CROHN'S & COLITIS UK

Crohn's & Colitis UK evidence submission: Senedd Health and Social Care Committee plan for transforming and modernising planned care and reducing waiting lists

[June 2022]

1. About this submission

1.1. **Crohn's & Colitis UK**[1] is the leading charity for people affected by 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.

1.2. Over 26,000 people in Wales have Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn's Disease and Ulcerative Colitis.[2] These are lifelong diseases of the gut. They can affect almost every part of the body and every aspect of life: from digestion and joints to energy levels, mental health, education and the ability to work. There is no known cure.

1.3. Crohn's and Colitis requires tight monitoring and management, often over several decades from the age of diagnosis. 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.[3]

1.4. The number of people living with Crohn's or Colitis in the UK increases from 1 in every 123 people to 1 in every 67 people in those aged over 70.[4] This aging population is more likely to have several other long-term conditions including chronic obstructive pulmonary disease, chronic liver disease, arthritis and heart disease.[5] Meeting their needs will pose a substantial social and economic burden on governments and health systems in the coming years.

1.5. This submission outlines our response to the Senedd Health and Social Care Committee plan for transforming and modernising planned care and reducing waiting lists.

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[1] www.crohnsandcolitis.org.uk

[2] Crohn's & Colitis UK (2022). New research shows over 1 in 123 people in UK living with Crohn's or Colitis (crohnsandcolitis.org.uk)

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

[4] Ibid

[5] Irving, P., Barrett, K., Nijher, M. *et al.*, (2021). Prevalence of depression and anxiety in people with inflammatory bowel disease and associated healthcare use: population-based cohort study. *Evidence-based mental health*, 24(3), 102–109.

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2. Overall views of the plan

2.1. We welcome the plan to address the backlogs in routine care and reduce long waits, including the recognition to address health inequalities in both primary and secondary care.

2.2. However, we are disappointed that the current plan focuses on high-profile priorities such as cancer and heart disease, and overlooks serious and long-term conditions such as Crohn's and Colitis, which carry comparable costs to the health service.[6]

2.3. The Welsh Government has committed to implementing IBD Standards[7] and appointed the All-Wales Clinical Lead, a position that is proving to be a catalyst in service improvements across the country. However, IBD care in Wales remains understaffed and under-resourced. Even before the pandemic, services were struggling to meet the demand. We urge you to recommit to IBD Standards and deliver equity of care for people living with Crohn's and Colitis.

2.4. There is currently vast variation in the implementation of IBD Standards across Health Boards in Wales. Regional approaches alone will not result in preventing delayed diagnosis, treatment and surge of emergency surgeries. We recommend the plan reinstate IBD Standards and make commitments to invest in digital tools to monitor their implementation alongside patient outcomes in regions to drive up equity in care.

2.5. To encourage people with Crohn's or Colitis to come forward, we urge the government to partner with patient organisations in public awareness campaigns, invest in the development of community healthcare professionals to spot symptoms and use tests effectively, and develop and invest in a patient-led diagnostic pathway standardising the use of tests (FCP and FIT) in primary care.

2.6. To effectively diagnose and treat people with Crohn's and Colitis, we urge the government to review and expand endoscopy capacity by revisiting working models (e.g. GIRFT) and adding capacity to existing departments, rather than addressing the shortfall through hubs.

2.7. To support patient self-management, we recommend: communications to promote choice and personalisation, ensure service regularly monitor patients rather than deliver reactive care, and services have clear pathways for patients out and back into PIFU when they have flare ups.

2.8. To manage surgery times, we recommend that Health Boards are mandated to publish their surgery timetables to ensure the Federation of Surgical Specialty Associations (FSSA) guidance is followed.[8]

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[6] Luces, C. and Bodger, K. (2006). Economic burden of inflammatory bowel disease: A UK perspective. *Expert Review of Pharmacoeconomics & Outcomes Research*. 6: 471-482.
[7] IBD UK (2019). *IBD Standards Core Statements*. IBD-Standards-Core-Statements.pdf
[8] Clinical guide to surgical prioritisation during the coronavirus pandemic — Royal College of Surgeons (rcseng.ac.uk)

3. Meeting people's needs

a) Ensuring that people who have health needs come forward:

3.1. For people with Crohn's or Colitis, delays to diagnosis, treatment or planned surgery are associated with a rise in emergency surgery, more extensive surgery and life-threatening complications, increased risks of cancer, mortality and disease progression. In 2020, IBD UK patient survey revealed that 1 in 4 people with Crohn's or Colitis in Wales reported waiting more than a year for a diagnosis, with almost half (47%) visiting A&E at least once before being diagnosed.[9] The pandemic has exacerbated these problems - lack of access to specialists, medicines, tests and procedures have led to flares, complications and poorer mental health for many.[10]

3.2. There are numerous reasons for people living with Crohn's or Colitis not to come forward, including:

- **Lack of public understanding and awareness** of Crohn's and Colitis and its symptoms. 80% of those responding to the IBD UK Patient Survey felt that the public have limited or no understanding of Crohn's and Colitis.
- **Symptoms that can be associated with a range of other conditions.** These include irritable bowel syndrome (IBS), bowel cancer, coeliac disease, endometriosis and ovarian cancer.
- **Symptoms can present atypically.** E.g. while diarrhoea is the most common symptom, this is not present in all adults with Crohn's or Colitis; and up to 44% of children with IBD do not experience diarrhoea.[11]

3.3. There are systemic barriers for patients to come forward, as revealed by a recent independent survey[12] commissioned by Crohn's & Colitis UK:

- 1 in 3 report difficulties in getting a GP appointment
- 1 in 7 report difficulties in discussing sensitive symptom information with receptionists
- 1 in 7 worry the key symptoms (diarrhoea, weight loss and abdominal pain) would not be taken seriously.

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[9] IBD UK (2021). *Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change*. CROJ8096-IBD-National-Report-WEB-210427-2.pdf

[10] Crohn's & Colitis UK (2020). Life in Lockdown: What patients told us about their healthcare | Crohn's & Colitis UK (crohnsandcolitis.org.uk)

[11] Sandhu BK, Fell JME, Beattie RM et al. on behalf of the IBD Working Group of the British Society of Paediatric Gastroenterology, Hepatology, and Nutrition (2010). Guidelines for the management of inflammatory bowel disease (IBD) in children in the United Kingdom. *Journal of Pediatric Gastroenterology and Nutrition*. 50 (Suppl 1): S1–S13. https://doi.org/10.1097/ MPG.0b013e3181c92c53

[12] UK wide with a sample size of 2,026 participants.

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3.4. The public poll confirms research we conducted with the Royal College of General Practitioners[13] which highlighted:

- Lack of knowledge about IBD in community healthcare professionals and the need for more training in IBD.
- Lack of confidence in the use of faecal calprotectin (FCP) testing.

3.5. To encourage people with Crohn's or Colitis to come forward, we urge the government to partner with patient organisations in public awareness campaigns, improve availability of GP appointments, invest in the development of community healthcare professionals to spot symptoms and use tests effectively, and develop and invest in a patient-led diagnostic pathway standardising the use of tests [14] in primary care.

b. Supporting people who are waiting a long time for and supporting self-management

3.6. We welcome the plan's commitments to provide clear communication to patients. Communications must meet their individual needs, foster shared decision-making, and signpost to patient organisations for further information and wide-ranging support.

3.7. We welcome the plan's commitments to offer a combination of virtual and face-to-face outpatient appointments. While remote care may be welcome to some for its convenience and ability to reduce travel, it will not be appropriate for everyone. It is essential that services promote choice and take into consideration individuals' needs, preferences, and circumstances.

3.8. We recommend the use of Patient initiated Follow-Up (PIFU) for the following conditions/situations:

- Crohn's or Colitis patients with stable conditions and a personalised care plan with tight monitoring
- Primary care follow-up with low risk and stable Colitis based on a shared care model and tight monitoring, remaining on the colonoscopy surveillance list.

3.9. However, PIFU would be unsuitable for the following conditions:

- Newly diagnosed patients
- Young adults transitioning from children to adult services.
- Uncontrolled/refractory or flaring Crohn's or Colitis.
- Complex fistulising Crohn's or Colitis that is unstable.
- Patients not adhering to medication
- Severe acute colitis.

3.10. Furthermore, the gastroenterology specific risks to patients on the PIFU pathway should be minimised by:

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[13] RCGP and Crohn's & Colitis UK Inflammatory Bowel Disease Spotlight Project 2017–2020, www.crohnsandcolitis.org.uk/ improving-care-services/health-services

[14] Including faecal calprotectin, faecal immunochemical test, C-reactive protein, coeliac screen, ferritin, liver function test, thyroid function +/- stool culture checked in primary care.

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- **Regular monitoring rather than reactive care:** Access to FCP can mitigate against the lag between the beginning of a flare and symptoms.
- **Surveillance for people** with Crohn's or Colitis **with high risk of cancer.**
- **Clear pathways out and back into PIFU**: to minimise delays or barriers to flaring patients getting back into services and accessing specialist advice promptly when flaring.

3.11. Some IBD services have been using portals and apps to support more joined-up patient-centred care, including Patient Knows Best, MyChart, My IBD Care and the IBD Portal.[15] Together with personalised care planning, including supported self-management, and FCP at home, these offer great potential for a more effective and efficient approach to ongoing care for a proportion of patients.

c) Meeting the needs of those with the greatest clinical needs, and those who have been waiting a long time

3.12. Prior to the Covid-19 pandemic, waits for elective Crohn's and Colitis 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. A third (30%) of patients reported waiting longer than 18 weeks for elective IBD surgery.[16]

3.13. The pandemic has exacerbated the existing issues with Crohn's and Colitis care and has led to:

- A reduction in reported diagnoses of Crohn's and Colitis[17]
- Cancellation of and reduced access to endoscopy and surgery for Crohn's and Colitis[18]
- Delayed appointments and difficulties accessing IBD specialists and GPs
- Disrupted access to essential medication.

This has resulted in people with Crohn's and Colitis experiencing:

- Flares, which may cause further bowel damage and increase cancer risk
- Likely increased need for more high-cost drug treatment and complex surgery.[19]

3.14. Investment needs to be focused not just on high-profile priorities such as cancer and heart disease, but also on conditions such as Crohn's and Colitis, which are often overlooked, but carry comparable costs to the health service.[20]

3.15. The plan lacks a clear definition for the term 'clinically urgent' (p. 23) within its approach to patient prioritisation**. In addition to the clinical view, it is essential that patients are involved in their 'clinically urgent' definition development process.**

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[15] I want to offer remote care and/or monitoring for patients - Gastroenterology digital playbook - NHS Transformation Directorate (nhsx.nhs.uk)

[16] IBD UK (2021). *Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change*. CROJ8096-IBD-National-Report-WEB-210427-2.pdf

[17] Bodger, K., Bloom, S., Dobson, L. *et al*., (2021). PMO-37 COVID-19 impact on care and prescribing for inflammatory bowel disease: Data from the IBD Registry. *Gut*, **70:**A95-A96.

[18] Deputy, M., Sahnan, K., Worley, G. et al., (2022). The use of, and outcomes for, inflammatory bowel disease services during the Covid-19 pandemic: a nationwide observational study. *Aliment Pharmacol Ther*, **55**(7), 836-846.

[19] Crohn's & Colitis UK (2020). Life in Lockdown: What patients told us about their healthcare | Crohn's & Colitis UK (crohnsandcolitis.org.uk)

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

3.16. **We recommend the development and implementation of a patient-led diagnostic pathway standardising the use of tests[21] for patients with non-cancer related lower gastrointestinal (GI) symptoms.** Research suggests that FCP and faecal immunochemical test (FIT) have similar accuracy in the diagnosis of both colorectal cancer and IBD.[22] [23] [24] [25]

3.17. The current plan for prioritising diagnostic services is reliant on more equipment, new facilities and the expansion of the diagnostic workforce. However, the GIRFT speciality report for gastroenterology suggests that optimising current capacity through service design and workforce organisation is as important and cost-effective.[26] **We therefore recommend that the plan expands endoscopy capacity by capping specialist time or adding capacity in the existing departments.**

3.18. **We recommend Health Boards to be mandated to publish their surgery timelines to ensure IBD surgeries are prioritised in line with the Federation of Surgical Specialty Associations (FSSA) guidance**.[27] We have heard from both patients and clinicians that the implementation of this guidance in Wales is inconsistent. Failure to rectify this will result in the presentation of emergency IBD surgeries, which tend to be more complex and costly.

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[21] Including faecal calprotectin, faecal immunochemical test, C-reactive protein, coeliac screen, ferritin, liver function test, thyroid function +/- stool culture checked in primary care.

[22] Mowat, C., Digby, J., Strachan, J.A., *et al*. (2016) Faecal haemoglobin and faecal calprotectin as indicators of bowel disease in patients presenting to primary care with bowel symptoms. *Gut*, **65**(9), 1463-1469.

[23] Elias, S.G., Kok, L., de Wit, N.J., *et al.*, (2016). Is there an added value of faecal calprotectin and haemoglobin in the diagnostic work-up for primary care patients suspected of significant colorectal disease? A cross-sectional diagnostic study. *BMC medicine*, **14**(1), 1-11.

[24] Widlak, M., Thomas, C., Thomas, M. *et al.*, (2017). Diagnostic accuracy of faecal biomarkers in detecting colorectal cancer and adenoma in symptomatic patients. *Alimentary pharmacology & therapeutics*, **45**(2), 354-363.

[25] Högberg, C., Karling, P., Rutegård, J. *et al.*, (2017. Diagnosing colorectal cancer and inflammatory bowel disease in primary care: The usefulness of tests for faecal haemoglobin, faecal calprotectin, anaemia and iron deficiency. *A prospective study. Scand J Gastroenterol*, **52**(1), 69-75

[26] Oates, B. (2021). Gastroenterology: GIRFT Programme National Specialty Report. Layout 1 (gettingitrightfirsttime.co.uk)

[27] Clinical guide to surgical prioritisation during the coronavirus pandemic — Royal College of Surgeons (rcseng.ac.uk)

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4. Leadership and national direction

4.1 We welcome the appointment of the All-Wales IBD clinical lead who is proving to be a catalyst in service improvements across the country. Through this leadership, IBD Wales[28] have prioritised a list of actions required to implement IBD Standards across the country.[29]

4.2. However, there are a number of items that have yet to be actioned by Health Boards:

- Routine use of FCP in primary care with fast-track to direct colonoscopy of those with high levels
- All hospitals to have dedicated IBD consultant clinics
- Support to be given to business case development for appointing additional staff where there is a clear need with evidence that lack of staff is affecting patient care
- All health boards should have dedicated clerical or administrative support to work alongside specialist nurses
- IBD specific dietary support should be available in a timely fashion in all IBD services, provided through a combination of face-to-face and telephone appointments
- Business cases should be supported to provide psychology sessions, including options for individualised on-line treatment programmes which may be more cost-effective.

4.3 **To meet these targets, we need the plan to promote shared leadership across the region, with clear mandated targets.**

4.4 **We also recommend setting up a Specialist Gastroenterology Network**, which include two operational networks: one for coordinating action specifically on endoscopy, and another on IBD treatment.

[28] A joint initiative led and facilitated by Crohn's & Colitis UK that aims to develop a strategic approach to the improvement of standards of care for IBD patients of all ages across Wales and includes patients and representation from all NHS Wales Local Health Boards.
[29] IBD UK (2019). *IBD Standards Core Statements*. IBD-Standards-Core-Statements.pdf

5. Targets and timescales

5.1. Table 1 shows the results for a selection of indicators from the IBD Patient Survey and Service Self-Assessment[30] for the hospitals in Wales who responded.[31] The table provides a snapshot of the variation in the achievement of the IBD Standards and quality of care across health boards in Wales. We urge the Government to lead an assessment of the impact of these variations in IBD services have on patient outcomes, as part of its commitment to address health inequalities across the country.

5.2. We would also like the Government to ensure Health Boards to publish their **surgery timetables** to ensure the Federation of Surgical Specialty Associations (FSSA) guidance is followed.[32]

5.3. Whilst we acknowledge that regional approaches maybe required to reduce waiting times and to build sustainable planned care capacity, we are concerned about the impact this may have on IBD patient outcomes, given the considerable variation in quality of care across the country. Investment in digital tools to monitor how and where IBD patients are accessing secondary care is essential.

5.4. We therefore urge the government to set clear national targets to rectify these issues and work with Health Boards to progress the implementation of the IBD Standards.

[30] Carried out between July 2019 and January 2020.
[31] IBD UK (2021). *Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change*. CROJ8096-IBD-National-Report-WEB-210427-2.pdf
[32] Clinical guide to surgical prioritisation during the coronavirus pandemic — Royal College of Surgeons (rcseng.ac.uk)

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Hospital	Population Coverage	No. IBD Patients Supported	No. Patient Survey Respondents	Quality of care (good, very good and excellent)	Patients with IBD are seen within 4 weeks from their first referral	All elective IBD surgery takes place within 18 weeks	All IBD patients have a personalised care plan based on a holistic needs assessment	All patients have access to non-acute endoscopy and imaging within 4 weeks and within 24 hours for patients who are acutely unwell or require admission to hospital	All patients with confirmed IBD are recorded in an electronic clinical management system
Ysbyty Gwynedd	194,139	1,300	40	59%					
Glan Clwyd	225,000	700	33	43%					
Wrexham Maelor	387,000	1,824	58	76%					
Withybush	125,055	450	34	91%					
Morriston (Paediatric)	500,000	51	N/A	N/A					
Neath Port Talbot	142,906	750	15	92%					
Princess Of Wales	150,000	1,500	8	57%					
Royal Glamorgan	150,000	600	31	55%					
Prince Charles	200,000	700	17	50%					
University Hospital Of Wales And University Hospital Llandough	650,000	3,000	99	83%					
Royal Gwent, Nevill Hall And Ysbyty Ystrad Fawr	750,000	3,513	95	61%					
Total (Achieved)					**0**	**5**	**4**	**5**	**1**

Table 1. Results for a selection indicators from the 2020 IBD Patient Survey and Service Self-Assessment for the hospitals in Wales who responded. Red indicates where the indicator has not yet been achieved, green indicates where it has been achieved.

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This submission has been written by Amy Deptford, Policy Manager at Crohn's & Colitis UK. For further information, please write to policy@crohnsandcolitis.org.uk