



# IBD Digest

Our study continues to move forward, and we are making excellent progress. In this issue, we'll introduce a few of our patient stakeholders and offer suggestions on how to get healthy in 2022. We'll also talk about the Person-Centered Outcomes Research Institute (PCORI)—the organization that provided funding for this study—and how its research focus influences the work we are doing.

## What is PCORI?

PCORI is an independent, nonprofit organization. Its mission is to fund research that gives patients, their caregivers, and clinicians the evidence-based information they need to make better-informed health care decisions.

PCORI is committed to continually seeking input from a broad range of stakeholders to guide its work. For more information about PCORI's funding, you can visit [pcori.org](https://www.pcori.org).

## What, exactly, does PCORI do?

PCORI funds comparative clinical effectiveness research (CER) that focuses on options and outcomes that are important to patients. The organization recently provided funds for improving maternal and infant health, promoting healthy aging, improving outcomes for people with chronic conditions, and other efforts.

PCORI has adopted the [National Priorities for Health](https://www.hhs.gov/national-priorities-for-health/) to guide its funding of patient-centered CER and other engagement, dissemination, implementation, and research infrastructure initiatives. The National Priorities for Health include:

- Achieving health equity.
- Increasing evidence for existing interventions and emerging Innovations in health.
- Enhancing infrastructure to accelerate patient-centered outcomes research.
- Advancing the science of dissemination, implementation, and health communication.

## How is PCORI involved in this research study?

Our study team works with PCORI to monitor research activities and make adjustments to the study when necessary. Through this study, we are hoping to learn:

- How health care delivery can be improved for patients with complex chronic conditions like Crohn's disease and ulcerative colitis.
- How health care providers can provide care based on patients' needs and preferences while achieving the best possible outcomes.

You can learn more about our study's focus on patient-centeredness by reading about two of our stakeholders on the next page.

## STUDY PROGRESS

As of Nov. 24, 2021,  
we had enrolled

# 361

participants across the  
three study locations!

We are 36% of the  
way to our goal.

## REMEMBER!

Participants are asked  
to complete questionnaires at  
three points:

- Upon enrolling in the study
- Six months after enrolling
- One year after enrolling

You will be paid \$20 each for the  
initial and six-month  
questionnaires and \$40 for the  
final questionnaire.



## Meet the study's patient stakeholders

A core element of all PCORI studies is engaging with people who may be affected by the research. These people—who include patients, doctors, health insurers, patient advocacy groups, and others—are called our stakeholders. For this study, we have a Stakeholder Advisory Board. This group meets multiple times a year to provide important feedback to the study team. The group's feedback helps us determine what is important to patients and their health, how we can improve our study processes, and how we can share our findings with different groups.

Jake Ryan is a member of the board, providing his perspective as a younger patient with IBD. We also regularly consult with our stakeholder co-Investigator Dr. Jane Kogan. As a UPMC researcher who has IBD, Dr. Kogan brings both professional knowledge and personal experience to the study team.

### Jake Ryan

Stakeholder Advisory Board representative

**Tell us a little bit about you.** I grew up and live on Long Island in New York. I attended Syracuse University, where I studied political science and was a member of the ski club and swim team. I am a program coordinator for a nonprofit on Long Island, and one of my main roles is working on a project to develop an IT infrastructure that allows for multi-directional data sharing among health care providers. In my free time, I love to read, ski, golf, and travel.

**What made you want to participate on this study's Stakeholder Advisory Board?** I wanted to participate in the SAB because I have seen firsthand how virtual medicine can provide valuable benefits to patients. While I was in college, the only way I was able to connect with my doctors at Mount Sinai Hospital was through telemedicine, and it was truly a lifesaver. When I had the opportunity to participate in a study that focused on virtual medicine, I jumped on it.

**How has having IBD affected your life?** I was diagnosed with IBD when I was 15 years old. Before being diagnosed, it was difficult to play sports with friends or go out to dinner. Looking back on that time makes me realize just how much IBD hindered my social life and added to my anxiety. I think one of the most difficult aspects was that it took a few years for me to fully grasp what a chronic disease is and that I needed to stay on top of my health because IBD wasn't going anywhere.

**How does your experience with IBD help in your role as a patient stakeholder?** My experience with IBD gives me a unique perspective. I have experience with both in-person and virtual care, so I have a good idea which type of care works best for me depending on my symptoms and needs. I have also been on the patient side of a research study, which helps me imagine how a patient might react to different aspects of the study.

**What excites you about this study, and what are you most looking forward to finding out?** I am most excited to see if virtual care is as successful for others as it was for me. I believe this type of care can benefit and provide a great deal of comfort because it gives a patient—regardless of where they may be—the opportunity to talk directly with their health care provider.

**What's your favorite way to de-stress?** When I need to de-stress and don't have any IBD symptoms, I love to exercise and get together with friends. If my symptoms make it difficult to exercise, I tend to watch sports and movies to help get my mind off the IBD.



### Jane Kogan, PhD

Associate Chief Research and Translation Officer, UPMC Center for High-Value Health Care; Stakeholder Co-Investigator

**Tell us about your career journey and how it led you to your current role.** I pursued a PhD in clinical psychology, where I was trained as both a scientist and a practitioner. My post-doctoral training and continued work

occurred in a large academic center where we studied and used best clinical practices. This translated to better outcomes for the patients I served. As a researcher, I made many efforts to share what I was learning with communities that did not have the same resources. This was incredibly challenging because so many obstacles existed in getting these optimal care strategies into the hands of many. These early career experiences and frustrations shaped my interest in working with stakeholder teams to get better care to all individuals in all places.

**What impact has having IBD had on your life, and how has that influenced your research interests?** I was diagnosed with IBD in my late teens. For 35 years, IBD and all that comes with it has impacted my daily life in so many ways: managing flare-ups while working and having a family, making decisions about medications and managing side effects, considering what to eat (and not eat), managing changes in providers. The list goes on and on. While this may sound overwhelming; living with a chronic condition has empowered me to seek solutions; bond with others who have the disease; and, most importantly, be hopeful.

**What is your role as this study's stakeholder co-investigator?** Most important to me is that I bring my personal, first-hand experience of living with IBD, navigating health care, and looking for better and personalized solutions for this challenging condition. I strive to bring a patient voice that includes more than my own experience and reflects broad patient perspective. I also bring my experience as a health care systems researcher and team player, recognizing that it takes many ideas and lots of teamwork to carry out large-scale studies like ours.

**What are you hoping to learn from this study?** I hope (and expect) that our research team will answer important questions about how to best tailor care approaches for IBD that maximize individual patient outcomes. Most importantly, I hope we will analyze and share the knowledge at a quick pace and in ways that improve the health care experience for people with IBD.

**If you could live anywhere in the world for one year, where would it be and why?** A hilltop farming town in southern Italy where I could rise each day without an alarm clock, grow my own/family food supply, and ride my bike into town every few days to replenish our olive oil and red wine. I would revel in the slower pace, playing in the soil every day, and eating a casual and delicious harvest from my garden!

## TIPS

### Getting healthy in the new year

Every January, we hear a lot of from our friends and family about wanting to “improve” themselves in some way in the new year. Resolutions related to health—including changes in diet, exercise, and other lifestyle factors—are very common. While each person’s health needs are different, there are some steps that everyone can take to get a jump-start on a healthy 2022.

#### ***Schedule preventive appointments for the year***

Preventive appointments help you and your doctors monitor your health over time. Scheduling these visits at the beginning of the year will ensure that you do not forget and that you can get timely access to your providers. Here are a few providers that everyone should visit:

- **Primary care provider (PCP).** Your PCP is probably the provider who has the most well-rounded knowledge of your health, which is why the [U.S. Office of Disease Prevention and Health Promotion](#) (ODPHP) recommends regular visits. Your PCP can provide a variety of services, including physical exams, vaccinations, and screenings for health metrics such as blood pressure and cholesterol. Your PCP can also recommend a specialist if you need additional support.
- **Dentist.** The [American Dental Association](#) recommends visiting a dentist once every six months. Regular cleanings can help keep your teeth and gums in good condition.
- **Optometrist or ophthalmologist.** Even if you don’t wear eyeglasses or contact lenses, visiting the eye doctor every one to two years as recommended by the [American Optometric Association](#) can be a good idea. Your provider can catch any signs of worsening eyesight or serious conditions early. Wondering about the difference between an optometrist and an ophthalmologist? Ophthalmologists have a Doctor of Medicine degree and can perform surgeries. Optometrists receive an Doctor of Optometry degree and primarily treat common eye conditions.

Individuals who have IBD should schedule regular appointments with their **gastroenterologist**. How often you should go depends on your disease, symptoms, and any complications, but study co-investigator Dr. Benjamin Click of [Cleveland Clinic](#) suggests going at least annually.



#### ***Ask your doctor for personalized recommendations***

Your health needs will depend your gender, age, family medical history, personal medical history, and lifestyle. For example:

- The ODPHP recommends annual [well-women](#) appointments for patients who were assigned female at birth. The visits may involve discussing reproductive health and conducting screenings for breast and ovarian cancer.
- The [American Cancer Society](#) recommends that patients assigned male at birth have prostate cancer screenings starting as early as age 40 for those at high risk.
- The [Skin Cancer Foundation](#) recommends that individuals with skin cancer risk factors—including a fair complexion or family history of the disease—visit a dermatologist at least once a year.
- The [Centers for Disease Control and Prevention](#) recommends several age-specific vaccinations, such as a shingles vaccine for adults older than 50 and HPV for those ages 19 to 26.

Talk with your doctor about what might be right for you.

#### ***Review your insurance coverage***

It is important to review what your UPMC Health Plan insurance covers before you make your 2022 appointments. A number of in-network [preventive services](#)—such as annual physical exams and flu vaccines—are available at no cost to you. Depending on your plan, you may have a copayment to see specialists, or you may be expected to pay out-of-pocket up to a certain amount. UPMC Health Plan also provides access to [additional resources](#), such as UPMC AnywhereCare virtual appointments, health and wellness coaching programs, and substance misuse resources. You can check your insurance details by calling the number on your medical ID card or logging in to your [MyHealth OnLine](#) account.



## Contact

If you have any questions, please contact a member of the research team at **412-208-5235** or email us at **IBDStudy@upmc.edu**. We can help you:

Address concerns about your Vincent Payment Card.

Update your contact information.

Resolve issues you may be having with the RxWell app.

Schedule a time to complete your follow-up questionnaires.