



Engaging Patients for Research That Matters: IBD Partners

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Engaging Patients for Research That Matters: IBD Partners

By Elena Fagotto

Project on Transparency and Technology for Better Health

March 7, 2019



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ABOUT THE PROJECT ON TRANSPARENCY AND TECHNOLOGY FOR BETTER HEALTH

The Project on Transparency and Technology for Better Health studies how sharing data and information may engage patients and improve health outcomes. New platforms, fueled by advances in digital technologies, promise to empower patients by allowing them not only to access information, but also to produce and share their own health data and connect with patients, physicians and doctors. Yet the connections between data sharing and patient action remain poorly understood and underdeveloped in the literature. By conducting comparative case studies on platforms that engage patients through information we provide an inventory and typology of health information initiatives. Our research explores which characteristics are more likely to support patient engagement, at a general level and for under-served populations, and offers lessons to improve the design of future data sharing platforms. This project is part of the Transparency Policy Project at the Ash Center for Democratic Governance and Innovation at Harvard Kennedy School. Archon Fung, Winthrop Laflin McCormack Professor of Citizenship and Self-Government at Harvard Kennedy School, is the Principal Investigator. Elena Fagotto is the Project's Co-Investigator and the Transparency Policy Project's Director of Research. Victoria Alsina Burgues is the Project's Research Assistant. The Project on Transparency and Technology for Better Health was funded by the Commonwealth Fund, Grant No. 20170973.

Learn more at transparencyforhealth.ash.harvard.edu.

ABOUT THE AUTHOR

Elena Fagotto is the Transparency Policy Project's Director of Research. She has been affiliated with the Project since its inception and her research focuses on information disclosure to minimize health and safety risks to the public, regulatory policy, and transnational regulatory regimes. She investigates how technology changes the dynamics of transparency and empowers citizens. She has analyzed dozens of US and international transparency policies, and has published extensively on the role

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of information disclosure as a regulatory tool and on institutional designs to make transparency more effective. She is a graduate of Harvard Kennedy School and LUISS University in Rome. She has a PhD in Law and Economics from Erasmus University Rotterdam. Fagotto can be contacted at elena_fagotto@hks.harvard.edu.

ABOUT THE ASH CENTER

The Roy and Lila Ash Center for Democratic Governance and Innovation advances excellence and innovation in governance and public policy through research, education, and public discussion. By training the very best leaders, developing powerful new ideas, and disseminating innovative solutions and institutional reforms, the Center's goal is to meet the profound challenges facing the world's citizens. The Ford Foundation is a founding donor of the Center. Additional information about the Ash Center is available at ash.harvard.edu.

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“Seeing your research idea turned into a study
is the very embodiment of empowerment.”
(Patient A, October 1, 2017)

INTRODUCTION

Crohn’s disease and ulcerative colitis are chronic inflammatory bowel diseases (IBD) that affect 1.6 million Americans.¹ IBD Partners is a research network connecting nearly 15,500 IBD patients with over 300 researchers. Patients can contribute their self-reported health data for research by filling out surveys on their health twice a year. This way, patient-generated data feeds into an extensive database that can be accessed by researchers to conduct longitudinal studies, to connect with patients for clinical trials and for prospective studies.

Patients can also use the platform to suggest research questions and vote for the most interesting ideas, generating a truly patient-driven research agenda. To date, patients have proposed 170 research questions and expressed nearly 1,900 votes. The research prioritization is dynamic and involves online discussion among patients but also feedback from researchers, who may, for example, summarize existing research to answer patients’ questions. Some of these questions resulted in studies that clarified the role of fiber consumption and sleep in IBD. Studies that use IBD Partners data are returned to patients to close the circle between sharing data and receiving research findings. Patients are actively involved in the platform’s governance and in selecting research proposals. Some patients even serve as co-principal investigators in studies. By letting patients donate and access their health data, as well as prioritize research, IBD Partners is producing research that is relevant to patients’ needs and fostering a community of citizen scientists.

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¹ <http://www.crohnscolitisfoundation.org/assets/pdfs/updatedibdfactbook.pdf> accessed January 11, 2018.

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ORIGINS AND EVOLUTION

Founded in 2011, IBD Partners, formerly known as “CCFA Partners,” is the result of a partnership between the Crohn’s & Colitis Foundation of America and the University of North Carolina at Chapel Hill (UNC). The original idea came from a patient and philanthropist who proposed to use the extensive Crohn’s & Colitis Foundation’s (CCFA) contact list and the Internet to collect a vast amount of patient data for IBD research.² If, commonly, patient registries are populated by data that is collected by doctors and nurses at each clinical encounter, the Internet opens up new possibilities to collect data generated directly by patients in an inexpensive and efficient way. Additionally, patients can contribute data no matter where they receive treatment, which means data could potentially come from anywhere in the US and abroad. As the platform’s leaders explain “prospective cohort studies have been extraordinarily expensive to conduct due to the need for large personnel resources to recruit and follow patients over time. The availability and widespread use of the Internet creates an unparalleled opportunity to create an online community of inflammatory bowel diseases (IBD) patients that could be used for education programs and research at dramatically reduced costs” (Long et al., 2012).

The Crohn’s & Colitis Foundation reached out to UNC, its long-term partner and data manager for the Foundation’s clinical research alliance, to test the idea of a pilot Internet survey. The pilot received a good response and CCFA decided to fund this initiative. The original idea was to use patient data to study rare outcomes and complications associated with IBD. But it soon evolved into a more comprehensive effort to recruit patients to understand how factors such as behavior, diet, exercise and mood impact their disease course, making research outcomes much more relevant for patients trying to manage a chronic condition.³

Traditionally, research has focused on understanding the disease and finding the cure, without focusing on “the experience of having the disease [and] the factors that are important to patients.”⁴ Creating an Internet cohort taps into insights that only patients have, like what is helping them manage IBD, which is “a great complement to

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2 Platform leader A interview with author, August 29, 2017.
3 Platform leader A interview with author, August 29, 2017.
4 CCFA staff A interview with author, September 14, 2017.

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clinical research to understand the broad impact of the disease on patients.”⁵ Collecting patient-reported outcomes allows researchers to “understand patients in the real world and [...] what matters the most to patients.”⁶

In 2011, IBD Partners started as an Internet-based registry where patients could contribute their health data by completing periodic surveys. The Crohn’s & Colitis Foundation used its extensive mailing list to encourage patients to sign up, which resulted in a total of 7,819 adults with IBD joining IBD Partners through August, 2011 (Long et al., 2012). At the beginning, the initiative focused mostly on extracting data from patients using surveys that were distributed to members via email and turning data to researchers.

In 2013, IBD Partners evolved into a patient-powered research network (PPRN) supported by the Patient Centered Outcomes Research Institute (PCORI), a government-funded organization that promotes patient-centered comparative effectiveness studies. Becoming a PPRN expanded IBD Partners’ objectives, adding patient engagement in research and dissemination of research findings and data among patients, thus closing the circle between patients and researchers. As Doctor Millie Long, a professor at UNC and platform leader, explains, when they became a PPRN, they started exploring what was important to patients, established a shared research agenda, and developed the tracking tools they thought would help patients manage their condition.⁷ That transition gave patients more control over the initiative, with the addition of a patient governance committee and the involvement of patients in the evaluation of research projects.⁸ Adding tools for research transparency, from dissemination of findings to letting patients see who uses their data, marked a significant evolution. “Now patients truly drive the research agenda,” a platform leader explained.⁹

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5 CCFA staff A interview with author, September 14, 2017.

6 CCFA staff B interview with author, September 12, 2017.

7 Long, Millie, Susan Johnson, and Nick Uzl. 16 June, 2015. ‘Webinar: CCFA Partners, A Patient Powered Research Network.’ *Crohn’s & Colitis Foundation YoutubeChannel*. Accessed 23-26 July, 2017. <https://www.youtube.com/watch?v=GujNcNaxELo>.

8 Platform leader B interview with author, July 25, 2017.

9 Platform leader C interview with author, September 20, 2017.

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The online portal <https://ccfa.med.unc.edu> was launched in 2015. Patients can log in to the portal to fill out their surveys, visualize their data, and propose research ideas.¹⁰

Today, the platform aspires to fulfill the following objectives:

“1) enhance network growth, diversity, and retention; 2) build a robust network community, including patient governance structures that allow greater involvement of patients in research; 3) expand the network data system to include electronic health records, data from mobile health applications (apps) and wearables, and biological samples; 4) develop a customized, scalable, and adaptable distributed data network; 5) develop and test patient- and provider-focused tools that utilize individual patient data to improve health behaviors, health care decisions, and, ultimately, outcomes; 6) further engage the scientific community through open collaboration and data sharing; and 7) rapidly disseminate new knowledge back to patients, enabling them to improve their health” (Chung et al., 2016).

IBD Partners has met some of its goals. About 15,500 patients, predominantly from the United States, have signed up with the platform. About three quarters of members are women, and members’ ages range from 18 to over 70, with a median age of 42 (Long et al., 2012). In terms of disease phenotype, about 60% of members have Crohn’s disease and over 30% present ulcerative colitis.¹¹ Of the 15,500 total members, about 4,000 have registered with the portal.¹² Thousands of patients joined the platform between 2011–2014, before the portal was launched, and may fill out surveys they receive via email even if they have not registered in the portal.

As a platform leader explained, patients play a key role in determining the research agenda and in governing the platform. They crowdsource research priorities so that “the research that we do, that relies so heavily on member participation, answers some of the questions that our members are interested in.”¹³ A Crohn’s & Colitis Foundation

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10 In this case study, I use the terms “the platform” to describe IBD Partners and “the portal” to describe its website: <https://ccfa.med.unc.edu>.

11 <https://ccfa.med.unc.edu/members> accessed November 13, 2017.

12 Platform leader B interview with author, November 20, 2017.

13 Platform leader A interview with author, August 29, 2017.

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representative noted that, whereas many initiatives that gather patient-reported outcomes are “a one way street,” IBD Partners differs because it provides patients with tools to understand their disease and help in disease management.¹⁴

For IBD Partners, transparency on how the data is used, and by whom, is essential to their patient engagement efforts. Patients can access all studies that used IBD Partners’ data. They can also access the health data they contributed and visualize their health trends. Accessing their own data can help patients gain awareness of their condition and understand which behaviors trigger or calm their disease activity. The platform includes some social networking features and allows patients to learn more about other members using the portal.

However, few members access the portal to look at their data with regularity. Therefore the objective of using data to improve patients’ health behavior, or to test tools in conjunction with their clinicians, seems not fully achieved yet. The platform aspires to usher in an era of personalized medicine and enable patients and providers to co-decide on treatment options based on patients’ data and priorities (Chung et al., 2016). Yet limited use of data by patients indicates that personalized medicine may still be a distant objective. At the moment, patients appear to be drawn to the platform to pool their data and crowdsource research priorities more than to use their health data to manage their condition.

PATIENTS CAN EASILY ACCESS RESEARCH ON IBD

The platform’s portal, ccfa.med.unc.edu, can be accessed via computer, tablet and smartphone because it is designed to adjust to different screen sizes. A mobile application is not available due to its cost.

IBD Partners disseminates information about IBD research to anyone, whether they are members of its network or not. The portal provides access to all the research articles that were published using IBD Partners data. By clicking on the “Research” tab, one can access as many as forty studies, including conference abstracts and

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¹⁴ CCFA staff B interview with author, September 12, 2017.

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published articles, that used IBD patients’ self-reported data.¹⁵ For each study, one can read a summary that highlights the research question, methodology and key findings in a simplified format, as well as the full manuscript.

Studies examine a variety of topics, from the role of diet to how factors such as aging affect IBD. One study found that yogurt and rice helped patients control IBD (Cohen et al., 2012). Research also explored the role of fiber in IBD, a priority for patients given the conflicting advice given by physicians, with some recommending avoiding fiber altogether and others encouraging consumption. A survey of IBD Partners’ members found that a diet rich in fiber actually reduced the risk of flares among Crohn’s patients, whereas fiber did not seem to influence flares for patients with ulcerative colitis (Brotherton et al., 2016). This study was particularly relevant because it demystified the advice on fiber with clear evidence, resulting in actionable knowledge for patients.¹⁶ Another study found that post-menopausal women with IBD experienced an increased disease activity, indicating that aging and hormonal fluctuation affect disease activity, even though hormone-replacement therapy does not seem to make a difference.¹⁷ Studies also examined a variety of topics, from the impact of an ostomy on patients’ quality of life (Abdalla et al., 2016); to the effects of depression on Crohn’s disease activity (Gaines et al., 2016); and the association between exercise and IBD (Jones et al., 2015).

Findings are summarized clearly and written at a middle school level to facilitate understanding. Most studies examine topics that are very relevant to members because they were prioritized by patients. Additionally, because research deals with topics like sleep, exercise and diet, patients may be able to use findings to make changes in their health behaviors, giving them more control over IBD. On the “Research” section, patients can also learn more about opportunities to get involved in ongoing studies conducted by IBD Partners researchers and beyond.¹⁸

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¹⁵ https://ccfa.med.unc.edu/research_completed_research accessed November 13, 2017.

¹⁶ CCFA staff A interview with author, September 14, 2017.

¹⁷ <https://cgibd.med.unc.edu/ccfapartners/docs/menopause%20abstract-DDW%202016.pdf> accessed November 13, 2017.

¹⁸ https://ccfa.med.unc.edu/research_active_studies accessed November 13, 2017.

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Research dissemination is an important priority for IBD Partners, therefore findings are also shared in periodic newsletters to reach members who are not registered in the portal, as well as registered members who access the portal sporadically. The platform also offers webinars, often using CCFA’s channels, to share findings with patients. For example, they organized a webinar with a psychologist so patients could learn about a study linking low mood to flares and how to discuss the impact of mood with their clinicians.¹⁹ IBD Partners also used popular IBD online communities like crohnology.com to share research findings. IBD Partners does not use social media, but news about research and recruiting efforts are disseminated by CCFA via Twitter, Facebook and YouTube.

Many of the patients interviewed for this case study observed that being able to access research that is summarized in lay terms is a very helpful feature.²⁰ A patient found it particularly useful to learn about research on depression and IBD and started thinking about the feasibility of screening patients for mental health, indicating that returning research results to patients may increase IBD awareness and trigger new questions going forward.²¹ Another patient finds tremendous value in “being updated on what goes on in the research community, what is in the pipeline.”²²

Whereas the features described above are in the section of the portal that is open to the general public, other features, like prioritizing research, sharing and accessing health data, are available only to those who are registered in the portal. Registered patients can also log in and track which specific studies used their health information by clicking on a tab called “my contributions,” a unique feature to show concretely how their data helped IBD research.²³ This section lets patients see the name and affiliation of the investigator who used their data, the date of access and a description of the study. Data from one of the patients interviewed for this case was used in sixteen different studies, which the patient found “very empowering [because] I’m helping everybody, including myself.”²⁴ Another patient reflected that transparency on who

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19 Platform leaders A and B interview with author, June 13, 2017.

20 Patient B interview with author, September 22, 2017; patient D interview with author, September 11, 2017.

21 Patient D interview with author, September 11, 2017.

22 Patient B interview with author, September 22, 2017.

23 https://ccfa.med.unc.edu/research_my_contributions accessed November 13, 2017.

24 Patient D interview with author, September 11, 2017.

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is using the data and on the end results gives a patient “a sense of control, that you are doing something about your disease,” rather than being passive and letting the disease prevail.²⁵

The founders of IBD Partners wanted to avoid building a “black box” that would simply aggregate patient data without providing value to its community. Since IBD Partners is primarily a research network, transparency on research outcomes is paramount not only because it motivates members to contribute data, but also because it closes the circle by returning relevant findings to those who donated their health data, and beyond.²⁶

PATIENTS CONTRIBUTE THEIR HEALTH DATA BUT FEW ACCESS DATA TO IMPROVE THEIR HEALTH

Anyone who is 18 years of age or older and was diagnosed with Crohn’s disease or ulcerative colitis can sign up to IBD Partners. During enrollment, patients sign an online informed consent form where they are reminded to complete their bi-annual surveys and to take part in the prioritization effort (Chung et al., 2016). Privacy terms inform patients that their data will not be sold and that their identity will not be disclosed without their permission.²⁷

As of November 2017, 3,997 members, or 26% of IBD Partners members, were registered in the portal.²⁸ About 46% of registered users are members who joined IBD Partners before it launched its online portal, the rest are new members enrolled. The total number of portal logins was 9,611.²⁹ The table below reports the number of portal logins per user. The table only reports data up to five logins.

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25 Patient C interview with author, September 20, 2017.

26 Platform leader A interview with author, August 29, 2017.

27 https://ccfa.med.unc.edu/privacy_policy_document accessed November 13, 2017.

28 Platform leader B interview with author, November 20, 2017.

29 Platform leader B interview with author, November 20, 2017.

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TABLE 1: PORTAL LOGINS PER USER³⁰

Number of Logins	Number of Users
0	1,003
1	2,933
2	1,004
3	423
4	233
5	106

Portal logins do not reveal why patients used the portal, whether to add data or to access information, but they indicate that sustained portal use is relatively modest.

Patients sharing data

Patients contribute their health data to the network by filling in periodic surveys, connecting wearable devices, and responding to health check-in questions when they log in to the portal.

First, patients start by responding to a baseline survey that takes about 30 minutes to complete. The survey consist of questions in the following categories: “1) contact information; 2) demographics including age, gender, race/ethnicity, educational status, etc.; 3) disease characteristics including disease type and clinical characteristics, family history of IBD, surgical history, hospitalization history, cancer history, etc.; 4) health behaviors including medication use, adherence, smoking, etc.; and 5) disease outcomes, including current disease-related symptoms, quality of life assessments, and other patient reported outcomes (PROs)” (Chung et al., 2016).

Once they complete the baseline survey, patients are reminded to take shorter surveys every six months, so they can provide updates on their health and medications. IBD Partners contacts patients by email to remind them to take their six months survey and follows up with two messages when they fail to take it.³¹ Still, getting patients to fill

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³⁰ Platform leader B interview with author, November 20, 2017.

³¹ Platform leader B interview with author, July 25, 2017.

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out their surveys regularly is a significant challenge, as shown in Table 2. Out of 15,495 registered users, 34% only took the baseline survey and 16% took two. Only 677 members, or 4%, took thirteen surveys. These are the most committed patients who were there since the platform’s launch and have filled out all surveys twice a year.

TABLE 2: MEMBERS WHO TOOK ONE OR MORE SURVEYS³²

Number of Surveys	Number of Users
1	5,267
2	2,440
3	1,524
4	1,153
5	857
13	677

Second, patients can also choose to connect any wearable device, such as Fitbit or Jawbone, to their profile data.³³ Currently, IBD Partners has 350 devices connected, mostly Fitbit trackers.³⁴ As platform leaders explain, the objective of adding wearable devices is “to capture observations of daily living through these mobile health apps and wearables so that patients can continuously add their own experiences and knowledge to enrich our database of PGHD [person-generated health data]” (Chung et al., 2016). Passive data from wearable devices is easy to collect because connected devices upload data onto the platform automatically. This data is important not only to researchers, but also to individual members, as it clarifies how activities like exercise and sleep may be linked to disease activity.

Third, every time patients log onto the portal, they are asked one to four questions on their health, depending on their condition. These simple questions, like “how are you feeling today” and “how would you describe your general well-being over the last week,” are known as “health check-ins.” They can be answered in one minute, and

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³² Platform leader B interview with author, November 20, 2017.

³³ https://ccfa.med.unc.edu/health_data/my_connections accessed November 13, 2017.

³⁴ Platform leader B interview with author, November 20, 2017.

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capture the mood and disease activity of patients between surveys.³⁵ Health check-in data also populates data in members’ “My health” section of the portal. Patients answer the health check-in questions very rarely, a total of 2,786 health check-ins were completed.³⁶ Table 3 displays how many users had one to five health check-ins.

TABLE 3: HEALTH CHECK-INS PER USER

Number of Health Check-ins	Number of Users
1	1,184
2	341
3	122
4	46
5	20

IBD Partners is also experimenting with letting patients share their electronic health record data with the platform in partnership with a company called “CareBox,” whose focus is health care data interoperability.³⁷ Researchers have examined the possibility of collecting biospecimens from the IBD Partners cohort and concluded that members would be willing to contribute biospecimens, indicating that IBD Partners members could help with genetic and translational research (Randell et al., 2016).

To incentivize members to fill out surveys and health check-ins and to participate in research prioritization, IBD Partners uses a badging system that rewards patients for their contribution. Let us now turn to how IBD Partners shares data back with patients.

IBD Partners returns data to members

IBD Partners returns data to patients in clear and simple formats. Once they log in, patients can access the “My Health Data” section, where they can see their health

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³⁵ Platform leaders A and B interview with author June 13, 2017.

³⁶ Platform leader B interview with author, November 20, 2017.

³⁷ Platform leaders A and B interview with author June 13, 2017.

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trends and how they compare to other patients on the portal.³⁸ Patients can see a score for their disease activity and compare that to the median score of all members and the clinical remission score. They can get similar scores for pain, fatigue, anxiety and other symptoms. Patients can also access a dashboard where they can learn more about their mood, their disease’s level of activation as well as data from their wearables, if connected, such as number of steps, calories burned and amount of sleep. A “trends” section lets patients see the same metrics presented in the dashboard over time, going up to twelve months back, so they can develop long-term insights on their condition.³⁹ Patients can also see their connected wearable devices as well as their medical records, if they decided to share these with IBD Partners using Carebox.

Accessing their data should give patients tools to understand how their condition is evolving, identify trends and adopt behaviors that are likely to reduce IBD symptoms. As a platform leader noted, “the frustrating thing is that, even as 2017 draws to a close, the medical community knows very little about the drivers of these conditions.”⁴⁰ Building standardized tools for patients to track their disease activity and record what might be drivers and mitigators of the disease might give patients unique insights, or “hunches,” on IBD.⁴¹

These hunches are important for self-management. For example, data could show patients how they are doing before and after their medication infusion, which generally occurs every eight weeks. Some patients may see their symptoms exacerbating at seven weeks from infusion, and may ask their clinicians to switch them to a more frequent schedule.⁴² Sharing data with patients could enrich the way patients manage their condition, and enable them to have more data-driven conversations with their clinicians. Some of these hunches may even turn into research ideas and be included in research studies.⁴³ This has the potential to make research more patient-driven and meaningful for the community as “these are things that only patients can think about, only patients can have these hunches.”⁴⁴

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38 https://ccfa.med.unc.edu/health_data accessed November 15, 2017.

39 Platform leaders A and B interview with author June 13, 2017.

40 Platform leader A interview with author, August 29, 2017.

41 Platform leader A interview with author, August 29, 2017.

42 Platform leader A interview with author, August 29, 2017.

43 Platform leader A interview with author, August 29, 2017.

44 Platform leader A interview with author, August 29, 2017.

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The patients interviewed for this case study report occasionally logging in to access their data. A patient describes logging in every few months to fill out surveys and track his data. Although he does not contribute data with a wearable device because he found that too labor intensive, he finds value in accessing his data. “I look back at data to see how they match my perception of the severity of my condition,” he commented, and described how patients can forget symptoms or misjudge them, so it is important to rely on data because of their objectivity. For example when he switched to prednisone (an immunosuppressant medication) he was able to see how he reacted through the data. He did the same when he switched to biologics therapy. He described how data “helps me look backward to see how tracking matches my perception [and] it gives a more accurate picture of what is working and what is not.”⁴⁵

A patient accesses her data often, especially when her disease is more active. She finds it helpful to have objective measures of her symptoms. By using data in conjunction with her Fitbit, she understood that exercise and sleep affect her condition, and that especially lack of sleep results in flares with bloody diarrhea. She now tries to get regular sleep to control her symptoms. She also explained that the patient experience of the disease is multifaceted: for some a good day is one with fewer bowel movements, for others it means a day with less pain. Tracking tools can help gain awareness of one’s unique symptoms and ways to alleviate them.⁴⁶

Another patient logs in every other week to take the health check-ins and look at his data, but he recognizes that he is more the exception than the rule, as most patients log in only for their bi-annual survey, if they log in at all.⁴⁷

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45 Patient B interview with author, September 22, 2017.

46 Patient A interview with author, October 1, 2017.

47 Patient C interview with author, September 20, 2017.

Several patients report bringing their IBD Partners data to their clinicians to have more informed and data-driven clinical encounters.⁴⁸ They explain how it is often hard to remember symptoms and when they happened, and how data can support their recollection of the disease. A patient takes written notes based on his data to his doctor to help kick start the conversation. He observed that doctors are experts and that discussing with them can be intimidating, but data can help patients have informed discussions. “I find it empowering to make decisions having data to back them up,” he explained.⁴⁹

The patients interviewed for this research are highly engaged, vocal and educated and do not represent typical network members. It appears that only a small number of patients log in regularly to access their health data. Some patients may not be data-driven. Others may have more incentives to track their health when their disease is active, and be less inclined to check their data when IBD is dormant. For example, a patient who has been in remission for four years describes that he does not need the data to manage his condition, but he occasionally checks his data to get a sense of his overall health.⁵⁰

The platform’s leadership is trying to address limited data use by members by adding enhanced features, such as new graphs, and better ways to show comparative information on members’ health so patients can contextualize their health.⁵¹ If members received more value out of logging in, they may be more likely to complete their surveys, which would help with patient retention, one of the platform’s main deficiencies.

CONNECTING TO DEFINE A CROWDSOURCED RESEARCH AGENDA

The central philosophy of IBD Partners is that the most important research topics can only come from patients living with IBD (Chung et al., 2016). Therefore, defining a

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48 Patient B interview with author, September 22, 2017; patient C interview with author, September 20, 2017; and patient D interview with author, September 11, 2017.

49 Patient C interview with author, September 20, 2017.

50 Patient D interview with author, September 11, 2017.

51 Platform leader B interview with author, July 25, 2017.

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shared research agenda is an iterative process that involves connecting members with one another and with the research community. Members can use the portal to connect with their peers and propose, discuss and vote on research ideas.⁵² Each member can express a maximum of five preferences at any time. If a member would like to vote for a new question but has already expressed five votes, she has to revoke an earlier vote to use it again. Researchers take part in the online discussion by providing feedback on proposed research topics and by helping patients develop their ideas.

Some popular research questions include “We need to find an effective way to properly detect our bodies food intolerance’s” [*sic*] (40 votes); “Female menstrual cycle and the worsening of symptoms with each cycle. Is this hormone related and would contraception ease symptoms?” (24 votes); and “Is there a relationship between Crohn’s and chronic acne? Could long term antibiotic use for acne be associated with the development of Crohn’s in young adults?” (22 votes).⁵³

The most popular research question is “We should compare individuals who manage their disease with medication and those who manage their disease with popular diets in the IBD community, such as SCD, FODMAPS, paleo, etc.” This question received 130 votes and stimulated a vigorous debate. Many patients shared comments on how diet has helped them control their condition. Several expressed support for the topic and shared suggestions on how to refine it. One patient cited a question on the consumption of cellulose that she had posed and linked it to the question on diet. Another patient noted that research in this field was much needed to convince skeptical clinicians that diet is a viable treatment option and suggested investigating the impact of grain-free diets on IBD. A member proposed to investigate also food sensitivities and allergies in relation to IBD. These comments exemplify how debate in the community helps clarify and develop a research topic based on patients’ crowdsourced ideas. This research question was used in a call for proposals to fund research on patient-expressed priorities and was eventually funded. Some of the patients behind this question helped develop the research protocols and continue to be engaged in this project.⁵⁴

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52 Anyone can see the list of questions proposed by members and how many votes they received visiting <https://ccfa.med.unc.edu/research>.

53 https://ccfa.med.unc.edu/research?active_tab=popular accessed November 13, 2017.

54 Platform leaders A and B interview with author June 13, 2017.

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IBD Partners’ Research Team is part of this dynamic process. Researchers review all new questions and comments on a monthly basis and provide feedback to members. If certain questions have already been addressed in other research, members of the research team write a response summarizing the existing research, and post it on the portal as a comment to the original question. The research team also assigns categories to different research ideas such as “top priority” (if the topic is important and feasible), “being researched” (if researchers are already investigating the topic), “better answered elsewhere” (if research on the topic is not feasible using IBD Partners’ data), and “under development” (if the research team is in the process of designing a study to answer the question).⁵⁵

Interestingly, researchers do not have the final say on proposed research ideas: patients can question researchers’ conclusions and push their agenda forward.⁵⁶ A question on the use of cannabis to treat Crohn’s disease symptoms is a good example. Such research question received ten votes and Dr. Long, speaking for the research team, posted a comment summarizing existing research, which showed benefits but also risks associated with cannabis consumption. She concluded that IBD Partners was not the best venue for this type of research because of the challenges of distributing cannabis to study participants and monitoring their safety. Later, Dr. Long added another comment to the cannabis question explaining that, due to the community’s continued interest in this topic, the research team had reconsidered its initial response and would ask members questions on marijuana consumption to gather enough evidence to further develop this question. This interaction shows that patient priorities are taken seriously and that continuous engagement by patients can help resurface research ideas that had initially been rejected. The question on cannabis is now “under development.”

As of November 2017, patients expressed 170 questions and over 1,895 votes were cast to select the best research ideas,⁵⁷ twenty-seven of which are being researched.⁵⁸ Many members do not propose questions, but may still engage by discussing ideas

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55 Platform leader B interview with author, November 20, 2017.

56 Platform leaders A and B interview with author June 13, 2017.

57 Platform leader B interview with author, November 20, 2017.

58 Platform leaders A and B interview with author June 13, 2017.

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online or voting. Over 613 members have participated in some way, either by submitting ideas, discussing them or voting.⁵⁹

Letting patients influence the research agenda is an important step forward in empowerment because patients are eager to learn more about behaviors, from diet to sleep and exercise, they can control to improve their health.⁶⁰ Albeit very relevant to patients, these topics were not part of traditional research. By investigating these questions, IBD Partners generates new knowledge that patients can use to improve their health decisions.⁶¹ A platform leader, for example, credited IBD Partners for investigating the role of mental health in IBD, a popular research priority among members.⁶² This research may have empowered some patients to talk about depression more openly and ask for support when seeing their gastroenterologists.⁶³

Because developing research ideas is a process requiring multiple iterations between patients and researchers, it not only strengthens the connections among these groups, but it builds patients' capacity for long-term engagement in research, creating a body of citizen scientists, as envisioned by platform leaders (Chung et al., 2016).

Patients that were interviewed for this case study agree that the platform is genuinely patient-driven. Having a voice at the research table is very valuable because members can promote research topics that matter to them and to the larger patient community. A patient is deeply engaged in the platform because patients are treated as peers, something she finds extremely empowering. Her question on the role of diet in IBD was supported by the community and ended up being incorporated in a well-funded study. She described this as “the very embodiment of empowerment” and emphasized that patient voice in IBD Partners “is not just lip service, it is real input.”⁶⁴ For another patient, donating his health data and being able to shape the research agenda, makes him feel proactive about his condition and helpful to the broader community.⁶⁵

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59 Platform leader B interview with author, July 25, 2017.

60 Platform leader C interview with author, September 20, 2017.

61 Platform leader C interview with author, September 20, 2017.

62 Platform leader C interview with author, September 20, 2017.

63 Platform leader C interview with author, September 20, 2017.

64 Patient A interview with author, October 1, 2017.

65 Patient C interview with author, September 20, 2017.

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A small number of dedicated patients connect with researchers even more closely by volunteering in the Patient Governance Committee (PGC). The PGC makes sure that all information on the portal, from web materials to the way research is returned to members, is comprehensible and patient-friendly. The PGC also focuses on ways to recruit more members.⁶⁶ Patients members of the Research Committee review research proposals that want to utilize IBD Partners data to make sure they meet the needs and priorities of patients and may suggest changes to proposals, such as adding patients to the research team, or making surveys less burdensome and more relevant to members.⁶⁷ As a patient explained, whereas researchers may evaluate proposals by examining the capability to carry out research goals, or IRB compliance, patients look at issues like “is this study too cumbersome for patients?” “is the language clear?” and “will it enhance patient care? What will patients get out of it?”⁶⁸

Finally, the portal also has a modest social networking component. When creating a profile, members can choose a name, add a picture, and may opt to make their profile public so other members can see their information. Members who turn their social profile on can be seen on a map showing where other members live. Currently, 523 members from 308 unique locations have visible profiles, about 13% of members who have registered in the portal. Members cannot connect via private messaging, but they can post comments to research questions posted in the “Research” section or to blog posts. Some of the patients interviewed for this case study reported that the social networking feature is not very helpful for them because they are drawn to the platform to help the IBD research effort, not to socialize with their peers.⁶⁹

THE INFORMATION PATIENTS GET IS MODERATELY ACTIONABLE

The information patients can access in the research section of the website is moderately actionable. Lay summaries of articles are written at a middle school level and can

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66 Patient D interview with author, September 11, 2017.

67 CCFA staff B interview with author, September 12, 2017.

68 Patient B interview with author, September 22, 2017.

69 Patient C interview with author, September 20, 2017 and Patient D interview with author, September 11, 2017.

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help patients learn more about the impact of sleep, diet, exercise and aging on IBD. Information is presented as simplified research findings, for example “We found that symptoms of depression predicted CD activity a year later,” or “Results of this study suggest that for patients with Crohn’s disease (and possibly for patients with UC and IC) who are in remission, higher levels of exercise may reduce the risk of developing active disease in the short-term.”

A patient described that his clinician had advised him to avoid fiber, but he reintroduced fiber in his diet after reading a study on this topic on IBD Partners research section.⁷⁰ Research, as currently presented, might help change health behaviors, however this effect may be confined to more sophisticated and involved patients, like the ones we interviewed for this case study. In general, findings do not offer concrete tips on how to handle depression, how much to exercise, or which foods to avoid and may not be very actionable for less educated members. Additionally, the research section offers as many as 40 studies and patients have to read all the summaries to find knowledge that is relevant to their specific needs.

Similarly, the proposed research questions may offer somewhat actionable information in the comment section, if, for example, patients offer insights on a question, or researchers respond summarizing research that has already answered that question. For example, the question “Look for correlation between IBD & post nasal drip” received answers like “Disease does seem more active during spring and fall or allergy seasons which are associated with PND” and “I too suffer from a constantly dripping nose and PND. I take [name of medication] year around for my allergies (which seem to be worse with age).” Here too, however, patients have to translate research summaries and comments into information they can act upon.

The information in the research section is not personalized because it is not tailored to the specific health needs and circumstances of patients. Research is presented as a chronological list of studies and patients can refine what they want to see by categories such as “life style” “diet” and “mental health.” However categories are rather broad, the “mental health” one, for example, includes a study on the impact of menopause on IBD and research on depression in the elderly, all topics that may not be relevant to a young male patient.

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⁷⁰ Patient D interview with author, September 11, 2017.

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When patients access their data through the “My health data” section of the portal they get highly personalized information that is only moderately actionable. When they look at their data, patients can understand what triggers or calms the disease and understand “what is working for [their] bodies and what is not.”⁷¹ Yet information is not actionable, as patients do not get guidance on how to improve their health. For example, they do not receive clear indications recommending more sleep or more exercise based on their specific data. Patients have to derive these conclusions by looking at their health trends. IBD Partners is trying to improve the way in which it provides feedback and is developing infographics to assist its members.⁷² Additional enhancements also include adding features to improve personalization, like letting patients add notes on events, such as stress, that might result in flares.⁷³

THE PLATFORM IS MORE APPEALING TO CERTAIN PATIENTS

Women constitute the majority of platform users, making up three quarters of all members, a common problem among online health platforms.⁷⁴ Research confirms that platform users are mostly female, white and educated patients (Chung et al., 2016). Most of the people in the sample have Crohn’s, have more severe symptoms, are involved in the advocacy effort and are more educated.⁷⁵ The fact that many members responded to the Foundation’s initial appeal may explain why participants are more educated and motivated than the larger population of IBD patients (Randell et al., 2014). IBD Partners is also aware that barriers like scarce Internet access, poor literacy and low income can limit participation, even though Internet use is growing fast among these groups (Randell et al., 2014).

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71 CCFA Partners. 17 February, 2015. “Promotional video: CCFA Partners: A patient-powered research network.” *Crohn’s & Colitis Foundation Youtube Channel*. Accessed 23–26 July. <https://www.youtube.com/watch?v=Q75xaBhgjus>.

72 CCFA staff B interview with author, September 12, 2017.

73 CCFA staff B interview with author, September 12, 2017.

74 CCFA staff A interview with author, September 14, 2017 and CCFA staff B interview with author, September 12, 2017.

75 Platform leader C interview with author, September 20, 2017.

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At the same time, however, since IBD Partners is an Internet-based registry, it potentially allows any patient to participate in research, irrespective of where the patient receives treatment.⁷⁶ The Internet dramatically expands the possibilities for involvement in research for patients who are not cared for at major research hospitals, giving all patients who can go online a chance to participate. The problem is raising awareness about the platform and showing how it can bring valuable knowledge to those who are not currently involved.

Even though IBD is not as prevalent among African Americans and Latinos as it is among Caucasians, the platform acknowledges the lack of diversity of its members. A patient described that the current lack of diversity is a concern and should be addressed to make research relevant to a broader population.⁷⁷ IBD Partners is actively trying to increase diversity by, for example, focusing on recruiting African American patients with a pilot project in Detroit, where 83% of the population is African American.⁷⁸ CCFA may also use its large network of local chapters to target recruiting of less represented populations, which would result in a “more holistic picture” of IBD patients and their needs.⁷⁹

CONCLUSION AND CHALLENGES

IBD Partners is a unique platform that lets patients contribute their health data and insights to help IBD research and shape the research agenda. Patients connect with one another and with researchers to propose and discuss research ideas. IBD Partners values patients’ input and members feel they are treated as peers in the research effort, which motivates the most dedicated patients to keep contributing to the platform. What sets IBD Partners apart from other initiatives is that, thanks to the platform’s transparency, patients see their data and ideas turned into relevant research and get research findings in return, closing the cycle between contributing health data and learning about research outcomes.

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⁷⁶ Platform leader C interview with author, September 20, 2017.

⁷⁷ Patient A interview with author, October 1, 2017.

⁷⁸ Platform leader B interview with author, July 25, 2017.

⁷⁹ CCFA staff B interview with author, September 12, 2017.

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The dynamic nature of setting a shared research agenda, based on the continued interaction among patients and researchers, is likely to build the basis for long-term engagement for some patients. This may create a group of active citizen scientists, as envisioned by platform leaders. Whereas the platform also offers some social networking features and tools to use IBD data for disease self-management, members use it mostly to learn about new research and to help develop research ideas.

The platform also faces several challenges, from slow enrollment, to a high drop out rate, and limited use of its data tools by patients. Let us discuss these in order, together with strategies that the platform is trying to overcome these barriers.

First, enrolling new patients has been an ongoing challenge. The majority of patients in the database signed up in response to CCFA’s original outreach to its list-serv, when the initiative was launched. Since then, some new members enroll every day, but growth remains slow.⁸⁰ From January 2015, when the portal was launched, to date, the platform was able to add 2,190 new members, about 64 new members every month. According to a patient, there has been a “steady march to engage patients,” but more needs to be done to increase enrollment and to reach out to a more diverse population, not only from an ethnic and racial point of view, but also by gender, age, disease type, and location.⁸¹ Personalizing outreach efforts to engage different communities could help add more members and make the community more diverse.⁸² Whereas CCFA promotes the platform online and at local events, leveraging its local chapters and explaining how the platform helps members may motivate enrollment (Chung et al., 2016). A platform leader suggested that the platform should improve its marketing efforts to communicate to patients the importance and “the value of being part of this.”⁸³ Using social media, advocacy, and inviting clinicians to promote the platform with their patients may also help with recruitment.

Second, retaining members and creating incentives for them to keep coming to the portal and fill out their surveys is a significant challenge, as discontinuity in the data reduces its longitudinal value. A platform leader observed that the “platform is

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80 Platform leader B interview with author, July 25, 2017.

81 Patient C interview with author, September 20, 2017.

82 CCFA staff A interview with author, September 14, 2017.

83 Platform leader C interview with author, September 20, 2017.

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like an onion,” with concentric circles of engagement: some members fill out surveys, others propose questions, some are involved in platform governance.⁸⁴ Yet these layers of engagement are not sufficient to keep patients coming back. A patient suggested that finding alternative ways to engage, like promoting the platform at meetings and at local Crohn’s & Colitis Foundation chapters, something that CCFA is already doing, may persuade more members to engage.⁸⁵ Much of the opportunities to engage are currently online; adding ways to connect face-to-face may reduce the dropout rate.

Third, patients are not taking advantage of the data tools that the portal offers. IBD Partners wants to tie data from wearable devices into the database to help patients understand their condition, expand data for researchers, and return more relevant research and data tools to patients, making their work “a complete cycle,” a platform leader explained.⁸⁶ Yet only few patients have connected their wearable devices. Offering better ways for patients to track their health and use the data would give more value to patients in return for their data. Enhanced data tools may also motivate more patients to enroll and keep engaging with the platform, helping with the previous limitations.

IBD Partners has been trying to improve the ways in which it returns data to patients so they can monitor their disease.⁸⁷ Possible strategies include presenting data and information in more accessible formats, so that it is helpful to a broader patient population, and making the information more personalized.⁸⁸ As a CCFA staff explained, personalization of the content offered is particularly important because “the more you personalize the experience, the better they engage.”⁸⁹ Also focusing on the actionability of research findings and data tools like the “dashboard” and “trends” sections may help. Currently, patients need to process research summaries as well as their data to draw lessons applicable to their health choices. Adding infographics and concrete suggestions based on individual members’ data may increase use by patients. To facilitate data use, IBD Partners plans on returning data that will identify

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84 Platform leaders A and B interview with author June 13, 2017.

85 Patient D interview with author, September 11, 2017.

86 Platform leader A interview with author, August 29, 2017.

87 Platform leader A interview with author, August 29, 2017.

88 CCFA staff A interview with author, September 14, 2017.

89 CCFA staff A interview with author, September 14, 2017.

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more clearly the correlation between behavior (sleep, exercise, diet) and health outcomes. The use of machine learning will help achieve this goal. Platform leaders are also working on creating PDF report cards that patients can share with their clinicians to make the information more useful during clinical encounters.⁹⁰

The platform hopes to revamp its social networking feature in an effort to offer a broader portfolio and attract and retain more members.⁹¹ In the future, members will be able to send messages to other members and generate wall posts. A patient wished that the portal became more like a one stop shop, containing a patient’s information deriving from self-tracking, surveys, but also electronic medical records, physician’s notes, comorbidities and medication calendar. This would help reduce fragmentation of health data and provide a more useful tool for patients, as “it would be nice to keep everything in one place.”⁹²

In sum, the distinctive feature of IBD Partners is its level of patient engagement to co-create research. Patient use of data for self-management and to co-decide treatment options with clinicians remain limited. As a patient explained “now the value is more for researchers than for patients” but the platform has to become attractive to a broader base of patients to keep them coming back because “now, the main incentive is to help with research, but not everybody is motivated by that.”⁹³

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90 Platform leaders A and B interview with author June 13, 2017.

91 Patient A interview with author, October 1, 2017.

92 Patient C interview with author, September 20, 2017.

93 Patient B interview with author, September 22, 2017.

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