

Proposing Ideas, Prioritizing Research

IBD Partners
Patient-Generated Research Agenda

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About IBD Partners

IBD Partners is a patient-powered research network created by a partnership between the **University of North Carolina School of Medicine** and the **Crohn's & Colitis Foundation**. This partnership brings together over 15,000 inflammatory bowel disease (IBD) patients and researchers in a revolutionary online study aimed at optimizing treatment of IBD.

The mission of **IBD Partners** is to empower patients, researchers, and healthcare providers to partner in finding answers to research questions patients care about and ultimately improve the health and lives of patients living with these conditions. Central to our engagement philosophy is the belief that patients should have a voice in research prioritization. We invite participants to propose, discuss, and vote on the most pressing research topics. We encourage you to share this crowd-sourced, patient-prioritized IBD research agenda with colleagues who may be able to undertake this necessary research.

Notable Characteristics of IBD Partners

- **Patient-centeredness:** We place great emphasis on making all aspects of the IBD Partners study patient-centered. We believe patient input is critical to the research process. A patient governance committee guides the network and provides input into all important study-related decisions.
- **High volume enrollment:** IBD Partners is a large study with over 15,000 participants. Thus, we are able to study how different treatments or behaviors affect a variety of outcomes, including assessment of heterogeneity of treatment effects.
- **Longitudinal data:** Crohn's disease and ulcerative colitis are chronic, lifelong conditions. IBD Partners collects survey data and other person-generated health data twice a year. Already, many patients have contributed > 5 years of data.
- **Research prioritization:** A cornerstone of our PPRN is crowd-sourcing the most pressing knowledge gaps to increase the quality and patient-centeredness of research that addresses the needs of patients and informs important clinical decisions. Participants can suggest, discuss, and vote on the research questions that they'd like answered. The question categories and questions with the most votes are summarized in this document for distribution.

Developing the Agenda

We conducted a mixed-methods analysis of patient-submitted research questions on the IBD Partners portal. Using an inductive approach with a team of researchers, patients, and patient advocates, we determined domains and subdomains into which patient submitted research questions would be categorized. Then, we had a patient and patient advocate categorize each of the 250 patient-submitted questions into domains and subdomains, which were then discussed and finalized with a researcher (an IBD Partners Co-PI). Finally, votes associated with each question were tallied, generating the following list of the most important domains and questions that patients want to see researched in the future.

Top Patient Priorities for Research



Six focus areas were identified as being the most important unmet needs in adult IBD research from the patient perspective, with two areas - diet and alternative medicines – being highest priority.

Diet

The impact of diet on disease symptoms and/or natural history is the most important area of research for IBD patients. Patients want to understand if alternatives to a typical Western diet, notably the specific carbohydrate diet, paleo diet, low-FODMAP diet, dairy elimination, or vegan diet could help patients achieve and maintain remission and/or improve symptoms or quality of life. Patients face diet decisions daily and many have undertaken food elimination or exclusion to control flares. In addition to the diets above, patients also expressed interest in research about whether gluten, food additives or emulsifiers affect intestinal inflammation and/or symptoms.

Alternative Medicines

Many IBD patients seek non-pharmacological or non-prescription alternatives or complementary treatments to help manage their symptoms. Of keen interest is researching whether medicinal cannabis has an anti-inflammatory response or can reduce disease activity or symptom burden. Additionally, patients use and want to learn about probiotics to control or prevent flares, especially VSL#3. Patients priorities also include understanding new potential treatment techniques like fecal microbiota transplant (FMT).

Medications

Patients' priorities for research on medications points to a desire for precision medicine – understanding why some drugs work for some people but not others and in the sequencing and positioning of different therapies in different patient populations. Additional interests are in the long-term side effects of IBD medications, especially immunosuppressive drugs, as well as optimal sequencing of medications after non-response.

Comorbidities

The presence of psychological comorbidities like anxiety and depression is well documented in IBD. Patients want to know what role stress plays in inflammation, how many patients are receiving mental health treatment through medications or counseling, and whether the relationship between IBD and psychological comorbidities is causative. Also of high interest is research on the associations between IBD and other autoimmune diseases, fibromyalgia, post-nasal drip, acne, sleep disorders, periodontal disease, and Irritable Bowel Syndrome.

Course of Disease

Factors that may influence the likelihood of remission or flare during the disease course of IBD are important to patients. Top priorities are understanding if hormones and hormone changes, nicotine use, or getting a colonoscopy affect relapse. Additionally, patients are interested in better ways to measure quality of life and understanding how IBD affects lifestyle factors like intimacy and physical activity. Patients are also interested in research about how changes in the physical environment (e.g. weather, seasonal allergens, etc.) affect disease course.

Cause of Disease

Given the rapid rise of IBD incidence in certain geographic regions, patients want to understand how geographic exposures – including due to immigration, urban environment, or veteran status – might contribute to disease development. Additionally, there is strong interest in whether early life exposures to infections, tobacco smoke, medications, chemicals, or psychological stress might contribute. Finally, patients want to explore associations between components of the microbiome and IBD occurrence, and further define the genetic component of IBD etiology. Patients are particularly interested further understanding the IBD risk in their children.

Patients also nominated surgery outcomes, pregnancy, access to care, and diagnostic methods as important areas for future research.





Resources

What is IBD?

IBD stands for inflammatory bowel disease, which is an umbrella term used to describe disorders that cause chronic inflammation of the gastrointestinal (GI) tract. The two most common forms of IBD are Crohn's disease and ulcerative colitis.

If you're new to IBD research, the Crohn's & Colitis Foundation provides hundreds of resources to help get you up to speed. We recommend the following:

- [IBD Factbook](#)
- [IBS vs. IBD](#)
- [Challenges in IBD Research](#)

Find your funding opportunity

The Crohn's & Colitis Foundation funds research projects across the research continuum, including basic, translational, and clinical research. The Foundation is committed to supporting a robust pipeline of investigators interested in a career in IBD. As a patient organization, the Foundation seeks research proposals that would address top research priorities of patients. We encourage you to learn more about the below opportunities.

- [Student Research Fellowship Awards](#)
- [Research Fellowship Awards](#)
- [Career Development Awards](#)
- [Senior Research Awards](#)
- [Litwin IBD Pioneers](#)
- [Clinical Research Networks](#)
- [IBD Ventures](#)
- [Academic RFP](#)