




World IBD Day 2021: breaking the silence on the holistic burden of IBD

World IBD Day is an annual global event led by patient organisations representing people living with IBD from over 50 countries and coordinated by the European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA). Each year on World IBD Day, these organisations come together with healthcare professionals (HCPs) in gastroenterology, patients and the pharmaceutical industry worldwide to shed light on the extent to which IBD impacts a person's holistic wellbeing.

On 19 May 2021, famous landmarks all over the world will be lit in purple to raise awareness about the daily challenges of living with IBD. This year's event will focus on highlighting how IBD affects patients beyond physical symptoms and continues to impact quality of life (QoL) even in remission.

The breadth of impact of IBD on patients is extensive

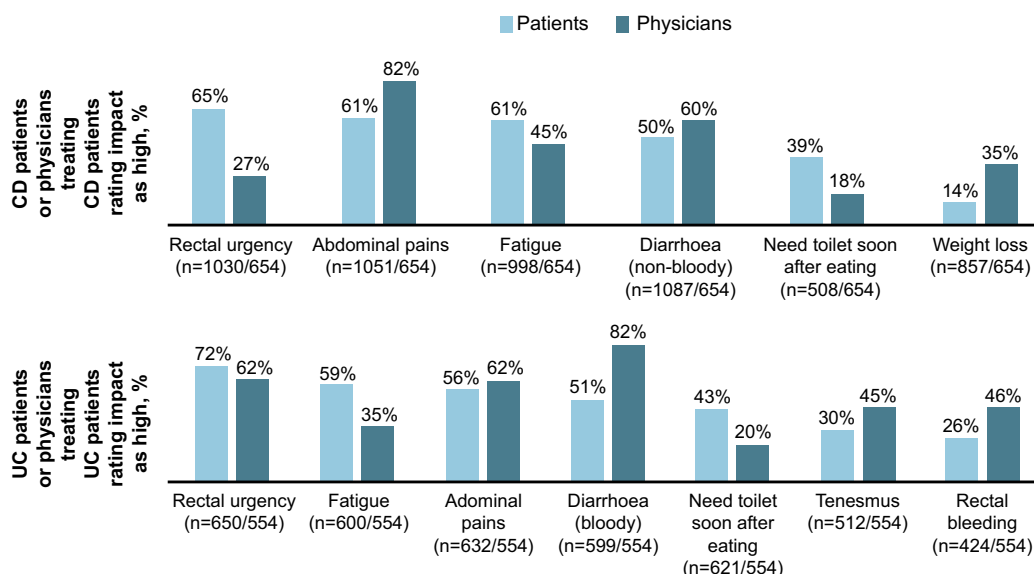
Physical symptoms ¹	Psychological symptoms ¹	Everyday life ²⁻⁴
<ul style="list-style-type: none"> Diarrhoea Urgency Rectal bleeding Pain Risk of long-term complications 	<ul style="list-style-type: none"> Fatigue Anxiety Depression 	<ul style="list-style-type: none"> Home life Relationships Sex life Work: job loss, absence, impact on career choice



65% of patients with UC feel that it controls their life³

Physician and patient perspectives on how IBD impacts QoL are not well aligned

In the recently published Global Assessment of Patient and Physician Unmet Need Survey (IBD GAPPS), Rubin et al. identified four key areas of misalignment between patients and physicians: ratings of symptom severity, definitions of remission, expectations about treatment durability, and corticosteroid use. Notably, physicians underestimated the impact of rectal urgency, fatigue, and needing to use the toilet soon after eating on patient QoL (see figure below).¹

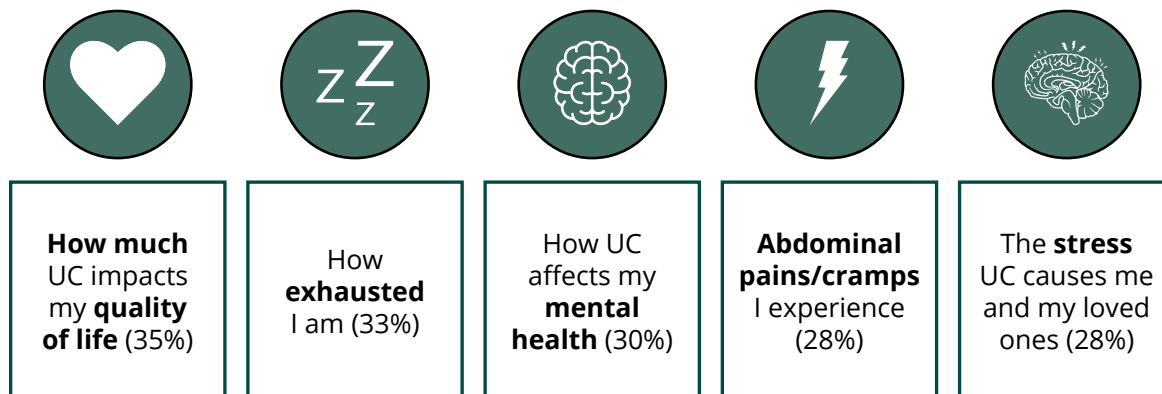


IBD GAPPS: IBD symptoms with greatest impact on QoL according to patients (N=2398) and physicians (N=654).¹ CD, Crohn's disease; UC, ulcerative colitis. Figure reproduced with permission from Rubin DT, et al. 2021¹

Patients wish HCPs better understood how IBD impacts their mental wellbeing³

IBD GAPPS also highlighted that **exhaustion, anxiety** and **depression** were the most likely symptoms to be reported as severe by patients with IBD;¹ however, recent data from Dubinsky et al. assessing the impacts of living with UC, reported that **only 23% of physicians regularly discuss the impact of IBD on mental and emotional health with their patients**, and 51% of physicians do not discuss this topic with their patients at all.³ Together, these data underline the need for enhanced physician education on the impact of IBD on patients' overall wellbeing.¹

Top five concerns that patients with UC would like their physicians to understand better:³



'It's so much more than just symptoms. The symptoms do have an impact but it affects people in so many other different ways. It affects them with their employment, it affects them with their relationships, socially, being able to go out with friends.'

Kay Greveson, Lead IBD Clinical Nurse Specialist, Royal Free Hospital

How can HCPs support patients with IBD?

Encouraging open and honest communication about patients' wellbeing and treatment goals and including patients in shared decision-making can enhance patient engagement, improve treatment adherence, outcomes and QoL, and increase treatment satisfaction.^{5,6}

By effectively managing the holistic impact of IBD on QoL and mental health, and increasing alignment on IBD treatment goals, patients and physicians can build a strong relationship, which is key to improving treatment outcomes.¹

Keen to hear some best practice tips on how to do this?

Kay Greveson and Aileen Fraser are leading IBD Clinical Nursing Specialists with a passion for championing patient-centred approach to IBD care. Listen to their thoughts on **'World IBD Day 2021: Raising awareness of the burden of IBD'** and **'How can HCPs support patients with IBD?'** in our [Hot Topics](#) page.



'Talk to your patients but listen. And really listen. Listen to what they're saying and also listen to what they're not saying. Sometimes you just need to scratch under the surface.'

Aileen Fraser, IBD Advanced Clinical Nurse Practitioner, Bristol Royal Infirmary

Galapagos UK at World IBD Day 2021

Galapagos UK are delighted to be supporting the EFCCA's #breakthesilence campaign and to be partnering with Crohn's & Colitis UK for World IBD Day 2021, where people living with IBD can come together and raise awareness of the disease and how it impacts their lives, and share ideas.

Make sure to look out for our World IBD Day activities on LinkedIn and Twitter

References: 1. Rubin DT, et al. *Inflamm Bowel Dis* 2021; doi: 10.1093/ibd/izab006 [Epub ahead of print]; 2. Zhao M, et al. *J Crohns Colitis* 2021; doi: 10.1093/ecco-jcc/jjab029 [Epub ahead of print]; 3. Dubinsky MC, et al. *Inflamm Bowel Dis* 2021; doi: 10.1093/ibd/izab016 [Epub ahead of print]; 4. Ghosh S and Mitchell R. *J Crohn's Colitis* 2007;1:10–20; 5. Jackson B and De Cruz P. *Expert Rev Gastroenterol Hepatol* 2018;12:1079–1100; 6. Fox JC and Lipstein EA. *Mayo Clin Proc Inn Qual Outl* 2020;4:183–189.