

Breaking through the Pain Barrier: Insights on Pain in Irritable Bowel Syndrome (IBS) and Inflammatory Bowel Disease (IBD)

On the 23rd of October 2025, supported by the National Public and Patient Involvement Festival Fund, this event drew people with lived experience, patient organisations, researchers, clinicians, students, and members of the public together at the University of Galway for an evening of listening, learning, and meaningful discussion from diverse perspectives, around pain in IBS and IBD, to ultimately guide future research in this area.



Pain in IBS and IBD

Pain is a common symptom of IBS and IBD that can have a profound impact on the quality of life of patients. Up to 70% of people living with IBD, a chronic inflammatory disease of the gastrointestinal tract, experience abdominal pain at some time during their journey, often persisting over the long-term. Around 1 in 5 report persistent pain even when there is no active inflammation. Patients may also experience pain outside of the gut, in joints for example, that may be linked to their IBD. Irritable Bowel Syndrome on the other hand, affects between 6–20% of the population, with abdominal pain a defining feature, alongside changes in bowel habit. Unlike in IBD, pain in IBS occurs in the absence of any inflammation. Compared to the general public, people living with IBS are more likely to experience other overlapping pain conditions (e.g., headache, fibromyalgia). To add to this, IBD and IBS can occur together in the one patient, which can make diagnosis and management even more complex. Pain in these conditions is closely linked to poorer mood, and higher levels of fatigue, increasing the overall impact of these conditions on daily life.

Patient Perspectives

The patient speakers on the night offered powerful insights into the lived experience of IBD and IBS. Victoria Spillane, Chief Operations Officer with Crohn's and Colitis Ireland, described her journey with Crohn's disease (a type of IBD), including years of fluctuating symptoms, the eventual decision to undergo surgery to remove part of her bowel and form a stoma, and the challenges encountered at different stages of life, from navigating school with limited understanding from peers to managing extraintestinal manifestations and body-image changes in adulthood. She emphasised the vital role of family and community support and highlighted the valuable work and support offered by Crohn's and Colitis Ireland (www.crohnscolitis.ie) for patients and families at various stages of their journey. Emma Barry, a secondary school teacher living with Crohn's disease and IBS, outlined her experience of delayed diagnosis, the challenges associated with accepting a chronic condition, and the ongoing impact on daily life, work, and wellbeing, noting that clinical tests do not always truly reflect lived symptoms. She emphasised the importance of self-advocacy, as well as having supportive personal networks and workplaces. Emma also spoke about her decision to take part in research on pain in IBD and IBS, as a research participant, and PPI contributor, explaining that she hoped it would help lead to better understanding and care for others in similar circumstances. Together, their experiences illustrated not only the complexity of living with these conditions but also the resilience and inner strength that can emerge, offering a sense of hope for others facing chronic illness. Audience questions reflected common concerns among people living with IBD and IBS, centring on diet and symptom management, the link between mental health and gut health, and the impact of body image. The discussion reinforced that patient experiences are multifaceted and that empathetic and holistic care is vital.

"The event left me both uplifted and deeply moved. After more than ten years of living with Crohn's disease, hearing about the research underway and truly understanding more about the condition and its pain was eye-opening. I left with a renewed sense of hope in the incredible work researchers are doing to support those of us who face pain every day."

~ Emma Barry, Research Participant & PPI Contributor, living with Crohn's Disease and IBS

Clinical Perspective

Prof. Laurence Egan, Consultant Gastroenterologist at Galway University Hospital with over 35 years of experience treating patients with IBS and IBD, offered a clinical perspective on managing these conditions. He outlined the key differences between Ulcerative Colitis and Crohn's Disease, illustrating these differences using colonoscopy images. He discussed biologic therapies as a revolutionary advance in treatment, emphasising that starting these therapies as early as possible often leads to better outcomes, though they are not a perfect solution as many patients stop responding over time. He described the typical disease trajectory: a major flare often leads to diagnosis, followed by periods of remission, with subsequent flare-ups possible. In some cases, surgery becomes necessary due to the build-up of damage from repeated inflammation. He also highlighted current research priorities, including early diagnosis, risk stratification, non-invasive monitoring, understanding disease mechanisms, new therapies and combinations of therapies, and innovative clinical trial designs. Finally, he differentiated IBS from IBD, noting that IBS patients present with normal test results, but experience spasms and hypersensitivity in the gut, with treatments focused on dietary changes and medications that reduce spasms.

Ongoing Research at University of Galway

Prof. David Finn, Professor of Pharmacology and Therapeutics, and Co-Director of the Centre for Pain Research at the University of Galway, provided an overview of the biology of pain and our internal pain-suppression systems, which involve the body's own opioids and "cannabis-like" endocannabinoids. He also discussed current access to cannabinoid-based medicines, noting that conditions like chronic pain, IBD, and IBS are not currently included in access programmes for medicinal cannabis in Ireland. Rebecca Lane, a PhD candidate in Pharmacology and Therapeutics at the University of Galway, then described her research on pain in IBD and IBS, highlighting the influence of psychological and social factors as well as the underlying biology of pain and the importance of the gut-brain connection. Her study is comparing pain sensitivity, the endocannabinoid system, and gut microbiota in people with IBS and IBD who experience chronic gut pain, with healthy participants. Through analysis of blood, stool, and physical measures of pain, combined with questionnaires that gather broader relevant data, she aims to identify the biological mechanisms driving gut pain and associated symptoms. This work, funded by Research Ireland, could help identify biological markers for abdominal pain, and inform the development of more personalised treatments, improving diagnosis and care for people with IBD and IBS. The evening also featured a tour of the cutting-edge facilities that make this research possible within the Discipline of Pharmacology and Therapeutics and Centre for Pain Research at University of Galway.



Improving Future Research

In a post-event survey, the audience were asked to provide their insights on research priorities for pain in IBS and IBD, how to improve research relevance, and the barriers that may hinder IBS and IBD communities from participating in research on pain, which are displayed on the infographic. It is hoped that these insights spark conversation and help inform future research.

"This event has fuelled my desire to continue doing research alongside patients as much as possible. Not only do people with lived experience contribute insights which can shape the research, making it more relevant, but knowing they see the value in it provides great motivation to continue doing it to the best of my ability."

~Rebecca Lane, PhD Candidate researching pain in IBS and IBD

This National PPI Festival Event has shown the power of connection and cross-community dialogue and has planted seeds for future research and collaboration in the under researched area of pain in IBS and IBD.



If you are interested in participating in pain research or future pain-related PPI events and activities at University of Galway, please contact Rebecca at r.lane2@universityofgalway.ie.

Photographer: Mike Shaughnessy