD nurse specialists, colorectal surgeons, stoma nurses, dietitians, pharmacists, psychologists, radiologists and histopathologists. The MDT should hold regular, effective meetings, supported by an administrator.
2. Commissioners and managers should ensure that pathways are in place to deliver well-coordinated care across specialties, including joint medical/surgical clinics, and between paediatric and adult services and primary and secondary care, supported by effective data systems.
3. Every IBD service should have a leadership team in place, including a manager, to plan and develop IBD services effectively and efficiently, ensuring patient involvement and co-production.

## Conclusions

The data highlights specific areas where action needs to be taken and some common overarching themes and principles. These need to be considered alongside the recommendations to deliver high-quality, safe, consistent, personalised care for people with IBD, whatever their age and wherever they live in the UK.

**1. Care should be personalised, proactive and preventative, not reactive.**

Everyone with IBD should receive an early and accurate diagnosis and have a personalised care plan. This must include access to the full range of specialist support, including rapid response when required, and ongoing monitoring and review.

**2. Information and support are fundamental to people with IBD feeling confident and able to live well with their condition.**

Everyone with IBD should receive accessible information at all stages of their care. This must meet their individual needs, as part of shared decision-making, and signpost to patient organisations for further information and wide-ranging support.

**3. IBD nurse specialists are central to high-quality IBD care as part of the complete IBD multidisciplinary team.**

Everyone with IBD should have access to an IBD nurse specialist and all IBD services should meet the standard for IBD nursing provision.<sup>4</sup>

**4. Data and IT systems should underpin patient care, service planning and audit.**

Everyone with IBD should be entered on a clinical IBD system to enable coordinated care, with data provided to support local and national audit and service improvement.

# Introduction

## What is IBD? What are its effects?

Ongoing research is revealing that over 500,000 people in the UK have Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn's Disease and Ulcerative Colitis. That's at least one in every 133 people.<sup>1</sup>

IBD is a painful, debilitating and lifelong condition, with periods of relapse (often known as "flares") and remission. The cause isn't yet fully understood but is thought to be a mix of genetic susceptibility, gut microbiome, environmental factors and a defective immune response. Crohn's Disease causes ulcers and 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 include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue and weight loss, with associated anxiety and depression. They lead to time off school and work, withdrawal from social relationships and inability to carry out everyday activities,

such as shopping and exercise. IBD doesn't 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, with thousands of people suffering in silence.

You can develop IBD at any age, but most people are diagnosed between the ages of 15 and 40 – meaning it has a significant impact on their working life. In a pan-European survey,<sup>5</sup> 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. As the population ages, the number of older people with IBD and a range of co-morbidities is set to increase – a time bomb for the NHS.

There is as yet no cure for IBD. Treatment may be medical, surgical or a combination of both. It aims to manage flares, support people to stay well and monitor long-term risks. People living with IBD face

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a lifetime of medication and, in many cases, major surgery. If left untreated, complications from the conditions can be life-threatening. Medical treatment includes steroids, immunosuppressants and biologic medicines.<sup>6</sup>

21% of people with Crohn's will have resection surgery within five years of diagnosis and 26% within 10 years.<sup>7</sup> 10–15% of people with Ulcerative Colitis are likely to require surgery at 5–10 years.<sup>8</sup> People with extensive disease are at risk of potentially life-threatening complications – such as a complete blockage or perforation of the bowel – if surgery is not considered in a timely fashion. Lifetime costs for IBD are comparable to a number of major diseases, including heart disease and cancer.<sup>9</sup>

## Setting the standard for IBD care

This report brings together the results of a unique approach – combining comprehensive feedback from both people with IBD and hospital IBD services – to discover how well IBD services across the UK are providing care against the [2019 IBD Standards](#).<sup>10</sup>

**With 166 adult and paediatric IBD services (72%) and 10,222 adults, children and young people with IBD taking part, we have the evidence and a vital opportunity to improve care for everyone with IBD.**

The first audit of Inflammatory Bowel Disease (IBD) services in 2006<sup>11</sup> highlighted large variation in standards of care and the need for authoritative published standards defining what a good IBD service should look like. 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 *NICE quality standard for Inflammatory Bowel Disease*, published in 2015<sup>12</sup> and *Scotland Leading the Way – the National Blueprint for Inflammatory Bowel Disease*, published in 2016.<sup>13</sup>

The IBD Quality Improvement Programme, led by the Royal College of Physicians,<sup>2</sup> and concerted programmes of work across the four nations, have maintained a focus on IBD service improvement.

## IBD UK, the IBD Standards and IBD Benchmarking Tool

[IBD UK](#) was launched in 2017 as a partnership of 17 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, personalised care, whatever their age and wherever they live in the UK.

IBD UK worked together with over 150 healthcare professionals and over 700 people living with IBD to develop the 2019 IBD Standards,<sup>14</sup> which set out what high-quality, personalised care should look like at every point of the patient journey – from first symptoms to treatment and ongoing care – and how IBD services need to be organised to deliver this. These were developed in alignment with the British Society of Gastroenterology consensus guidelines on the management of Inflammatory Bowel Disease in adults<sup>15</sup> and Association of Coloproctology of Great Britain and

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Ireland consensus guidelines in surgery for Inflammatory Bowel Disease.<sup>16</sup>

The [IBD Benchmarking Tool](#) was designed to assess how well services are performing against the IBD Standards, highlighting excellent care and helping services to plan improvements. It includes a Service Self-Assessment, completed by individual IBD services, and the IBD Patient Survey, completed by people with IBD using each service. The data helps us to understand the different perceptions of services and their patients. Local reports showing how individual services are doing against the IBD Standards were released in March 2020 and those publicly available can be downloaded from [www.ibduk.org](http://www.ibduk.org).

## **Making IBD services more equitable**

COVID-19 has highlighted the importance of addressing inequalities and understanding whole population needs in providing good care. Feedback from the IBD Patient Survey highlighted the need for IBD care to recognise and reflect the needs of different groups in the community.

## **Next steps for IBD care**

This report highlights pockets of excellent practice, but also demonstrates considerable variation in care, including some differences between paediatric and adult services and across the four nations.

There are system-wide issues that need to be addressed to enable services to deliver consistent, high-quality, personalised care for people with IBD, whatever their age and wherever they live in the UK. These will be explored in detail in the following chapters.

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**RHIANNON, DIAGNOSED WITH  
ULCERATIVE COLITIS IN 2011**

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# Improvements to diagnosis and information provision



## The impact of delayed diagnosis

Most people are diagnosed with IBD between the ages of 15 and 40, although IBD can develop at any age and there is a second smaller peak in diagnosis for those in their fifties, sixties and seventies.<sup>17</sup> This means that many people with IBD live most of their lives with the conditions and will require specialist treatment and healthcare throughout, at significant cost to the NHS.

While people are waiting for diagnosis, the impact of symptoms can be profound, leading to time off school and work, withdrawal from social relationships and inability to carry out everyday activities such as shopping and exercise. Children may experience delayed growth and development. As most people are diagnosed at a young age, when they are just starting out in their independent

lives, this can be particularly difficult to deal with and have a lifelong impact, limiting opportunities and aspirations. This has societal and economic, as well as individual consequences.



waited more than a year for a diagnosis.

Prompt diagnosis and treatment will lessen the significant costs and potentially worse outcomes associated with delayed diagnosis. These include reduced response to medical treatments and higher incidence of urgent and emergency surgical intervention.<sup>18</sup> Those who experience symptoms for more than six months prior to their diagnosis of Ulcerative Colitis are more likely to undergo colectomy.<sup>19</sup>



## PATIENT STORY

### Jacob, diagnosed with Crohn's Disease in 2018



“I had blood in my poo and crippling stomach cramps, was exhausted and veered from being

constipated to going to the toilet several times a day. Over 1–2 years before I was diagnosed, I went to the GP several times. I was given iron supplements and felt as if the GP was trying to rule out other things.

My diagnosis was sudden and scary. At 4am one morning, I was in terrible

pain and couldn't move an inch. I felt like something inside was going to pop, so an ambulance was called. The hospital thought it was suspected appendicitis, but I had a CT scan which showed that my bowel was perforated and I had contracted sepsis. I needed emergency surgery, which resulted in a stoma being formed to allow my bowel to rest. I woke up from surgery to be given a diagnosis of Crohn's Disease. At 17, I had no knowledge of Crohn's or stomas and was forced to grow up very quickly. It had a big impact on my mental health.” ●

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## Survey findings on diagnosis

1,826 adults and 295 children and young people who had been diagnosed with IBD in the previous two years responded to questions on diagnosis in the IBD Patient Survey.

Those who said they had been seen by a specialist more quickly, i.e. within the recommended referral time frame of four weeks, were more likely to:

- Rate the overall quality of their care highly
- Rate their condition as less severe

66% of the survey free-text comments relating to diagnosis mentioned the length of time to diagnosis.

It is therefore very concerning that, of those responding to the Patient Survey, diagnosis was reported to take:

- More than six months for 39%
- Over a year for 26%

These figures were broadly similar for adults and children and young people.

The data also showed that delayed diagnosis was associated with significant use of Accident and Emergency (A&E) departments:

- 41% reported visiting A&E at least once before diagnosis.
- More than 1 in 10 (12%) reported visiting A&E three or more times.

**“The biggest problem is initial diagnosis. I’ve just had surgery and I believe this could have been delayed or avoided if I’d received the appropriate treatment when the symptoms started.”**

Those who reported waiting longer for their diagnosis were more likely to visit A&E more often. This reflects previous findings from the European-wide IBD2020 survey which reported that more than half of the patients surveyed (4,221; 56.7%) sought emergency care prior to diagnosis.<sup>20</sup>



visited A&E at least once before being diagnosed, with 12% visiting three or more times.

The impact of COVID-19 will clearly have resulted in further delays in diagnosis for people with suspected IBD given more restricted access to general practitioners (GPs) and specialists, and to investigative tests such as endoscopy needed to confirm diagnosis.

## Why is diagnosis being delayed?

There are several reasons why it can take some time to receive a diagnosis.

- **Lack of public understanding and awareness of Crohn’s and Colitis.**

This results in symptoms not being recognised by individuals themselves, or by family members. 80% of those responding to the Patient Survey felt that the public have limited or no understanding of Crohn’s and Colitis.

- **Stigma associated with the symptoms.** This is an issue for most people with IBD but can pose particular problems for people with different cultural backgrounds. For example, in some communities, ill health can affect someone’s perceived “marriageability” and create unfounded concerns for the health of future offspring.<sup>21</sup>

- **Symptoms that can be associated with a range of other conditions.**

These include irritable bowel syndrome (IBS), bowel cancer, coeliac disease, eating disorders, endometriosis and ovarian cancer. GPs are likely to see many more people with IBS (10% of the population) than IBD (estimated to be less than 1% of the population).<sup>22</sup> One in six individuals with IBD initially receive a diagnosis of IBS.<sup>23</sup> This includes those who were initially misdiagnosed with IBS and those who develop IBD on a background of IBS, something that is not currently well-understood.

A recent study found people with IBD experienced significantly more gastrointestinal symptoms, like diarrhoea and abdominal pain, in the five years before they were diagnosed compared to the general population, potentially attributable to undiagnosed disease.<sup>24</sup>

- **Symptoms can present atypically.**

For example, while diarrhoea is the most common symptom, this is not present in all adults with Crohn’s or Colitis; and up to 44% of children with IBD do not experience diarrhoea.<sup>25</sup> Other symptoms can include fever, weight loss, anaemia, inflammation of the joints, eyes or skin, and mouth ulcers.



- **Lack of knowledge about IBD in community healthcare professionals.**

A UK-wide survey of GPs in 2020 for the Royal College of General Practitioners (RCGP) and Crohn's & Colitis UK IBD Spotlight Project found that there was a need for more training in IBD.<sup>26</sup>

- **Lack of understanding and confidence in the use of faecal calprotectin testing.** This test measures inflammatory markers and can help to differentiate between IBS and possible IBD. A 2017 survey for the IBD Spotlight Project found that 33% of GPs were not confident or less than confident in requesting and interpreting faecal calprotectin results.

## Improving diagnosis: referral to a specialist in four weeks

The IBD Standards and the National Institute for Health and Care Excellence (NICE) quality standard for Inflammatory Bowel Disease<sup>12</sup> set out that people with suspected IBD should be seen by a specialist within four weeks of referral by a primary healthcare professional. However, only 29% of those responding to the Patient Survey said they had been seen by a specialist within four weeks of referral. Those who felt their care was well-coordinated between their GP and specialist were more likely to say they were seen within four weeks.

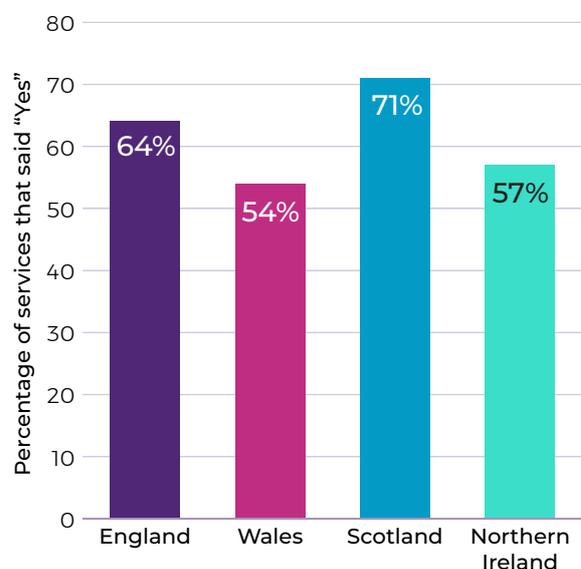
There was wide variation across the UK, and between paediatric and adult services, in meeting the four-week guideline. These differences were reported by people with IBD and by clinical teams.

Referral pathways support the timely identification of suspected IBD and other lower gastrointestinal conditions. Where these pathways are clear, well-understood and supported by good primary and secondary care coordination, they can work very effectively. However, only 64% of services reported having these in place. There were some differences between the four nations, as shown in Figure 2.

Just 1 in 4 (24%) of IBD services reported having referral pathways in place and being able to see over 90% of those with suspected IBD within four weeks of referral. Paediatric IBD services were more likely than adult services to report that they met these criteria (38% versus 21%).

Faecal calprotectin tests are an important tool for improving diagnosis and referral from primary care. They are a simple

**Figure 2: Is there an agreed referral pathway for suspected IBD between primary and secondary care?**



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stool test to measure inflammatory markers and cost only around £25 per test.<sup>27</sup> Supported by British Society of Gastroenterology (BSG) IBD guidelines<sup>15</sup> and NICE recommendations,<sup>28</sup> these tests can help determine if further investigation of gastrointestinal symptoms is needed, and support rapid and appropriate referrals.

## Keeping patients informed and involved

The period of waiting for the outcome of tests and investigations can be

a particularly anxious time, so clear, timely communication is vital.<sup>29</sup> The IBD Standards set out that all patients should be provided with a point of contact and clear information about pathways and timescales while awaiting the outcome of tests and investigations.

However, only 44% of those responding to the Patient Survey said they were given clear information while waiting for the outcome of tests. 72% of services overall said they had a process for this, ranging from 79% in Scotland



### BEST PRACTICE: YORK FAECAL CALPROTECTIN PATHWAY

The Yorkshire & Humber Academic Health Science Network worked with York Teaching Hospital NHS Foundation Trust to develop a pathway for faecal calprotectin testing to improve diagnosis. This included providing templates and leaflets – for GPs and patients – to help them use and understand the process.

A pilot roll out in 2017 across seven clinical commissioning groups (CCGs) and 198 GP practices in the North of England resulted in (per 1,000 patients tested):

- Financial benefits of up to £160,000 in savings to the health economy, including a saving of £42,000 in endoscopy services
- A reduction of up to 267 unnecessary outpatient appointments
- A reduction of up to 289 unnecessary colonoscopies
- A reduction in waiting times for patients
- A reduction in the number of patients referred to secondary care who are not subsequently diagnosed with IBD
- A reduction in the number of referrals from primary care after a patient had undertaken a faecal calprotectin test from 24% to 13% – meaning endoscopy services could be used more efficiently, for those in most need

The pathway demonstrated a quality adjusted life years (QALY) benefit compared to all comparator pathways. By the end of 2019, the pathway had been rolled out to 71 CCGs in England.

[Click here to read the full case study](#)

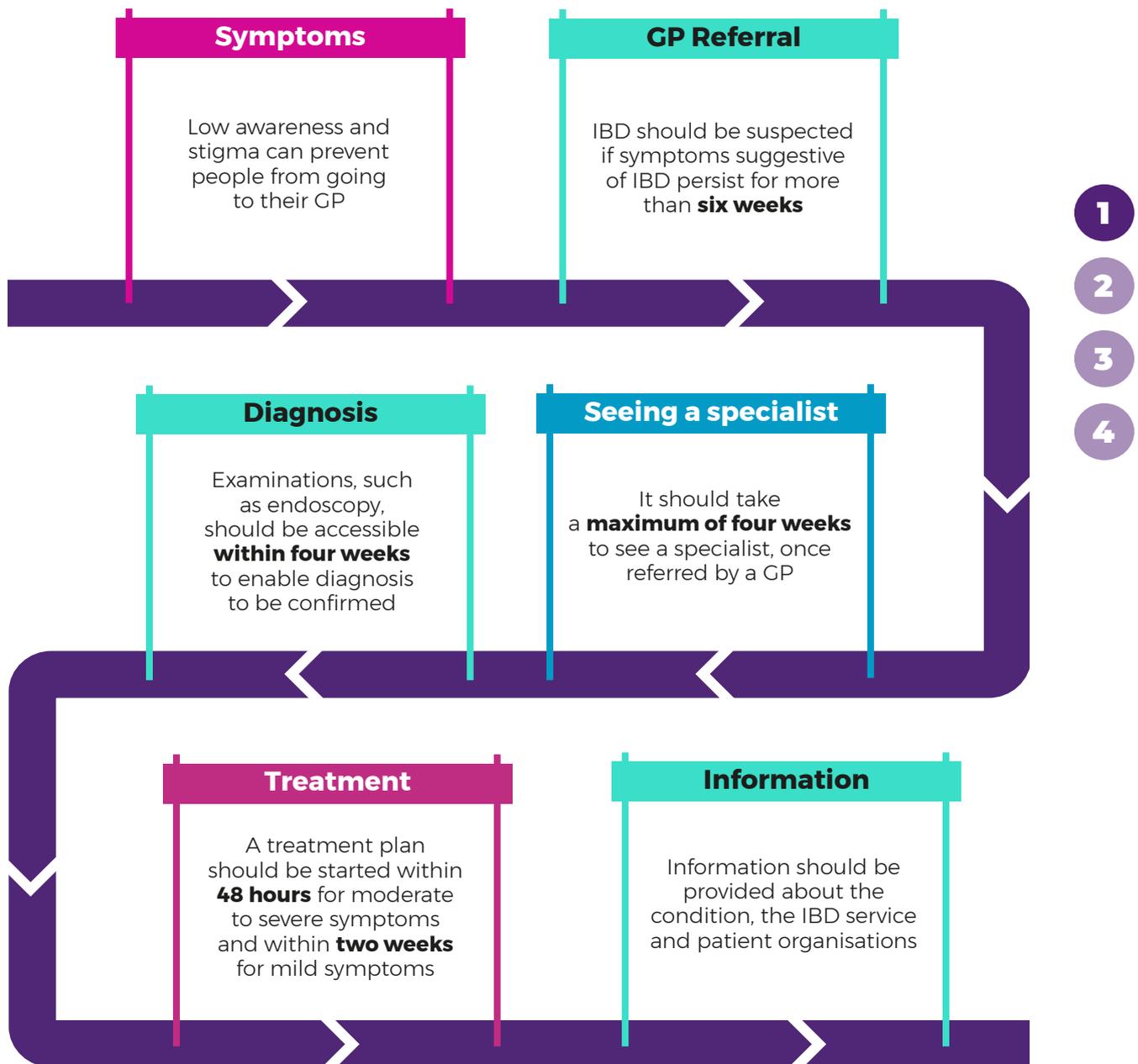


to 62% in Wales, and 94% of paediatric services versus 66% of adult services. There is clearly more work to do to ensure all patients receive accessible information at this time.

Information is also extremely important at the point of diagnosis. Providing tailored information and support which

gives people greater knowledge, skills and confidence in the management of their condition has been significantly associated with a range of benefits, including positive self-management of illness, reduced mental health symptoms, healthier coping strategies and more consistent adherence to medication regimens.<sup>30</sup>

**Figure 3: The journey to diagnosis**



Timeframes taken from the NICE quality standard for IBD<sup>12</sup> and IBD Standards 2019. Urgent and emergency referral should take place sooner if symptoms are severe or red flags are indicated.

However, around one-third of those responding to the Patient Survey said they were not offered any information when they were diagnosed about:

- Their condition (32%)
- The IBD service (37%)
- Patient organisations (32%)

Those that said they were offered written information were more likely to:

- Say they had contact with an IBD nurse specialist
- Rate the quality of their care highly

Children and their parents/carers were more likely to be offered written information than adults (96% versus 64%).

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 personal goals fully into account. The benefits, risks and expectations of different treatment options should be discussed with patients.



were not offered any information about their condition when diagnosed.

This should include nutritional therapy, such as exclusive enteral nutrition in Crohn's Disease, where appropriate. Clear guidance should also be provided about what to do and who to contact if side effects or continued or worsened symptoms are experienced and how and when treatment will be reviewed. This should include the number of the IBD service advice line as well as emergency/out-of-hours contact details.

**“I’ve found out quite a lot of information over the last year on how to manage the Colitis but when I was diagnosed there was no help at all.”**

People who are newly diagnosed with IBD should be given appropriate information about their condition and its treatment to support shared decision-making, including details of:

- The diagnosis and which parts of their gut or elsewhere are affected
- Their initial treatment, including details of the drug regimen, dietary or surgical interventions – with anticipated benefits and possible side effects
- Support for self-management, including pain and fatigue
- Monitoring and follow-up needs
- Likely course of their illness in the future, including associated conditions and potential complications
- Advice on possible lifestyle implications including smoking, alcohol, exercise, nutrition, education, employment, social activities, sex, contraception, family planning and pregnancy



However, of those responding to the Patient Survey who had been recently diagnosed:

- Only 50% reported that they had been given enough information about potential treatments and care, including benefits and possible side effects, to understand the options available to them and make an informed choice.
- Just 34% felt they were ‘definitely involved’ as much as they wanted to be with decisions about their care and treatment.



## BEST PRACTICE: NEW DIAGNOSIS CLINIC AT ST MARK'S HOSPITAL, LONDON

St Mark's Hospital set up a new diagnosis clinic to offer education to newly diagnosed patients and signpost them to other information and resources. Empowering patients with knowledge, skills and confidence ("patient activation") is associated with better outcomes in many chronic diseases.

Patient empowerment was measured using the Patient Activation Measure (PAM) before and after the first consultation. PAM is a validated questionnaire that measures knowledge, skills and confidence in patients and captures the extent to which people feel engaged and confident in taking care of their condition. Anxiety and depression were also assessed using the Generalised Anxiety Disorder scale and Patient Health Questionnaire at the first clinic visit.

The PAM showed that half of the patients attending the clinic had low levels of activation before the first consultation. With tailored education, 57% had an improved PAM score. Depression was also found to be a potential barrier to patient empowerment. Early assessment of patients' activation levels and mental health was recommended to guide healthcare providers to offer individualised care.

[Click here to read the full case study](#)

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The IBD Standards also state that patients should be signposted to information and support from patient organisations. Patient organisations, including Crohn's & Colitis UK, CICRA (Crohn's in Childhood Research Association) and the Ileostomy & Internal Pouch Association, produce patient information in digital and hard-copy formats. These resources have been designed especially for people who are newly diagnosed, in consultation with patients, carers and healthcare professionals.

These three organisations alone distribute hundreds of thousands of printed publications each year to people affected by IBD and see even more visits to their online resources. The one-to-one and family support they provide is also vital.

### Getting treatment underway

Once a diagnosis of IBD has been confirmed, it is important to put a treatment plan in place as soon as possible. This gives the best chance of getting symptoms under control and improving outcomes and quality of life.

However, 24% of those responding to the Patient Survey who had been diagnosed within the previous two years said it had taken longer than two weeks to start treatment after diagnosis.

The IBD Standards set out that people newly diagnosed with IBD should have a treatment plan within 48 hours if they have moderate to severe symptoms, or

within two weeks for mild symptoms. 58% of services said they had processes in place which enabled them to meet this standard.

It is important to understand that this is far from the end of the initial journey for many people with IBD as it can take some time to find the best treatment regimen.



## RECOMMENDATIONS FOR ACTION

- 1.** There should be a public health campaign to raise awareness of the symptoms of Crohn's and Colitis.
- 2.** Healthcare professional associations, training bodies and patient organisations need to work together to upskill community healthcare professionals in recognising potential IBD.
- 3.** Faecal calprotectin testing must be used consistently and appropriately in primary care, as part of agreed referral pathways between primary and secondary care, and emergency and specialist teams. These referral pathways should be in place in every service.
- 4.** Governments across the four nations should ensure that services are resourced to enable people with suspected IBD to be seen, investigated, diagnosed and treated in line with the time frames set out in the IBD Standards.

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**ALWINE, DIAGNOSED WITH  
ULCERATIVE COLITIS IN 1986**

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# Personalised care and support for self-management



Following diagnosis, people with IBD don't just want to survive or exist, they want to live well and thrive, regardless of the challenges the conditions bring. For this to happen, they must be able to access high-quality specialist IBD care easily when they need it, and in a way that recognises their unique preferences and needs. People with IBD struggle to receive vital support for mental wellbeing, diet, pain and fatigue. The clear message from people with IBD who responded to the Patient Survey is that care needs to look beyond their bowel or their drug treatments and recognise the many and varied ways IBD affects their bodies, minds and lives.

## What is personalised or person-centred care?

Past surveys of healthcare professionals and people living with IBD suggest understanding of what personalised

care planning and supported self-management mean can vary significantly. Personalised care for people with IBD is:

- **Personal:** It focuses on “What matters to you?” rather than “What’s the matter with you?”
- **Holistic:** It recognises that you are more than just a diagnosis, and instead addresses your physical, emotional wellbeing and social care needs together as one.
- **Involves shared decision-making:** It actively involves you in decisions about your care. For example, in decisions about medications or surgical interventions.
- **Supports self-management:** It empowers you to take an active role in your care by giving you the information, skills and confidence to self-manage and live as well as possible.

- **Equal:** It treats you as an equal partner in decisions about your care, not doing things to you but *with* you.
- **Coordinated:** It delivers good joined-up care, where information and decisions are shared in a timely manner and include everyone involved in your care.

Delivered well, personalised care has positive effects on patients' decision-making, levels of confidence and ability to manage a health condition. It has been shown to reduce admissions and contact with the NHS.<sup>31</sup> Personalised care and holistic approaches to care are not just a "nice to do", but fundamental to sustaining the NHS as the population ages. This has been reflected in strategic policy, including [NHS England's Long-Term Plan](#) and [NHS Scotland's 2020 Vision for Health and Social Care](#). However, while conditions such as cancer and dementia have seen investment and commitment to meet these needs,<sup>32</sup> there hasn't been the same recognition, urgency or proliferation of holistic or person-centred interventions in IBD.

The IBD Standards state that a personalised care plan should be in place for everyone with IBD, alongside access to an IBD nurse specialist and telephone and/or email advice line. These plans should be

**“My whole life is upside-down because of this disease. Taking my Humira is a very small part of my life – the rest of my life is not treated. For instance, my nutrition, not knowing what to eat. I live alone and don't cope well with the tiredness and so on. I feel so alone.”**

developed following a holistic needs assessment – which addresses physical, social and emotional needs and preferences.<sup>33</sup> A personalised care plan differs from a hospital follow-up letter, treatment plan, or a digital app that records patient-entered data on symptoms.

Personalised care plans are produced with the patient and shared with and updated by the wider multidisciplinary team (MDT) and GP. They set out what matters to the person, identify goals and describe how these will be achieved. For example, goals might include going back to university, starting a family or being able to ride a bicycle again.

- Only 9% of those responding to the Patient Survey reported having a written personalised care plan.
- Children were more likely to have a personalised care plan than adults (27% versus 8%).
- 30% of services responding to the Service Self-Assessment said that all patients had a personalised care plan, developed as part of a defined care planning process.

This highlights differences between what people with IBD feel they have in place and what services believe they are providing.

Those who reported having a personalised care plan were more likely to:

- Say that they had the information and skills to confidently manage everyday symptoms and live as well as possible
- Rate the quality of their care highly

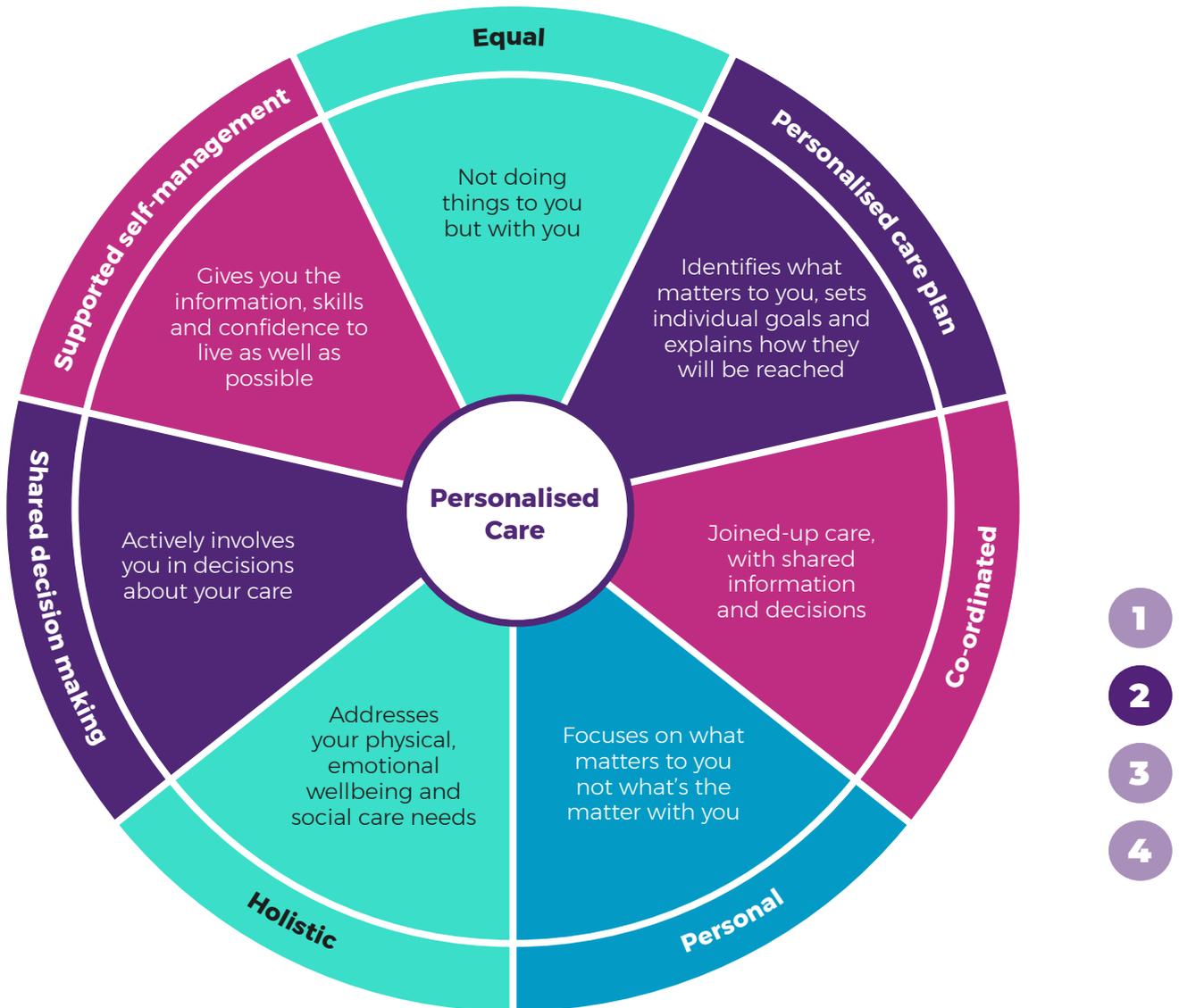
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**Figure 4: What is personalised or person-centred care?**



**Meaningful conversations**

Patient survey comments indicated that good communication strongly influenced the quality of people's experience. This included feeling listened to and having the opportunity to focus on what mattered to them.

- 86% of services reported that consultations allow for discussion with patients about wider life goals and aims from treatment.
- However, only 30% of those responding to the Patient Survey reported discussing wider life goals in their consultations.

- 54% of those who had been recently diagnosed said that what mattered to them was considered when planning treatment.

Differences were evident across the four countries. In Northern Ireland, only one service reported having a defined care planning process in place which includes discussion about wider life goals and aims from treatment. In England, 56% of services reported having such a process.

Those who reported contact with an IBD nurse specialist were more likely to say they had:

- Been given information on treatments and care after diagnosis
- The information and skills to manage their condition

IBD services and staff must be resourced to support meaningful conversations and goal setting.

Holistic needs assessments and conversations about what matters to patients (including physical, social

and emotional needs) must be prioritised throughout the patient journey.

### More than just the gut

People with IBD are affected by more than just their bowel symptoms. Up to 50% will experience extraintestinal manifestations, involving different parts of their body, commonly joints, skin, bones, eyes, kidneys and liver.<sup>34</sup>

The IBD Standards set out that, after diagnosis, everyone with IBD should have a full assessment of disease, nutritional



#### PATIENT STORY

### Paul, diagnosed with Ulcerative Colitis in 1986



“I had to move hospital to get good care. My previous hospital dished out course after course of prednisolone tablets, leaving

me with osteopenia (weak bones) and a weight problem.

The care at my current hospital has been exemplary. When it became apparent that azathioprine was no longer controlling my flares, my consultant offered me a choice of adalimumab subcutaneous injections or infliximab intravenous infusions and discussed these options with me. I haven't needed prednisolone since and I'm not overweight anymore.

At the same consultation we agreed a treatment plan if my treatment was to stop working.

After every appointment, I get an electronic copy of the letter from my hospital to my GP through the MyChart app and website – this means we're all on the same page. In between appointments, my hospital's IBD nurses respond by the end of the next working day latest to messages on MyChart, which enables prompt adjustment of medication to maintain tight disease control.

My hospital is genuinely committed to giving patients a voice. It has set up an IBD Patient Panel, of which I am the secretary. We meet four times a year and the IBD lead consultant, senior IBD nurse and IBD psychologist regularly attend.” ●

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status, bone health and mental health, in order to develop a personalised care plan.

Of those who responded to the Patient Survey, having been recently diagnosed:

- 45% reported that the severity of their Crohn's or Colitis had been assessed
- 28% reported that signs of malnutrition and/or nutritional deficiencies had been assessed
- 10% reported that how well they were coping emotionally had been assessed
- 5% reported that their bone health had been assessed

Those responding to the Patient Survey who said they were asked about complications outside the gut, pain, fatigue and mental health were more likely to:

- Rate the quality of their care highly
- Report feeling more able to cope



had found it hard to cope with having Crohn's or Colitis over the last year.

47% of those responding to the Patient Survey said they were not asked during appointments about IBD-related complications and/or conditions outside of the gut, so were not able to discuss treatment options for these.

Pain and fatigue can be major problems for people with IBD – during flares and when in remission. Research shows that 86% of people with active IBD report fatigue and, even in remission, 40% say fatigue is their greatest concern.<sup>35</sup> Pain can affect people with

active and inactive IBD. For around half, pain is an ongoing problem.<sup>36</sup> Both fatigue and pain can contribute to low mood and anxiety, with a significant impact on everyday life – including the ability to do household tasks, socialise and work.

The IBD Standards state that pain and fatigue should be investigated and managed.

- 48% of those responding to the Patient Survey said that they were not asked at appointments about fatigue/tiredness or able to discuss possible treatment options.
- Just over a quarter (29%) reported that they were not asked about pain or able to discuss possible treatment options.
- 13% of services said they have protocols in place for the investigation of patients with pain and fatigue.

IBD can affect people's emotional wellbeing. This can be due to a range of issues including coming to terms with having a lifelong and often debilitating condition, sleep disturbance, the unpredictable nature of the symptoms or loss of self-esteem related to body changes or surgery. 60% of those responding to the Patient Survey said they were not asked about their mental health during appointments.

Psychological support needs to be offered throughout the patient journey, as set out in the IBD Standards. Alongside the need for integrated specialist psychological support as part of the multidisciplinary team, this should include referral and signposting to community services such as the

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## BEST PRACTICE: PATIENT AND PARENT PANEL AT BIRMINGHAM CHILDREN'S HOSPITAL

Birmingham Children's Hospital (BCH) is unique in organising a Patient and Parent Panel, which has been running since 2010. It meets three to four times a year on a Saturday and on average 20–30 families attend. It is an informal setting where children and young people with IBD and their parents can raise issues with the IBD service and hear about changes made as a result of previous feedback. It is an opportunity to hear from healthcare professionals about IBD, from other young people about their experiences and from Crohn's & Colitis UK about the support on offer.

Parents value the opportunity to speak to other parents to allay fears about the impact of IBD on their child. Children and young people value the opportunity to talk about their experiences at the youth club and the option to have an individual meeting with a member of their IBD team. In addition to being highly valued by young people and their parents, the Patient and Parent Panel has played a key role in developing the IBD service at BCH. As a result of feedback, there is now more emphasis on psychological provision and transition to adult services, and more afternoon clinics – which suit young people and their parents.

[Click here to read the full case study](#)

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[Improving Access to Psychological Therapies \(IAPT\) programme.](#)

### 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.

The desire to be involved in shared decision-making will vary. The 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.<sup>37</sup>

- 25% of those responding to the Patient Survey said they hadn't been given enough information about potential treatments and care, including benefits and possible side effects, to understand the options available to them and make an informed choice.

- Just under half (47%) felt they were definitely involved as much as they wanted to be with decisions about their care and treatment.
- These results were very similar for children and adults.
- Nearly all services (97%) said they provided patients with written information about IBD and treatments, including co-designed booklets from patient organisations.

The findings raise questions about how services can improve shared decision-making. This will include increasing access to the information they provide and ensuring it is provided in accessible and easy-to-understand formats.

### **Self-management needs to be properly supported**

When people with IBD have difficulties self-managing their condition, this can lead to complications, and poorer mental and physical health outcomes.<sup>38</sup> The evidence shows that good self-management means fewer symptoms and hospitalisations and less need for treatment escalation.

**“It has always been left to me to educate myself about my IBD and medication, to the point where consultants have told me to use Google. That is why Crohn’s & Colitis UK is so invaluable to me. In the future I would like to see the NHS offer more practical advice and the opportunity to attend talks/meetings to learn more about my IBD.”**

The 2014 IBD Audit<sup>39</sup> found that “Patient education is of fundamental importance, given the nature of IBD, and needs to be an integral part of IBD care.” It went on to recommend that “Services should be encouraged to develop innovative approaches to deliver patient and family education.” Self-management in IBD enables people to have more control over their lives by giving them the knowledge and skills to plan (for example, to start a family or travel), make healthy choices and manage their condition.



said they had not been offered opportunities to learn more about treating and/or living with Crohn’s or Colitis.

The IBD Standards state that people with IBD should be supported in self-management through referral or signposting to education, groups and support.

The Patient Survey asked if opportunities had been offered during the previous 12 months for people to attend a course on IBD, educational talks or an IBD open day at their local hospital to learn more about treating and/or living with Crohn’s or Colitis.

- 78% said they had not been offered any of these opportunities.
- 9% had been offered the opportunity to attend educational talks.
- 10% had been offered the opportunity to attend an IBD open day at their local hospital.

In contrast, 58% of services said educational and networking opportunities exist to support

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self-management, with signposting to externally run educational opportunities.

Patient organisations offer wide-ranging, high-quality information and support.

- 28% of those responding to the Patient Survey said they were not offered any information about patient organisations as part of their ongoing care.
- 74% of services said they make information about patient organisations available in all settings. However, only 9% said that this information is actively offered to patients, and regularly reviewed with patient feedback to address any gaps.

Those that were offered information about patient organisations were more likely to:

- Feel that they had been given enough information about potential treatments and care to make informed decisions
- Feel they had the information and skills to confidently manage everyday symptoms and live as well as possible
- Rate the quality of their care highly
- Report having found it easier to cope with having Crohn's or Colitis over the past 12 months

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.



### **BEST PRACTICE: DEVELOPMENT OF THE FLARE CARD AND CARE PLAN IN SCOTLAND**

Crohn's & Colitis UK partnered with the Scottish Government's Modernising Patient Pathways Programme to develop a Flare Card and Individualised Care Plan. The Flare Card helps people with IBD to recognise the symptoms of a flare, tells them what they can do for themselves and signposts to appropriate support.

It is planned for these tools to be integrated into a structured self-management programme in Scotland, delivered by IBD services with the support of Crohn's & Colitis UK and their broad range of accredited resources. This will help people with Crohn's and Colitis to self-manage their condition, offering a more person-centred approach to their diagnosis and ongoing care.

The Flare Card won the Alliance Self-Management Resource of the Year Award 2020 and is now available to all IBD services across Scotland.

[Click here to read the full case study](#)

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## Importance of regular reviews

The IBD Standards state that patients should be reviewed at regular intervals.

- 65% of those responding to the Patient Survey said they had regular reviews regardless of whether they were well or not.
- 4% said that they had never been reviewed.
- 39% of services had a clear protocol in place for determining how frequently review and monitoring of IBD patients should take place.

Those who had regular reviews were more likely to:

- Rate the quality of their care highly
- Report having “never” found it hard to cope in the last 12 months
- Rate their disease as less severe

Where people reported having no reviews, they were less likely to say they had a personalised care plan.

People with IBD have an increased risk of bowel cancer, particularly those with more extensive or active disease. The IBD Standards recommend regular surveillance, in line with national guidance.

- Only 18% of those responding to the Patient Survey reported that they knew when their screening colonoscopy was due and would receive a reminder.
- 52% of services said there is a clear, documented process for colorectal cancer surveillance which is communicated to patients.

There has been a huge shift to virtual consultations during the COVID-19 pandemic, which has advantages, for

example reducing the need to travel to hospitals for reviews. But we must ensure that personalised care remains a priority and that those who are already disadvantaged are not further marginalised by the digital divide.

## Surgery

Given the potentially life-changing nature of choosing surgery, and its physical and emotional impact, the IBD Standards recommend providing patients with information and psychological input to help them fully understand the impact of their decision.

86% of services said that people with IBD who were considering surgery were routinely directed to patient information leaflets, decision aids or other media to support decision-making and informed consent.

This compares well with feedback from those responding to the Patient Survey, with 82% reporting that they had been given information in a format that helped them understand the benefits and risks of surgery.

However, when looking further into the kinds of information and support offered to help with decision-making, there is much room for improvement.

- 8% said they were offered the opportunity to speak to or meet with someone who has had the same kind of surgery.

**“I recently had J-pouch surgery. I had no contact with my stoma nurse whilst in hospital or since discharge. I did not know who to contact with any issues.”**

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- 7% said they were able to understand outcomes data from the surgeon's previous surgeries, and were able to choose another surgeon if they wished.
- 28% said they were able to consider laparoscopic surgery.
- 5% said they were offered the opportunity to speak to a counsellor.

Decisions about where to have surgery can affect both care and outcomes. For example, 80% of hospitals perform less than one pouch operation per year and do not have a pouch nurse.<sup>40</sup>

It is also important that people receive good information when they are discharged from hospital after surgery, to ensure they can manage at home.

- Only 23% of those responding to the Patient Survey said they had been given clear information to help them manage care after discharge from hospital, including medicines, post-operative wound and stoma care.
- 93% of services said information is available for patients/carers about post-operative care before discharge.

This difference between what services consider is available and what patients say they are receiving suggests that resources and information are often not provided or signposted to in the right way, or at the right time – if at all.

### **It takes a team to deliver personalised care**

Where people with IBD reported having contact with an IBD nurse specialist, they were more likely to have the information and skills to manage their condition.

However, personalised care is the responsibility of the whole IBD team. To deliver it effectively, the traditional ways in which patients, doctors and nurses behave, act and communicate all need to change. It is important that all members of the IBD multidisciplinary team are trained in, and regularly using, personalised care approaches.<sup>41</sup>

IBD UK have developed a personalised care toolkit to support the delivery of personalised care in IBD services.<sup>42</sup>



## **RECOMMENDATIONS FOR ACTION**

- 1.** Everyone with IBD should have a personalised care plan from diagnosis, based on a holistic needs assessment, detailing specific multidisciplinary support, and flare (relapse) management.
- 2.** Structured self-management programmes should be co-produced with patients and commissioned for everyone with IBD.
- 3.** Everyone with IBD should have regular review and monitoring that meets their individual needs, both in terms of frequency and delivery.

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**MOEED, DIAGNOSED WITH  
CROHN'S DISEASE IN 2011**

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# Faster access to specialist advice and treatment

## Rapid access is vital for high-quality care

As a chronic, fluctuating condition with the potential for complications to be serious and potentially life-threatening, rapid access to specialists is essential for people with IBD. Timely management is also cost-effective for the NHS, preventing expensive inpatient stays or trips to A&E.

The annual cost of treating a flare (relapse) of Ulcerative Colitis or Crohn's Disease is up to six times greater than treating a patient in remission.<sup>43</sup>

The annual cost of treating patients with Ulcerative Colitis is estimated to be:

- £1,693 for those in remission
- £2,903 for those experiencing a flare
- £10,760 for those experiencing a severe flare

The annual cost of treating patients with Crohn's Disease is estimated to be:

- £1,800 for those in remission
- £10,513 for those experiencing flares

Previous research has found that 50% of people with IBD will experience at least one flare every year, when the condition is active.<sup>44</sup>

Flares can last from weeks to months and impact on all aspects of life. Symptoms can include urgent and frequent diarrhoea, which may be with blood and mucus, severe abdominal pain, extreme fatigue and weight loss.

Notably, flares aren't always just in the gut – extraintestinal manifestations can include inflammatory symptoms outside the bowel such as mouth ulcers, joint pain, skin rashes and eye inflammation.

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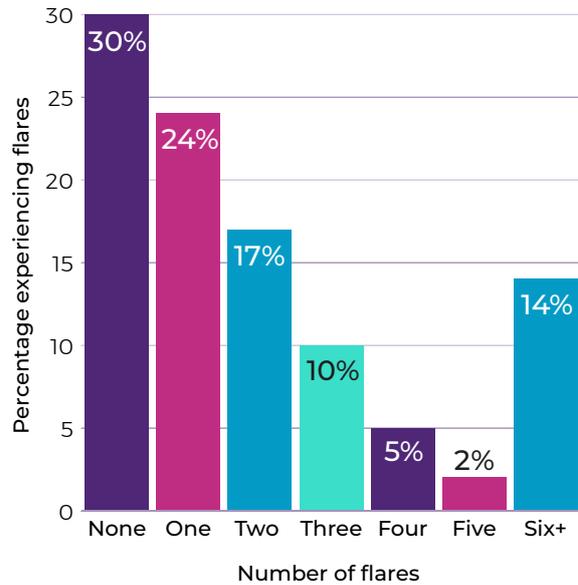
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Flares are disruptive and life-limiting. They can mean you have to miss school or do a different job and affect earning power, relationships, self-esteem and social networks. This can be devastating at any age and inhibit people’s life choices.

Of those who responded to the Patient Survey, 70% (6,732) said they had experienced one or more flares during the previous 12 months, with 14% reporting more than five flares over this period.

**Figure 5: How many flares have you experienced in the last 12 months?**



**PATIENT STORY**

Rhian, diagnosed with Crohn’s Disease in 2000



“I was diagnosed with Crohn’s Disease 20 years ago, in 2000, when I was 10. In recent years, I unfortunately experienced a deterioration in my health.

Despite being in a severe flare, I waited months for an appointment and then for a colonoscopy. Less than a month after that, I was admitted to hospital with a perforated bowel and, towards the end of 2019, I had no choice but to undergo emergency stoma surgery to save my life.

I waited five days for surgery. I was admitted onto a link ward rather than a colorectal surgical ward, where there were no stoma nurses on hand to prepare me before and aid my recovery afterwards. My stoma surgery went well, and I am very grateful to my surgeon for the very good job she did for me.

However, my recovery was very traumatic. I remained on the link ward. I felt unsupported and isolated from the IBD and stoma nurse specialists who were best placed to treat me. I spent hours with a nappy to my stomach, waiting for a stoma nurse to attend after my first bag leak. I still find these experiences traumatising today.” ●

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People who reported having fewer flares were more likely to:

- Have contact with an IBD nurse specialist
- Report having regular reviews for their Crohn's or Colitis
- Consider that their GP was knowledgeable about IBD and how to treat it

Those who reported having more flares were more likely to:

- Say they had found it hard to cope with having Crohn's or Colitis over the previous 12 months
- Rate the quality of their care lower

Flares that are untreated can allow the inflammation to progress, leading to:

- **Dehydration and malnutrition:** Diarrhoea, abdominal pain and cramping may make it difficult for enough nutrients to be absorbed.
- **Bowel obstruction:** Over time, parts of the bowel can thicken and narrow, which may block the flow of digestive contents.
- **Fistulas:** Sometimes inflammation can extend completely through the intestinal wall, creating a fistula (an abnormal connection between different body parts).
- **Intestinal rupture, or perforation:** This may be caused by the colon rapidly widening and swelling.
- **Increased risk of cancer:** Risk is linked to severity and duration of disease.
- **Impact on mental health:** Including stress, anxiety and depression.

It is therefore extremely important that people with IBD can recognise a potential flare and know what to do when one occurs.

- Only 23% of those who responded to the Patient Survey said they had been given information on how to recognise the first signs of a flare.
- 46% said they had received written details about who to contact and when if they thought they were experiencing a flare.
- 35% had been given information on how to stay well or reduce their risks of a flare.
- 31% said they had received no information on flare management.
- 57% of services reported providing information to all IBD patients on flare management.

This suggests that, while a range of information is being provided about flare management, most people with IBD are not receiving comprehensive information to enable them to manage flares effectively.

The IBD Standards state that all patients with IBD should be provided with clear information to support self-management and early intervention in the case of a flare. This should be part of a personalised care plan which includes specific guidance on how to recognise a potential flare and what steps to take if you have a flare.<sup>45</sup>

When looking at how people had managed their last flare:

- 40% of those who had experienced a flare in the previous 12 months said they had contacted their IBD nurse specialist or IBD advice line.
- 29% reported managing it themselves.
- 14% contacted their GP in the first instance.
- Only 1% reported referring to a treatment/flare or care plan.



**“When I know a flare is starting, a swift response can make all the difference to its severity. It’s very frustrating when you can’t get hold of anyone quickly or get blood tests done for a week or have to wait five days for a stool sample kit to arrive... by then it’s really too late to nip it in the bud.”**

## **Expert advice when it’s needed**

The IBD Standards state that rapid access to specialist advice should be available to people with IBD to guide early flare intervention, including access to a telephone/email advice line with response by the end of the next working day. Most IBD services run advice lines to provide expert support for people who have concerns between appointments, including potential flares. These can reduce the need for urgent care through enabling prompt and appropriate action to investigate, manage and treat a flare.



### **BEST PRACTICE: RAPID ACCESS CLINIC AT WESTERN GENERAL HOSPITAL, EDINBURGH**

From the mid-2000s onwards, the IBD team at Western General Hospital have been testing innovative ways of delivering services to help them cope with growing numbers of patients and deliver more patient-centred care. One of the most pressing challenges was to provide faster access to specialist advice and guidance during flares – to bring the disease under control without the need for a hospital admission. A new rapid access clinic was established to which IBD nurse specialists staffing the advice line and community clinics can refer patients directly. The new clinic enables people with IBD to see an on-call consultant gastroenterologist on the day who can institute the right treatment regime immediately.

The team uses a responsive model of patient-initiated follow-up care – based on individual needs – in which patients contact the service if they need to see a clinician. Information is provided about how to do this together with information about the advice line, community clinics and rapid access clinics. Clinicians identify patients who might struggle to use this system and follow up proactively with them, ensuring a personalised approach.

[Click here to read the full case study](#)

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72% of those responding to the Patient Survey agreed that they received a response by the end of the next working day when they contacted the IBD advice line, while 22% disagreed. As IBD service advice lines are supported by IBD nurse specialists, having sufficient IBD nurse specialist staffing is fundamental to ensuring a quick response to calls or emails.

## The importance of effective flare pathways

It is clearly important that GPs are able to support their patients who are experiencing flares effectively, including making a timely referral to the specialist service.

A survey of GPs, conducted as part of the RCGP and Crohn's & Colitis UK IBD Spotlight Project, found that 52% of GPs reported being less than confident or not confident in helping a patient with known IBD when they came to a clinic with a flare. Consequently, the Spotlight Project produced optimal flare pathways for Crohn's Disease and Ulcerative Colitis, which have been endorsed by the RCGP, Primary Care Society for Gastroenterology, British Society of Gastroenterology and Crohn's & Colitis UK.<sup>46</sup>

**“I have to try and manage everything myself and have constant issues trying to get help from anyone when I need it. I have no IBD nurse to contact and no ongoing support apart from six-monthly appointments.”**

The IBD Standards state that local treatment protocols and clear pathways should be in place for the management of IBD patients experiencing flares and include advice for primary care. Of the 132 adult IBD services that completed the Service Self-Assessment, only 49% had these in place.

Where services did have flare pathways in place, those responding to the Patient Survey were more likely to:

- Rate the quality of their care highly
- Report finding it easier to cope with having Crohn's or Colitis over the past 12 months

If specialist review is needed, it is important that services are able to free up time in clinics for urgent appointments.

The IBD Standards set out that patients with IBD should have access to review by the IBD team within a maximum of five working days and be able to escalate/start a treatment plan within 48 hours of review.

- 49% of those responding to the Patient Survey said they were able to start treatment for their last flare within 48 hours.
- 25% reported being able to start treatment after two to seven days.
- 15% said they had to wait more than two weeks to start treatment.
- 86% of services reported having an agreed process for access to specialist review within five working days and escalation/initiation of a treatment plan within 48 hours for all patients.

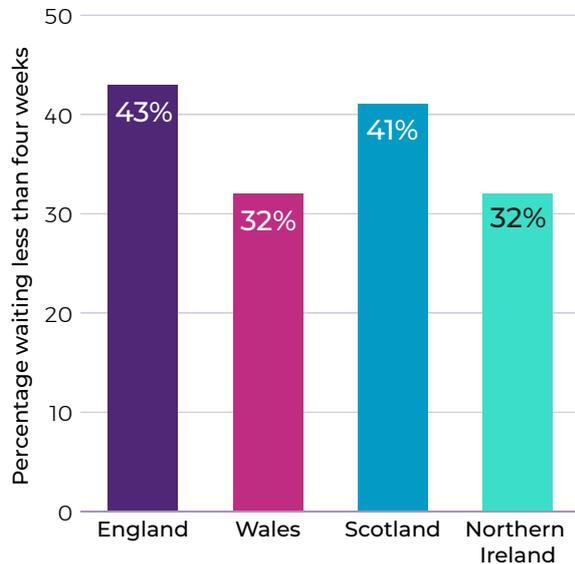
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**Figure 6: If you had an investigative test in the past 12 months, on average how long did you wait?**



### Waits for investigations

Investigations – including endoscopy and imaging – are often needed to identify the most appropriate treatment options.

UK-wide, 58% of those responding to the Patient Survey who had needed an investigation during the previous 12 months reported waiting more than four weeks for this. Waits varied across the UK and between paediatric and adult services.

- 68% waited more than four weeks in Wales and Northern Ireland, with 11% waiting more than six months in Wales.
- People were more likely to report waiting less than four weeks for an investigative test in paediatric than adult services (54% versus 41%).

The IBD Standards state that endoscopic assessment and imaging should be accessible within four weeks, and within 24 hours where patients are

acutely unwell or require admission to hospital. When using imaging, emphasis should be placed on MR enterography and ultrasound as they do not expose patients to ionising radiation.<sup>15</sup>

The shorter the time people had to wait for an investigative test the more likely they were to:

- Rate the quality of their care highly
- Report that their Crohn’s or Colitis was less active over the previous three months

### Specialist inpatient care and waits for surgery

Of those responding to the Patient Survey, 23% (2,292) had been admitted to hospital for an overnight stay or longer during the previous 12 months.

Of this group, 72% were emergency admissions, while 9% had been admitted more than once during the same 12-month period. Emergency admissions and emergency surgery are often a result of missed opportunities for earlier treatment.



of hospital admissions were emergency admissions.

Personalising patient care by involving a surgeon early in the treatment pathway is essential. This should happen through multidisciplinary discussion of patients and the regular use of joint clinics – involving both medics and surgeons. The options of medical and surgical intervention can be discussed, allowing full shared decision-making,



effective planning and swift intervention if required.

Once a decision and referral has been made for non-emergency, consultant-led surgery to take place on the NHS, this should happen within the small window of time when the patient has been optimised. This means that any infection has been treated, nutrition has been improved and medications weaned to as low as possible without inducing another flare. Operating outside this window results in more complications.<sup>47</sup>

Although current government guidance is for elective surgery to occur within 18 weeks of referral in England and Scotland and 36 weeks in Wales,<sup>48</sup> many patients require surgery well before this time.

The IBD Standards state that elective surgery for IBD should be performed

as soon as the patient's clinical status has been optimised and within 18 weeks of referral for surgery.

- 22% of those responding to the Patient Survey reported waiting longer than 18 weeks for their surgery.
- 69% of services reported that elective IBD surgery takes place for all patients within 18 weeks of referral.

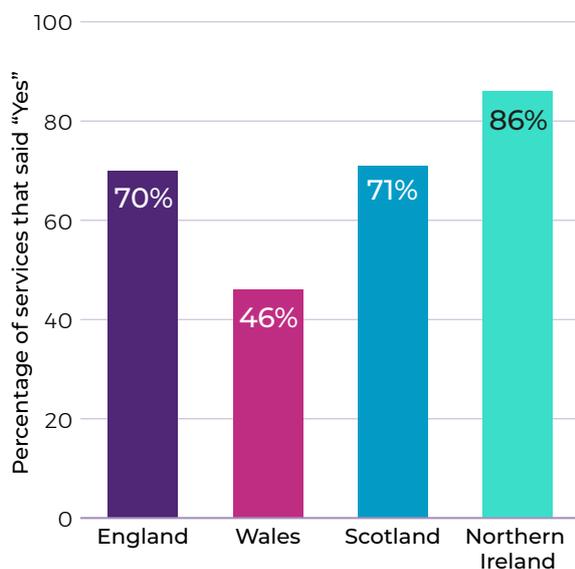
While these findings closely match, there are striking differences between paediatric and adult services, with 91% of paediatric services reporting that surgery takes place within 18 weeks of referral versus 63% of adult services. There is also wide variation between the UK nations, as shown in Figure 7.



waited longer than 18 weeks for surgery.

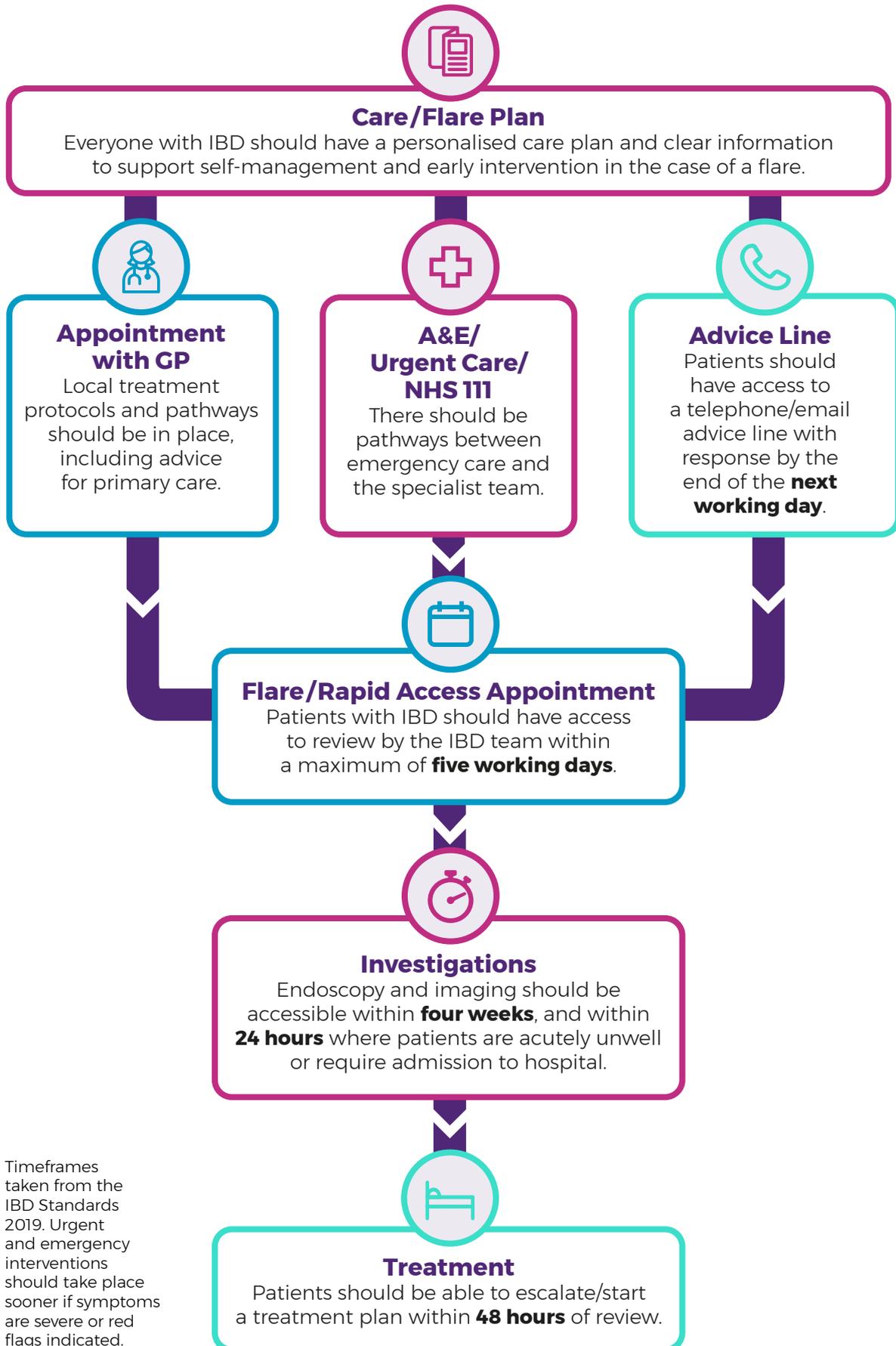
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**Figure 7: Does elective IBD surgery take place within 18 weeks of referral?**



These findings highlight real issues with access to critical IBD surgery. The current emphasis on diagnosing and treating patients with cancer symptoms as a priority is not always clinically relevant. Given the tight window for operating and the significant complications that can occur outside this window, some IBD patients should be prioritised alongside cancer patients. This was recognised during the first wave of COVID-19, when the royal colleges prioritised patients with Crohn's Disease who needed surgery alongside those needing cancer surgery.<sup>49</sup> This recognition needs to continue post-COVID.

**Figure 8: Routes for access to specialists**



Timeframes taken from the IBD Standards 2019. Urgent and emergency interventions should take place sooner if symptoms are severe or red flags indicated.

## Admission to a specialist gastroenterology ward

Being on a designated specialist ward and having daily review by a consultant gastroenterologist are both essential components of giving people with IBD access to the right expertise, monitoring and facilities. This will also give them a better experience, as they will be with patients with similar conditions.

The IBD Standards set out that patients requiring inpatient care relating to their IBD should be admitted directly, or transferred within 24–48 hours, to a designated specialist ward area under the care of a consultant gastroenterologist and/or colorectal surgeon. They also state that all IBD inpatients should have access to an IBD nurse specialist.

Having access to an IBD nurse specialist as an inpatient helps to support continuity and coordination of care while in hospital, as well as effective follow-up after discharge.

Those that were admitted to a gastroenterology ward were more likely to:

- Report being given the opportunity to speak to an IBD nurse specialist
- Rate the quality of their care highly

However, 42% of those responding to the Patient Survey who had been admitted within the previous 12 months said that they had not stayed on a gastroenterology ward.



### RECOMMENDATIONS FOR ACTION

1. All IBD services should ensure that everyone with IBD: (i) has a plan in place detailing steps to take in the case of a flare and (ii) can receive a response from an IBD advice line by the end of the next working day.
2. Commissioners and managers should ensure that rapid access clinics and prompt access to investigations are in place in every service, supported by flare pathways that are agreed between primary, secondary, and emergency care.
3. There should be a clear process for admission to a specialist gastroenterology/colorectal ward in every IBD service. Job plans for IBD nurse specialists should include time for inpatient visits.
4. Surgery for IBD needs to be prioritised appropriately, alongside surgery for other conditions, given the significant risk to patients of delays.

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**SUSIE WEN, DALJIT CHOCHAN,  
GINI HAY AND VIDA CAIRNES,  
CROHN'S & COLITIS UK NURSE  
SPECIALISTS**

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# Effective multidisciplinary team (MDT) working

## Why is MDT care so important?

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

The concept of MDT care was first implemented for the clinical decision-making and management of conditions like cancer, stroke and diabetes. MDT meetings involve all key professional groups in the consideration of complex patients and/or diagnostic dilemmas to create a clear care plan.<sup>50</sup> MDT-driven care has demonstrated

an improvement in survival across various conditions and has become integral to the care of patients with IBD. The UK IBD Audit found that 91% of participating institutions held some form of MDT meeting for patients with IBD.<sup>51</sup>

The IBD Standards call for everyone living with IBD to have safe, consistent, high-quality, personalised care. A clearly defined, well-organised and managed local IBD service is essential to delivering this.

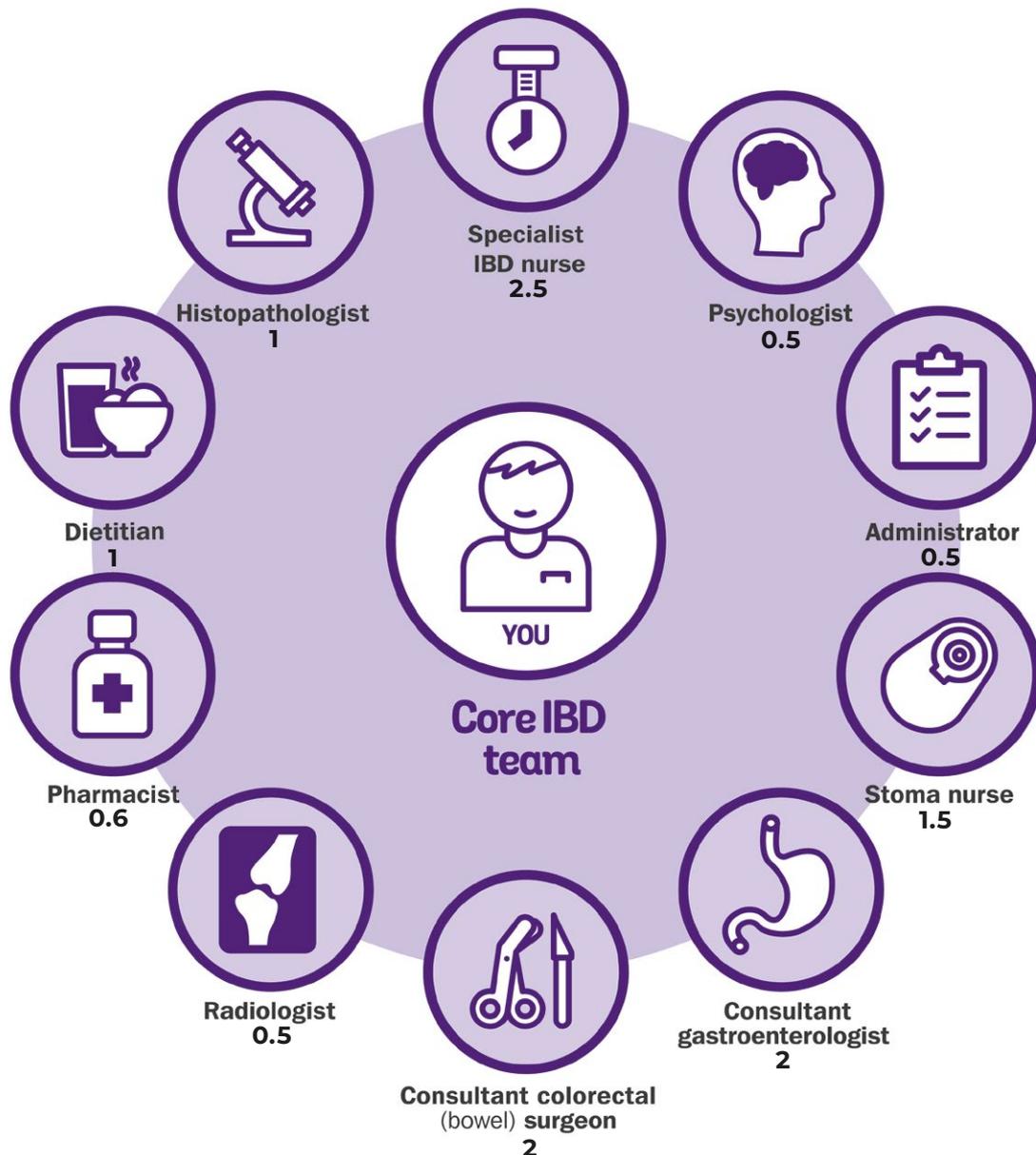
Those that responded to the Patient Survey who said they were supported by a team of IBD specialists to help them manage their condition were more likely to:

- Rate the quality of their care highly
- Report having felt able to cope with having Crohn's or Colitis



### Figure 9: The IBD team

The IBD Standards outline the range of professionals that should be included in the IBD team. For adult services, shown below each role is the number required per 250,000 catchment population.<sup>3</sup>



However, 22% did not feel they were supported by a team of IBD specialists.

### Is there a staffing problem?

The IBD Standards define the required composition of an IBD team in an adult IBD service.<sup>3</sup> None of the 132 adult IBD services that completed the Service Self-Assessment met the IBD Standards recommendations for all

roles across the team. Some met the requirements for all members of the team they had, but did not have the full range of specialists, whilst others had the full range of specialists but did not meet the standard level for all of them. The proportion of adult services<sup>52</sup> meeting the IBD Standards whole time equivalent (WTE) staffing recommendations were:

- Gastroenterologists – 31%
- IBD nurse specialists – 14%
- Stoma nurses – 23%
- Colorectal surgeons – 16%
- Pharmacists – 13%
- Dietitians – 7%
- Psychologists – 2%
- Radiologists – 37%
- Histopathologists – 8%
- Administrators – 25%

There is a clear need for more resourcing, to ensure IBD services are providing the most effective care at the right time in the most appropriate location. IBD teams

also need support to maintain their own wellbeing and resilience.

It should be noted that services reported difficulties in calculating the percentage of time that each member of the MDT spent specifically on IBD. Improved data is needed on the composition of the MDT and time spent on IBD specified in job plans, to strengthen this analysis. Services also identified difficulties in reporting the catchment population of their hospital – essential information when planning services. The fact that this information is not available to all services



## PATIENT STORY

### Anisha, diagnosed with Ulcerative Colitis in 2008



“Having access to an IBD nurse has been a game-changer for how quickly I can access support and guidance regarding

flares, questions on medication or any other advice that may affect my IBD. Through the IBD nurses, I’ve also learned how to self-manage, where appropriate.

I’ve needed to access dietitians, mental health professionals and rheumatologists linked to my IBD. Although I’m an educated university graduate, I’ve struggled when services haven’t been joined-up or easy

to access. I’ve rarely been asked about my mental health or fatigue, although these have been hugely debilitating. Over the years, I’ve played the middleman, managing my care between my GP and consultants. I have to ask the GP to print blood test results for me so I can send them to my IBD nurses for my hospital record.

As a British-Asian woman, there’s sometimes stigma in South Asian communities around living with a chronic illness or disability, which can make it even more challenging living with IBD. Managing my IBD often feels like a full-time job. I choose to live positively with IBD but everything I do on a daily basis takes into consideration the fact that I live with this disease.” ●

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could have damaging consequences: how can services be appropriately planned and resourced without an understanding of the population served?

## Every MDT specialism matters

IBD nurse specialists play a central, and crucial, role within the MDT. Their remit has expanded significantly in recent years, and includes provision of cost-effective patient education, disease management and therapy monitoring, patient support, continuity of care, rapid access for advice and review during flares. Crohn's & Colitis UK's *More IBD Nurses – Better Care* campaign has contributed to an increase of 32% in the numbers of IBD nurse specialists.<sup>53</sup> However, most services still fail to meet the recommended standard of 2.5 per 250,000 patient population.

Only 14% of services across the UK reported having enough IBD nurse specialists to meet the standards.

Where services reported meeting the standards for IBD nurse specialists, those responding to the Patient Survey were more likely to:

- Rate the quality of their care highly
- Have regular reviews for their Crohn's or Colitis

Encouragingly, 84% of those responding to the Patient Survey said they have contact with an IBD nurse specialist. The importance of IBD nurse specialists is a key theme throughout this report. Improved workforce planning is needed to ensure we have enough IBD nurse specialists now and to meet the needs of the growing number of people with IBD in the future.

Pharmacists have a crucial role in advising the MDT on governance of therapeutic drug monitoring, ensuring the safety of potentially harmful medication, and optimising medication. They are the key to providing information about medicines to patients on discharge – which has been found to be lacking in past IBD audits. Also to facilitating shared decision-making through information and support, for example when considering starting a biologic drug. With more and more new treatments becoming available, the role of the pharmacist will become increasingly important.

Only 13% of services across the UK reported having enough pharmacists to meet the standards.

Where services reported meeting the IBD Standards criteria for the number of expert pharmacists in IBD, those responding to the Patient Survey were more likely to have said they were given appropriate information about potential treatments to help them make informed decisions. It was also more likely that the ward pharmacist had access to an expert pharmacist in IBD, or equivalent, to seek advice for

**“The chief pharmacist was brilliant – I just wish I could have met her before when I had flares. Before seeing her, a registrar had casually put me onto steroid enemas without any reflection on how this would impact on my life. I wish there was more continuity of staff – rarely meet the same person twice.”**

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medication review and optimisation, and personalised consultations.



did not feel they were supported by a team of IBD specialists.

Those responding to the Patient Survey who reported having access to specialist advice or support with diet and nutrition if they needed it were more likely to:

- Rate the quality of their care highly
- Report having the information and skills to confidently manage everyday symptoms and live as well as possible

Information sheets about diet and nutrition are one of the most downloaded resources from the Crohn's & Colitis UK website.

However, only 7% of services across the UK reported having enough dietitians to meet the standards.

From the comments provided in the Patient Survey, the fifth most common topic was nutritional advice – either not being given it, it not being sufficiently thorough or accurate, or being given it by staff who were not qualified to do so. Only 43% of those responding to the Patient Survey agreed that they had access to specialist advice or support with diet and nutrition if they should want it (41% for adults versus 73% for children). This is clear evidence that more nutritional advice needs to be available.

Mental health was also a common topic in responses to the Patient Survey – specifically that more mental health

support was needed and that staff were not qualified to give it.

Only 2% of services across the UK reported having enough psychologists to meet the standards.

## The importance of regular MDT meetings

People's needs are often complex. For those with IBD, there are often multiple professionals involved in their care, requiring MDT meetings to ensure support is coordinated in the right way.

However, only 65% of services reported that MDT meetings take place frequently (weekly or fortnightly) with clearly defined criteria and administrative support, attended by medical, radiological, surgical and nursing representatives, with decisions recorded.

This breaks down to 68% for England, 57% for Northern Ireland, 57% for Scotland and 39% for Wales. Adult services were more likely than paediatric services to report that MDT meetings were taking place frequently (69% versus 47%).

Where MDT meetings were taking place frequently, those responding to the Patient Survey were more likely to say they had:

- Waited less than four weeks for an investigative test
- Waited less than 18 weeks for an operation
- The information and skills to confidently manage everyday symptoms and live as well as possible
- Found it easier to cope with having Crohn's or Colitis

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## BEST PRACTICE: AWARE-IBD, SHEFFIELD

Crohn's & Colitis UK are working with Sheffield Teaching Hospitals NHS Foundation Trust, the University of Sheffield, Epigenesys and Sheffield Microsystems Coaching Academy (MCA) to deliver a three-year project under a new Health Foundation programme called Common Ambition. The project aims to redesign IBD services, shaped by those who use them – putting people affected by Crohn's and Colitis in control of their care. The team will design a structure for people to tell IBD teams what is important to them, their families, and carers, and to ensure their voice is heard in appointments. This will include an app to collect information and deliver it to healthcare professionals.

Patient engagement is at the heart of the project. A person with Crohn's or Colitis will be trained by the MCA to help steer the redesign of services and all 4,000 of the Trust's IBD patients will be invited to engage with the project. Advocacy support will ensure that people with Crohn's and Colitis of all ages, genders, and ethnicities are represented. Evaluation will show how, and by how much, putting patients in control of their care improves outcomes. The project is being delivered in Sheffield, but the learning will lead to better outcomes for people who live with Crohn's and Colitis across the UK.

[Click here to read the full case study](#)

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They were also more likely to:

- Say they were supported by a team of specialists
- Rate the quality of their care highly

Where MDT meetings were taking place frequently, services were more likely to:

- See all newly diagnosed IBD patients in a dedicated multidisciplinary IBD clinic
- Have an agreed departmental process for disease/needs assessment for IBD patients after diagnosis

### Communication between services: continuity of care

These results clearly highlight the benefits of a well-functioning MDT

in managing multiple health needs.

However, more needs to be done to break down the barriers in our complex health system and ensure that the way services are commissioned, funded and managed supports a more integrated approach. Coordination across primary and secondary care is key and the GP should be a member of the MDT.

- 95% of services reported that they can refer directly to essential supporting services.
- However, only 48% of those responding to the Patient Survey felt their care was coordinated between their IBD team and other services they see for their other medical needs.

Importantly, those that did feel their care was well-coordinated were more likely to:

- Rate the quality of their care highly
- Report finding it easier to cope with having Crohn's or Colitis

It is imperative that surgical and medical teams work well together to support people with IBD. However, 17% of those responding to the Patient Survey felt that this was not the case. In addition, only 30% of services said they have established, regular, joint consultant surgical/medical combined clinics.

A total of 305 free-text comments were made about poor continuity of care – a key part of personalised care.

Communication between GPs and specialist teams came through strongly as an issue in the feedback.



felt their care was coordinated with other services.

The IBD Standards state that clear written information about follow-up care should be provided before discharge from the ward. This should include a number/person to contact in the event of clinical urgency, details of prescribed medications and a date for clinical review. It should be emailed to the GP within 48 hours of discharge.



### **BEST PRACTICE: SURGICAL IBD NURSE AT UNIVERSITY COLLEGE LONDON HOSPITALS**

University College London Hospitals NHS Foundation Trust (UCLH) now employs a surgical IBD nurse – an innovative post bridging the medical and surgical teams. Before this post was established there was often a disconnect between the two teams, which led to sub-optimal patient preparation for surgery and delays in post-operative care and medication reviews. The IBD nurse specialists also received a large volume of pre- and post-op queries via the advice line, which could be difficult to manage, as they required surgical expertise.

The surgical IBD nurse is now an integral part of the IBD team. She has a background in stoma care and post-operative recovery and can support patients throughout their surgical journey. She sees patients in clinic to support them with decision-making and liaises with dietetic colleagues to ensure that patients are optimised for surgery. While patients are in hospital, she reviews them on the ward. She has protocols in place to review patients after discharge and replies to surgical queries to the IBD advice line.

[Click here to read the full case study](#)

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**“Keep the same consultant for appointments so they understand your needs. I've been transferred to new ones before who tell me to come off medication and then I go back and see my consultant who says I shouldn't have come off and then end up with a bad flare up! Consistency is needed when you have a long-term illness.”**

62% of services said that they are meeting this standard. However only 42% of those responding to the Patient Survey felt that their care was well-coordinated between their gastroenterologist and their GP.

Where people felt their care was well-coordinated between their GP and gastroenterologist, they were more likely to:

- Rate the quality of their care highly
- Say they had the information and skills to confidently manage everyday symptoms and live as well as possible
- Report finding it easier to cope with having Crohn's or Colitis
- Report having had fewer flares in the previous 12 months
- Report having had a shorter course of steroids

They were also almost three times more likely to say that they had been diagnosed in less than four weeks.

### **The difficult transition from paediatric to adult care**

Moving from paediatric to adult care (“transition”) can be a difficult time for

young people; healthcare providers need to have a clear protocol in place.

Transition is an individual experience, and one that requires shared decision-making and flexible timings. By planning for transition – and using joint clinics – healthcare professionals can improve the way they manage this critical event for young people with IBD.

The IBD Standards support quality standards from the British Society for Paediatric Gastroenterology, Hepatology and Nutrition and the Royal College of Paediatrics and Child Health,<sup>54</sup> as well as NICE,<sup>55</sup> on transition.

Overall, 45% of services said that they had protocols in place for transition. This breaks down to 71% for Northern Ireland, 64% for Scotland, 45% for England and 15% for Wales. Paediatric services were more likely to say they had protocols in place for transition than adult services (78% versus 37%).

289 young people reported having been moved or transitioned into adult gastroenterology services within the previous 12 months. Of these:

- 6% said they had an individual transition plan
- 17% said they had a named coordinator
- 20% said they were given information about what to expect from transition
- 24% said they attended joint clinics with members of the paediatric and adult teams

The Patient Survey responses clearly showed that transition from paediatric to adult services can cause anxiety.

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**“Please help me transition into adult services better. I am scared and need help, support and a coordinated approach. I have limited opportunities at school, life, eating, going out etc.”**

### **Leadership teams support high-quality care**

The IBD Standards state that IBD 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.

Encouragingly, 78% of services reported having a leadership team. Adult services were more likely than paediatric services to have a leadership team (81% versus 63%). This could relate to the fact that paediatric services work in networks across different hospitals – a different approach to adult services.

Having a leadership team in place makes it more likely that:

- MDT meetings take place, and all core members attend
- Transition protocols are in place
- Patients are involved in co-producing service development initiatives
- Referral pathways between primary and secondary care are in place
- Guidance around steroid use is available to all staff

Having a leadership team in place that includes a senior clinician, IBD nurse specialist and manager makes it more likely that patients are supported to self-manage.

### **Patient involvement: the final piece of the MDT puzzle**

The IBD Standards state that patients and parents/carers should have a voice and direct involvement in the development of the service. However:

- 79% of those responding to the Patient Survey had not been given the opportunity to feed back specifically on their Crohn's or Colitis care over the previous 12 months.
- 14% of services reported that IBD patients were directly involved in co-producing service development initiatives, in addition to gathering patient feedback over and above comment cards, feedback forms and the friends and family test.

Where services said they involved patients in service development, those responding to the Patient Survey were more likely to report having been given appropriate information about potential treatments.

### **Data and IT systems are fundamental**

Technology is essential to supporting and enabling efficient, cost-effective and high-quality, person-centred care. The IBD Standards state that all patients with IBD should be recorded in an electronic clinical management system and that data should be provided to the IBD Registry. This helps to ensure greater coordination and continuity of care, as well as appropriate monitoring.

68% of services said that there is electronic recording of IBD patients and/or data provided to the IBD

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Registry to inform national planning and research. However, only 25% were providing complete and regular electronic recording of all IBD patients.

Better local data, collected electronically, would help teams to manage their IBD service more effectively.

70% of services who completed the Service Self-Assessment had to estimate their patient population, with only 30% reporting being able to consult electronic databases for their figures. This needs to improve.



## RECOMMENDATIONS FOR ACTION

- 1.** Commissioners and managers should ensure that every IBD service is resourced to meet the staffing requirements for the IBD team, including gastroenterologists, IBD nurse specialists, colorectal surgeons, stoma nurses, dietitians, pharmacists, psychologists, radiologists and histopathologists. The MDT should hold regular, effective meetings, supported by an administrator.
- 2.** Commissioners and managers should ensure that pathways are in place to deliver well-coordinated care across specialties, including joint medical/surgical clinics, and between paediatric and adult services and primary and secondary care, supported by effective data systems.
- 3.** Every IBD service should have a leadership team in place, including a manager, to plan and develop IBD services effectively and efficiently, ensuring patient involvement and co-production.

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# Conclusions

The recommendations set out in this report call for greater recognition of the healthcare needs of the estimated 500,000 people with IBD across the UK and concerted action at all levels to change the way that care is delivered.

The Patient Survey and Service Self-Assessment revealed common, overarching themes that cut across the four chapter areas. These themes and underpinning principles need to be considered alongside the recommendations to deliver consistent, high-quality, personalised care for people with IBD wherever they live in the UK.

The current model of IBD care is largely reactive and this leads to a high number of emergency admissions. Focusing on a more proactive and personalised approach to care from diagnosis – which equips people with the information, skills and confidence they need to manage their condition effectively and become active partners in their care – should lead to improved outcomes and quality of life.

As a complex and multi-faceted condition, full multidisciplinary care is essential, but the IBD nurse specialist role is pivotal in coordinating care, supporting patient education and involvement, and driving service development. Under-resourcing has far-reaching consequences and needs to be urgently addressed. IT and data systems are underutilised: if effectively harnessed, they could support significant transformation in IBD care.

## 1. Care should be personalised, proactive and preventative, not reactive.

Everyone with IBD should receive an early and accurate diagnosis and have a personalised care plan. This must include access to the full range of specialist support, including rapid response when required, and ongoing monitoring and review.

## 2. Information and support are fundamental to people with IBD feeling confident and able to live well with their condition.

Everyone with IBD should receive accessible information at all stages of their care. This must meet their individual needs, as part of shared decision-making, and signpost to patient organisations for further information and wide-ranging support.

## 3. IBD nurse specialists are central to high-quality IBD care as part of the complete IBD multidisciplinary team.

Everyone with IBD should have access to an IBD nurse specialist and all IBD services should meet the standard for IBD nursing provision.<sup>4</sup>

## 4. Data and IT systems should underpin patient care, service planning and audit.

Everyone with IBD should be entered on a clinical IBD system to enable coordinated care, with data provided to support audit and service improvement.

We can and must work together to improve IBD care now and in the future.

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# Appendix

## About the IBD Patient Survey, Service Self-Assessment and data analysis

### **How was the IBD Patient Survey developed?**

The questions in the IBD Patient Survey are based on the IBD Standards. The survey questions were further developed through extensive consultation with people affected by IBD and with IBD UK board members. As part of the consultation process, the questions were tested by people affected by IBD. This involved focus groups to review how the questions were interpreted and what people felt they meant. Each round of consultation saw changes to the questions and the addition of guidance and definitions in both the digital and hard-copy versions of the survey, ensuring a shared understanding of the questions and terminology used.

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

The IBD Patient Survey was open from 8 July 2019 to 22 November 2019 and was widely promoted via printed flyers and digital methods, including emails and social media. Most people completed the survey online via the IBD UK website, but hard copies and translations were also available on request.

### **Who responded to the IBD Patient Survey?**

10,222 people with IBD across the UK completed the IBD Patient Survey – 9,757 adult responses and 465 paediatric responses – covering 99% of IBD services across the UK. Those under 18 were asked to complete the survey with a parent, carer or guardian. 79% of respondents were diagnosed more than two years ago. More adult responses were from females than males (66% vs 33%), but there was no gender difference in paediatric responses.

The proportion of responses from each UK country closely matched that expected from their population size: England represented 82% of responses; Scotland 8%; Wales 5%; and Northern Ireland 4%. 52% of respondents had Crohn's Disease; 44% had Ulcerative Colitis; 3% had Inflammatory Bowel Disease Unspecified; and 1% had Microscopic Colitis. In terms of severity of their condition, 15% described this as "not active"; 30% as "minimally active"; 26% as "mildly active"; 21% as "moderately active"; and 9% as "severely active".

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## How was the Service Self-Assessment developed?

The Service Self-Assessment questions are based on the IBD Standards. For each IBD Standard, a tiered set of questions was developed to identify to what extent the standard was being met. If the answer to the first question was “yes”, the second question in the tier was offered. If the answer to the second question was “yes”, the third and final question would be offered. For example:

1. “Is there an agreed referral pathway for suspected IBD between primary and secondary care?”
  - (If “no”, then the survey moves on to the next topic; if “yes”, the respondent is offered the second tier of this question):
2. “Does referral to specialist assessment take place within 8 weeks?”
  - (If “no”, then the survey moves on to the next topic; if “yes”, the respondent is offered the third tier of this question):
3. “Are more than 90% of patients with suspected IBD seen within 4 weeks of referral?”

The question framework was developed by a working group of IBD UK board members. It was piloted in several IBD services across the UK, and refinements to questions and guidance were made based on feedback.

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

The Service Self-Assessment was open from 1 October 2019 to 31 January 2020. 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?

166 IBD services across the UK (72% of all IBD services) completed the Service Self-Assessment. This includes 134 adult and 32 paediatric IBD services. In England 132 services completed the Service-Self Assessment (74% of services); 13 in Wales (76%); 14 in Scotland (64%); and 7 in Northern Ireland (64%).

The lead contact for the benchmarking process was most often an IBD nurse specialist (56%), followed by gastroenterologist (37%), pharmacist (1%), colorectal surgeon (1%) and other (5%). People that were involved in the process (expressed by % of services who included them) were: IBD nurse specialist (97%); the clinical lead (86%); gastroenterologist (85%); colorectal surgeon (48%); dietitian (43%); pharmacist (42%); manager (37%); administrator (25%); radiologist (25%); patient (24%); histopathologist (19%); audit lead (10%); psychologist or psychiatrist (10%); carer (5%); and other (5%).

## What methodology was followed for the analysis?

A chi-square test for independence was used to determine significant relationships between responses to questions. A *p* value of <0.01 was taken as being highly significant.

Any questions relating to staffing that have been cross-analysed will relate to adults only, as the IBD Standards do

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not specify minimum numbers of staff in relation to paediatrics.

Binary logistic regression analysis was used to predict the positive outcome of KPIs (dependent variables) using a combination of predictor variables. The binary logistic regression goes through various steps to remove variables that are not good predictors. The analysis culminated in a model that showed significant predictor variables for that KPI. Using this model, we were able to ascertain the responses to predictor questions that would make it more likely for someone to have

answered with a positive response to the KPI or dependent variable question. With some models the test included predictor variables that were not significant at a top level, and we took the decision to not include or refer to anything above the significance value  $p=0.05$ .

**If you have any queries, please email [info@ibduk.org](mailto:info@ibduk.org)**

**To view the questions asked in the IBD Patient Survey and Service Self-Assessment please visit [ibduk.org](http://ibduk.org)**

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## Endnotes

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## Further information and support

If reading this report has raised any concerns for you then please contact the **Crohn's & Colitis UK Helpline**  
0300 222 5700

[helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk)  
[www.crohnsandcolitis.org.uk](http://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](mailto:info@iasupport.org)  
[www.iasupport.org](http://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](mailto:support@cicra.org)  
[www.cicra.org](http://www.cicra.org)