

Hannah's story: Inflammatory bowel disease

An implementation support tool that highlights the variation between optimal and suboptimal care

June 2024



» Foreword

Inflammatory bowel disease (IBD) is an umbrella term that describes the main conditions, Crohn's disease and ulcerative colitis, which affect 1 in 123 people in the UK. They can be debilitating chronic conditions managed by high-risk medications and surgery, with high levels of disability, and if poorly managed, risk of mortality.

IBD can develop at any age but most people are diagnosed between the ages of 15 and 40. NHS activity related to IBD has increased over the years, with lifetime medical costs comparable to heart disease or cancer¹ and is predicted to increase as prevalence grows. However, in spite of this, public awareness is low. It remains a largely hidden condition that can cause stigma, fear and isolation.

Due to the coronavirus pandemic, the pressures on elective care and surgery have increased, seeing a reduction in diagnosis, referrals and planned surgeries, serving to exacerbate existing variation in access to specialist advice in crisis.

Numerous audits over the past 10 years have found variation in care in relation to defined consensus standards ([IBD Standards](#)). The challenges for local health systems are early diagnosis; rapid access to specialist advice and treatment; effective multidisciplinary working; and good patient education and personalised care approaches to enable appropriate self-management.

1 Luces C, Bodger K. (2006). Economic burden of inflammatory bowel disease: A UK perspective. Expert Review of Pharmacoeconomics & Outcomes Research. 6: 471–482.doi:10.1586/14737167.6.4.471.

To demonstrate the importance of optimal care in IBD we are using Crohn's disease as an example. This scenario highlights that while there may always be a core cohort of complex patients that will be managed in acute care, there are untapped opportunities to focus services on preventative and planned elective care, rather than reactive care.

This scenario draws attention to the need to deliver better integrated services with primary care, to deliver more and regular interventions that activate patients to self-manage, and to make better use of outpatient appointments and personalised care and support approaches.

We ask that this scenario be read in conjunction with the Getting It Right First Time (GIRFT) national specialty [report](#) on gastroenterology, [IBD Standards 2019](#) (which define high quality care) and the [IBD UK report \(2019\)](#) produced by [IBD UK](#).



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IBD remains a hidden condition that can cause stigma, fear and isolation

» What is a RightCare scenario?

RightCare scenarios put the person at the centre of the story. They use fictional patients to show the difference between a suboptimal, but realistic, pathway of care compared to an optimal one.

This IBD scenario is part of a series of RightCare scenarios that support local health systems to think strategically about designing optimal care for people (and their carers) with high impact conditions.

They help local systems understand how patient outcomes and quality of life can be improved as a result of shifting the care pathway from a suboptimal journey to one that consistently delivers timely, evidence-based excellence.

The suboptimal story in this scenario deliberately highlights where along the care pathway we know often requires improvement. We invite systems to consider the following questions when using this scenario:

- Do you recognise any elements of the patient journey highlighted in this scenario?
- Which journey best reflects the service within your area?
- What parts of the patient journey and experience can you improve?



This scenario has been developed with a group of expert stakeholders, including people with lived experience of Crohn's disease. The aim is to help clinicians and commissioners improve value and outcomes for this patient group. To see the full suite of RightCare products please visit the NHS England [website](#).

If you have any questions about this scenario or other RightCare products, please contact us at rightcare@nhs.net.

What is a RightCare scenario?



Use fictional patients to show the difference between optimal and suboptimal pathways of care

Put the person at the centre of the story



Spark strategic questions



- Do you recognise any elements of the patient journey?
- Which journey best reflects the service within your area?
- What parts of the patient experience can you improve?

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» Clinical introduction

Crohn's disease is one of the two main forms of inflammatory bowel disease (IBD), the other being ulcerative colitis. IBD affects over 500,000 people in the UK. 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, and can affect all layers of the bowel wall.

» IBD should not be confused with Irritable Bowel Syndrome (IBS), which is a functional gastrointestinal condition, although people can have both IBD and IBS

People experience flare-ups when the condition is active that can last from weeks to months, with periods of remission in between. Symptoms include urgent and frequent diarrhoea often with blood and mucus, severe abdominal pain, extreme fatigue and weight loss.

Up to half of people with Crohn's experience symptoms beyond the gut, with eyes, joints and skin most affected. As yet there is no cure and its cause(s) are not yet fully understood.

Management of Crohn's is complex, both in terms of medical management and meeting the emotional and social needs of those affected. IBD should not be confused with irritable bowel syndrome (IBS), which is a functional gastrointestinal condition although people can have both IBD and IBS.

The majority of treatment currently takes place in acute services, from running outpatient clinics and day cases for infusions and surgery, to treating relapses, flares and complications. There are significant costs incurred supporting complex patients with surgery and advanced therapies, such as biologics.

The aim is to treat flares, support people to stay well and monitor long-term risks. Treatment can include steroids, immunosuppressants and biologic medicines, some of which can be high risk. 21% of people with Crohn's will have resection surgery within five years of diagnosis and 26% within 10 years. People with extensive disease are at risk of potentially life-threatening complications such as complete blockage or perforation of the bowel, or cancer.

2 in 5 people with Crohn's have reported being unable to work due to ill health and nearly half had to make an adjustment at work because of their condition. IBD can also affect mental health, particularly in those who are younger, and those recently diagnosed.

» Introducing Hannah

For the purposes of this scenario we would like to introduce you to Hannah. Hannah is 24 years old and works full time in a busy office. She is confident and friendly with an active social life revolving around family and friends. She has several hobbies including travel, reading and cooking which she posts about on social media.



Hannah has recently been promoted into a job she loves and is already considering future opportunities in the company. She joined as a marketing officer and now works for the director. During busy periods of the year her job can be demanding but it is varied and she likes her colleagues. Last year she took three months out to go travelling with her sister in South America and they are planning another trip abroad in the next few years.

She is passionate about food and cooking and writes a food blog which she promotes on social media in her spare time. Being active and healthy is really important to Hannah. She goes to the gym at least three times a week, eats healthily and has always taken her good health as a given.

Hannah is very close to her family, especially her sister who is just two years older. Last year she moved away from home for the first time into a shared house with an old school friend. The transition to living independently was challenging at first but she is really enjoying sharing a flat. She has been in a relationship with her boyfriend Cameron for 18 months. They hit it off over their mutual love of travelling and food.

» The start of Hannah's journey

Hannah has been feeling unwell for over a month. She's had diarrhoea during the day and sometimes at night when she normally has one bowel movement a day.



She urgently needs to go to the toilet 6-8 times a day and sometimes the urge is so sudden that she's nearly had an accident. She now feels anxious when she's not close to a toilet. She is also self-conscious at work that people have noticed that she is spending more time in the toilet.

Her stomach constantly feels bloated and she experiences abdominal pain and cramps. She feels really down and her lack of energy means she's no longer going out or to the gym as much. She is arguing more with Cameron which they never did before her symptoms started and is worried that they might split up.

She is regularly buying anti-diarrhoea medicine, such as loperamide, from her community pharmacy and puts the symptoms down to the stress of having more responsibility at work and longer hours. Eventually she feels that she can no longer ignore her symptoms and makes an appointment with her GP.

Read on to see how Hannah experiences two very different journeys and outcomes.

Look out for 'Information points' throughout the suboptimal and optimal journeys; these highlight the key themes of optimal care for IBD. More information about these can be found on pages 14 and 15.

May, Year 1: Hannah visits her GP with symptoms

Hannah feels embarrassed talking to her GP about her symptoms. In response to the GP's questions she explains that her clothes are looser, she has no blood in her poo, her menstrual cycle is normal and that she's usually active and healthy. She says she has been stressed because of her recent promotion.

The doctor says she probably has irritable bowel syndrome (IBS) and gives her a diet sheet, lifestyle advice and advises Hannah to buy hyoscine butylbromide from the chemist for her abdominal pain. They suggest that Hannah comes back in a couple of weeks if her symptoms have not improved.

A week later, Hannah experiences severe abdominal pain and diarrhoea. Her housemate is so concerned that she takes her to A&E.

At A&E, her bloods are taken, urine dipped and she has an abdominal x-ray. She is given a saline drip and codeine and begins to improve. She has a slightly raised C-reactive protein (CRP) level and her x-ray is clear. She is discharged later the same day and is not referred to specialist services. The A&E doctor tells Hannah to return to her GP.

Hannah sees her GP again where she has a similar experience as before and the discussion focuses on her reducing stress at work. She doesn't feel she is being taken seriously.

December, Year 1: Hannah's symptoms continue and she develops an abscess

Seven months after she first saw her GP, Hannah attends A&E just before Christmas with a fever and an extremely angry looking lump on her perianal area which is agony to sit on. She is seen by an emergency surgeon who diagnoses and drains the abscess in theatre and discharges her into her GP's care. This causes her to miss work which adds to her anxiety.

She is avoiding eating to control her symptoms and just walking upstairs tires her out. She is avoiding Cameron, friends and family due to her low mood and lack of energy and hasn't updated her blogs for months. She has a miserable Christmas.

Hannah returns to her GP in January who takes her bloods and, given her recent abscess, refers her to a gastroenterologist.

After a twelve week wait she is seen by a gastroenterologist in April who discusses her symptoms, takes bloods and arranges a colonoscopy. She is given very little information about the procedure and she leaves feeling worried.

After her colonoscopy, Hannah is seen back in clinic six weeks later by a gastroenterologist who tells her that she has Crohn's disease. She finds the diagnosis and subsequent conversation hard to take in. She is told to take a course of prednisolone steroids for eight weeks and 5-aminosalicylic acid (5-ASAs) daily for the foreseeable future. She is not prescribed bone protection medication alongside the steroid.

1 Information point: Monitoring the effectiveness of treatment and shared care

Hannah is given no information on living with Crohn's disease. She isn't told about the IBD service or who to contact if her symptoms get worse. She is just told that she needs to attend the hospital for regular blood tests and reviews.

Hannah has a blood test before she leaves and is told that she will receive a follow-up appointment in the post and that they will write to her GP.

After the appointment she has lots of unanswered questions and feels anxious about how Crohn's will affect her life.

August, Year 2: Uncontrolled symptoms and lack of support

Hannah takes her course of steroids, tapering them as instructed. Her friends and colleagues comment on how well she looks. However, despite the outside improvement, as the medication is reduced, loose diarrhoea with blood and mucus, and abdominal pain return.

Hannah comes to the end of the course of steroids but her next outpatient appointment is still several weeks away.

She isn't sure what to do next. She still doesn't know how to discuss her condition with her boyfriend, friends or colleagues and feels embarrassed and upset.

Her lack of understanding of Crohn's disease has meant she has begun to normalise her situation. She thinks that her symptoms are an unavoidable part of 'having Crohn's'.

It's now August and Hannah is unable to work. She goes to her GP to ask to be signed off sick. The GP prescribes more prednisolone and says that they will chase her gastroenterology appointment. There is no locally agreed flare pathway.

12 weeks after her diagnosis she is seen in the gastroenterology clinic by a new doctor. She is weighed which confirms she has lost more weight.

She is tearful discussing her symptoms and experience and tells them she isn't coping. She's upset that she's regularly having to take time off work and worries she'll never be able to travel abroad again. She no longer enjoys cooking and has stopped doing simple things she used to enjoy like reading because she can't concentrate.

Her doctor acknowledges she is upset but the discussion focuses on symptoms, tests and medication review. The gastroenterologist is unaware that Hannah was prescribed steroids by her GP until she mentioned them.

She would like to discuss how to manage fatigue but is told that her tests show she isn't anaemic and that this is something to expect with IBD. How to manage fatigue is not explored.

Hannah is not referred for mental health or dietetic support, or signposted to a patient organisation such as [Crohn's & Colitis UK](#) or somewhere to access peer support. No care plan is discussed or set up.

The doctor orders bloods and Hannah leaves feeling that the issues that mattered to her most weren't discussed.

Hannah continues in a cycle of flares and uncontrolled symptoms and sees her GP in between gastroenterology appointments. She is still finding it difficult to accept her diagnosis and has become disengaged with health services. She doesn't always attend her appointments as she hasn't seen any improvement in her symptoms and so doesn't see the benefit of attending.

She has several emergency care attendances that led to three unplanned emergency admissions to hospital which were treated with steroids. She also had two more perianal abscesses that were treated in A&E by incision and drainage - one of which was done at a different hospital.

Hannah's day is now planned around making sure that if she has to go out there are toilets nearby at all times and that she has a spare change of clothes. She no longer goes out unless she has to.

Her manager agrees for her to reduce her hours and take a demotion in an attempt to manage her tiredness and anxiety.

She develops extra-intestinal manifestations on her skin in the form of erythema nodosum (painful red lumps on her shins). These aren't picked up at first as she isn't aware that this can be a symptom of Crohn's, but when they are, her GP refers her to a dermatologist.

December, Year 3: Hannah has emergency surgery

Over several weeks Hannah experiences progressive abdominal pain. One evening in December this becomes unbearable. Her housemate takes her to A&E where a CT scan shows an abscess in her abdomen around the terminal ileum, secondary to severe and uncontrolled Crohn's inflammation.

Hannah requires a resection of a segment of her small intestine and formation of a temporary stoma and is placed on a general surgical ward.

After the operation a member of the stoma team visits Hannah on the ward and shows her how to change her bag. She is given extra bags to keep her going until she leaves hospital and is told she will need to go to her GP to arrange follow-up deliveries. A follow-up appointment with the stoma team is arranged in two weeks.

After her surgery she struggles to come to terms with having a temporary stoma and is worried about how to manage it. She feels like she has failed and isolates herself from her friends and family who she believes will react differently to her.

She struggles with her stoma, especially at night, and by the time she attends her first stoma appointment her skin is red and sore.

She has not left her house in weeks and is feeling very low and depressed. The emotional stress has put enormous strain on her personal relationships, especially intimacy, and her relationship with Cameron breaks down. She is struggling to cope and doesn't know how she is to going to return to work. She has no long-term plan for her recovery or care, and she doesn't feel in control of her Crohn's or future.

May, Year 4: Hannah has a second operation to reverse her ileostomy

In May, Hannah is well enough to have a second operation to reverse her ileostomy. The procedure goes well and she is discharged after four days. She goes home to her parents to recover and has the usual symptoms following this procedure of diarrhoea for a few weeks.

As her symptoms ease she moves back to her flat and returns to work.

Hannah should have had a follow-up endoscopy six months after the reversal to ensure there has been no recurrence. But as she still has no named gastroenterologist no endoscopy is arranged.

December, Year 4: Hannah develops another perianal abscess and starts correct treatment

In December, Hannah develops abdominal pain and another perianal abscess. Again, she takes time off work and goes back to A&E where she has an MRI on her small bowel and pelvis, and a colonoscopy which confirms perianal Crohn's and recurrent ileal Crohn's.

Hannah is really upset and fed up at the setback as she thought she was improving following the reversal of the ileostomy. Again, she is given little information as to what this means.

She is admitted to hospital where she undergoes examination under anaesthesia to drain the abscess and is discharged the same day. An appointment is made to see the gastroenterologist.

12 weeks later she sees the gastroenterologist in clinic who prescribes infliximab and azathioprine. They explain to Hannah she will need to take these for the foreseeable future.

Over the next few weeks, Hannah's Crohn's symptoms ease. She returns to work and after six months is able to return to full time. Hannah is pleased her Crohn's is under control but is confused and angry as to why it's taken this long to start the right treatment.

Let's see how Hannah's journey could be so much better. We start at the same place as the suboptimal story...

May, Year 1: Hannah visits her GP to discuss symptoms

The GP asks Hannah whether she has any family history of bowel conditions, changes to her menstrual cycle and if she's been losing weight (they note that she doesn't appear obviously anaemic). They ask questions about the colour and consistency of her poo and if she has seen any mucus or blood, explaining what this might look like.

The GP probes a little more into the causes of Hannah's stress. She explains she has experienced stress before at university but the symptoms are new. Based on her symptoms and age, cancer is not suspected. The GP uses the Advice & Guidance e-Referral Service (e-RS) system to seek specialist advice.

A consultant responds within 24 hours and advises the GP to rule out infection, screen for coeliac disease and to do a faecal calprotectin test (FCP). The GP also orders a full blood count, urea and electrolytes, C-reactive protein and screens for coeliac disease.

The GP contacts Hannah to arrange for her to complete the tests at her local community diagnostic hub and advises that the FCP test can be completed at home. They explain what each test means in a way that Hannah understands and signpost her to information online.

June, Year 1: Hannah receives a timely diagnosis and supportive information

Hannah's faecal calprotectin test reveals a level of 954. As this is over 250mcg/g it falls into the 'high risk' category for IBD. Hannah is referred for a colonoscopy and biopsy to confirm the IBD diagnosis using the local referral pathway agreed between primary and secondary care.

The GP explains their suspicions to Hannah and what's involved with a colonoscopy and how to prep for it. They signpost her to online information about colonoscopies that she may find helpful.

Hannah attends her colonoscopy appointment in June which was within four weeks of the referral. The colonoscopist tells Hannah that she may have Crohn's disease and recommends the [Crohn's & Colitis UK](#) website for further information, and arranges an urgent out-patient consultation in a new diagnosis clinic.

Histological processing and reporting of her urgent biopsy samples is completed within two weeks.

Two weeks after her colonoscopy she is seen in the new diagnosis clinic where it is confirmed she has Crohn's disease. Hannah is upset but was prepared due to the information she had already received from her GP and the endoscopy team.

2 Information point: Timely identification and referral

The consultant explains the results of her tests and that her Crohn's disease is affecting the terminal ileum. They do this in simple terms and use diagrams to ensure that Hannah understands. They inform Hannah that this information will be recorded in her treatment plan which will be shared with her and her GP within 48 hours. She is recommended to have timely (within four weeks) and complete imaging of her small bowel using tests that do not involve radiation such as MR enterography or intestinal ultrasound.

Hannah is offered exclusive enteral nutrition, prednisolone or budesonide (steroids) as induction therapy and the risks and benefits of each are explained. Hannah is concerned about the side effects of prednisolone and chooses to take budesonide.

The consultant talks about the importance of treatment but also putting in place the right strategies to help self-manage her condition and long-term emotional wellbeing. They confirm that Hannah will be referred to an IBD nurse specialist who will cover this in more detail and support her with her diagnosis.

Hannah is assigned a named consultant gastroenterologist and is given information about the IBD advice line and IBD nursing service.

Following her diagnosis, Hannah is referred to an IBD specialist nurse. The nurse carries out a full assessment of her disease including nutritional status and bone health with baseline infection screen. Her mental health is also discussed.

Together they write Hannah's personalised care and support plan starting with Hannah's aspirations, goals and needs. They identify that coming to terms with having Crohn's and making sure this doesn't impact her job are most important to her. The nurse reassures Hannah that this plan will be reviewed on a regular basis and shared with her GP.

Hannah is also given a patient pack which includes information on Crohn's and local groups for people living with the condition. She is advised that she may benefit from counselling or peer support and she is reminded that [Crohn's & Colitis UK](#) is a helpful charity for further information, advice and support, including around employment.

The IBD nurse gives Hannah the chance to ask any questions and checks at the end of this conversation that Hannah feels confident that she has what she needs to manage her IBD, and knows how and when to get in touch.

She is also referred to a dietitian to help her create a diet plan that compensates for her nutrition deficiencies, unintended weight loss and to help manage symptoms. She is told that she will have an annual review and is given contact details if she needs advice in the interim.

September, Year 1: Hannah learns to come to terms with her diagnosis and receives personalised care

Hannah is reviewed back in a consultant clinic. She did well initially on budesonide but as the dose has been reduced she has developed further symptoms of diarrhoea.

They agree to continue the budesonide and initiate azathioprine as a steroid-sparing agent. An appointment with a pharmacist is made in six weeks with blood tests and virtual review at two and four weeks.

Hannah has found it really difficult to accept the diagnosis and how this may affect her life. The IBD nurse specialist takes their time to answer Hannah's questions and really helps her to come to terms with the diagnosis and ensures Hannah understands what this means.

They agree an ongoing management plan that includes putting Hannah on a patient initiated follow-up (PIFU) pathway. It also supports her to navigate and access specialist advice and treatment quickly when she needs to, aiming to reduce the impact of flares on her work. As part of this conversation, they discuss what the early symptoms of a flare look like for Hannah, and when and how she would need to contact the IBD service.

The nurse reminds Hannah of how valuable Crohn's & Colitis UK can be in supporting her with coming to terms with her diagnosis and providing advice.

Within 48 hours of her appointment, Hannah's IBD team email her GP with her personalised care plan and clear guidance about what to do and who to contact if her symptoms flare.

Although the diagnosis is still a shock, Hannah feels that she has the information and support to discuss her Crohn's with Cameron, family and work. She also feels confident in knowing her IBD nurse specialist is on hand to answer any questions or concerns.

3 **Information point:**
Importance of personalised care and self-management

May, Year 2: Hannah accesses specialist advice to manage complications

Hannah develops a perianal abscess. She follows her PIFU pathway and calls her IBD nurse specialist who responds the next day and refers her to the on-call surgical team using the local abscess pathway. An abscess and fistula are diagnosed on MRI and treated with surgical drainage and seton suture insertion.

4 Information point: Rapid access to specialist advice and treatment

She is given an emergency contact number and discharge information that is clearly explained to her. As her wound heals, she attends regular appointments with the GP practice nurse. Due to her condition advancing it is decided to initiate infliximab.

Hannah has annual reviews with her IBD nurse specialist and gastroenterologist. These are usually done over video call which easily fits in with her work schedule. The calls are an opportunity to review her personalised care and support plan. This includes advice around attendance for cervical screening and ensuring she has her annual flu vaccines, as well as sexual health and family planning which she finds hugely valuable. She also repeats the faecal calprotectin test and the intestinal ultrasound test every year to monitor her response to treatment.

Last year, when her symptoms flared up, Hannah phoned the IBD advice line and was booked to see a gastroenterologist the next day.

This meant her flare was managed quickly with minimal impact to her work. She also had a review with her dietitian to see how her diet plan can help minimise the risk of future flares.

During this time Hannah moves to a new city for a promotion at work. She was initially anxious that this would affect her treatment but a thorough handover was provided to the new IBD service.



5 Information point: Effective multidisciplinary working

She has developed a good relationship with her new IBD team and is reassured by their regular communication with each other and commitment to her care plan. She feels empowered and confident to contact her IBD nurse specialist to discuss any concerns she may have.

Her relationship with her boyfriend is also going well and they decide to move in together. He has gained an understanding of her Crohn's through the education days organised by the hospital and has learnt how to best offer support.

They decide they would like to have children in the future so she contacts the IBD nurse specialist for advice. The nurse reassures Hannah and tells her that pre-conception counselling is available and that she can be seen in a joint IBD-obstetric clinic. This makes Hannah and Cameron more confident about their future.

February, Year 5: Hannah undergoes elective bowel surgery

Hannah has been fully engaged with her treatment and has attended all appointments as required. She has found having a personalised care plan really helpful and the encouragement and support she has received from the IBD nurse specialist has been invaluable.

She has stayed well with no time off work and has been able to stay fit, travel and write her food blog.

However, despite changes to her medication, Hannah is no longer responsive to treatment and bowel surgery is required.

She is aware that surgery is a treatment option as this was covered on the education days she attended. It has also been discussed as part of her personalised care planning.

Prior to surgery Hannah is referred for an MR enterography to help map out her disease and allow for optimal surgical planning. She has a nutritional risk assessment by a dietitian who gives her supplements to optimise her nutritional status before surgery and has pre-op assessment with an IBD pharmacist to review her medication. She is also given the opportunity to meet a patient with a stoma to discuss their experience which she finds extremely helpful.

She is seen in advance in a joint medical and surgical clinic and the surgery is carried out in a unit which undertakes this surgery on a regular basis by a surgeon with the appropriate experience and skills.

Her IBD service has developed a series of patient videos which Hannah is able to view ahead of her surgery. The videos are of patients in her situation sharing their experience of surgery and living with a stoma. From this, and all the information and support she has received since her diagnosis, she knows she can still live a fulfilling life.

6 Information point: Addressing delays to surgery and driving up quality

The operation takes place within the 18 week maximum wait and she stays on a specialist ward where her mental health, nutrition and pain are assessed. She is reviewed on the ward regularly and visited by the stoma nurse and an outpatient clinic appointment is made. She is counselled at discharge by the ward pharmacist.

Hannah's medication is reviewed, and the stoma team ensure that Hannah is confident in managing the stoma before she is discharged. They continue to monitor and support Hannah at the community wound clinic and joint medical and surgical follow-up appointment is made.

Due to the support given by her care team and from organisations such as [Crohn's & Colitis UK](#) and [Ileostomy & Internal Pouch Association](#), Hannah feels like she can talk to people confidently and openly about the surgery.

In March the following year, she undergoes elective surgery to reverse her stoma and discusses the range of medical options available to her to prevent post-operative relapse of her Crohn's disease.

While it's been a challenging period she has felt supported by her family and the IBD service throughout. She is confident in managing her Crohn's and knows what to do and where to go when she needs support and advice.

Although it has impacted her life at times, her career, relationships and personal life have not been affected. She has booked a holiday to Japan for the following year with Cameron and is looking forward to trying all the food!

» Information points

Throughout Hannah's journeys we have highlighted key themes of optimal care that are supported by national guidance and standards. See below for more information about each of these themes and links to further information.

1 Monitoring the effectiveness of treatment and shared care

Inappropriate steroid prescribing can result in dependence and side effects and can be an indicator of poor quality care. Services should routinely collect and audit data including on patients receiving excessive steroids each year and have protocols in place for communicating and recording steroid use between primary and secondary care. Shared care protocols should also be in place for immunosuppressants.

- NICE Quality Standard ([QS81](#)): Statement 4: Monitoring drug treatment
- IBD standard [Section 4](#): Flare management - steroid management, IBD UK
- IBD Standard [Section 7](#): Ongoing care and monitoring - shared care, IBD UK

2 Timely identification and referral

People with suspected IBD should have a specialist assessment within four weeks of referral, or sooner if urgent. Delayed diagnosis is linked to multiple primary care and A&E attendance(s), higher incidence of surgery and complications, reduced response to medication and more expensive treatments. Clear local protocols for faecal calprotectin testing in primary care, as part of agreed referral pathways between primary and secondary care, and emergency and specialist teams should be in place and monitored. Information about the IBD advice line should be shared.

- NICE Quality Standard ([QS81](#)): Statement 1: Specialist assessment
- IBD Standard [Section 2](#): Pre-diagnosis
- IBD Standard [Section 3](#): Newly diagnosed, IBD UK
- [ECCO-ESGAR Guideline for Diagnostic Assessment in IBD Part 1](#): Initial diagnosis, monitoring of known IBD, detection of complications

3 Importance of personalised care and self-management

Inability to self-manage is associated with complications, poorer mental and physical health. Every patient should have a personalised care and support plan which is regularly reviewed. Structured self-management programmes should be commissioned.

- IBD Standard [Section 4](#): Flare management - self-management, IBD UK

» Information points

4

Rapid access to specialist advice and treatment

Flare-ups require rapid active management to minimise the impact of relapse on physical wellbeing and social functioning. Every patient should have a flare plan. Rapid access clinics, advice lines and prompt access to investigations should be in place in every service, supported by flare pathways that are agreed between primary, secondary and emergency care.

- IBD Standard [Section 7](#): Ongoing care and monitoring, IBD UK

5

Effective multidisciplinary working

Multidisciplinary working is associated with higher quality care. The IBD service should be resourced to meet the staffing requirements defined by the IBD Standards and NICE Quality Standard. Pathways should deliver coordinated care and every service should have a leadership team to drive development and involve patients in service development.

- NICE Quality Standard ([QS81](#)): Statement 2: Multidisciplinary team support
- IBD Standard [Section 1](#): The IBD Service, IBD UK

6

Addressing delays to surgery and driving up quality

People having surgery for inflammatory bowel disease have it undertaken by a colorectal surgeon who is a core member of the inflammatory bowel disease multidisciplinary team. The expertise and experience of the clinical team will enable the best judgement of when to undertake surgery, and should ensure the quality of clinical care before, during and after surgery.

- NICE Quality Standard (QS81), [Statement 3](#): Surgery

» The 'bills' and how they compare

The difference between the two journeys to Hannah's life in terms of quality and outcomes is stark. In the optimal journey Hannah is able to maintain her lifestyle and continue to do everything that is important to her. Her relationship with Cameron goes from strength to strength and her career remains unaffected.

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

Estimated costs of the optimal and suboptimal journeys

National average Reference Costs (2022/23) and similar data sources have been used to calculate the indicative healthcare costs of two hypothetical pathways of care for an individual fictionalised 'typical' patient, and therefore do not represent the local cost of service provision.

It is recommended that systems work with local clinical leaders and costing colleagues to map existing pathways, taking into account local circumstances and evidence, and reflecting the make-up of the local population and services already in place.

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

The optimal journey clearly demonstrates how, through early diagnosis, timely and appropriate treatment, access to specialist support, and taking an MDT approach to care, people can confidently manage their IBD. This is in contrast to the suboptimal journey where it took 12 months for Hannah to get a diagnosis and, due to a lack of disease management and support, her uncontrolled symptoms resulted in six A&E visits over the course of her patient journey.

Although Hannah ended up having bowel surgery in both journeys the circumstances were very different. In the optimal journey surgery was performed electively and only after alternative treatment was explored. Because Hannah was given appropriate education and information about all aspects of the disease, including the possibility of surgery, from diagnosis, she felt prepared and knew what to expect. In the suboptimal journey Hannah underwent surgery as an emergency procedure. This came as a huge shock and left her feeling anxious, unsure how to deal with it and how it would affect her future.

» Areas for systems to consider

At a local population level, 1 in 123 live with inflammatory bowel disease. The following questions address some action areas that can lead to improvement within local health systems:



- » Are there clear referral and emergency pathways and protocols in place between primary and secondary care for the investigation of persistent lower gastroenterological symptoms in both children and adults including the appropriate use of faecal calprotectin testing?
- » Are there clear local pathways and protocols in place between primary, secondary and emergency care for the management of IBD including shared care protocols for immunosuppressants, in particular when patients are experiencing flares, thus making the most of every contact and reducing inappropriate attendances to A&E and admissions?
- » Does your local IBD Service have an appropriately staffed multidisciplinary team, as defined by the IBD Standards 2019, in order to support every aspect of IBD care, including diagnosis, initial treatment, rapid access to specialist review and support, surgery, and ongoing care?
- » Are regular structured self-management learning and education opportunities for children and adults with IBD provided locally?
- » Are information materials available in a range of formats and languages to suit individual needs and preferences, with patient feedback audited to identify and address any gaps in provision?
- » Are patients routinely provided with their written personalised care plans to support self-management, which include their diagnosis and current treatment, who to contact for advice and support, what to do in the event of a flare and cancer surveillance colonoscopy due dates?
- » Does your local IBD service have mechanisms in place to conduct routine reviews and monitoring with options for patients, including face-to-face IBD nurse and dietetic specialist clinics and expert pharmacist clinics, IBD advice lines and virtual clinics?

» Additional resources, guidance and tools

For more information about inflammatory bowel disease, its management, guidelines, policy and tools, you may wish to look at the following resources:

Key resources

- The [Model Health System](#): a data-driven improvement tool that enables NHS health systems and trusts to benchmark quality and productivity.
- Getting It Right First Time (GIRFT) [Academy Resources](#)
- NHS England: [Transforming Gastroenterology Elective Care Services](#) - This handbook has been created to support the improvement of local health and care systems for gastroenterology elective care services.
- NHSX: [Gastroenterology Digital Playbooks](#) - This resource provides support to clinical teams and organisations that are looking for digital tools to support the delivery of patient pathways
- IBD UK: The [IBD Standards](#) say what high-quality care should look like at every point of a patient's journey – from first symptoms, to diagnosis, treatment, and ongoing care.
- National Confidential Enquiry into Patient Outcome and Death: [Crohn's Disease](#)
- Royal College of General Practitioners: [IBD Toolkit](#) for GPs and other primary care professionals

- Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change ([IBDUK](#), 2019)

Patient organisations

- [Crohn's & Colitis UK](#)
- [CICRA](#) – better lives for children with Crohn's and colitis
- [Ileostomy & Internal Pouch Association](#)

National Institute for Health and Care Excellence (NICE) guidance

- Inflammatory Bowel Disease Quality Standard ([QS81](#))
- Crohn's disease: management ([NG129](#)) guidance
- Ulcerative Colitis: management ([NG130](#)) guidance
- Colorectal cancer prevention: colonoscopic surveillance in adults with ulcerative colitis, Crohn's disease and adenomas ([CG118](#)) guideline
- Faecal calprotectin diagnostic tests for inflammatory diseases of the bowel ([DG11](#)) diagnostics guidance

- British National Formulary: Key information on the selection, prescribing, dispensing and administration of medicines, [Chron's disease](#)

National guidelines

- British Society of Gastroenterology: [Consensus guidelines on the management of inflammatory bowel disease in adults](#)
- Royal College of Paediatrics and Child Health (RCPCH) and British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN): [Quality standards for specialist paediatric gastroenterology, hepatology and nutrition](#)
- Association of Coloproctology of Great Britain and Ireland: [Consensus guidelines in surgery for IBD](#)
- British Society of Gastroenterology: [Guideline on transition of adolescent and young persons with chronic digestive diseases from paediatric to adult care](#)

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