CROHN'S & COLITIS UK

DEPARTMENT OF HEALTH AND SOCIAL CARE CONSULTATION – JULY 2026

INFORMING THE MENTAL HEALTH STRATEGY FOR ENGLAND

HOSPITAL TO COMMUNITIY

How can mental health services work more effectively across physical health, employment, housing, addiction, and social care? Please provide examples of cross-sector pathways in practice.

Crohn's and Colitis are lifelong, incurable gut conditions, whose unpredictable, exhausting symptoms can put work and education on hold, and place wellbeing under strain. Because gut-brain links are bi-directional, mental health problems cannot be treated in isolation from Crohn's or Colitis, and effective support must reach across health, employment, welfare, housing, and social care. Low awareness of these invisible conditions increases stigma and limits access to support, while poor coordination of care leaves people falling through the gaps.

Services ultimately work best when someone is responsible for connecting them. Social prescribing and care navigation are the practical mechanism for this: an IBD clinical nurse specialist or GP who identifies psychological or social need can route the person, through a link worker, to self-management, employment support, welfare advice, housing help or social care. Where chronic pain or distress leads to dependence on drugs or alcohol, the same route should connect people to addiction support. This turns a single clinical contact into a cross-sector pathway built around the person.

Condition-specific charities are a vital part of those pathways. Crohn's & Colitis UK's Talking Toolkit helps people share the impact of their condition, reducing stigma and opening routes to practical support, while the Are You IN? programme provides employment-specific advice to help people stay in work while managing a long-term condition. Accessed through clinical signposting and self-referral, these connect NHS care to the workplace and the voluntary sector in practice.

The Mental Health Plan for England should embed partnership with condition-specific charities into cross-sector pathways, and resource social prescribing and care navigation so that clinical, employment, housing, welfare and social care support connect around people living with long-term conditions and co-morbid mental health needs.

What are the main barriers to continuity of care across transitions between hospital and community services, and between different levels of care, including child to adult services?

Crohn's and Colitis are often accompanied by co-morbid mental health conditions and are managed mainly in secondary care. Because gut-brain links are bi-directional, poor mental health is often linked to disease activity, so shared care across hospital and community is essential. However, 37% of adults did not feel that care was well co-ordinated between their GP and Inflammatory Bowel Disease (IBD) team, often because information and mental health needs do not transfer reliably between settings.[1]

A second barrier is that little travels with the patient. A personalised care plan should carry a person's needs across services and levels of care, yet only 7% of adults living with Crohn's or Colitis reported having one, so each transition risks starting from scratch. Embedding IBD UK's Personalised Care Toolkit into standard operating procedures, and using the new shared care record, would help needs follow the person rather than being rebuilt at every handover. [2]

The sharpest barrier is the move from paediatric to adult services. Personalised, psychologically-aware care is more common in paediatric IBD and can be lost on transfer, often with no structured handover of psychological needs. 49% of children with Crohn's or Colitis reported being asked about their mental health, compared to just 20% of adults. Half of paediatric IBD services reported psychologists attending multi-disciplinary team meetings compared to 6% adult IBD services.[3] Without a standardised transition protocol and sufficient capacity in adult services, young people face a cliff edge of mental health support at a critical stage of their lives.

The Mental Health Strategy should enable psychologists to work within long-term condition services, such as IBD, and participation in IBD MDTs reflected in job plans, building the capacity needed to sustain continuity of care, including mental health support, across every transition.

[1] IBD UK (2024), The State of IBD Care in the UK
[2] IBD UK (2024), The State of IBD Care in the UK
[3] IBD UK (2024), The State of IBD Care in the UK

SICKNESS TO PREVENTION

Which preventative approaches have the strongest evidence for reducing incidence or severity of mental health problems and promoting good mental health?

Crohn's and Colitis can have serious psychological impacts; at diagnosis, during active disease and when facing life-changing surgery.[4] Almost half of the 500,000 people with IBD report an impact on their mental health, while anxiety, depression and other mental health disorders (MHDs) are more common than in the wider population.[5][6]

The strongest preventative evidence suggests managing physical disease and psychological need together. Active IBD is associated with higher likelihoods of psychological disorders, whilst gut-brain links suggest MHDs can contribute to IBD relapse and clinical deterioration. Therefore, timely access to treatment that controls disease activity is itself preventative, reducing the onset and severity of MHDs .[7]

Integrated psychological services should deliver stepped care moving from regular assessment, through to education and lifestyle advice, to treating reversible causes of psychological distress (including combined psychological treatments, like CBT, and antidepressants).[8] Embedding psychology within multidisciplinary teams (MDTs) helps prevent people reaching crisis point, improves quality of life, and reduces demand on services.

Good mental health should be promoted, not only protected. Wellbeing-focused, co-produced self-management support builds the confidence and skills to live well with lifelong conditions, while peer support and action on stigma and isolation address known drivers of distress.

Yet, prevention opportunities, like MHD screening in patients frequently reporting pain, are missed.[9] Only 20% of adults reported being asked about their mental health during

---

[4] Kiebles JL, Doerfler B, Keefer L. Preliminary evidence supporting a framework of psychological adjustment to inflammatory bowel disease. Inflamm Bowel Dis. 2010;16:1685–1695.

[5] Mikocka-Walus, A. *et al.* Psychological distress is highly prevalent in inflammatory bowel disease: A survey of psychological needs and attitudes. *JGH Open* **4**, 166–171 (2020).

[6] Kylee Lewis, Ruth Ann Marrie, Charles N Bernstein, Lesley A Graff, Scott B Patten, Jitender Sareen, John D Fisk, James M Bolton, CIHR Team in Defining the Burden and Managing the Effects of Immune-Mediated Inflammatory Disease , The Prevalence and Risk Factors of Undiagnosed Depression and Anxiety Disorders Among Patients With Inflammatory Bowel Disease, *Inflammatory Bowel Diseases*, Volume 25, Issue 10, October 2019, Pages 1674–1680, https://doi.org/10.1093/ibd/izz045

[7] Ge L, Liu S, Li S, Yang J, Hu G, Xu C and Song W (2022) Psychological stress in inflammatory bowel disease: Psychoneuroimmunological insights into bidirectional gut–brain communications. Front. Immunol. 13:1016578. doi: 10.3389/fimmu.2022.1016578

[8] Kok KB, Byrne P, Ibarra AR, Martin P, Rampton DS. Understanding and managing psychological disorders in patients with inflammatory bowel disease: a practical guide. Frontline Gastroenterol. 2022 May 24;14(1):78-86. doi: 10.1136/flgastro-2022-102094. PMID: 36561780; PMCID: PMC9763641.

[9] Understanding How Mental Health Influences IBD Outcomes: A Review of Potential Culprit Biological Mechanisms - PMC

care. Despite GIRFT and IBD UK recommendations, only 6% of adult IBD services reported psychologists as part of their IBD MDT in 2023, down from 18% in 2019.[10]

This strategy should recognise people with long-term conditions as a priority group for prevention, supporting routine assessment, personalised care planning and self-management within specialist services, and integrating psychologists into MDTs. Workforce planning must reflect the need for mental health support alongside physical care, enabling earlier intervention, before problems develop or worsen.

How can services better support the 'missing middle' - those with sustained needs (that affect their participation in community life, for example, in education or work) who may not meet the criteria for NHS mental health services?

People with Crohn's or Colitis (lifelong, incurable gut conditions) are 2–4 times more likely to develop depression and 3–5 times more likely to develop anxiety disorders than the general population.[11] Much of this distress is sustained but sits below the threshold for NHS mental health services, or is too entangled with physical symptoms for generic services to address. This is the 'missing middle' real, persistent need that falls between low-level support and specialist care. Unpredictable, invisible symptoms (including urgency, fatigue, and pain), appointments, new treatments, disrupt participation in education, work, and community life, while body image worries and stigma compound the impact. Gut-brain links mean co-morbid mental health can increase adverse outcomes and healthcare utilisation..[12]

The most effective response is to deliver mental health support within the IBD pathway, rather than relying on referral to services people will not meet the criteria for. Self-management is an effective first line, building information, skills, and confidence. Structured, wellbeing-focused programmes should be co-produced with people living with Crohn's or Colitis, responding to the impact of their physical health.

IBD Clinical Nurse Specialists are essential to early support. Yet only 20% of adult IBD services met recommended staffing levels.[13] With demand rising an urgent staffing uplift is needed, to prevent mental health disorders, manage symptoms, and improve outcomes.

---

[10] GIRFT-IBD-Handbook-FINAL-updated-April-2026.pdf, p.4.
[11] Graff LA, Walker JR, Bernstein CN. Depression and anxiety in inflammatory bowel disease: a review of comorbidity and management. Inflamm Bowel Dis. 2009;15:1105–1118.
[12] Abdelbadiee S, Yoon G, Pearman K, Kumar A, Harvey PR. Understanding How Mental Health Influences IBD Outcomes: A Review of Potential Culprit Biological Mechanisms. Biomedicines. 2025 Nov 28;13(12):2916. doi: 10.3390/biomedicines13122916. PMID: 41462928; PMCID: PMC12731159.
[13] IBD UK (2024), The State of IBD Care in the UK

Mental health should be addressed throughout the diagnosis and treatment journey. However, only 11% of adult IBD services reported existing processes to assess newly diagnosed people's mental health.[14] Patients are left without appropriate support and complexity of care increases, adding further pressure to services. The IBD Disk can assess disease activity and mental health burden simultaneously, suiting time-poor clinics.[15] Embedding a psychologist in the multi-disciplinary team would build confidence so all IBD staff can support patients with their mental health.

For any questions, please contact policy@crohnsandcolitis.org.uk

[14] IBD UK (2024), The State of IBD Care in the UK

[15] Rimmer P, Stoica V, Ibrahim M, Javed A, Hazel K, Owusu M, Regan-Komito D, Cooney R, Iqbal AJ, Chapple I, Harvey P and Iqbal TH (2025) The IBD-disk accurately assesses disability and psychological burden at IBD diagnosis and predicts adverse outcomes in both UC and Crohn's disease during the first year of treatment: a prospective observational cohort study. Front. Gastroenterol. 4:1642061. doi: 10.3389/fgstr.2025.1642061