Getting what is needed, when it's needed: Sharing information, knowledge, and know-how in a Collaborative Learning Health System

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Abstract

Background: Collaborative Learning Health Systems (CLHS) improve outcomes in part by facilitating collaboration among all stakeholders. One way to facilitate collaboration is by creating conditions for the production and sharing of medical and non-medical resources (information, knowledge, and knowhow [IKK]) so anybody can get "what is needed, when it's needed" (WINWIN) to act in ways that improve health and healthcare. Matching resources to needs can facilitate accurate diagnosis, appropriate prescribing, answered questions, provision of emotional and social support, and uptake of innovations.

Objectives: We describe efforts in ImproveCareNow, a CLHS improving outcomes in pediatric inflammatory bowel disease (IBD), to increase the number of patients and families creating and accessing IKK, and the challenges faced in that process.

Methods: We applied tactics such as outreach through trusted messengers, community organizing, and digital outreach such as sharing resources on our website, via social media, and email to increase the number of people producing, able to access, and accessing IKK. We applied an existing measurement system to track our progress and supplemented this with community feedback.

Results: In August of 2017 we identified and began measuring specific actions to track community growth. The number of patients and families producing IKK has increased by a factor of 2.7, using resources has increased by a factor of 4.1 and aware of resources as increased by a factor of 4.0. We identified challenges to measurement and scaling.

Conclusions: It is possible to intentionally increase the number of patients and caregivers engaged with a CLHS to produce and share resources to improve their health.

KEYWORDS
collaborative learning health systems, engagement, patients and families

1 | INTRODUCTION

Collaborative Learning Health Systems (CLHSs) are communities of patients, families, clinicians, and researchers who can all act as improvers by collaborating to improve healthcare and health outcomes.[1] CLHSs facilitate collaboration by supporting effective communication between patient advocates and providers, shared goal development, mutual responsibility, and accountability for the production and sharing of resources - information, knowledge, and knowhow (IKK) - so that people can find "what is needed, when it's needed" (WINWIN) to solve problems.[1-4] For example, in ImproveCareNow,[5-7] a CLHS for pediatric inflammatory bowel disease (IBD), highly engaged patient advocates with IBD, recognizing the lack of psychosocial education and the potential negative impact on their ability to adjust postoperatively to having an ostomy, created an "ostomy toolkit," reviewed by other community members like clinicians,[8] to share experiences of patients who had undergone an ostomy.[9] In the presence of resources such as this, shared with the community, pediatric patients and their families considering this treatment option are more likely to have the psychosocial education to facilitate positive postoperative adjustment. We hypothesize that the more high-quality resources there are, and the easier it is for people to find these, the more people will be able to match resources to needs (access WINWIN) and act in ways that improve health and health care.

Getting WINWIN is partially dependent on the "network effect," also called Metcalfe's Law.[10] In short, the network effect describes a situation in which the value of a service to a user depends on the number of other users. For example, a single telephone is useless, but its value increases proportionally to the square of the number of other telephones in the network. A challenge faced by all network organizations, including CLHSs, is achieving the critical mass necessary such that the value of the existing network to new users is sufficiently great to create a positive feedback loop. At early stages of networks, incentives to adopt the new technology are low. Why buy a telephone when no one else has one? Similarly, in ImproveCareNow, while members of the community could find value in existing and new resources, there was an opportunity to increase the number of resources and people who could access these. Overcoming the initial phase of the network effect, when there may be few resources available and few people able to access them, requires intentional effort. The challenge is amplified when potential users are spread over a wide geographic area, there is not a central congregating point, and when laws such as HIPAA make it difficult to identify who might benefit from involvement. Our challenge was to make connections and facilitate creation and sharing of IKK between thousands of community members so more patients and families could get WINWIN.

We conceptualize the making and sharing of IKK in terms of engagement and coproduction in a CLHS,[2] with people at different levels of engagement: aware, participating, contributing, and owning. Contributors and owners are people who improve and create IKK. People who have knowledge of the IKK are considered aware and those using the IKK are participating. People who are aware and participating are also future contributors and owners. For example, in the case of the ostomy toolkit, owners led the committee creating the toolkit, contributors provided content for the toolkit, participants read the toolkit, and

people who are aware received communication that the toolkit was available. Thus, achieving the network effect requires (a) increasing the number of contributors and owners, (b) increasing the number aware and participating, and (c) moving people up the "ladder of engagement" from participants to contributors and owners.

In this paper we describe our experience from August 2017 to December 2020 in the CLHS ImproveCareNow (ICN) in increasing the number of patients and caregivers taking part in creating and sharing resources.

2 | METHODS

2.1 | Ethics statement

The goal of our efforts was to improve and scale engagement activities within ICN. We did not undertake this work for the purpose of producing generalizable knowledge. These efforts are considered operational improvement. The purpose of this report is to share what we have learned from our efforts. Data referenced are governed by ICN's community data privacy policy, which can be found at https://www.improvecarenow.org/privacy_policy.

2.2 | Setting

ICN is a CLHS focused on pediatric IBD (Crohn's disease and ulcerative colitis), which uses Wagner's Chronic Care Model[11] and the Institute for Healthcare Improvement's Breakthrough Series[12] as models for improvement. As of December 2020, 109 care centers are members of ICN. Those care centers range from small private practices to centers associated with academic medical centers and include 970 pediatric gastroenterologists. There are approximately 30 400 patients who receive care at these centers. They and their caregivers are considered to be part of ICN. ICN has seen a steady increase in remission rates (82%) and sustained remission rates (57%) since 2010.[13] Data in the report includes patients or caregivers representing 91 care centers that had at least one patient or caregiver in our engagement database as of 13 January 2021 or information shared with us based on care center engagement activity. A number of activities can trigger a patient or caregiver to be added to the database including actions like opting into email communication, attending ICN events, or joining groups like the Patient Advisory Council (PAC) and Parent Working Group (PWG).

As above, patients and parents are involved at different levels of engagement.[2] Although many patients and parents are aware of ICN, it is possible to receive care at one of the ICN care centers (and therefore be "part of ICN") without being aware of ICN or the fact that your care center is part of the CLHS. There are many ways to participate, contribute, and be an "owner," both at the network level and at the local care centers. Participation (using IKK), for example, could include accessing www.improvecarenow.org and viewing or downloading tools and resources housed there, reading the LOOP blog that shares community member stories and project reports, attending in person and online learning sessions, or responding to surveys.

Contribution (improving IKK) could include, for example, writing an article to the LOOP blog, teaching at a learning session, or being part of a QI team. And ownership (creating new IKK) could include, for example, creating new toolkits, or leading a QI effort.

2.3 | Interventions

2.3.1 | Contributors and owners

Our strategy for increasing the production of useful resources involves growing the number of contributors and owners. We started with a small group of highly engaged volunteers, where trust could be developed, the needs of stakeholders could be identified, expectations set, and co-production could begin. There were a number of interventions implemented at the national and center level. Some examples at the national level include working with affinity groups such as the PAC and PWG, creation of IBD resources, curation of the LOOP blog, and various IBD events. Center level interventions included local events, such as IBD Education days, patient/family social hours, support group, and local affinity groups. These opportunities give more patients and families the opportunity to be aware of the organization and to be involved in developing and presenting content and creating more resources.

As resources began to be developed and value was demonstrated to a wider audience, we shifted some of our focus to sharing that value, persuading clinics to invest in expanding awareness, and growing the community.

2.3.2 | Awareness and participation

We made people aware of ICN and facilitated their access to available resources by asking patients and families to opt in to the CIRCLE eNewsletter, which links patients and caregivers to resources on the website, toolkits, local education days, and national in-person and virtual learning sessions. We used two main strategies. At the beginning of our efforts, we carried out social media campaigns to advertise the Circle eNewsletter. Traditional awareness campaigns usually involve some sort of direct outreach. We could not do this, given laws that protect the privacy of patients and families. Instead, we enlisted care center staff to make patients and caregivers aware and developed a set of tools and interventions to facilitate this process.

2.3.3 | Moving up the ladder of engagement

We used a community-organizing approach to move people from awareness to contribution and ownership. Community organizers identify people in the population of interest, develop relationships, and make connections to other community members so they can work together to identify their needs and take collective action.[14] Those collective actions produce value that can persuade others in the population of interest to invest in the movement. As the community grows, existing leaders empower new community members and encourage them to become leaders. When that happens, the community becomes self-sustaining. In our case, ICN staff focused on growing commitment via "one-on-ones" - individual meetings that establish a relationship and present an ask - and in increasing opportunities, such as co-producing training materials, for people to move up the ladder of engagement.

3 | MEASURES

We used an existing measurement architecture to track awareness, participation, contribution, and ownership.[15] This approach uses an ontology of engagement behaviors to assign "tags" based on an individual's behavior (eg, "receives:email_circle" or "attends: Learning Session"), which are then used to classify that individual to a level of engagement (Figure 1).

The measurement architecture relies on observing the behaviors. Behaviors denoting contribution and ownership are typically observable (eg, reviewing, teaching or leading) and many result in tangible products (eg, a LOOP blog post, a training module). Behaviors denoting awareness or
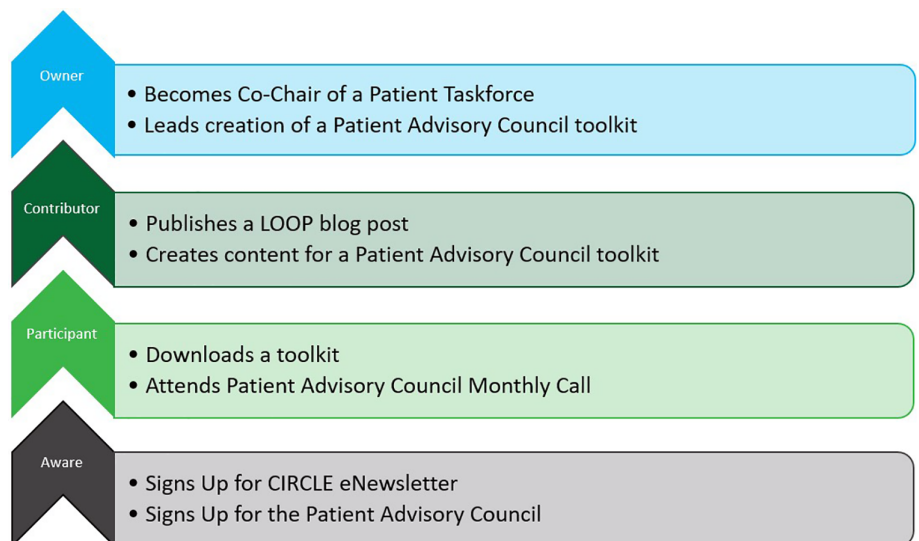

FIGURE 1 Engagement behaviors of a theoretical person in ICN and the level on the ladder of engagement (Adapted from Hartley et al[15])

Owner
• Becomes Co-Chair of a Patient Taskforce
• Leads creation of a Patient Advisory Council toolkit

Contributor
• Publishes a LOOP blog post
• Creates content for a Patient Advisory Council toolkit

Participant
• Downloads a toolkit
• Attends Patient Advisory Council Monthly Call

Aware
• Signs Up for CIRCLE eNewsletter
• Signs Up for the Patient Advisory Council

participation are harder to observe and many of the observable behaviors have an electronic component like opting into an email list or downloading a resource. We measured our community in three ways to assess growth and resource usage. Starting in August of 2017 we began to track observable actions by individual patients and parents in the online database Nationbuilder (https://nationbuilder.com/). We knew that we were not able to track every individual who access our resources through that method. We began tracking web analytics that measure the number of unique users accessing specific resources, reading blog posts, or interacting on social media to provide additional insight into the true number of people accessing ICN resources. We cannot identify the role of unique web users to determine if they are patients or parents. We do not attempt proxy methods to identify the role of unique web users. We treat all unique users as general members of the ICN community. In addition, to provide better insight into local engagement activity, we asked care centers, starting in June 2019, to report on the number of patient/parents they email each month, the number of patients and families that attend events, and what resources they are co-producing with patients and families.

4 | RESULTS

4.1 | Contribution and ownership

ICN staff have held 272 one-on-one meetings with 66 patients or caregivers since the study began. The number of contributors tracked in NationBuilder has increased from 71 at baseline to 190 (167% increase) and the number of owners has increased from 14 to 62 (342% increase) (Figure 2). ICN has also grown the number of resources available: There

have been 192 LOOP posts published since August 2017 and dozens of resources, including 11 toolkits and guides, made available on the ICN website. Forty patients or parents have served in leadership of our PAC or PWG. Forty-four care centers have reported 149 actions that involve local co-production.

4.2 | Awareness and participation

2547 patients or family members have become aware by opting into our network communications or by joining ICN's PAC or PWG (Figure 3). The number of unique visitors to the ICN website increased from 30 697 in August 2017 to 167 640 by the end of 2020 (Figure 4). That number includes unique visitors to ICN's "tools" page, which houses community produced resources (9865 since August 2017) and unique visitors to the LOOP blog, where community members share their stories (10 000 since August 2017). One-thousand-thirteen patients or family members participated, by downloading one of our IBD resources, such as the Disordered Eating Toolkit, developed by the PAC; read a LOOP blog post; or attended an event. This effort has also resulted in increased local activity, with clinics reporting 1351 patient or parents attending local events or webinars.

5 | DISCUSSION

While other studies have demonstrated the value of engaged patients and families,[16] described an organizational framework to facilitate collaboration between those actors,[7] and sustainable production of
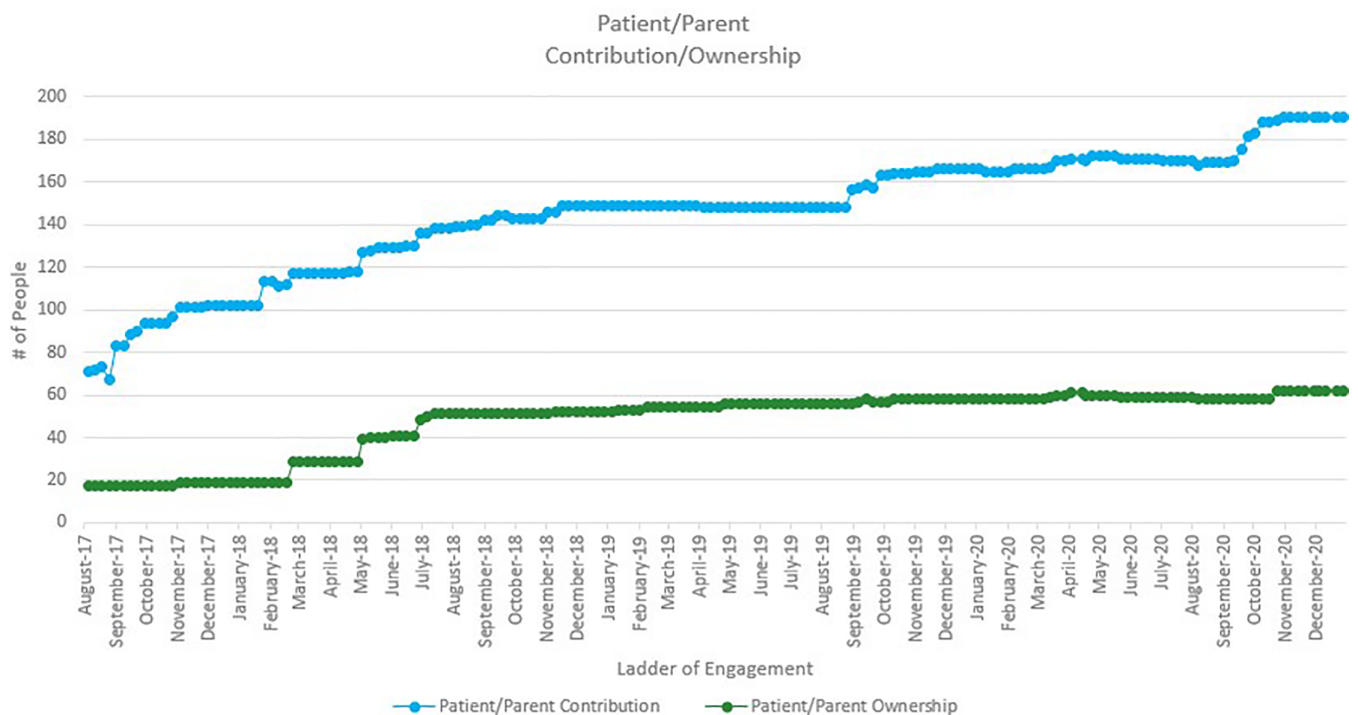

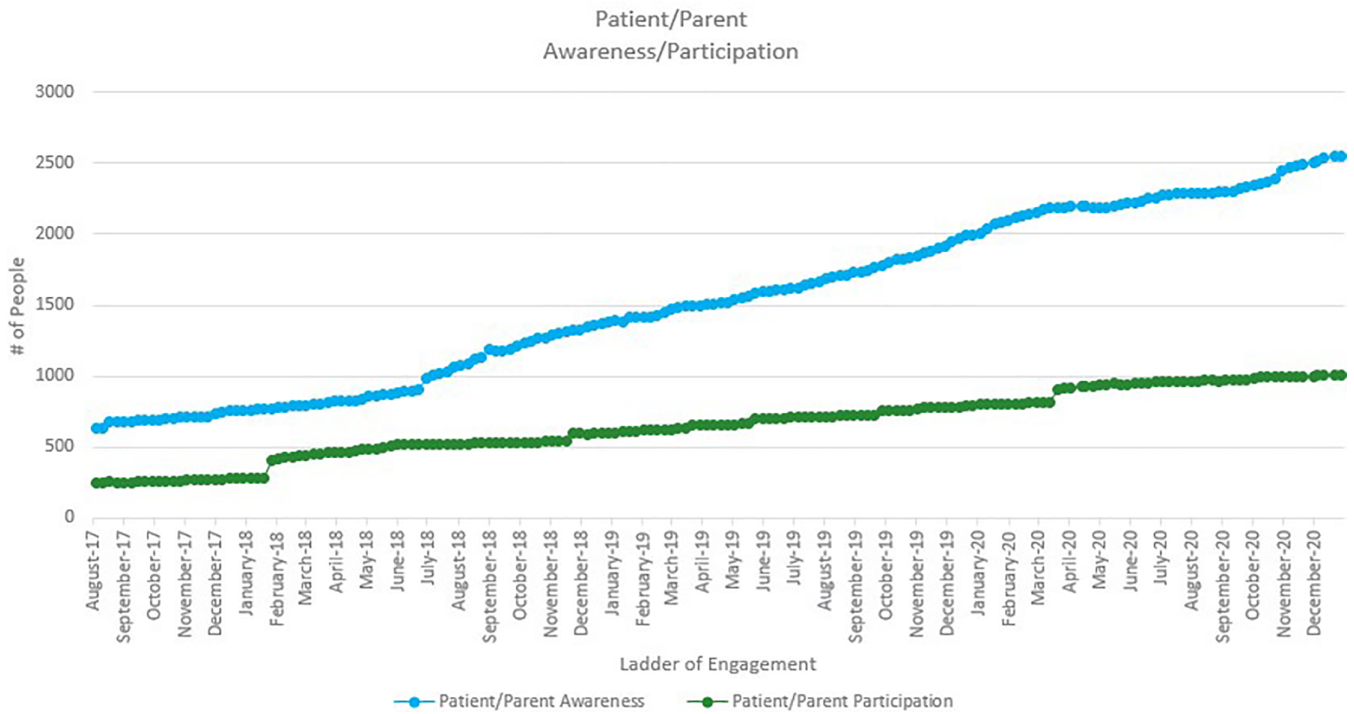**FIGURE 2** Contribution and ownership growth in ICN patient and parents

FIGURE 3 Awareness and Participation Growth in ICN patients and parent
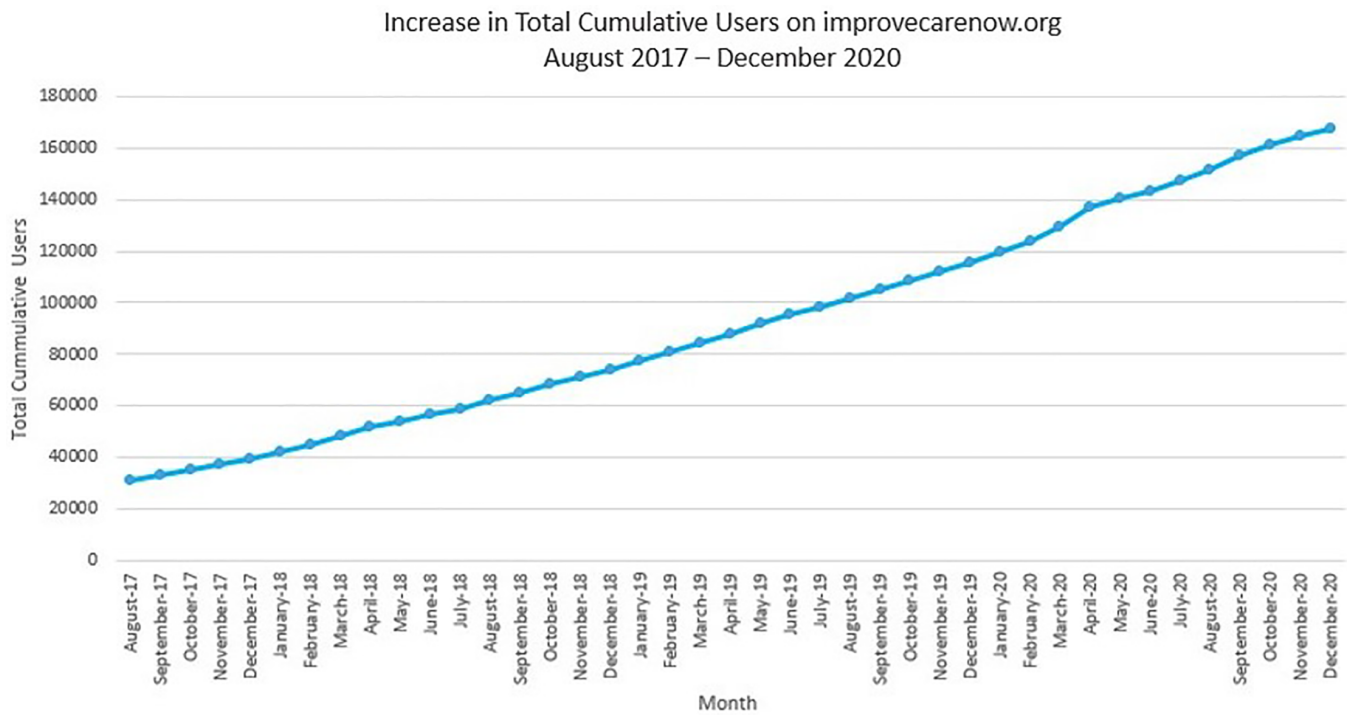

FIGURE 4 Increase in total users on ICN's website

patient-driven resources,[8] this work focuses on how to increase patient and family involvement in creation and usage of IKK. Community organizing tactics were adapted from studies of political organizations that rely on volunteers becoming progressive more engaged[17] and organizations focused on sustaining healthcare improvement.[18] Beginning in August 2017, we set out to increase the

number of patients and families aware of ICN, using the resources available, contributing to the improvement of, and creating new resources. We utilized social media campaigns and direct outreach via care centers to increase awareness, and community organizing (leadership development, resource co-production, and inviting more people to join), to increase participation, contribution, and ownership. This has resulted in a steady increase in the number of patients and families engaged in ICN.

We hypothesize that CLHSs such as ICN make it easier for people to access IKK to get WINWIN to act in ways that improve health. If people are aware of a CLHS, they are likely to utilize available resources (participation) and get WINWIN. Similarly, awareness and participation may lead to contribution and ownership: The more community members get WINWIN, the more value they find in the work, and the more likely they are to invest in growing the community. This picture suggests that intentionally increasing the number of people engaged is possible starting with a few highly motivated owners and contributors who invest in development and sharing of an initial pool of resources.

Our experience with 109 care centers demonstrates that a CLHS can integrate patients and caregivers at scale as consumers and producers of IKK. The approaches used can serve as a blueprint for how to build a system incorporating thousands of new actors, each who have the potential to contribute, thereby building on the ICN experience and growing new communities faster. Patients and families play a key role in creating a sustainable community.[8] As they become contributors and owners they play a larger role in supporting new members of the community through one-on-one outreach, training, and leadership development. When patients and families are connected to each other, they become a force multiplier for the spread, production, and improvement of IKK so that everyone gets more WINWIN.

This work has several limitations. First, it includes information from one pediatric CLHS. Research is needed to replicate this phenomenon and to generalize it beyond pediatrics. Second, of the community members whose roles we can identify, the number of caregivers exceeds the number of patients more than 2:1. If caring for a child provides more motivation to engage with resources than caring for an adult or oneself, that may limit generalizability. Third, we do not know the impact of the informal and formal connections that had already been made. ICN was already well established (founded in 2007), nearly 10 years before this study began. Fourth, we were unable to ascertain the extent to which we were able to capture all activity that is occurring at all 109 care centers. Some centers communicate their activity with ICN more reliably. Fifth, additional research is needed to tie engagement to specific health outcomes. While patients and families report that they find value in their engagement, we do not yet have evidence of a link between engagement and health outcomes, like remission. Sixth, although it would be useful to know whether efforts to increase engagement were more successful in the outreach/social media posts vs local centers engaging their own patients, we did not have the capability of determining whether sign-ups were as a result of social media vs local center efforts.

Nonetheless, this experience report demonstrates that it is possible to increase the number of patients and families creating and accessing IKK in a learning health system.

One of the wicked challenges with patient and family engagement is equity – often those with the capacity to participate as process owners have higher levels of income and education and access to resources and are less likely to come from communities of color where relational trust with the healthcare system is often low. We did not have data on these factors in the current study, but future work is planned to address health equity in ImproveCareNow generally, as well as in regard to engagement.

Though the methods described have successfully increased levels of engagement, the actual numbers of engaged and highly engaged patients remain low as an overall percentage of the >30 000 patients in the network. Efforts continue to enhance the number of aware and participating, though we expect that only a small percent of patients or families will become "lead users"[19] contributing and owning.

Demonstrating the value of patient and family co-production to ICN teams has been essential to the success of this project. Teams that found success started with a core team of contributors and owners of multiple stakeholder groups (clinicians and patient/families). This collaboration resulted in patients and parents presenting at conferences, joining local QI teams and initiatives, and then self-organizing into affinity groups such as the PAC and PWG. This, in turn, attracted more stakeholders, increasing the number of people aware and participating, and creating a virtuous cycle.

We have seen how intentionally engaging patients and parents through a systematic approach can lead to more people creating and improving IKK. Further work is under way to accelerate awareness and participation, as well as contribution and ownership, throughout ICN. We expect that with sufficient numbers of engaged stakeholders, we will begin to see more people getting WINWIN and will be in position to understand the mechanisms by which this happens and, thus, facilitate this process. We hope this work will be useful to practitioners and leaders in other CLHSs.

CONFLICT OF INTEREST

Michael Seid and Peter A. Margolis are inventors of intellectual property licensed by CCHMC to Hive Networks, Inc., a for-profit company that provides software and services to support collaborative learning health systems.

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