Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy’n aros am ddiagnosis neu driniaeth

This response was submitted to the Health and Social Care Committee consultation on the impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

WT 34
Ymateb gan: | Response from: Crohn's & Colitis UK

CROHN'S & COLITIS UK

SENEDD HEALTH AND SOCIAL CARE COMMITTEE INQUIRY: IMPACT OF THE WAITING TIMES BACKLOG ON PEOPLE WAITING FOR DIAGNOSIS OR TREATMENT

CROHN'S & COLITIS UK SUBMISSION
[January 2022]

Crohn’s & Colitis UK submission: Senedd Health and Social Care Committee inquiry into the impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

January 2022

1. About us

1.1 Crohn’s & Colitis UK welcomes the opportunity to respond to this inquiry on the impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment.

1.2 Crohn’s & Colitis UK is the leading charity for Crohn’s and Colitis in the UK. We work to improve diagnosis, treatment, and care, to fund research into a cure, to raise awareness and to provide information and support.[1]

1.3 Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn’s Disease and Ulcerative Colitis, affects 24,000 children and adults or 1:117 people in Wales.[2] They are lifelong, often debilitating conditions, with no cure.[3] Symptoms include urgent and frequent diarrhoea (often with blood), abdominal pain, fatigue, and weight loss, with associated anxiety and depression. They lead to time off school and work, withdrawal from social relationships and inability to carry out everyday activities, such as shopping and exercise. IBD doesn’t just affect the gut. It can affect almost every part of the body and every aspect of life: from digestion, eyes and joints to energy levels and mental health. With many of these symptoms invisible, it can appear that someone looks healthy when they are in fact incredibly unwell. This creates stigma and misunderstanding, with thousands of people suffering in silence.

1.4 People can be diagnosed at any age, with most diagnosed between the ages of 15 and 40. IBD requires tight monitoring and management, often over several decades depending on age of diagnosis. Care is managed across primary and secondary care, often with high-cost medications or surgery, or a combination of both. Delayed diagnosis increases the likelihood of surgery or more expensive treatments and results in a poorer prognosis.[4] If left untreated, poorly managed or in cases of severe disease, Crohn’s and Colitis can cause serious complications, which require emergency medical and/or surgical intervention. The burden of Crohn’s and Colitis on the NHS is increasing year on year and per patient costs are comparable to cancer and heart disease.[5] The annual cost of treating a flare (relapse) is up to six times greater than for treating a patient in remission.[6]

1.5 Our submission draws on a range of sources, including published articles, existing guidance, IBD Registry[7] data, and surveys of and direct testimony from healthcare professionals and people with Crohn’s and Colitis, which assess the provision of IBD care before and during the coronavirus pandemic.

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[1] www.crohnsandcolitis.org.uk

[2] SAIL databank, Swansea University

[3] About Inflammatory Bowel Disease | Crohn's & Colitis UK (crohnsandcolitis.org.uk)

[4] Mozdiak E, O’Malley J, Arasaradnam R (2015). Inflammatory bowel disease. *BMJ*. 351: h4416. Inflammatory bowel disease | The BMJ

[5] Luces C, Bodger K (2006). Economic burden of inflammatory bowel disease: A UK perspective. *Expert Review of Pharmacoeconomics & Outcomes Research*. 6: 471-482.

[6] Ghosh N, Premchand P (2015). A UK cost of care model for inflammatory bowel disease. Frontline Gastroenterology. 6: 169–174. doi:10.1136/flgastro-2014-100514.

[7] Home - UK IBD Registry

2 Summary of key points and recommendations

2.1 IBD care is reactive and delivered by understaffed services which were already struggling to meet the demand resulting in delayed treatment and emergency surgery with higher rates of complications.

2.2 Lack of IT and digital support contribute to significant inefficiencies and poor coordination of care.

2.3 The coronavirus pandemic has exacerbated existing issues with IBD care for people with Crohn's and Colitis and has led to:
  i. A reduction in reported diagnoses of IBD
  ii. Cancellation of and reduced access to endoscopy and surgery for IBD
  iii. Delayed appointments and difficulties accessing IBD specialists and GPs
  iv. Disrupted access to essential medication

2.4 This has resulted in people with Crohn's & Colitis experiencing:
  i. Flares, which may cause further bowel damage and increase cancer risk
  ii. High need for mental health support
  iii. Likely increased need for more high-cost drug treatment and complex surgery

2.5 There is little appropriate provision for pain management or psychological support – long waiting lists mean this is not accessible while people are waiting to be seen for diagnosis or treatment.

2.6 Priorities for clearing the backlog should include:
  i. Access to faecal calprotectin testing in primary care in all areas to support direct to test and speed up diagnosis
  ii. Focused effort to increase endoscopy provision and surgery safely, ensuring that IBD endoscopy and surgery is appropriately prioritised according to clinical need
  iii. Clearer communication to patients about waits, how to access care and how they can stay as well as possible while waiting
  iv. Increasing provision of psychological support and ensuring that services are appropriately resourced and configured to meet the demand
  v. Improving the use of IT across all health boards and utilising opportunities for remote monitoring, including faecal calprotectin testing and supported self-management

2.7 Opportunities to redesign care, such as remote appointments and shifts to subcutaneous treatments must involve patients and be based on delivering personalised care and shared decision-making.

2.8 Continued active support for the NHS Wales Health Collaborative's IBD Work Programme is needed to drive improvements in care and accelerate innovation across the system.

3 Service capacity and provision in Wales

3.1 Data collected in 2019/2020,[8] based on the most comprehensive assessment of IBD care undertaken, revealed high levels of urgent and emergency care, the result of services

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[8] Crohn's and Colitis Care: The Hidden Cost and a Vision for Change, IBD UK, 2021

under strain. This manifested in delays in diagnosis, investigations and surgery and a lack of personalised, proactive care.

i. 47% of the patients in Wales who responded to the IBD Patient Survey, and had been diagnosed in the previous two years, had visited A&E at least once before diagnosis
ii. 90% had found it hard to cope with having Crohn's or Colitis during the previous year
iii. No IBD service in Wales met the IBD Standards staffing requirements for all members of the team

3.2 Recent insight from the IBD Wales Health Board Surveys, conducted in July and August 2021 as part of the NHS Wales Health Collaborative's IBD Work Programme,[9] found that:

i. IBD care is reactive and delivered by understaffed services struggling to meet the demand, resulting in delayed treatment leading to more emergency admissions, more emergency surgery, and increased surgical complications (with more stoma formation).
ii. Endoscopy waiting times are a key determinant in delayed diagnosis, which nearly always requires colonoscopy or flexible sigmoidoscopy and should be direct to test based on faecal calprotectin or faecal immunochemical test done in primary care when IBD suspected. Calprotectin is still not available directly to GPs in Swansea Bay and the Bridgend area.
iii. Lack of IT and digital support is greatly lacking. This results in delays and inefficiency which could be avoided. For example, electronic referral systems for GPs which enable consultants to respond rapidly with advice through the Welsh Clinical Portal is not available for gastroenterology referrals in Aneurin Bevan, Betsi Cadwaladr, and Cwm Taf Morgannwg. In other areas it has resulted in >40% reduction in routine waiting list numbers for gastroenterology clinics.

4 Impact of the pandemic on care for people with Crohn's and Colitis

4.1 Diagnosis

4.1.1 IBD is not well understood either by the public or by GPs, who see a high proportion of patients with lower gastrointestinal symptoms. This creates delays in people recognising they have symptoms that should be investigated and in GPs carrying out the relevant tests and making the necessary referrals to secondary care. There are often further delays before a specialist can be seen and then before treatment is initiated. The pandemic has created additional challenges at each of these stages, due to difficulties accessing appointments, tests, and investigations.

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[9] Further information available on request

4.1.2 IBD Registry data from April to June 2020, compared with the same period in 2019, shows that the rate of new diagnoses of IBD recorded fell from 49 to 13 per 1,000 events (-74%).[10] Diagnosis is also taking longer than before the pandemic.

4.1.3 11% of the 308 people living in Wales who responded to our Healthcare Survey 2021 had been diagnosed in the previous 12 months.

i. 29% who had been recently diagnosed said this had taken more than a year (29% UK-wide, based on 7,149 respondents)
ii. 46% said it had taken more than two weeks for treatment to start after diagnosis (41% UK-wide)

> *"I had been ill for over a year before I saw a doctor and for weeks was just told to go to A&E as my GP wouldn't give me an appointment."*
>
> *"Doctors refused to see me due to Covid, ended up in hospital and having blood transfusions after becoming severally anaemic with a BMI lower than 17."*

4.2 Access to endoscopy and surgery for IBD

4.2.1 IBD patients require endoscopy for diagnosis, monitoring, surveillance, and treatment. People with IBD have an increased risk of bowel cancer, particularly those with more extensive or active disease or Primary Sclerosing Cholangitis (PSC). NICE and BSG guidelines and the IBD Standards recommend regular cancer surveillance, in line with national guidance.

4.2.2 The pandemic has had a significant impact on endoscopy in line with national guidance,[11] with much of this cancelled during the first lockdown. Studies have shown stark decreases in lower gastrointestinal endoscopy, including both diagnostic and therapeutic colonoscopy and flexible sigmoidoscopy.[12] Enhanced safety procedures present challenges in terms of managing the backlog but can be addressed more efficiently and effectively in line with guidelines given the appropriate effort, leadership and drive.

4.2.3 Crohn's & Colitis UK's Healthcare Survey 2021 found that 24% of those in Wales who said they had needed a colonoscopy during the previous six months reported waiting more than the recommended limit of four weeks for this, with 37% of these saying their colonoscopy had been cancelled with no new date for when this would take place. Most colonoscopies were required for diagnosis or investigation and appropriate management of flares.

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[10] Bodger K *et al* on behalf of the UK IBD Registry Collaboration. **COVID-19 impact on care and prescribing for inflammatory bowel disease: Data from the IBD Registry**. PMO-37 COVID-19 impact on care and prescribing for inflammatory bowel disease: Data from the IBD Registry | Gut (bmj.com)

[11] Endoscopy activity and COVID-19: BSG and JAG guidance | The British Society of Gastroenterology

[12] M Deputy, O Faiz et al The provision of, and outcomes for, inflammatory bowel disease services during the Covid-19 pandemic: a nationwide observational study (unpublished, journal submission pending)

> *"I had to wait 16 months for my sigmoidoscopy* [needed for diagnosis]*."*
>
> *"Need a new biologic. Have been off it for over 12 months and in flare and on steroids for ten months waiting for appointments and treatment to be approved."*
>
> *"Worried about melanoma becoming cancerous and because of no colonoscopy for another year."*

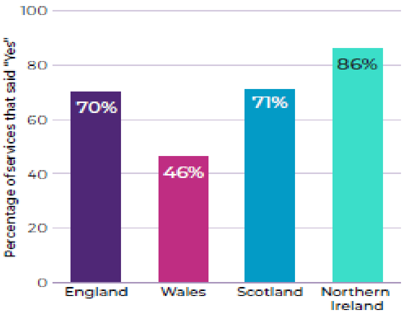
4.2.4 21% of people with Crohn's will have resection surgery within five years of diagnosis and 26% within 10 years. 10–15% of people with Ulcerative Colitis are likely to require surgery at five to 10 years. People with extensive disease are at risk of potentially life-threatening complications – such as a complete blockage or perforation of the bowel – if surgery is not considered in a timely fashion.

4.2.5 Crohn's & Colitis UK's Healthcare Survey found that:

i. UK-wide, 29% of those who needed surgery during the previous 12 months had had this cancelled, and over half of these still did not have a new date for the surgery to take place
ii. More than one third of the operations needed were for unplanned emergency surgery, which might have been avoided had appropriate treatment been possible at an earlier stage

4.2.6 Prior to the Covid-19 pandemic, waits for elective IBD surgery in Wales were the longest of all four UK nations, with only 46% of services reporting that this took place within 18 weeks of referral and 30% of patients reporting waiting longer than 18 weeks for elective IBD surgery.

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



4.3 Access to IBD specialists, GPs, and medication

4.3.1 As a chronic, fluctuating condition with the potential for complications to be serious and potentially life-threatening, rapid access to specialists is essential for people with Crohn's or Colitis both for effective condition management and for support while people are waiting for investigation and treatment.

4.3.2 The IBD Standards[13] state that people should get a response from their IBD advice line by the end of the next working day.

i. Around one in four (24%) of those who had tried to contact their IBD advice line said they did not usually or always get a response by the end of the next working day (27% UK-wide)
ii. 32% of those who had needed care from their GP during the previous six months said they had been unable to get the care they needed (41% UK-wide)

4.3.3 Issues highlighted included difficulties getting appointments, poor coordination of care between GPs and specialists and delivery and supply issues with medication.

"Told day after day no appointments available, which nearly left me being admitted to hospital."

"I contact my GP and they tell me to contact my gastro specialist. I ring the number for the IBD nurse team and get a recorded message saying that the service has been disbanded because of staff shortages and that I should contact my GP or look on your website for information. I tried contacting my gastro specialist on 4 different occasions and was never successful."

"Blood tests difficult to book so prescription couldn't be released."

"Had a telephone appointment 2 weeks ago, still waiting for my prescription to come through the post. I also have no one to contact in relation to it."

"Pharmacy out of stock on a regular basis and being told to keep coming back to see if they have received it."

5 Services in place for people who are waiting for diagnostics and treatment, particularly pain management support

5.1 Our healthcare survey shows that many people living with Crohn's and Colitis in Wales have been struggling to get a diagnosis and the care and treatment they need over the past 12 months, including appropriate support while waiting for diagnostics and treatment. This has resulted in flares of their condition, hospital admissions and surgery and has affected their mental wellbeing, relationships, and ability to work.

i. 19% of those who had needed health services or treatment during the previous six months said that difficulties accessing this had resulted in a flare of their condition
ii. 19% of those who had needed health services or treatment during the previous six months said that difficulties accessing this had affected their mental health

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[13] www.ibduk.org/ibd-standards

> *"Extremely distressing as a young person, I find it really difficult to talk to anyone about this and then when I did, I felt I was being treated like a child being talked down to and being dismissed as a nuisance."*
>
> *"Not been able to get ANY help. GP is clueless and hospital is short staffed in gastro. Had to guess and self-treat for a six week flare up. It can be very scary not knowing if I'm doing the right thing or not and just hoped by not eating food for 6 weeks would help."*
>
> *"To date I haven't been given any treatment other than Salofalk granules. The flares are awful and its weeks before I begin to feel well again. I'm constantly afraid of the next flare, and it's so unpredictable that I hardly ever leave the house."*

5.2 Despite this impact, there is no provision for appropriate pain management support for people with Crohn's and Colitis, with the only option being referral to chronic pain management services. However, this is inappropriate for those with undiagnosed conditions and waiting times are generally extremely long, so any support is unlikely to be provided before the specialist appointment takes place.

6 Access to psychological therapies and emotional support for those who may be experiencing anxiety or distress as a result of long waiting times

6.1 While extremely important for IBD care, given the significant mental health impact of the conditions and treatment, and the fact that stress and anxiety exacerbate symptoms, no health board in Wales has appropriate staffing for adults with Crohn's and Colitis for psychological support. Most have no service at all, with very long waiting lists where provision does exist.

> *"The lack of support and information and feeling like I was then taking up someone's time unnecessarily also impacted my mental health. When I have been able to access some support, I mentioned several times about severe tiredness and mental health, with no options discussed and medication focused on the bleeding and diarrhoea. Treatment has been reactive rather than ways to proactively manage my condition and learn how I can best live with it."*

7 The contribution the third sector can make in providing peer support and information to patients on an NHS waiting list

7.1 The third sector makes an important contribution in providing access to peer support and high-quality evidence-based information to patients waiting on an NHS waiting list. Crohn's & Colitis UK have seen calls to our Helpline and traffic to our website increase significantly over this period. We produce and have highlighted information on what to do if you are having a flare and mental wellbeing and have provided virtual social events and Facebook Lives on themes such as mental wellbeing, which have been very well-received.

7.2 However, we complement rather than replace health services and support collective recommendations produced by health and social care charities for:

i. Clear communications to patients about lengths of waits and decisions about their care and treatment
ii. Clear communications to patients to continue to seek help and how to access the right care, at the right time and in the right place
iii. A focus on supporting self-management and patient education to empower patients to keep themselves as well as possible and avoid hospital admission or emergency surgery (where possible)

8 Plans to fully restore planned NHS care in Wales

8.1 Priorities for restoring care for people with Crohn's and Colitis in Wales should focus on:

i. Improving access to faecal calprotectin testing in primary care in all areas of Wales – faecal calprotectin is a simple and inexpensive stool test, which can support referral direct to endoscopy and speed up diagnosis
ii. Focused effort to increase endoscopy provision safely – many units are still running at 30%-50% of previous levels of activity despite considerable potential to increase efficiency and activity in line with guidelines[14]
iii. Appropriate prioritisation for endoscopy and surgery according to clinical need – despite guidance from the Federation of Surgical Specialty Associations,[15]
iv. A focus on cancer and high-volume surgical targets can impact on and result in delays to urgent IBD surgery, although this may be more time-critical in terms of potential complications
vi. Clearer communication to patients about how long they can expect to wait, how to access care and what they can do to stay as well as possible while waiting
vii. Increasing provision of psychological support and ensuring that services are appropriately resourced and configured to meet the demand
viii. Improving the use of IT across all health boards in Wales and utilising opportunities for remote monitoring, including faecal calprotectin testing and supported self-management – this is an area of innovation which could be expedited to enable more proactive, responsive, and efficient care

8.2 Opportunities to redesign care, such as remote appointments and shifts to subcutaneous treatments must involve patients and be based on delivering personalised care and shared decision-making.

8.3 Continued active support for the NHS Wales Health Collaborative's IBD Work Programme[16] is needed to drive improvements in care and accelerate innovation across the system.

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[14] British Society of Gastroenterology's guidelines for colonoscopy for high-risk surveillance patients during COVID-19.
[15] Clinical Guide to Surgical Prioritisation in the recovery from the Coronavirus Pandemic
[16] Personal stories are making a difference to Crohn's and Colitis care in Wales | Crohn's & Colitis UK (crohnsandcolitis.org.uk)

"The pandemic has highlighted the severe constraints that the NHS has faced for many years. Inflammatory Bowel Disease is a chronic disease affecting young people and requiring long-term management. The pandemic has required diversion of staff time and diagnostic resources into the frontline, and as with so many other patient groups, this has caused huge problems for IBD patients.

The increase in endoscopy and elective surgical waiting lists, and the prioritisation of cancer or suspected cancer have caused real hardship and an increase in emergency admissions, and emergency surgery for those IBD patients with active disease that had not been managed in a timely fashion. Despite being described as a 'benign' condition, this has all too often resulted in life-threatening complications.

The work to bring down waiting times should be dealt with now with the same urgency that was applied at the start of the pandemic to those directly affected by COVID".

Dr AB Hawthorne, All-Wales Clinical Lead, NHS Wales Health Collaborative IBD Work Programme