

# Levelling up care for people living with Inflammatory Bowel Disease (IBD):

A spotlight on service exemplars

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500,000

REASONS

WHY

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# Foreword

Across the UK, we can be proud of the many examples of best practice in IBD care and treatment, often driven by hard-working clinicians. These initiatives continue to be vital in driving forward improvements to services, resulting in benefits for the NHS, and most importantly, people living with IBD.

It's estimated that there are over 500,000 people living with IBD in the UK,<sup>1</sup> with prevalence of the disease expected to grow by over 10% by 2025.<sup>2</sup> If we can make positive change to the care and treatment in IBD, we believe we can make a meaningful difference to the lives of many patients up and down the country, both now and into the future.

As it stands, patients across the UK can receive different standards of care from diagnosis through to treatment, depending on where they live. This unfortunately results in different outcomes and varying levels of quality of life for patients. One of the biggest challenges in IBD care is to reduce this unwarranted variation in IBD services, and it is one the community has been trying to tackle for many years. The recent COVID pandemic has placed further pressure on these services, resulting in changes to the way some patients have been able to access care, exasperating the variation that currently exists.

This year, NHS Getting It Right First Time (GIRFT), a national programme designed to improve the treatment and care of patients through in-depth review of services, benchmarking, and presenting a data-driven evidence base to support change, published a National Speciality Report on gastroenterology which analysed the delivery of services across England, reviewed unwarranted variation in practice and identified how the NHS can adapt to keep pace with rising demand.<sup>3</sup> The report recognises that variation exists across gastroenterology services, and discusses ways in which this variation can be reduced. Takeda welcomes GIRFT's findings and its support of sharing best practice, and we strive to support the NHS to reduce this variation to improve patient outcomes.

Takeda has worked collaboratively with patients, clinicians and the NHS to realise improvements in patient outcomes across all stages of the patient pathway: we have independently commissioned and funded clinical experts to develop an Optimal Care Pathway (OCP) which details the best practice standard of care at all points along the patient pathway.

*Levelling up care for people living with Inflammatory Bowel Disease (IBD): a spotlight on service exemplars* report is designed to draw attention to some of the real-life examples of best practice at all points along the IBD care pathway from across the UK.

This report forms a significant part of our efforts, enhancing our knowledge of where individual trusts have provided innovative solutions to challenges in IBD care and celebrating their achievements, so we may support the system to optimise their services and improve patient outcomes.

If we can embed best practice, there should be no reason why more patients are not able to achieve remission and enjoy a better quality of life.

We at Takeda want to support nationwide conversations around how every patient can achieve the best outcome, in order to help drive solutions so that all patients across the country receive the care they deserve.



Theresa Frezzo,  
Business Unit Director, Takeda UK

# Overview

Over 500,000 people are currently living with Inflammatory Bowel Disease (IBD) in the UK, however despite this condition affecting one in 133 people,<sup>1</sup> unwarranted variation in IBD care is prevalent across the UK's healthcare system, resulting in patients receiving different levels of care based on where they live.

Whilst good practice does exist, unwarranted variation has been a long-standing feature of IBD care. Variation was a key finding of the first audit of IBD services in 2006, which led to the development of the 2009 and 2013 IBD Standards.<sup>4</sup> Whilst these standards outlined a number of recommendations designed to rectify these shortcomings, they were not applied uniformly and inequality in care remains a reality for people living with IBD in the UK.<sup>5</sup> There is a strong support to level up care in IBD, however to drive fundamental change, a national strategy is needed to ensure the clinical community is supported to make the best decisions for their patients. Levelling up care for people living with Inflammatory Bowel Disease (IBD): a spotlight on service exemplars report builds upon previous audits and standards, demonstrating how NHS trusts across the UK have innovated to improve care for patients with IBD. It aims to provide support to clinicians and the NHS on ways in which services can be improved.

A companion to Takeda's Optimal Care Pathway (OCP), and forming part of Takeda's 500,000 Reasons Why campaign, this report provides examples of how best practice was achieved by NHS services across the UK, and details key learnings and recommendations. The case studies in this report highlight what good looks like across the patient pathway and demonstrates how best practice could be replicated across healthcare services.

The findings of the report demonstrate the importance of taking a long-term view of care. The case studies referenced in this report demonstrate the importance of placing clinical perspective at the heart of treatment choice, taking a holistic approach to patient care by supporting patients through the psychological impact of IBD, the need to be responsive to the patient voice, the key role of IBD nurses and the need for a wider multidisciplinary team to support patients through their journey.

## What is IBD?

**Crohn's disease** (Crohn's) and **ulcerative colitis** (UC) are the two main forms of IBD, which is a chronic condition that is characterised by chronic inflammation of the **gastrointestinal (GI) tract**.<sup>6</sup>



The disease can impact people of any age, but is usually diagnosed between the ages of **15 and 40**.<sup>6</sup>



In both Crohn's and UC **the immune system doesn't work properly**, and the body starts attacking itself, causing ulcers and inflammation.<sup>1</sup>



**Over 500,000 people** are currently living with IBD in the UK,<sup>1</sup> with prevalence of the disease expected to **grow by over 10%** by 2025.<sup>2</sup>



**Currently, there's no known cure for IBD** and treatment focuses on reducing symptoms in order to bring a person's IBD into long-term remission.<sup>6</sup>



## Impact on Patients

Living with IBD can have major impacts on physical and emotional well-being and imposes considerable challenges on managing daily activities.<sup>7</sup> Many patients find it challenging to discuss their condition, and sometimes patients may find symptoms embarrassing which can have an impact on a person's quality of life.<sup>8</sup>

People living with IBD can also face challenges with their mental health. A survey by patient advocacy group Crohn's & Colitis UK found that one in ten young people reported experiencing severe anxiety, depression and/or loneliness due to their condition.<sup>9</sup> Higher levels of anxiety and depression were associated with the age of diagnosis – with older patients suffering more acutely; level of abdominal pain; with these factors often leading to patients experiencing a lower sense of self belief.<sup>9</sup> Similarly, the level at which a patient was embarrassed about their diagnosis was a key determinant in whether they reported issues associated with mental health, including loneliness.<sup>9</sup> Similarly, a major anxiety for people living with the condition is being refused access to toilets or being confronted about using a 'disabled' toilet.<sup>10</sup> This contributes to the anxiety and mental health issues that IBD patients commonly encounter.<sup>10</sup>

“

**I had my late teens and early twenties taken away from me. I've had time to think about this especially over the last year. There was a lot of pressure at that age and I didn't have the confidence to meet girls or go out as I was so underweight and looked really ill. I didn't want to go out, and sometimes I couldn't. I felt I was letting my mates down, but I'd get anxious and scared about what people looking at me might think. I was about 8.5 stone and some people thought it was a lifestyle choice.**

”

Male patient, early forties, Liverpool

IBD has a significant socioeconomic impact because the majority of people with IBD are of working age when they are diagnosed.<sup>11</sup> In a report published by Demos on the economic impact of IBD (November 2021), 57% of survey respondents stated they have, at some point, either reduced their working hours or gone part-time because of their IBD.<sup>12</sup> It also found that 51% of respondents had applied for lower-paid work because of their IBD, with 72% stating that they felt their IBD had prevented them from working either “a fair amount” or “a great deal” over the previous six months. Support was also needed in early stages of life with respondents noting that IBD had impacted their educational attainment, with 63% of respondents stating that the effect on their education was “somewhat” or “significantly” negative, with individuals typically missing nine to ten days per year of school, college or university because of their condition.<sup>12</sup>



IBD sufferers experience higher levels of **anxiety** and **depression**.<sup>9</sup>



**57%** of people had applied for reduced hours or gone part-time due to their IBD.<sup>12</sup>



**63%** of respondents stated that the effect on their education was ‘somewhat’ or ‘significantly’ negative.<sup>12</sup>

In the UK,  
an estimated  
**500,000 people**  
live with IBD<sup>1</sup>

## Impact on the NHS

IBD is a life-long condition, and people need the right care and support to live well.<sup>4</sup> Crohn's & Colitis UK estimates that the lifelong cost of IBD to the NHS is approximately £900 million per year, comparable to diabetes or cancer.<sup>13</sup> However, there is an opportunity to reduce the cost of IBD through optimal management.

Patients with IBD require a substantial level of healthcare,<sup>14</sup> which increases with disease severity.<sup>14</sup> In any given time period, a minority of patients require hospital in-patient care, and hospital care accounts for the majority of costs associated with IBD.<sup>15</sup> One UK study found that 14% of all patients known to a hospital IBD service were hospitalised in a six-month period.<sup>16</sup> The recent *Getting It Right First Time* (GIRFT) report on gastroenterology found that some trusts had over 20% emergency IBD admissions,<sup>3</sup> non-elective inpatient spells and A&E attendances which may reflect poor access to specialist care, long wait times for consultation, referral for diagnostic endoscopies and appropriate treatment.<sup>17</sup>

IBD is a condition which needs significant management, and good management can lead to improvement in quality of life ensuring that patients have fewer flare-ups and are able to manage their condition outside of the hospital with the right support. Through enhanced partnership between patients and healthcare professionals, there is a potential to address inequalities in healthcare provision, to enhance shared decision-making and to promote the development of personalised care models.

However, to ensure patients can access the best care, attention needs to be given to the unwarranted variation experienced across the UK.

## Variation in Care

As it stands, patients across the UK can receive a variable standard of care based on their postcode, sadly resulting in different outcomes and varying quality of life. One of the biggest challenges healthcare leaders currently face in relation to IBD is how to reduce this unwarranted variation in services.

From the first IBD audit in 2006,<sup>18</sup> through to the IBD standards in 2009,<sup>4</sup> all the way through to the IBD UK national report<sup>1</sup> in 2021, each has identified the challenge of unwarranted variation in services. While development of the IBD Standards has led to significant improvements in care provisions, variation remains a reality for many people with IBD in the UK.<sup>19</sup>

Most recently, the GIRFT report found that variation existed across different parts of the pathway and throughout gastroenterology services.<sup>3</sup> Examples of variation identified by GIRFT included variation in waiting times for a new patient appointment in gastroenterology clinics, which varied from one week to 27 weeks; rate of colectomies for IBD; and the psychological support for patients with IBD with only 28.9% able to provide support.<sup>3</sup>

Clinicians work tirelessly to improve services for their patients, and support such as the OCP and IBD Standards exist to provide guidance on how they can optimise patient care. Whilst pockets of good practice and service innovation exist, more needs to be done to ensure that all patients enjoy a high standard of care – from diagnosis to treatment and ongoing management.



IBD is estimated to cost the NHS approximately **£900 million per year.**<sup>13</sup>



One UK study found that **14%** of all patients known to a hospital IBD service were **hospitalised** in a six-month period.<sup>16</sup>



From the first IBD audit in 2006,<sup>18</sup> through to the IBD standards in 2009,<sup>4</sup> all the way through to the IBD UK national report in 2021,<sup>1</sup> each has identified **the challenge of unwarranted variation in services.**

# Developing an Optimal Care Pathway

Takeda has independently commissioned and funded clinical experts to develop an Optimal Care Pathway (OCP) which details the best practice standard of care at all points along the patient pathway.

The OCP uses the NHS Right Care Methodology and could support the NHS GIRFT teams to identify good practice, which trusts can learn from to improve the quality and efficiency of patient care along an entire end-to-end pathway, thereby reducing unwarranted variation. These care pathways have been developed with patient case studies which can be used in national reports, other published materials or in direct communications with NHS colleagues.



**The problem that we were collectively attempting to solve was the long-standing issue of variation in care that exists for people living with IBD. We wanted to understand where there is a divergence in practice across the pathway, including restrictions of access to diagnosis and medicines used to treat UC and CD and access to specialist nurse support, in order to articulate what good should look like thereby supporting hard-working clinicians to improve care for patients across the country.**

**The solution that we developed is a real-life clinical consensus of what optimal care could look like at every point across a patient's care journey. We demonstrated the potential benefits to the NHS of reduced demand on IBD and Accident and Emergency services, allowing the system to realise cost-savings and efficiencies that could be reinvested back into services. Most importantly, the benefits are to the patients, providing optimal quality care and thereby improving their long-term outcomes and quality of life.**



Anusha Patel, Advanced Pharmacist, Regional Homecare Lead (East Midlands) and High-Cost Medicines Pharmacist, Kettering Hospital. Patel is the author and member of clinical advisory group responsible for developing Optimal Care Pathway.





# Why do we need an Optimal Care Pathway?

**Many patients are unable to move through the pathway, from diagnosis to treatment**

**Many patients do not have access to an IBD multidisciplinary team**

**Current care and treatment approaches can be overly hospital centric**

**There is a lack of focus on the most appropriate treatments for patients to achieve better quality of life**

We need **targeted action** across the patient pathway:



## Moving patients through the pathway

- Provide further education of IBD symptoms in primary care and more rapid diagnosis.
- Ensure access to an IBD specialist for newly diagnosed patients, and ensure regular follow-ups to define and assess against treatment goals.



## Greater workforce and specialist support

- Ensure patients are cared for by a defined multidisciplinary IBD team.
- Make sure patients have access to additional counselling and mental health support.
- Ensure services have the appropriate amount of IBD nurses.



## Shared decision making and empowering patients

- Ensure patients receive information and support to make informed treatment choices.
- See that patients are supported in their choice of follow-up care.
- Make sure patients are informed of how they can discuss their care with their IBD team and/or obtain a second opinion.



## Patients must have access to the most appropriate treatment

- Treatments should be regularly reviewed to ensure the patient is on the most appropriate therapy for them.
- Decisions on treatments should focus on delivering optimal long-term outcomes for patients, reflecting their individual circumstances -- mental health, work and social life -- and ability to manage their condition outside of hospital settings.

### The OCP demonstrates how the optimal treatment and management of moderate to severe IBD can:

- Improve patient quality of care by ensuring they have access to the right support through a multidisciplinary team.
- Demonstrate more efficient use of NHS resources along the whole pathway, and specific long-term cost reductions.
- Empower patients to play an active role in their care, from decisions made about their treatment to how they receive care. This can enable them to better manage their condition.

# Identifying Best Practice Across the Patient Pathways

The case studies in this report were identified and formulated following engagement with clinicians, including those involved in the projects, and independent research. They represent a diverse range of trusts, including from the size of their patient population, resource allocations and their location, to ensure that the key learnings resonate with all trusts across the UK. They demonstrate how trusts can deliver excellence across different parts of the pathway which align closely to those themes set out in the OCP.



## Moving patients through the pathway

### Case studies:

- Stockport NHS Foundation Trust
- Western General Hospital, Edinburgh



## Greater workforce and specialist support

### Case studies:

- St Marks Hospital, London
- Brighton and Sussex University Hospitals NHS Trust



## Shared decision making and empowering patients

### Case studies:

- Sheffield Teaching Hospital



## Patients must have access to the most appropriate treatment

### Case studies:

- Kettering General Hospital
- Manchester Royal Infirmary

# Case Studies

## Moving patients through the pathway

### Stockport NHS Foundation Trust

Interview: Rachel Campbell, IBD Specialist Nurse at Stockport NHS Trust



### Context

Delay in receiving a diagnosis not only has a negative impact on patients, it is also detrimental for the NHS, with delayed diagnosis resulting in a higher likelihood of surgery and a poorer prognosis.<sup>20</sup> Yet, many people are waiting too long for an IBD diagnosis. According to a survey by Crohn's & Colitis UK, almost half of patients take one year to get diagnosed – with nearly one in five people waiting over five years.<sup>20</sup> A recent survey funded by Takeda found that 79% felt the length of time to be diagnosed and receive treatment negatively impacted at least one aspect of their life.<sup>21</sup>

As part of the Elective Care 100-day challenge programme, which aimed to manage rising patient demand as efficiently as possible, Stockport NHS Foundation Trust was asked to change the referral process for IBD patients. Stockport NHS Foundation Trust's gastroenterology services were experiencing increasing referrals and follow up appointments, resulting in 18 weeks+ waiting times for many suspected IBD patients.

When asked about the impact this had on both staff and patients, IBD Specialist Nurse Rachel Campbell said, "There is nothing worse than having a patient stuck in primary care waiting for a referral in [to a consultant], then waiting again to be seen by that consultant, and then waiting again to be seen for an investigation".<sup>22</sup> She added that as a result, many patients were "going back to the GP multiple times for flare up symptoms, and possibly into the emergency department, which costs money. So, this idea came about so that we could improve the flow, diagnose patients quicker, and save some money in the process."<sup>22</sup>

### Solution

The team saw an opportunity to improve access to care for people with IBD, while providing advice and guidance for GPs to help avoid unnecessary referrals.

Rachel Campbell set up a rapid access clinic at Stepping Hill Hospital for patients with suspected IBD, where the model contained two main elements:

**1. Rapid access clinic (RAC) for suspected IBD cases**, with patients booked into a clinic within approximately two weeks.<sup>23</sup> This was formed in 2016 with the initiative to improve patient diagnosis and to liaise with primary care. The clinic remains largely unchanged since its creation.

The model allows GPs that see patients with bowel problems to have access to an algorithm which helps them ensure use of the best pathway. If test results suggest possible IBD, the GP is then able to refer straight to Rachel Campbell, who triages patients and brings them into the rapid access clinic.<sup>22</sup>

**2. Flare up clinic:** People with IBD are now given less frequent follow ups but have direct access to the IBD specialist nurse for telephone advice when they need it, and if required can be brought quickly into clinic for review.<sup>23</sup> This was a slightly newer project and was extended during the Covid-19 pandemic with all clinics being moved to over the phone.

The RAC is run by Rachel Campbell with Flare up clinics ("hot clinics") being run by Rachel Campbell and one of her colleagues. There are seven clinics run every week for patients. Whilst the clinics initially only involved nurses, the RAC ensures that all GI team members are using it.

### Outcomes

Setting up the clinic took three weeks from concept to implementation<sup>22</sup> and the pathway saw a reduction of 30 weeks to nine weeks that patients had to wait from referral to diagnosis.<sup>22</sup> There were around 25 new referrals a month with patients being seen within seven days.

Rachel Campbell also noted the cost savings from the project, "just by doing this clinic, I've brought in five patients rather than them going through A&E, so that was a potential £9,000 saving. And the difference between me doing a clinic and a consultant doing a clinic for the first 100 days of the project was about £4,000. It's putting my skills to best use as well."<sup>22</sup> From May 2016 - April 2017 there have been between £40,000 to £60,00 worth of savings. This has come as a result of patients no longer needing to attend A&E, removing the need for unnecessary investigations and having the opportunity to see a triage nurse, as opposed to a GI consultant.

**Support** needs to be given to IBD Nurses and other members of the IBD team **to use their expertise and connections** with primary care leaders and practitioners, **whilst being mindful of their capacity.**

The RAC and flare up clinics offers patients an opportunity to access the support of a specialist team, reducing the need to attend emergency services and a delay in diagnosis. Rachel Campbell noted that it is apparent from this project, that the IBD nurse is perfectly placed to triage and review suspected new patients improving patient experience, as the waiting times are reduced and the IBD nurse could identify and manage differential diagnoses. However, Rachel Campbell acknowledged that there is a need to upskill IBD nurses to ensure there is someone available to look at the "bigger picture" for new patients, to confirm they get the right support.

When referring to the challenges, Rachel Campbell noted the importance of finding an optimum cut off for the faecal calprotectin to eliminate low sensitivity and specificity for aiding diagnosis of IBD, as well as engaging with primary care colleagues to support the referral pathway. It is recommended that the referral pathway is a suitable method for suspected IBD patients to be seen, but that more education within primary care is required to improve patient experience and increase appropriate patient referrals.

### Learnings

Moving patients through the pathway relies heavily on collaboration between primary and secondary care. The IBD Benchmarking Tool<sup>24</sup> conducted by IBD UK showed that Stockport's main hospital, Stepping Hill was successful in having all patients seen within four weeks from their referral enabling them to be moved through the pathway.

The key learning from this Trust is that for collaboration to take place, support needs to be given to IBD Nurses and other members of the IBD team to use their expertise and connections with primary care leaders and practitioners, whilst being mindful of their capacity. Discussions should be had with the IBD team about ways in which they can be supported, to ensure that patients with suspected IBD are moved through the pathway quickly and provided with the right support.

## Moving patients through the pathway

### Western General Hospital, Edinburgh

Interviewees: Dr Charlie Lees, Consultant Gastroenterologist, Western General Hospital, Edinburgh, Angus Crawford Clinical Nurse Specialist, NHS Lothian and Dr Eleanor Watson, Consultant Gastroenterologist, NHS Lothian



### Context

Almost half of IBD patients have at least one flare a year, having an impact on patients physical and emotional wellbeing.<sup>25</sup> An IBD flare can present with a broad range of signs and symptoms. When specialists are able to assess these worsening symptoms early, they can create a timely and effective treatment plan. This can reduce the risk of complications, including excessive steroid use and unscheduled emergency department attendances.<sup>26</sup> An IBD UK report found that people with IBD are not able to get specialist treatment and care quickly enough, resulting in high numbers of emergency hospital admissions and potentially avoidable flares, where their condition is not well-controlled and serious complications can arise.<sup>1</sup> Therefore prompt access to advice and support is very important.<sup>26</sup>

The IBD service at Western General Hospital in Edinburgh delivers care for people with IBD in Edinburgh and Lothian in Scotland. The service was facing a multitude of challenges that ranged from delivering speedy access to clinics, how best to empower and educate patients, and starting new treatments in a timely way. Angus Crawford, IBD Clinical Nurse Specialist at NHS Lothian, found that due to the area that Western General Hospital covers, many patients had to travel long distances to come in for their annual IBD review.

The need to change the way patients accessed care became a huge driver for the service. In the early 2010s, the team established a nurse-led IBD telephone helpline to provide rapid IBD nurse advice for patients on flare ups or other IBD related problems. After the success of the telephone service, the team began to develop ideas for restructuring its consultant and nurse-led outpatient services, so that patients can see the right person quickly while avoiding unnecessary travel.

### Solution

Angus Crawford explained that one of the solutions to this problem was to start outreach clinics where an IBD specialist nurse runs a clinic in hospital settings out with the Western General Hospital. This meant that patients are able to see a specialist nurse much closer to home. These clinics reduce journey times, with an environmental benefit. They also allow the nurse to provide holistic care and

support self-management. During COVID, these clinics were run with a blended approach with patients speaking to IBD nurses over video conference, which was beneficial to those patients required to shield or who were unable to attend appointments. Dr Eleanor Watson, Consultant Gastroenterologist at Western General Hospital, added that the process was not only good for patients, but it also reduced some of the pressure on the consultant-led clinic, so they could see the people that needed more support with more complex treatment options and care. The service has been able to set up and maintain a daily flare clinic for unwell IBD patients run by the on-call consultant and an IBD nurse. This has allowed more rapid escalation of treatment in patients where a delay in treatment is likely to lead to hospital admission.

The service now has different types of follow up: consultant-led clinic, nurse-led clinic, patient initiated follow up, and a hybrid model where a consultant would see a patient once a year, and the nurse would see them every six months. The process determining which clinic type is needed is fluid, meaning that if a patient needs to change from nurse led follow up to consultant review, or vice versa, that this is done as smoothly as possible.

### Outcomes

Although no cost savings assessment has been made yet, both Angus Crawford and Dr Watson noted that the project aimed to reduce hospital admissions and operations, which they acknowledged was difficult to measure. Dr Watson stated that “we think we have avoided a certain number of consultant-led clinic appointments which will be a cost saving”, with Angus Crawford adding that “though we spent more on medicines we probably saved money having fewer hospital admissions and less operations.”

Western General Hospital built assessment into its model, and there is a desire to further involve patients with an engagement group to discuss all levels of the service. The service held a patient survey in 2016 on the entire IBD service, from the attentiveness of the doctor to the general accessibility of the service such as car parking. The IBD Unit is planning to do a full assessment of the service at some point in the future.

**Each Trust is unique**, and therefore whilst some may find historic service configuration works for their population, others many need to **create new ways of working** to enable accessibility of services.

Good documentation was vital for this project to succeed. Clear letters including a problem list are helpful when patients move to nurse led follow up. Dr Watson also noted that if the project was to be replicated in another area, a range of supporting documentation would help manage each stage of the patient's pathway. IBD nurses were also critical as the hub of the project, as well as communicating with other consultants, communicating within the team, and within the wider medical community, including primary care.

Both Dr Watson and Angus Crawford felt that one of the key learnings of the project was the importance of holistic care, which included important life steps which would impact patients at all stages of their lives such as mental health, family planning, conception or having children, moving away/transferring and how the service could be tailored to each patient, ensuring they remain at the core of the service itself. They noted that as the service would be tailored to the community it served, all services would look different.

### Learnings

Accessing specialist support can be a challenge for many patients, and whilst Western General represents a more unique case due to the geographic spread of its patient population, it demonstrates the need to provide flexibility in services. Each Trust is unique, and therefore whilst some may find historic service configuration works for their population, others many need to create new ways of working to enable accessibility of services. This does not always have to be in-person adaptations but can also include remote services like IBD nurse hotlines to provide flexible support for patients who need it.

## Greater workforce and specialist support

### St Marks Hospital, London

Interview: Professor Ailsa Hart, Consultant Gastroenterologist and sub-dean at St Mark's Academic Institute



### Context

Multidisciplinary teams (MDTs) in IBD services consist of consultant gastroenterologists, surgeons, registrars, pharmacists, nurses and dieticians, all with a specialist knowledge of IBD. The role of MDTs is an underlying theme of both the OCP and IBD standards, which state that patients should be cared for by a defined multidisciplinary team led by a named consultant adult or paediatric gastroenterologist. This recommendation was also present throughout the GIRFT report which recommended the use of MDTs to help plan capacity, improve patient outcomes, improve training, and provide more holistic care.<sup>3</sup>

The London North West Hospitals NHS Trust benefits from a specialist and world-renowned IBD service, predominately based at St Mark's Hospital, but also covering Northwick Park, Central Middlesex and Ealing Hospitals. The IBD unit at St Mark's Hospital provides a tertiary referral service that encompasses all aspects of care for one of the largest cohorts of patients with IBD in the UK. Approximately five years ago, St Marks undertook an audit, which looked at different aspects of its service and required the whole body of staff to look at what improvements needed to be made across different parts of the patient pathway.

Previous evaluation of outpatient services at the unit demonstrated the need for a more integrated approach, with consistent messaging about strategies of care. For example, patients reported having appointments with clinicians from different disciplines on different days, requiring them to make multiple trips to the hospital, and expressed general dissatisfaction with clinic space and capacity.

### Solution

In order to improve the care patients received and to ensure options were presented to patients, a joint IBD clinic was implemented. At this clinic, patients are able to be assessed by a gastroenterologist, a surgeon and other members of the multidisciplinary team, such as dieticians and IBD specialist nurses, as required within the same appointment. The overall aim of the clinic is to provide streamlined, consistent care.

The specialist IBD team consists of gastroenterology consultants, IBD specialist nurses, colorectal surgeon consultants, clinical fellows, IBD dietitians and pharmacists supported by psychological service, administrative and secretarial staff. The system also requires the triage and review of patients who are at 'crossroads' in their care, for whom the full spectrum of conservative, medical and surgical treatment options require a more in-depth discussion.<sup>27</sup>

### Outcomes

To understand the impact of the joint clinic, all patients who were routinely referred to the joint medical-surgical IBD clinic over a period of six months were asked to complete an anonymous questionnaire at the end of their appointment. The majority of respondents viewed the clinic in a favourable light, with overall responses indicating that joint clinic appointments were preferred to seeing the gastroenterologist and surgeon separately.<sup>27</sup> Multidisciplinary care is recommended in the management of IBD by NICE Quality Standards and by expert opinion.<sup>28</sup> However, it was noted that the involvement of multiple clinicians, especially when seen separately, can run the risk of disseminating conflicting information and overburdening patients so that key messages become diluted or contradicted.<sup>29</sup>

Professor Ailsa Hart, Consultant Gastroenterologist and sub-dean at St Mark's Academic Institute, acknowledged that as well as reducing the number of times patients were required to come into the site, the programme also helped the team at St Mark's learn about the overall management of patients and allowed the team to work together as one. Adding that whilst at some points the programme meant patients took longer to make decisions around their care, overall, this meant patients were seen less in the future, ensuring the right decisions were made with the right information, helping to establish a long-term vision for patients.

Between September 2019 and March 2020, a total of 44 patients, out of a possible 93, completed and returned the questionnaires giving a response rate of 48%. The majority of respondents viewed the clinic positively, with overall responses indicating that joint clinic appointments were preferred to

seeing the gastroenterologist and surgeon separately. For those patients that responded with lower scores, further analysis showed that three patients "disagreed" or "strongly disagreed" that the joint IBD clinic aided decision-making. This was due to one patient disagreeing that seeing a surgeon and gastroenterologist together made them feel less anxious, and the other patient stated their agreement that seeing both clinicians together made them feel pressured into making a decision.<sup>27</sup> Nevertheless, overall, the programme was well received by many patients.

### Learnings

At the heart of all service improvement is the need to look at the patient needs and provide ways in which patients can receive information and support from a multitude of clinicians. This Trust demonstrates a way in which patients can access a multidisciplinary team at the same time to ensure all their needs are met. If access to multiple clinicians is considered useful to patients in managing their condition, efforts should be made to ensure patients have the option to access a range of clinicians from different specialties on set days, to reduce the number of journeys made into hospital and to provide a joint care approach for patients.

**At the heart of all service improvement** is the need to look at the **patient needs** and provide ways in which patients can **receive information and support** from a multitude of clinicians.

## Greater workforce and specialist support

Brighton and Sussex University  
Hospitals NHS Trust



### Context

There is evidence that anxiety and depression are more common in patients with IBD, with symptoms being more severe when experiencing “flares”<sup>30,31</sup> resulting in a decreased quality of life for some patients.<sup>32</sup> IBD standards and NICE have previously stated that a psychologist or counsellor is among the ‘essential supporting services’ that the IBD team should have access to.<sup>33</sup> Furthermore, this has been identified locally at a Trust level by the IBD Patient Panel as an area of priority need.

There is insufficient access to psychological support services for patients with IBD in the UK.<sup>34</sup> Though there has been an increase in the awareness of the link between Crohn’s and UC and levels of emotional well-being, 45% of people surveyed said they were ‘dissatisfied’ or ‘somewhat dissatisfied’ with the emotional support they receive for their Crohn’s and Colitis.<sup>34</sup> The IBD Audit, which ceased in 2014, also found that only 53% of services could refer people with IBD for psychological support.<sup>35</sup>

This was a particular issue within the IBD service at Brighton and Sussex University Hospitals NHS Trust, who together with the IBD patient panel, identified unmet emotional and well-being needs within its patient population. However, clinicians within the IBD team felt that they lacked the expertise to deal with these psychological difficulties, and that as a result these patients were not being treated effectively.<sup>34</sup>

### Solution

Brighton and Sussex University Hospitals NHS Trust introduced a pilot service called Psychological Support Service for Patients with Inflammatory Bowel Disease (PSSPIBD) which was designed to introduce integrated multidisciplinary psychiatric and psychological support for patients with IBD. It was hoped that by providing high-quality mental health support, there would be an improvement in patients’ psychological wellbeing, how they interact with services (by reducing inappropriate service use) and their quality of life.<sup>36</sup> The service was open to all patients with IBD using the centre for management of IBD and all patients referred were seen for an initial assessment unless they were already under the care of secondary mental health services.<sup>36</sup>

The PSSPIBD was embedded and integrated within the IBD team, running for 18 months. Between October 2015 and March 2017, patients were assessed and treated by PSSPIBD, staffed by a liaison psychiatrist and a band of seven clinical health psychologists with special interests in IBD, enhanced by a shadowing period spent within the centre.<sup>34,36</sup> Referrals were made by the IBD team, including doctors, specialist nurses and pharmacists, and the initial assessment was carried out by a psychiatrist who made a formulation, diagnosis and comprehensive treatment plan.<sup>34</sup> This could include advice on psychotropic medications, signposting to support services in the community, referral to other mental health services in primary or secondary care, or referral on to the IBD psychologist, as well as liaising with the referrer and GP.<sup>34</sup> The number of sessions per patient was dependent on their needs, and whilst the average was five sessions it ranges from one to 12. The psychiatrist also attended the weekly IBD Multidisciplinary team meeting, to assist clinicians with the identification of patients for which PSSPIBD would be appropriate. They also provided support to clinicians in providing care for challenging patients with psychological difficulties who would not accept referral to the service.<sup>34</sup>

### Outcomes

Between October 2015 to March 2017, 85 patients were assessed and treated by the PSSPIBD, staffed by a psychiatrist and clinical health psychologist with special interests in IBD.<sup>34</sup> The pilot service demonstrated significant improvements across all symptoms’ domains in patients with IBD, notably IBD and the psychological impact of the condition.<sup>36</sup>

Patients and refer satisfaction with the service was also high with 90% of patients rating the service as excellent.<sup>34</sup> Key findings of the study revealed the most common reason for referral into the service was support adjusting to IBD and its symptoms, such as pain, fatigue, incontinence, tolerating uncertainty (55%), in addition to anxiety (30%) and low mood (10%).<sup>34</sup> The study also demonstrated significant improvements in all four domains of IBD symptoms: bowel problems, emotional health, systemic systems and social functioning, and a trend to improvement in quality of life. Statistically significant improvements were also seen in depression scores, and there was a strong trend to improvements in anxiety scores.<sup>34</sup> The pilot scheme also had a cost-

effective element with every £1 spent on the project reducing number of bed days by more than 60%, reducing inpatient admission by over 70%, and reducing the number of IBD follow up appointments by 60%.<sup>34</sup>

### Learnings

This example shows that a holistic approach to care is essential for good IBD outcomes, recognising that the patient may need support beyond physiological dimension of IBD. Trusts and clinicians should provide care that recognises the importance of quality of life for patients and provide them with support beyond their physical symptoms. This could mean working with colleagues outside of the immediate IBD team, with expertise that can support patients or directing patients to where they can receive that support, such as mental health charities and information provided by patient groups.

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## Shared decision making and empowering patients

Sheffield Teaching Hospital NHS Foundation

Interviewee: Professor Alan Lobo, Consultant Gastroenterologist at Sheffield Teaching Hospitals NHS Foundation Trust



### Context

Crohn's & Colitis UK has identified significant shortcomings in the interactions that people living with IBD have with health care services.<sup>37</sup> The UK-wide IBD UK Benchmarking Tool found that only 21% of respondents had the opportunity to give feedback on their care in the past 12 months<sup>38</sup> and highlighted a lack of education and opportunities for patient engagement, and the need to improve shared decision-making.<sup>37</sup> However, decision-making does not just refer to the clinical effectiveness of treatments, but also to people's personal goals and what matters to them. This is something that Professor Alan Lobo, Consultant Gastroenterologist at Sheffield Teaching Hospitals felt was an important change in perspective that could help IBD care.

The Sheffield Inflammatory Bowel Disease Centre and the School of Health and Related Research (ScHARR) at the University of Sheffield have been working with Crohn's & Colitis UK and local partners in Sheffield, as one of only four projects to be funded under a new Health Foundation programme called 'Common Ambition'. The partnership includes: Crohn's & Colitis UK, Sheffield Teaching Hospitals NHS Foundation Trust and their Microsystems Coaching Academy (MCA), the University of Sheffield, the University software company Epigenesys and VoiceAbility, a peer support organisation from the community. This three-year project aims to re-design IBD services with IBD patients at the centre. AWARE-IBD is unique in having people living with Crohn's and Colitis trained by the Sheffield Microsystems Coaching Academy to help steer the changes. It is led by Crohn's & Colitis UK with Professor Alan Lobo from Sheffield as Chief Investigator.

### Solution

The focus of the project is to make priorities explicit and to refocus clinical encounters on what is important to patients, their families and carers. The project asks the question "What matters to you?" both in relation to how the service is organised and individual consultations. Professor Lobo noted that clinicians may focus on biological markers – laboratory tests and endoscopy, whereas what might matter to patients could be elements like "can I get to work?" and "how does this impact my relationship?" Professor Lobo noted that whilst these are connected, overall, there needed to be an explicit understanding of what patients want.

The process has begun with the establishment of a Patient Oversight Committee and the development of a new patient reported experience measure (PREM) by a patient group. All 4,000 patients from the Trust have been invited to engage with the project, in an initial engagement exercise that has asked patients what matters to them. This will be fed into the service improvement process. The importance of "lesser heard voices" is also a key aspect of the project, including those from more deprived areas and those without English as their first language. Such groups may be more likely to present as an emergency. VoiceAbility – a peer support group – was brought into the project to reach out to those groups and help build workshops, where these voices could be captured to understand the barriers of engagement.

The sustainability of the involvement of patients remains at the heart of the project. Service improvement methodology has been developed through the Sheffield MCA, with the aim to improve the value and quality of care provided in Sheffield across all disciplines of Sheffield Teaching Hospital. It involves a small group of stakeholders who will pick up key themes from their own experience and through engagement exercises, such as those seen through AWARE-IBD, and feed them into a Plan-Do-Study-Act (PDSA) cycle to embed it into the service for longevity.

Once the initial engagement is complete and the changes have been made through service improvement methodology, the project will look at the effect on clinical outcomes such as hospitalisation, the need for surgery and disease control – but also the patient experience. Professor Lobo acknowledged that it was possible that a difference in clinical outcomes may not be seen, and instead the project might show a difference in experience which is also important. He noted that there is some debate about what experience is, what is quality and what is patient satisfaction. This therefore led to the development of a PREM for the project, designed with the principle of keeping patients at the core, which will be used as a measure of the effectiveness.

### Outcomes

The project is currently at the initial stage, having begun in March 2021 and therefore its true impact is yet to be seen. The patient oversight committee, a group of patients both local and national to oversee the project, has met regularly since March 2021. The PREM has also been finalised, and a launch webinar has also occurred. Local patients have been approached and an

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app has been developed by EpiGenesys that will collect information from people living with Crohn's or Colitis and deliver it to doctors, nurses and other healthcare professionals. A patient-led microsystem approach will design interventions to be tested.

The anticipated outcomes of the project are to make the priorities of those with IBD explicit in clinical encounters and therefore refocusing on what is important to them, to allow those with IBD to feel in control of their care and involved in service development, especially after conclusion of the project; to make social exclusion more visible and to include those from all backgrounds. It is hoped that lessons from this will impact on patient experience beyond Sheffield.

Professor Lobo noted that there is clear appetite for patients to be at the centre of the care. It was acknowledged that this partnership was possible due to the funding they received, however, on the whole, partnerships with patients should not be work intensive. The question of "what matters to you?" and understanding the importance of placing patients are key to any service. Whilst the project is being delivered in Sheffield, the learning from this project will be shared with the aim of leading to better outcomes for people who live with Crohn's and Colitis across the UK.

### Learnings

Listening to, understanding and acting upon the patient voice is the foundation of good care. A system with inclusion of the patient voice at its heart enables Trusts to deliver services that meet the needs of those it serves. Every patient is different, and what works for one Trust might not work for a different Trust's patient population.

Therefore, the key learning from this project is that services should use approaches suitable to their service to work with patients to further understand what "good care" means for them, learning from the patient and incorporating their voice into service development. This can be done in a variety of ways, including patient panels, regular surveys of patients and staff and conversations with patients and families, but should be embedded into the service and include less heard voices.



## Patients have access to the most appropriate treatment

### Kettering General Hospital & Manchester Royal Infirmary

Interviewees: Dr Scott Levison, Consultant Gastroenterologist at Manchester Royal Infirmary & Anusha Patel, Regional Homecare Lead Pharmacist High-Cost Medicines and Embedded Pharmacist for NHS England



Medicines are a vital part of managing and treating the symptoms of Crohn's and UC.<sup>39</sup> As a result, being able to access the most innovative range of evidenced-based treatments and new technologies is a key part of managing the condition for patients,<sup>39</sup> expanding options for patients. Two trusts, Kettering General Hospital (an acute trust employing 4,000 people) and Manchester Royal Infirmary (one of the largest acute trusts in the UK employing 20,000 people) created pathways for the use of high-cost drugs, to provide a guide for the most appropriate treatment options for patients.

## Manchester Royal Infirmary

### Context

In 2018, Greater Manchester Medicines Management Group (GMMMGM) began examining the region's use of biologics in the treatment for IBD, with the intention to reduce costs. Dr Scott Levison, Consultant Gastroenterologist at Manchester Royal Infirmary noted that there was an underlying fear that the clinicians' voice may be lost, when deciding what treatment was most suitable for patients to achieve better long-term outcomes.

### Solution

Dr Levison, amongst others in trusts across the Greater Manchester region, felt that the clinical voice was fundamental to any decisions that were made about the treatment options available to patients. He feared that without the clinical perspective, some treatments would be restricted without the necessary discussion about their wider value. This led to a range of clinicians, including local pharmacists and general practitioners approaching GMMMGM about their concerns, in order to ensure clinicians were at the heart of the decision-making process. These conversations were an ongoing development which allowed clinicians to detail why particular high-cost drugs were used and demonstrate what they meant for patient outcomes.

The intervention resulted in the development of Greater Manchester High-Cost drug IBD pathway, which is used as guidelines in the initiation and maintenance on high-cost drugs. The pathway simplifies clinical evidence which helps clinicians make decisions about the right first course of treatment for patients. The pathway is regularly reviewed (as of January 2022, on its third update) and was formed by retrospectively reviewing clinical response results over a three-year course, with data being pulled together within six months. The project was a clinical project implemented by Manchester Academic Health Science Centre, and a joint project between the gastroenterology departments of the Greater Manchester hospital trusts.

The pathway empowers clinicians to make judgements based on what is **best for their patients**, without being constrained by policy which does not accurately reflect the **complexity** of the situation in the ground.

### Outcomes

Dr Levison noted that the outcome of the pathway was "better for everyone" as it meant pharmacists had access to the best treatments for patients, and the clinician would be able to achieve a better result by placing patients on the best treatment first time.

Dr Levison remarked that the development of the pathway also strengthened the relationship between GMMMGM and the clinicians across Greater Manchester trusts. Reassuring the clinical community that their perspective would be considered in the decision-making process for future discussions, as opposed to being made at the GMMMGM level and then fed down to the local trusts. Dr Levison stated that the pathway empowers clinicians to make judgements based on what is best for their patients, without being constrained by policy which does not accurately reflect the complexity of the situation in the ground.

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## Kettering General Hospital

### Context

Anusha Patel started at Kettering General in 2015, which at the time had no pathway for the use of high-cost drugs in IBD. Anusha Patel was keen to ensure there was a pathway for clinicians to help them decide what treatments to use for their patients. The Clinical Commissioning Group (CCG) asked Anusha Patel to implement Blueteq for Gastroenterology, a system which enables them to monitor the use of high-cost treatments, to ensure that only therapies prescribed in line with local policy and National Institute for Health and Care Excellence (NICE) guidelines are reimbursed.

### Solution

Anusha Patel noted that one of the difficulties in implementing this request from the CCG was the lack of clinical engagement, as she felt that the forms tended to question clinician judgement, which was not well received. To overcome this barrier, it was decided that clinicians would be incorporated in the process of adjusting and developing the forms and pathway, allowing them to vocalise their concerns and needs according to their clinical practice. This led to individual treatment forms being amended to suit the population, with questions such as “Is the patient a smoker?” being added, as the department wanted to audit smoking and outcomes for Crohn’s and UC, in addition to the removal of bureaucratic elements to ensure clinicians felt comfortable ticking the box. The key takeaway was the need to create a collaborative approach to deciding which treatment patients should receive. To develop this, multiple meetings were held to decide the content of the form, permitting Blueteq to be implemented as requested by the CCG, whilst also empowering clinicians to have a choice in the treatments given to patients.

### Outcomes

Whilst there remains no official structured pathway for IBD, the Trust uses the treatment that is defined as “best for the patient”, and not just the biosimilar because it was the cheapest option. Blueteq forms reflect that biosimilars have been considered, but a free text box is available to justify why a different treatment has been used. Overall, biosimilars are used for 80% of patients first-line, demonstrating cost savings and optimisation which was important to the CCG, with 20% flexibility to use other agents for those patients who need it. Anusha Patel acknowledged that the changes being made at Kettering General Hospital found that if you optimise a patient’s treatment early and optimally, there is a reduction in cost and touch points elsewhere. Although Kettering is an acute Trust, they now have rapid innovative use of new NICE TA – with access in 30 days – with Anusha Patel ensuring that treatments are put onto the formulary as soon as NICE approves them. This pathway is not limited to IBD but can also be seen in dermatology and rheumatology.

Anusha Patel stressed the importance of cross-working with commissioners and across different specialities - allowing patients to receive support for their individual needs based on comorbidities. The pathway exhibited multiple benefits for patients and the clinician team at Kettering. The pathway allowed clinicians to provide the best treatment for the patient and saw a reduction in individual funding requests (IFR), which previously were rejected for not meeting the exceptionality criteria that IFRs have. This meant that for those IFRs that had come through, it was typically only for those patients who had been in the system prior to the pathway, and the appropriate time was spent discussing their case. It also saw patients entering remission quicker, improving their quality of life which saw a reduction in demand for other IBD services such as mental health support and the number of telephone helpline calls. Anusha Patel specifically remarked that patients were not calling helplines once in remission, to the same extent, alleviating pressure of the IBD team and wider service.

### Learnings

These initiatives demonstrate the importance of a clinical perspective in discussions around treatment decisions that work best for patients to promote a greater quality of life. Clinicians should be empowered to raise concerns within trusts around access to treatment for their patients, and where possible, work with commissioners to ensure their clinical viewpoint is included in the decision-making process. Efforts should also be made to ensure that patients are put on the right treatment for them, and that a review process is in place to regularly review their treatment plan.

**Clinicians should be empowered to raise concerns within trusts around access to treatment for their patients, and where possible, work with commissioners to ensure their clinical viewpoint is included in the decision-making process.**

# Conclusion

The case studies featured in this report showcase some of the best practices being undertaken across the country to improve IBD services and outcomes for patients.

They demonstrate several key themes which echo those in the IBD standards and the OCP, which are essential to driving improvement in IBD care. They represent a diverse range of trusts and services – from smaller District Hospitals like Kettering General to large research hospitals like St Mark's, London – from the make-up of their patient population, resource allocations and their location – to ensure that the key learnings can resonate with the range of IBD services.

**As NHS services focus on efforts to recover from the COVID-19 pandemic and deliver improved and sustainable care for patients, a national disease strategy for IBD should be developed to support all services to deliver long term improvements across the IBD patient journey. Drawing upon existing innovation and excellence will be critical to levelling up the standard of care for all those living with IBD across the country – therefore, efforts should also be made to identify and promote examples of best practice.**

Treating patients with a focus on long-term outcomes remains at core of service improvement, with a focus on improving quality of life for patients, as opposed to a focus on short-term fixes. This underpins all the case studies, whether that be access to treatment, enabling early diagnosis, or tailoring services to ensure patients can be seen by the right person at the right time.

The incorporation of the patient voice is a mechanism which can allow services to better understand where they need improvement, and these can be incorporated through tools such as surveys, patient panels and audits. Involving the patient in the development of the service is one of the key principles of the IBD Standards and a core part of the OCP. If services are to provide the best care, they need to understand what patients want and how the service can best meet their needs.

The value of a strong IBD team is also apparent, and the work of individuals within the workforce should not be undervalued. This includes the crucial role of the IBD nurse and the importance of access to a multidisciplinary team. The role of the IBD nurse is essential to service improvement, enabling patients to be seen in new environments, reducing the burden on consultants, and driving service improvement through communication with the wider IBD team and the patient. Access to a multidisciplinary team enables services to provide a more holistic approach to care, driving up patient experience and supporting them both physically, as well as emotionally through their IBD journey.

Each service in the UK will have its own unique set of challenges and opportunities in delivering IBD care. However, the principles identified in this report and in the OCP/IBD standards should help form the foundations of IBD care in the UK. While services can be tailored to fit their population and resources, it is critical that these principles underpin everything they do to ensure good care is experienced for all IBD patients. One of the challenges that remains in IBD care is irregular adoption of standards, and whilst good practice should be celebrated, we should focus on extending the opportunity of receiving best practice in care to all patients across the country.

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