

Exchanging Information to Create a Learning Health System: The ImproveCareNow Approach to Engagement

Elena Fagotto

Project on Transparency and Technology for Better Health

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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.

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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.

This research paper is one in a series published by the Ash Center for Democratic Governance and Innovation at Harvard Kennedy School. The views expressed in the Ash Center Policy Briefs Series are those of the author(s) and do not necessarily reflect those of Harvard Kennedy School or of Harvard University. The papers in this series are intended to elicit feedback and to encourage debate on important public policy challenges.

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INTRODUCTION

ImproveCareNow (ICN) is a network of clinicians, medical centers, patients, families and researchers working together to improve the lives of children with inflammatory bowel disease (IBD). Pediatric IBD is a group of chronic disorders that cause pain, inflammation, frequent diarrhea, weight loss and delayed growth. Besides these symptoms, pediatric IBD has negative repercussion on the mental health of patients, who may suffer from low self-esteem and depression. The most common types of IBD disorders are Crohn's Disease and ulcerative colitis. Although there is no cure for IBD, certain medications and dietary changes may help control symptoms. Some IBD patients end up having their colon removed and have to wear an ostomy pouch to collect their stools. Other patients experience long periods of remission thanks to medications and specific diets, but a cure to IBD does not exist. According to the Crohn's and Colitis Foundation of America (CCFA), there may be as many as 80,000 children with IBD in the United States.¹

ICN harnesses the power of networks to enable different groups to exchange knowledge and co-create a learning health system to improve pediatric IBD care. The success of this approach is remarkable. The percentage of patients in sustained remission (patients who have been in remission for at least a year) went from around 40% in 2010 to 53% in 2017. In the same period of time, patients in remission who are not taking a steroid drug went from around 65% to nearly 80% and 93% of patients show satisfactory growth.

ICN is a particularly interesting case to understand how the exchange of data and information helps individual patients make better decisions about their health while also improving care delivery at participating hospitals. ICN empowers patients and families to play an active role in health care improvement and uses patient data to identify areas of need and measure progress in those areas, generating better health outcomes for all the patients who receive care at ICN centers. Transparency, sharing patient data and creating a collaborative space where patients, families and clinicians can work together as peers are among the reasons of the success of this approach.

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1 <http://www.crohnscolitisfoundation.org/assets/pdfs/updatedibdfactbook.pdf>. Accessed October 11, 2017.

1. ORIGINS AND THE C3N MODEL

ImproveCareNow was launched in the early 2000s as a pediatric IBD network focused on quality improvement (Crandall et al. 2011). This initial effort was funded by the American Board of Pediatrics and in 2007 it gathered a small number of pediatric hospitals that were pioneers in their field.² The network was centered around pediatric gastroenterologists and their practices, but in 2009 it evolved and expanded significantly after partnering with researchers interested in developing an innovative model for chronic care called the Collaborative Chronic Care Network (C3N).

C3N was a new initiative leveraging patient data and collaboration among patients, caregivers, clinicians and researchers. Housed at the James M. Anderson Center for Health Systems Excellence at Cincinnati Children’s Hospital Medical Center, C3N was the brainchild of Peter Margolis and Michael Seid, two professors of pediatrics with an interest in innovative approaches to health care improvement. The problem that Margolis and Seid tried to address was that, despite their best intentions, clinicians often failed to deliver the indicated care, and patients often failed to do what it took to keep healthy, which, together, resulted in poor health care and suboptimal health outcomes (Seid et al. 2014). A fragmented approach to care is particularly detrimental for chronic conditions, where patient self-management and productive interactions with clinicians are key to successful health outcomes (Wagner et al. 2001). In the words of Margolis, “[a]ll participants in health care (patients and families, caregivers, clinicians, and researchers) care deeply about improving health. What is missing is a system to harness this motivation and focus participants’ collective intelligence toward transforming care and outcomes.”³ The goal of a C3N is to improve the health of chronic patients by enabling *all* health care participants to work together and unleash their expertise and passion to drive changes in care, building what the Institute of Medicine called a “learning health system” (Institute of Medicine (US) Roundtable on Evidence-Based Medicine 2007).

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² Platform leader A interview with author, September 29, 2017.

³ Margolis, P. A. 2012. “Improve Care Now and the Collaborative Chronic Care Network (C3N) project.” ImproveCare-Now Website. Accessed June 16, 2017. http://www.improvecarenow.org/collective_wisdom_to_improve_health_and_health_care.

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C3N’s vision is that facilitating frequent interactions and information sharing among groups of patients, clinicians and researchers can pool important knowledge to improve care. Joining networks of patients and families, care centers, and researchers and allowing them to share ideas and data enables the co-creation and the rapid spread of the best solutions to their respective networks. In the words of Margolis and Halfon “[t]he philosophy behind the project is that innovations and best practices spread faster through networks and that cooperation among clinicians, clinical centers, but also patients, can harness collective intelligence and achieve superior health outcomes” (Margolis and Halfon 2009).

Support from a prestigious National Institutes of Health grant, a vehicle to fund transformative approaches to healthcare, allowed Margolis and Seid to learn from other fields and bring those lessons to health care. The C3N model is deeply influenced by Harvard Law School’s Yochai Benkler and his work on commons-based peer production, a term used to describe collective efforts to build knowledge for public goods, such as Wikipedia, or the Human Genome Project (Benkler 2011; Benkler and Nissenbaum 2006). By distributing the means of producing information, knowledge and expertise among broad networks of patients, clinicians and researchers, Margolis and Seid hoped to facilitate the peer-production of a learning health system focused on improving chronic care management (Seid et al. 2014). Additionally, the complexity of improving chronic care is such that it exceeds the capacity of individuals or single organizations.⁴ A collaborative production method is particularly suited to services whose quality depends on the interaction of service users (patients) and service providers (the health care system).⁵ C3N also draws from the work of Harvard Kennedy School’s Marshall Ganz on engaging and organizing communities to achieve change on shared objectives. Ganz’s ideas were instrumental for the design of “distributed leadership teams” at the local centers that are part of the ICN network.

In the words of one of the platform leaders “the advantage of working in health care is that there is no place where people are more motivated to do the right thing, to

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4 Margolis, P. A. 2012. “Improve Care Now and the Collaborative Chronic Care Network (C3N) project.” ImproveCare-Now Website. Accessed June 16, 2017. http://www.improvecarenow.org/collective_wisdom_to_improve_health_and_health_care.

5 Platform leader B interview with author, August 31, 2017.

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invest their time and energy.”⁶ C3N decided to try its approach with ImproveCareNow to harness the knowledge and the energy of this network. ImproveCareNow became an ideal laboratory where C3N ideas and tools are tested and refined, but the broader objective of C3N is to use lessons learned in the context of pediatric IBD to create a groundbreaking health care model that is applicable to a variety of chronic conditions, the leading cause of death in the US and the source of 86% of total health care expenditures.⁷

2. ICN TODAY

According to ICN’s collaborative care vision, pediatric patients and their families are an integral part of chronic care improvement. For the first time, patients and families were treated as peers in a systemic approach to improve pediatric IBD care.⁸ This transformed an effort that had initially involved gastroenterologist and their clinical teams into a collaborative project of multiple stakeholders.

ICN can be conceptualized as the result of three operating systems working together. First, a social operating system where different networks collaborate to achieve a shared vision of healthcare; second, a technical operating system to collect and use patient data, from the data collected in a patient registry to patient-reported outcomes and passive data captured by mobile devices and wearables; and third, a scientific operating system to facilitate testing innovations and developing research (Margolis et al. 2013).

Engagement of different stakeholders is at the heart of the *social operating system*. Engagement is conceived along a ladder that begins with awareness (knowing that ICN exists) and moves to participation (using the knowledge and tools created by ICN), contribution (being member of a committee, helping with specific projects) and ownership (creating new tools to support ICN) (Seid et al. 2014). This ladder of engagement allows ICN members to participate at a level that is most suited to their

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6 Platform leader C interview with author, July 26, 2017.

7 <https://www.cdc.gov/chronicdisease/overview/index.htm>. Accessed October 11, 2017.

8 Platform leader A interview with author, September 29, 2017.

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needs. Inevitably, only a fraction of patients and families are willing to engage at the more demanding “contribution” and “ownership” levels, but that is true of all peer production networks like Wikipedia or Tripadvisor, where few individuals make the largest contribution.⁹ However, one of the goals of ICN is to increase awareness of the program and move more people up the ladder of engagement, removing the barriers that discourage members to contribute more.¹⁰ In 2017, ICN hired a community organizer to facilitate engagement and build the capacity of improvement teams, especially at the level of local centers that are members of the ICN network, to strengthen the sustainability of ICN from the grassroots up.¹¹ Interestingly, engagement is used not only to describe participation by patients and parents. It also describes involvement by clinicians and researchers, and has later expanded to dietitians, social workers and mental health specialists.¹² Engagement from all these stakeholders is necessary to make ICN’s social operating system work.

Building a *technical operating system* helps stakeholders work together productively and sustains their engagement in ICN. As a platform leader observed: “the real question is how do we enable that co-production to happen on a regular basis at the patient-provider level but also for a large group of people, like groups of doctors helping one another, groups of patients helping one another.”¹³ Building a robust digital infrastructure was the answer to that question. ICN has a suite of tools to facilitate the flow of information and data to achieve quality improvement and a patient-focused chronic care system. A website, an active social media presence, online chats and periodic virtual meetings help disseminate information and allow members to work together. Patients can also use pilot apps and tracking devices to participate in studies that test how they respond to changes in diet or medication and share the data with their providers.

Clinicians use technology to import patient data into the ICN2 Registry. Each time a patient is seen by a center that belongs to the ICN network, data on the patient’s

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9 Platform leader C interview with author, July 26, 2017.

10 Platform leader C interview with author, July 26, 2017.

11 Platform leader D interview with author, October 3, 2017.

12 Platform leader A interview with author, September 29, 2017.

13 Platform leader B interview with author, August 31, 2017.

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health is collected and entered into an extensive database, known as the ICN2 Registry. Patients are asked to consent to have their data collected into the registry.¹⁴ The registry contains data for the 28,000 patients in the network, capturing over 170,000 clinical encounters and is described as a “gold mine” for IBD researchers.¹⁵ The ability to capture patient data into the registry has improved over time, and nowadays data that doctors type into a patient’s electronic health record is automatically transferred to the ICN2 registry, avoiding duplications and mistakes.¹⁶

The database helps clinicians prepare for visits (pre-visit planning), understand how their patients respond to treatments, or carry out population management (for example identify acute subsets of the patient population that need follow-up). Registry data are longitudinal and track important measures such as how many patients are in remission and for how long, whether patients are growing appropriately and which medications they are on. These measures are also a tool for quality improvement as they allow comparing the performance of different centers and adopting improvement strategies at centers that are lagging behind. Without digital technologies it would be impossible for such vast and diverse networks to collaborate in a sustained way and share information and data for better IBD care.

Finally, a *scientific operating system* supports research and innovation testing in ICN. The ICN2 Registry is the largest available on a pediatric IBD population and has been used by a growing number of researchers.¹⁷ The research enabled by the registry can be divided into comparative effectiveness research, N of 1 trials to test how individual patients respond to treatments and regimens and evaluation of care delivery at the center level (Margolis et al. 2013). Several retrospective studies used ICN2 data to understand the prominence and effectiveness of certain IBD therapies, resulting in meaningful results for patients evaluating different treatment options (Benkov et al. 2016; Steiner et al. 2017). A prospective study emerged from priorities

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14 ICN. 2015. Improvement Coordinator Starter’s Manual. ICN Exchange Website. Accessed September 18, 2017. <http://improvecarenowexchange.org/node/6145>.

15 Platform leader A interview with author, September 29, 2017.

16 <http://archive.constantcontact.com/fs092/1108931207896/archive/1110758362962.html>. Accessed October 3, 2017.

17 C3N. No date. “Quality Improvement Infrastructure.” C3N Website. Accessed September 21, 2016. <http://www.improvecarenow.org/quality-improvement-infrastructure>.

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expressed by ICN patients to clarify the role of diet in IBD. The study, called PRODUCE, uses the N of 1 research design to understand how individual patients respond to the specific carbohydrate diet (a regimen that helps some patients control their symptoms by avoiding most carbs and certain dairy products) and to a modified version of that diet. Study participants will share data on their response to different diets using an app and a website and at the end of the study will receive personalized results on the impact of diet on their symptoms. Individual results will also be aggregated to evaluate the effectiveness of different diets on the entire study population.¹⁸ At the Center for Inflammatory Bowel Disease at Mass General Hospital for Children, registry data and pre-visit planning tools increased patients' remission rate from 77% to 83% (Savarino et al. 2016). At least twelve published studies used the ICN2 registry data.¹⁹

The research component of ICN became more robust in recent years with support from the Patient-Centered Outcomes Research Institute (PCORI), a non-profit organization created by the 2010 Patient Protection and Affordable Care Act to fund comparative effectiveness studies focused on the needs of patients.²⁰ In 2013, ICN received a \$1M grant from PCORI to implement a peer-production model to involve patients and families in research prioritization and start collecting patient-reported health data.²¹ Patient-reported health data, also known as "patient-reported outcomes," or PROs, differ from the data that are captured in the ICN2 Registry because they are collected and shared directly by patients generally by completing surveys, using mobile devices, apps, wearable devices or computers. This marked the evolution of ICN into a patient-powered research network (PPRN), emphasizing the central role of patients in determining research priorities and making their data available for research. In 2015, PCORI confirmed its support by funding phase II of the project with an award of \$1.8M to continue the effort to engage patients and families in research and to launch three studies emerging from the prioritization with patients.²² With funding from PCORI, ICN

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18 <https://www.nimbal.org/education/produce-study>. Accessed October 3, 2017.

19 www.improvecarenow.org. Accessed October 11, 2017.

20 www.pcori.org. Accessed September 26, 2017.

21 https://wwwcf.nlm.nih.gov/hsr_project/view_hsrproj_record.cfm?NLMUNIQUE_ID=20143605. Accessed September 26, 2017.

22 https://wwwcf.nlm.nih.gov/hsr_project/view_hsrproj_record.cfm?NLMUNIQUE_ID=20162210. Accessed September 26, 2017.

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is also building its ability to conduct patient-centered clinical trials, which will not only be useful to patients but will also generate revenues to sustain ICN.²³

Started with ten centers in 2007, the ImproveCareNow network has grown into 107 care centers, located mostly in the United States, with international members in Belgium, England and Qatar, 940 pediatric gastroenterologists and over 28,000 patients who are cared for at centers in the network.²⁴ The network has been growing steadily and it includes 44 of the top 50 pediatric gastroenterology centers in the United States. Currently about 55% of pediatric patients with Crohn’s disease and ulcerative colitis in the US receive their care at centers that are part of the ICN network.²⁵

3. ICN MAKES IBD INFORMATION EASILY ACCESSIBLE

ImproveCareNow provides access to a wealth of resources through its informative and well-maintained website, improvecarenow.com.

The information accessible through the website includes:

- a) background information on ICN (vision, mission and success);
- b) list of care centers within the network, also available as a searchable map;
- c) information on the Patient Advisory Council (PAC) and the Parent Working Group (PWG), representing the voices of ICN patients and parents;
- d) upcoming events and opportunities to get involved, like online chats and virtual meetings;
- e) the Loop, a blog by patients, families, physicians, and researchers to share important news but also personal stories on life with IBD and home of #myICN stories. The Loop blog is also used to summarize important research findings in ways that are approachable and relevant for families. Sometimes ICN parents who have a medical background have authored blog post to report on

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²³ ICN. No date. “Research in ImproveCareNow.” ICN Website. Accessed July 17, 2017. <http://www.improvecarenow.org/research-resources>.

²⁴ <http://www.improvecarenow.org/care-centers>. Accessed October 4, 2017.

²⁵ <http://www.improvecarenow.org/join-icn-network>. Accessed October 5, 2017.

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conferences they attended or to highlight research that is particularly meaningful to families;²⁶

- f) a “tools” section for patients and families including a Self Management Handbook to promote understanding of IBD and offer ways to manage the condition, from treatment, to diet, to positive attitudes; an Ostomy Toolkit, a lively guide on life with an ostomy, developed by patients for patients; information on SmartPatients, a digital platform connecting IBD patients and parents; general information about transitioning from childhood to adulthood;²⁷
- g) information on publications and ongoing research. When they sign up with the ICN website, patients receive news on a wide variety of topics including the most recent publications and research developments. Patients can access the “Research” section on the website to learn more about current research and browse short summaries of articles published between 2009–2017. Besides publications, patients can access information about ongoing studies, some of which may be recruiting patients, and contact study managers if they are eligible to be included in the research; and
- h) the ICNExchange, a Pinterest-type board where principally ICN coordinators and clinicians, but also patients and parents who are active ICN members, can access and share helpful tools. ICNExchange is accessible in a password-protected area of the website. It includes numerous materials on quality improvement and pre-visit planning shared by ICN coordinators, the heaviest users of this section of the website and the real “pollinators” who make sure that information spreads to other centers.²⁸ But ICNExchange also includes tools that are suited for families. For example, the Parents Helping Parents practical guide, developed by veteran IBD parents to support families whose children were just diagnosed, and documents explaining what is the best diet for sick patients, or how to organize the transition from pediatric to adult care.

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²⁶ <http://www.improvecarenow.org/loop>. Accessed October 16, 2017.

²⁷ <http://www.improvecarenow.org/tools>. Accessed October 16, 2017.

²⁸ Platform leader C interview with author, July 26, 2017.

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A video of an 11-year-old boy demonstrating how to self-administer a nasogastric tube for enteral feeding, a painful and complex procedure, has been particularly helpful to families but also nurses and clinicians and is often cited as an example of the important knowledge that patients can bring to the network.²⁹ One of ICN’s mottos is “share seamlessly, steal shamelessly,” a way to encourage the kind of extensive sharing that occurs on the ICNExchange and the rapid diffusion of useful tools across network members.

ICN also disseminates information with a very active social media presence. On Twitter, @improvecarenow posted 8,500 tweets and has 1,700 followers. ICN has a Youtube channel and its Facebook page reached 4,000 likes. @ICNPatients is the voice of the Patient Advisory Council (PAC) and has 4,300 tweets and 600 followers and is available also on Instagram. The active presence on numerous social media outlets demonstrates ICN’s effort to reach a broad and diverse audience, with Instagram and Youtube being particularly popular among younger audiences, to share information on resources and events and to attract people to their website. Furthermore, the ICN website is built on a community organizing software, called Nation Builder, which offers opportunities to sign up and engage at a level that is appropriate for everyone. Nation Builder allows ICN staff to see how individuals interact with ICN, on the website, on Facebook, on their blog, so they can target different audiences depending on their interaction and their level of interest.³⁰

The variety of topics treated on the website, from blog posts sharing personal stories, to life hacks, and information on research developments, resonate with patients and families with different interests, from social to scientific, making website resources appealing to a broad audience. Additionally, the fact that blog posts, but also resources on how to navigate life with IBD, are produced by patients and families makes the materials particularly accessible and relevant to users and amplifies the voice of patients in the network.

Even though ICN offers access to a wide collection of resources for IBD patients and their families through several channels, including social media, too many are still not

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²⁹ https://www.youtube.com/watch?time_continue=17&v=vCmCacP9j_I. Accessed October 5, 2017.

³⁰ Platform leader C interview with author, July 26, 2017.

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aware of ICN’s existence. It appears that only a fraction of the 28,000 patients whose data are in the ICN2 registry, and who receive care at an ICN center, know about ICN. A parent suggested that ICN should do a much better job at branding and promoting itself.³¹ Other interviews confirmed that awareness is still low and that it is a priority for ICN to increase it, so that, at a minimum, all those who receive care at an ICN center understand what ICN is.³² One patient suggested that, when patients consent to having their data collected in the ICN2 Registry, generally during a doctor’s appointment, they may be overwhelmed with information and forget about ICN. He suggested contacting patients a few weeks after they sign up to explain what ICN is could sustain awareness.³³

4. PATIENTS GENERATE VAST AMOUNTS OF DATA BUT CANNOT ACCESS REGISTRY DATA

Currently, 28,000 patients who are cared for at one of the over one hundred ICN care centers consent to have their health data stored in the ICN2 Registry. Once care centers have obtained IRB approval and signed legal documents, they are able to set up an ICN2 account to enter their patients’ data into the database. Care centers are responsible for registering their patients and undergo a training session to learn how to enter data into the database and use the registry. The registration data includes the patient’s name, address, medical record number, height, weight, diagnosis and phenotype.³⁴ Once a patient is registered, physicians collect 50 to 75 data elements at each clinical encounter and share them with the ICN2 Registry. Such data include symptoms (general well being, limitations in daily activities, abdominal pain), stools, exam (abdominal exam, perirectal disease exam, height, weight, current BMI), nutritional and growth status, and medications.³⁵ Clinicians must also upload any information on hospitalizations,

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31 Parent A interview with author, September 19, 2017.

32 Platform leader C interview with author, July 26, 2017.

33 Patient A interview with author, September 6, 2017.

34 ICN. No date. ICN Registry Manual. ICN Exchange Website. Accessed September 19, 2017. <http://www.icnexchange.org/node/5830>.

35 ICN. No date. ICN Registry Manual. ICN Exchange Website. Accessed September 19, 2017. <http://www.icnexchange.org/node/5830>.

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including date of admission, date of discharge, if intra-abdominal GI surgery was performed during admission, and any other comments the physician may consider. In sum, the bulk of patient data captured in the registry to manage patients, benchmark the performance of centers and to conduct research on IBD, is collected and entered by clinicians or members of clinical teams at the time of a visit.

ICN has also experimented with different apps and digital tools to capture passive data (like frequency of texting and other online social interactions) and active data (bowel movements, mood) reported directly by patients. These apps empower patients to track, understand and share their symptoms with their physicians. However, they have only been tested on small populations of ICN volunteers and they have not been incorporated in care delivery at ICN. Some examples are listed below.

- a) EMMA App is a gaming App for iPad that patients can play with in the waiting room, prior to their doctor’s appointment.³⁶ As they play a game, patients are asked questions to assess their knowledge in four areas that are critical to their wellbeing: quality of life, wellness, patient nutrition and general nutrition. Patients are also asked to rank their quality of life and emotional health.³⁷ The results of the game tell clinicians which areas and knowledge gaps should be addressed during the visit.³⁸ The results are also entered in the patient’s medical record.³⁹ The beta version of EMMA was tested at the University of Oklahoma and at the Mayo Clinic, both ICN members.⁴⁰
- b) E³ (Engaged, Empowered, Electronic) Healthcare app uses data to improve clinical interactions and shared decision-making. The app allows parents to track their children’s symptoms using easy visualizations to display how their health progresses between visits. Parents also receive weekly updates on

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36 C3N. No date. “EMMA.” C3N Website. Accessed September 14, 2016. http://c3nproject.org/sites/bmidrupal7pc3n.chmcres.cchmc.org/files/innovation-handouts/EMMA_C3N%20Innovation%20Handout_20130327_1.pdf.

37 C3N. No date. “EMMA app.” C3N Website. Accessed September 20, 2017. <http://c3nproject.org/innovations/emma-app>.

38 C3N. No date. “EMMA app.” C3N Website. Accessed September 20, 2017. http://c3nproject.org/sites/bmidrupal7pc3n.chmcres.cchmc.org/files/innovation-handouts/EMMA_C3N%20Innovation%20Handout_20130327_1.pdf.

39 C3N. No date. “EMMA app.” C3N Website. Accessed September 20, 2017. http://c3nproject.org/sites/bmidrupal7pc3n.chmcres.cchmc.org/files/innovation-handouts/EMMA_C3N%20Innovation%20Handout_20130327_1.pdf.

40 C3N. No date. “EMMA app.” C3N Website. Accessed September 20, 2017. http://c3nproject.org/sites/bmidrupal7pc3n.chmcres.cchmc.org/files/innovation-handouts/EMMA_C3N%20Innovation%20Handout_20130327_1.pdf.

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their children’s health. Using the app, parents can prepare for appointments, log their questions and identify any issues they may want to discuss with clinicians.⁴¹

- c) Passive PRO is an app and a web portal that allows the collection of passive smartphone data, such as information on calling, texting, location and movement. Patients can also generate active data by answering questions on their symptoms and wellbeing. Passive and active data are combined into a score that reflects the patient’s health status. Patients have ownership over their data because they receive customized reports that they can share with clinicians or caregivers. Passive PRO is a tracking tool for patients, but it also informs clinicians on their patients’ health between visits.⁴²
- d) Orchestra is an app that lets patients track their symptoms and communicate with providers. Orchestra also helps with pre-visit planning and allows testing how specific treatment plans or diets work for a patient to calibrate and personalize care.⁴³ Like Passive PRO, also Orchestra allows self-tracking and shared decision making with clinicians. A patient who tested Orchestra liked it because it only asked questions that mattered to her condition and symptoms, so she did not waste time with irrelevant information.⁴⁴ Orchestra can be used on a smartphone or computer and is currently being tested by the PRODUCE study on a population of about 100 ICN patients to run N of 1 studies on how patients respond to the specific carbohydrate diet.⁴⁵ This will give individual patients important data that they can use to adjust their nutrition, or discuss with their gastroenterologist. As Lisa Opiari Arrigan, Co-Principal Investigator, explained, through Orchestra “patients and their clinicians will be able to collaborate in low friction, high efficiency ways to learn about the personal

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41 http://c3nproject.org/sites/bmidrupal7pc3n.chmcrec.cchmc.org/files/innovation-handouts/E3HEALTHCARE_C3N%20Innovation%20Handout_20140123.pdf. Accessed September 12, 2016.

42 C3N. No date. “Passive PRO.” C3N Website. Accessed September 18, 2017. <http://c3nproject.org/innovations/patient-self-tracking-continuous-care/passive-pro>.

43 C3N. No date. “Orchestra.” C3N Website. Accessed September 20, 2017. <http://c3nproject.org/innovations/patient-self-tracking-continuous-care/orchestra>.

44 Patient B interview with author, September 7, 2017.

45 <https://www.nimbal.org/education/produce-study>. Accessed October 5, 2017.

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impact of varying diets on their health. This technology has the potential for broad application across chronic conditions to help patients and their clinicians identify whether a specific treatment works for them.”⁴⁶ This N of 1 study will answer questions on the links between diet and IBD, an urgent research priority expressed by the ICN community.

The apps listed above have been used only for testing purposes, they have not been incorporated in routine care. Currently, ICN does not offer self-tracking apps to members, even though some patients and parents use commercially available apps, like GIBuddy. Therefore, a seamless flow of data from patients to clinicians between visits, or the sharing of patient self-tracking data at the time of visits have not yet happened, even though C3N envisions a future where this kind of constant data exchange will be possible. For the time being, however, the tools to enable patients to generate and share data are being tested on small patient populations and improved.

Interviews revealed that self-tracking may not be for everyone. For example, patients and families may have more incentives to track when the disease is more active, and reduce tracking when they are in remission.⁴⁷ One mother interviewed for this case study is an avid tracker and uses the GIBuddy app to track her son’s symptoms, diet, flares, and get reminders to take medications. She uses her smartphone to share pictures of her son’s stools and notes with his clinical team. The team will add them to her son’s MyChart profile so that information will be available at next clinical encounter.⁴⁸ But other parents are more skeptical. A mother questions the reliability of self-tracking data because her son is so used to living with IBD that he tends to always say he is feeling well.⁴⁹ Another parent noted that “parents are really busy” they have a lot on their plate as parents, and on top of that there is managing a chronic condition, and a lot of the tracking tools are still very “work intensive.”⁵⁰

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⁴⁶ ICN. 2016. “ImproveCareNow Network to Participate in \$2.5 Million Research Study Evaluating Specific Carbohydrate Diet in Pediatric IBD.” ICN Website. Accessed September 18, 2017. http://www.improvecarenow.org/improvecarenow_network_to_participate_in_2_5_million_research_study_evaluating_scd_diet.

⁴⁷ Patient A interview with author, September 6, 2017.

⁴⁸ Parent B interview with author, September 13, 2017.

⁴⁹ Parent C interview with author, September 7, 2017.

⁵⁰ Parent A interview with author, September 19, 2017.

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Even though the creators of the C3N model envision a future where patients and clinicians connect around data, they also acknowledge the organizational, cultural, and technical barriers to this approach. One challenge is the way healthcare and the work of clinicians is organized, what is commonly defined as a “workflow” problem. From a doctor’s perspective, “if you have continuous monitoring data it is one more stream of information, you can’t have that information and do nothing about it” explained a platform leader.⁵¹ Clinicians have an established routine where they enter their patient’s data in the electronic medical record (EMR) at the time of visit. Their workflow would need to be revised in order to accommodate patient-generated data.

Another challenge is that doctors are trained on how to treat symptoms, but may have a hard time reacting to patient data on issues like well-being or quality of life, leaving patients’ problems unanswered. Some doctors may even feel that patient data threatens their traditional roles and their knowledge because “if you are a doctor, you act like a doctor, there are prescribed walls and there is a power differential.”⁵²

Absorbing patient-generated data into the EMR might pose technical challenges at the hospital level, at the EMR software level, as well as regulatory challenges to protect patients’ privacy and confidentiality. Patient-generated data could add significantly to the learning health system that C3N aspires to build, but “the health care delivery system is not yet designed to accommodate this information and respond to it.”⁵³ In sum, even though the apps developed by C3N may enable patients and doctors to use data in novel ways, bringing them to scale for the whole patient community and integrating patient-generated data into ICN knowledge and care delivery still pose significant challenges.

Patients generate vast amounts of data for the ICN2 Registry, but they cannot access their data. Registry data are only available (a) to clinicians and their teams to manage individual patients, (b) to care centers to understand in aggregate how their patients are doing and compare their performance to that of other centers, and (c) to the research community. Occasionally, clinicians may, at the time of the visit, turn their computer screens towards their patients to let them see charts and explain disease

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⁵¹ Platform leader C interview with author, July 26, 2017.

⁵² Platform leader B interview with author, August 31, 2017.

⁵³ Platform leader C interview with author, July 26, 2017.

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progression, but data are not systematically returned to patients. The ability to aggregate and display ICN2 data at a clinical encounter is still limited “it is much easier for a patient to bring in their iPad and share data with their doctor at this point.”⁵⁴ According to a parent, the fact that parents and patients are not allowed access to their own data in the registry is a missed opportunity.⁵⁵

Some active ICN parents are starting to discuss the feasibility of opening ICN2 data to patients. A panel at the ICN community conference in Chicago in September 2017 addressed how families could use registry data. A parent suggested that having access to his daughter’s health data could help him prepare for her doctor’s appointments, the same way the registry helps clinicians with pre-visit planning.⁵⁶ He also suggested that comparing his daughter’s data to the anonymized data of other patients in her cohort could give him more context to make sense of the data and understand how she is doing relative to others.⁵⁷ Also, more should be done to inform parents about the measures that are used in the registry. For example, the percentage of patients in remission is 80%, but patients in sustained remission for at least a year are above 50%; this difference should be explained more clearly to families so that they can better understand improvements in care.⁵⁸

Absent families’ access to the ICN2 registry, some parents access their children’s health data using patient portals. One parent uses her son’s patient portal to prepare for clinical encounters. She looks at trends, for example to see if her son’s weight has reached plateau, and brings these issues up with their clinician.⁵⁹ This is helpful, but it lacks comparative elements and the context necessary to understand how much a child is progressing relative to her peers with IBD. Another parent wished that families could access data on their care center’s performance within the ICN network. Aggregate performance data is transparent for clinics within the network to encourage learning and accountability, but it is not transparent for families and patients. The choice

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54 Platform leader B interview with author, August 31, 2017.

55 Parent D interview with author, September 14, 2017.

56 Parent D interview with author, September 14, 2017.

57 Parent D interview with author, September 14, 2017.

58 Parent A interview with author, September 19, 2017.

59 Parent C interview with author, September 7, 2017.

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of not disclosing clinic performance data was made so that network members would feel comfortable about their numbers and to encourage learning from the data, rather than shaming poor performing centers. Yet at this point the ICN community should be mature enough that clinics and families “should be able to handle this type of transparency,” suggested a parent.⁶⁰ Knowing how their care center is performing relative to other centers in the network may help patients and families select the best centers, or be a stimulus to engage in quality improvement work to improve the scores of the center where one receives care.

5. ICN CONNECTIONS HELP PATIENTS AND ADVANCE CARE

Connecting with other patients, with parents, with clinical care teams, and with researchers is an integral part of the approach that C3N is testing and it is what motivates many patients and parents to be actively engaged. Connecting can be defined as the act of conversing and establishing a rapport with others, either face to face or using digital tools. Members of the ICN community can connect face-to-face twice a year, during the ICN community conferences, two-day events where patients, families, clinicians and researchers get together to share ideas on IBD care and life with IBD. At the community conferences, whose motto is “all teach, all learn,” families and medical teams come together as peers to learn from one another and collaborate. Community conferences help build the social fabric that sustains the quality improvement work of ICN at the network level and also at the individual center level. These conferences draw patients and families for two reasons.

First, there is a *knowledge exchange* dimension. Most patients and parents decide to go to ICN community conferences to learn more about pediatric IBD and possible treatments. One mother appreciates that ICN gave her the opportunity to understand IBD “from a clinical perspective,” something she could not do at a doctor’s visit or by looking up her son’s disease on Google. She finds conferences a good way to learn about medications, biomarkers, triggers and nutrition because knowledge is

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⁶⁰ Parent A interview with author, September 19, 2017.

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presented in “layman terms.”⁶¹ One parent got involved to understand the research at a deeper level, from clinicians and researchers who are authorities in their field. As a lay person he was not equipped to understand the research he found using the Internet, but now he describes being able to understand “clinical options and also areas of uncertainty” and can discern what is more and less relevant.⁶² Conferences are also a good way to learn about the latest developments in research and opportunities to participate in trials and research studies.

Clinicians, care teams, and researchers learn too. “Patients may be the most underutilized resource in transforming care,” states the C3N website. Community conferences let patients and families share their knowledge with the medical community. At these conferences, patients are treated like peers and lead discussions and presentations to focus attention on problems that matter the most to IBD patients. At the fall 2017 community conference in Chicago, for example, patients held a panel on IBD and body image to explain how their condition affects their social life and suggested ways in which clinicians could discuss this important issue with their patients. Several panels discussed the mental health impact of IBD and available resources. This was in response to the spring 2017 community conference, where patients suggested mental health was an important topic that was often neglected in IBD care.⁶³ At a 2016 community conference multi-stakeholder groups discussed the five highest ranking research topics emerged from an online prioritization effort and came up with concrete research questions like “Do pediatric IBD patients in deep remission with dual therapy continue to require dual therapy?” and “What are the predictors of pediatric UC colectomy?”⁶⁴ Some of the research questions expressed by the ICN community were incorporated in research studies and may result in findings that are particularly relevant for patients and their families. Community conferences, and ICN in general, value the knowledge and involvement of patients and families, which motivates them to continue to attend and contribute knowledge. Some patients and parents reported that they are deeply involved in ICN

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61 Parent B interview with author, September 13, 2017.

62 Parent D interview with author, September 14, 2017.

63 Patient B interview with author, September 7, 2017.

64 http://www.improvecarenow.org/join_a_research_team. Accessed September 21, 2016.

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work for altruistic reasons, and hope they can make a difference in IBD care not just for themselves, but for all patients and families.

Second, and for many as important, there is a *social connection* dimension. Participants value the fact that they can connect with people who are facing similar problems, whether it is patients finding other patients, or parents connecting with parents. Chronic conditions can pose a significant emotional burden on families, leaving parents and patients feeling isolated. One patient explained that attending the conferences and being involved in ICN work helps patients mentally because “they can find friends they can talk to for anything,” establishing connections that go beyond the conference.⁶⁵ A mother described that when her son was diagnosed with ulcerative colitis she was “confronted with guilt, where did my child get this from?” and added that the diagnosis “feels like a sentence for your child.”⁶⁶ At the community conferences she was able to share these feelings with other parents and was comforted to learn that other mothers experienced similar reactions.⁶⁷ Parents form bonds that help them beyond the conference and stay connected using emails, text messages and phone calls.⁶⁸

Parents also enjoy shortening the distance between them and clinicians and researchers and being able to interact with them on an equal footing. One parent likes that community conferences create a “level playing field [where] everyone is nice, there is no pedigree” and credits ICN for being an environment set up with the expectation that parents and patients are there to help, so she never felt like “just a parent.”⁶⁹ For one parent it was valuable to develop relationships with parents and beyond “Now I have a network of people to go to, dietitians, patients, doctors . . .”⁷⁰

A father explained that it is important for him to be able to ask questions to the clinicians he meets at the ICN conference, a place where parents and clinicians are “comfortable to have a dialogue.”⁷¹ Another parent commented that attending the

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65 Patient B interview with author, September 7, 2017.

66 Parent B interview with author, September 13, 2017.

67 Parent B interview with author, September 13, 2017.

68 Parent C interview with author, September 7, 2017.

69 Parent B interview with author, September 13, 2017.

70 Parent C interview with author, September 7, 2017.

71 Parent D interview with author, September 14, 2017.

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conference allowed him to become familiar with a network of physicians, “it’s the who’s who in pediatric IBD.”⁷² Breaking the social barriers that normally exist between patients and their families and clinicians appears to be a powerful experience for participants and encourages repeat participation for families because they feel their voices matter. As a patient observed:

“One huge amazing thing is the bi-annual conference. There is empowerment in feeling connected. In health care there is a paternalistic model, but having access to clinicians allows to shorten the distance, to put them on an equal footing. Providers feel more touchable. They are people too, they want to learn from us as well.”⁷³

If community conferences bring the ICN community together face-to-face, ICN also offers opportunities to engage online. Patients and families who volunteer in ICN committees have periodic conference calls and webinars. For example, the Patient Advisory Council holds monthly “PAC chats” online. ICN recently introduced virtual community conferences using Go-To-Meeting webinar where members can come together and share the latest news on opportunities to engage, ongoing studies and tricks to improve the day-to-day management of IBD. Virtual community conferences are open to anyone who registers and are a good way to engage patients who cannot afford taking time off, or paying the costs associated with the actual conference. At one of these virtual conferences, parent Erika Allswang heard another parent talk about “Buzzy,” a device that mitigates the pain of medication injections by confusing nerves with vibration and temperature. Erika immediately bought a “Buzzy” for her four-year-old son who has Crohn’s disease and shared a story on the difference that made on injection day.⁷⁴

ICN also partnered with SmartPatients, an online platform where communities of patients and parents can connect and discuss. Clinicians and researchers are not part of the SmartPatients platform to allow members the latitude to have honest

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⁷² Parent A interview with author, September 19, 2017.

⁷³ Patient A interview with author, September 6, 2017.

⁷⁴ http://www.improvecarenow.org/the_virtual_community_conference_helped_me_help_my_son. Accessed September 25, 2017.

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conversations.⁷⁵ One patient suggested that most of the SmartPatients users are parents, because patients are not comfortable having open conversations “knowing that their mom might be listening in.”⁷⁶ The SmartPatients pediatric IBD community has 570 members.⁷⁷ In the past, C3N also tested YouMeIBD, a Facebook application using a matching algorithm to connect IBD patients for social support and knowledge about disease management.⁷⁸ This tool asks patients to play a game where they share information about themselves that allows the app to match them with similar patients.⁷⁹

Finally, it should be reminded that much of the work of ICN happens locally and between conferences. Many hospital centers involve parents and patients in their quality improvement teams and team meetings offer a chance to connect with clinicians, nurses, dietitians and mental health workers. These teams meet periodically to discuss quality improvement goals and measure progress. They are also in touch with other ICN centers to learn about tools they can apply and replicate successful strategies. Sometimes, patients involved in quality improvement efforts at their centers volunteer to train newly diagnosed patients, strengthening connections among patients from the same area.⁸⁰ Local ICN teams are the engine of ICN’s improvement work and a source of innovative ideas that are shared through ICNExchange, at webinars or at the bi-annual community conferences. One parent’s motivation to be part of ICN was precisely to accelerate improvement at his local clinic. By engaging at his care center, he and other parents were able to advocate for adding a nutritionist and a psychologist to their clinical team.⁸¹

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75 Platform leader B interview with author, August 31, 2017.

76 Patient A interview with author, September 6, 2017.

77 Michael Seid and Michelle Spotts “Quick question on connecting and ICN.” Email message to Elena Fagotto. October 15 and 16, 2017.

78 Provost, S. M. 2016. *Collaboration dynamics in virtual innovation teams: a longitudinal social network analysis*. Doctoral dissertation, The University of Texas at Austin.

79 Kennedy, S. 2012. “YouMeIBD: Making the Connection.” ImproveCareNow Website. Accessed June 16, 2017. http://www.improvecarenow.org/youmeibd_making_the_connection.

80 Patient A interview with author, September 6, 2017.

81 Parent A interview with author, September 19, 2017.

6. ACTIONABILITY AND PERSONALIZATION

Some of the information that patients can access on improvecarenow.org is actionable, especially information included in toolkits and other practical guides. The “Ostomy Toolkit, Gutsy Living with a Little Gutsy Help,” for example, addresses practical issues such as how to travel, play sports and what clothes to wear when you carry an ostomy bag. A visit planner asks parents simple questions like rating their understanding of their child’s condition to help parents develop a list of topics to discuss with their clinician.⁸² Parents can also find information on how to develop a plan to help their children with IBD issues in school. The information regarding research appears to be less actionable. For example there are no tools to compare medication effectiveness or diet effectiveness. PCORI focuses on patient-centered comparative effectiveness studies and it is possible that, since ICN is a Patient-Powered Research Network funded by PCORI, comparative effectiveness tools will become available in the future.

It appears that the information offered to patients is *not personalized*, meaning that the information is not presented in different formats, or with different levels of complexity, depending on the circumstances, literacy skills or cognitive abilities of users. ICN uses Nation Builder, an organizing software that collects users’ data from multiple sites, to manage their contact list. This may allow ICN to target emails on studies occurring at specific hospitals only to those who live within a certain radius from the hospitals, or to understand members’ interests and offer opportunities to engage accordingly. Nation Builder might be a first step toward personalizing information, yet not in ways that keep into account the cultural environment or the cognitive abilities of ICN members.

In the future, the use of mobile apps to conduct N of 1 studies may produce results that are actionable and personalized. The Orchestra app, for example, may help patients understand how their symptoms fluctuate and why. This awareness should help patients choose behaviors that help alleviate symptoms, like sleeping more, or avoiding certain foods. Patients using Orchestra within the PRODUCE study will be able to learn how their condition reacts to certain diets, getting clear indications on the diet

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82 <http://www.improvecarenow.org/visit-planners>. Accessed October 12, 2017.

that is most helpful to control IBD. Feedback based on patients' data is personalized because the data allows tailoring diets and treatment plans to the specific needs and circumstances of patients.

7. CONCLUSION: ICN'S PROMISE AND LIMITATIONS

ICN is helping families by giving them access to important information on IBD, from research summaries to practical toolkits. The patients and families interviewed for this case study appear to particularly enjoy community conferences because they help them connect with their peers and the medical community, while learning about the latest developments in research. The interactions among patients and parents offer helpful emotional support they often cannot find otherwise. Patients and caregivers get involved in ICN to learn more about IBD, and they continue to engage for years because they feel their participation has a positive impact on the entire patient community. Their interaction with clinicians brings important patient concerns into focus and helps promote research that is centered on the needs of patients. In describing how ICN empowered her, a mother told that when her son was diagnosed she was unsure about the topics she could bring up with their clinician, but being part of ICN gave her the confidence to ask questions and have challenging conversations with her son's clinical care team.⁸³ A patient reported that ICN helped him because "you become more engaged in the conversation with your doctor, you can ask questions, there is shared decision making. Another thing is self-management. By being better able to ask questions, you are able to self manage, which is important in transitioning from pediatric care, when your parents ask the questions, to adult care."⁸⁴

By design, ICN creates a fertile environment for patients, families and clinicians to co-create a learning health system, an approach that has already delivered significant improvements in care for patients of clinics that are part of the network. Additionally, the extensive use of patient data allows to identify areas of need, measure

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⁸³ Parent C interview with author, September 7, 2017.

⁸⁴ Patient A interview with author, September 6, 2017.

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improvement, and develop new research on IBD. The success of ICN suggests that the C3N model could bring significant improvements to chronic disease care. Currently, C3N creators are working to help launch similar networks for cystic fibrosis, hypoplastic left heart syndrome, and juvenile idiopathic arthritis.⁸⁵

This approach also has limitations. First, awareness of ICN, even among patients who consented to be part of the registry, remains very low. Only a fraction of families are accessing the knowledge, resources and connections that can help them manage IBD, have more productive clinical encounters, or get the emotional support they need. Especially community conferences are challenging to attend for parents with few resources, or who are more intimidated to speak up. A parent living in a diverse and low income neighborhood describes that she is the only parent involved in ICN and in quality improvement work at her hospital. Many parents cannot engage in ICN efforts because of language barriers, lack of time or because they come from single parent households. However, parents attend the teach nights where she explains pediatric IBD to families, showing that parents are eager to learn more about the disease.⁸⁶ ICN may be a good organizing vehicle to improve care and help those who are able to be heavily involved, the contributors and owners, in C3N's hierarchy of engagement. However it may be a less effective tool to make information and tools available to families that are unable to engage at such sustained levels.

Second, registry data are not returned to patients. This may limit patients' understanding of their condition and of the behaviors that help, or exacerbate, IBD. Returning data to patients in ways that are relevant and actionable could help improve patients' ability to self-manage. As a mother described, "when you have access to data you know better, you do better."⁸⁷

Finally, although ICN has piloted different apps and technology tools to connect patients and capture patient-reported data, these tools need to be refined and adopted more broadly into clinical care. Such wider adoption will also require altering clinical workflows and educating physicians on how to react to the data.

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⁸⁵ Platform leader C interview with author, July 26, 2017.

⁸⁶ Parent B interview with author, September 13, 2017.

⁸⁷ Parent B interview with author, September 13, 2017.

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