EXPERIENCE REPORT

Sustainable generation of patient-led resources in a learning health system

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Abstract

Background: Patient and Family Advisory Councils (PFACs) are an emerging mechanism to integrate patient and family voices into healthcare. One such PFAC is the Patient Advisory Council (PAC) of the ImproveCareNow (ICN) network, a learning health system dedicated to advancing the care of individuals with pediatric inflammatory bowel disease (IBD). Using quality improvement techniques and co-production, the PAC has made great strides in developing novel patient-led resources.

Methods: This paper, written by patients and providers from ICN, reviews current ICN data on PAC-generated resources, including creation processes and download statistics.

Results: Looking at different iterations of PAC infrastructure, this paper highlights specific leadership approaches used to increase patient involvement and improve resource creation. Emerging data suggests that the larger ICN learning health system has had limited interactions with these resources.

Conclusion: ICN provides a novel approach for meaningful integration of patient partners into learning health systems. This paper points to the incredible value of PFAC expertise in the resource creation process. Future work should seek to support PFAC development across other diseases and address the challenges of integrating patient-led resources into clinical care.

KEYWORDS
learning health system, patient advisory council, patient engagement, patient resources, QI

1 | INTRODUCTION

Co-production, an approach that harnesses the collaboration of service providers and users, is key in successful learning health systems (LHS).[1] An LHS incorporates science, quality improvement, and culture with the vision of leveraging all learning opportunities to improve care, its delivery, and the experience of receiving care.[2] Co-production of healthcare resources includes patients ("users") in planning, design, and delivery of services.[1] Establishing successful co-production systems can be difficult, particularly in healthcare, requiring collaboration between patients and physicians. Traditional doctor-patient relationships, where doctors provide expertise and patients passively accept care, must be redefined in co-production. In the spirit of co-production, this paper has been authored by patients and providers in an LHS.

Forming Patient Advisory Councils (PACs) or Patient and Family Advisory Councils (PFACs) is one way of encouraging collaboration/co-production within healthcare. PFACs are often considered a valuable resource for institutions, with growing recognition of how patients/families contribute unique voices and perspectives.[3] PFACs have taken various forms, such as formal meetings led by medical providers to elicit the patient/family experience[4] or patient/family feedback on care.[5] While PFACs help provide much-needed patient/family representation, physicians and researchers may struggle to integrate these perspectives in practice.[5-7] To patients/families—and likely the entire healthcare community—PFACs acknowledge that patient/family voices are essential. To the patient co-authors of this paper, this acknowledgement provides hope about the future of our healthcare.

Though PFACs are considered the gold standard for patient-centered care, patient/family involvement is often seen as a short-term endeavor. The literature on PFACs suggests that patient/family roles are often limited and in many cases serve to greenlight ideas which do not necessarily reflect their perspectives. Many lack administrative support, leaving limited opportunities for communication. Additionally, PFACs have historically been a means to elicit individual patient/family experiences, rather than address the needs of the larger disease community. When faced with these barriers, patients/families have limited ability to change healthcare experiences and outcomes. Continual investment in PFACs is necessary for healthcare organizations that wish to form collaborative partnerships and co-produced resources. In the following sections, we highlight an LHS that has successfully integrated PFACs into their organization and detail ways in which this particular PFAC's structure has evolved to support sustainable co-production.

2 | CASE STUDY: IMPROVECARENOW

ImproveCareNow (ICN) is an LHS that seeks to transform the health and care of children and adolescents with inflammatory bowel disease (IBD).[8,9] Patients, families, clinicians, and researchers work collaboratively to accelerate innovation and apply knowledge. ICN integrates quality improvement (QI) science into network practices by which systematic, iterative changes are made to processes for improvement.[10] ICN was first formed in 2007 and at present includes over 100 centers in the United States and abroad, including 38 states and Washington, DC, Belgium, Qatar, and the United Kingdom. In 2011, ICN founded their PAC, a patient council designed to provide input on research and improvement priorities. The PAC is central to ICN's structure, such that patient advocates across ICN sites collaborate on a single council at the national level. PAC members receive QI training through attendance at available QI training sessions at ICN conferences, archived QI videos from the network, and QI support facilitated by the PAC ICN staff liaison.

As of 2020, the PAC has co-produced nine resources, available within ICN and the larger healthcare community, through creative commons licenses. Further publication has been written on the Ostomy Toolkit and the Transfer Toolkit.[11,12] However, literature has not highlighted the novel processes and structure that allow for sustainable generation of patient-led, co-produced resources. This paper examines ways in which this PAC

has evolved its structure to increase patient involvement, identify community needs, and develop resources by (and for) patients.

To contextualize the work of ICN's PAC, we highlight examples of PFAC and individual patient/family engagement. The Cystic Fibrosis Learning Network (CFLN) is another LHS where patients/parents play essential roles as patient and family partners (PFPs). The CFLN has a partnership with the Cystic Fibrosis Foundation, which provides many resources of interest to patients/families (eg, managing CF during college). Consequently, the PFPs focused on integrating patients/parents into QI at local and network levels. The PFPs, alongside providers, received training in QI and prioritized co-production locally to reinforce centers' interest and involvement of patients/parents; utilizing patients/families locally shapes the culture of patient/family representation, fostering sustainability. Importantly, the nature of the disease and availability of resources within a disease community appear important in patient/family involvement. The CF community already had existing patient/parent resources from the CF Foundation, leading patients/families in the CFLN to invest energy in other activities to grow patient/family engagement and co-production.

Across healthcare, there are examples of patients and families who have individually engendered change. For some, they responded to their children's rare diagnoses to enact change.[13] Other individuals have tackled technology related to health, like Dana Lewis who lives with type I diabetes and hacked a glucose monitor to perform tasks[14]; device manufacturers noticed and integrated this capability into future devices. Sharon Terry, a mom to children with a rare genetic condition, felt understandable frustration when researchers would not share data and recognized the narrowness of research silos, the culture of competition instead of collaboration, and ultimately the overlapping needs of all patients with genetic conditions were poorly met.[15] Subsequently, Terry built the Genetic Alliance, an advocacy organization that serves as a megaphone for organizations to collaborate and optimize innovations. There are likely many patient/family-driven innovations, with limited media/academic publication to document these efforts. In all, this paper seeks to describe the novelty of ICN's PAC and its sustainable generation of patient-led resources.

3 | METHODS

Here we discuss the evolution of structural changes to the PAC, current PAC structure, engagement of PAC members, generation of toolkits by the PAC, and how PAC toolkits are reviewed within ICN at large. Understanding the iterative changes to the PAC's structure, engagement, and generation of toolkits is vital to the quality improvement soul of the LHS the PAC is embedded within and the PAC's ability to meaningfully adapt to the community's needs and goals.

3.1 | Structural changes to the PAC

In 2011, ICN's PAC was chaired by a single patient advocate and consisted of virtual communication. Members joined and communicated

through Facebook; new members were added to a Facebook group. Membership during this phase remained limited at approximately 10 patients. While PAC members had a shared sense of purpose, they lacked resources and procedure during this early stage.

In 2012, the PAC expanded their leadership team to two co-chairs. To increase involvement, members were encouraged to use the PAC's designated chat-board to discuss projects. During this time, the PAC released its first co-produced resource, the Ostomy Toolkit.[11] The co-chairs designed "task forces" (TFs) to group members with similar interests and organize duties. PAC members could choose to join the Advocacy, Communication, or Recruitment TFs. Despite these organizational improvements, PAC membership did not increase, with an average of 11 patients.

Observing limited growth, a series of standardization methods were implemented in 2015 by new co-chairs. Firstly, monthly all-PAC calls were implemented to provide regular updates on ongoing projects. PAC co-chairs and TF leaders also met separately monthly. Secondly, PAC leadership developed "welcome resources" to provide new members with relevant information. The Recruitment TF created a standardized welcome email for new members and connected members with a "buddy." Thirdly, an "Innovation Committee" was formed to standardize toolkit production. The Innovation committee reviewed toolkit proposals, discussed project feasibility, and oversaw development. Lastly, the PAC advocated for increased funding, to allow more patients to attend ICN conferences. By doubling the number of patient representatives at conferences, the patients, parents, and providers who had co-produced resources had opportunities to meet. Additionally, this provided visibility and accessibility of the PAC to the larger ICN network.

3.2 | Current PAC structure

The structure of the PAC has continued to evolve through generations of patient advocates. In 2018, PAC leadership opted to minimize role redundancy and maximize engagement opportunities. Leadership disbanded the Innovation Committee, as it was unneeded due to limited disputes over toolkit topics and its inclusion added unnecessary delays to projects. Members of the Advocacy TF subsumed these activities.

While recruitment had consistently increased in previous years, the number of actively engaged PAC members continued to stay stagnant. Previously, new PAC members were able to choose one of three TFs (Recruitment, Communications, or Advocacy), but few joined Communications or Recruitment. Advocacy, however, was overwhelmed with members, though ongoing engagement remained challenging.

To remedy these concerns, the Communication TF (responsible for PAC social media) decreased to two members in 2018. The same structure was applied to the Recruitment TF in 2019, as their responsibilities could be managed by two members. Instead of choosing a TF, new members were automatically placed in the Advocacy TF. New members completed a survey that included questions such

as preferred communication style (eg, text), the number of hours each week an individual would be able to contribute to a project, and task preferences (eg, editing). PAC integration appeared faster when joining a working team of patients (eg, an Advocacy project), rather than a TF with limited collaboration opportunities (eg, social media posts). Currently, Advocacy TF leads send out monthly surveys, allowing members to express interest in joining projects. This system allows members, even those involved in the Communications and Recruitment TFs, to join ongoing projects to promote representation of PAC voices. As noted previously, the PAC has seen a growth in its representation within ICN, where a PAC co-chair currently sits on ICN's Board of Directors.

Toolkit generation continues to be the main focus of PAC activity. A following section provides an in-depth look at the PAC's toolkit generation process.

3.3 | Engagement

The PAC has long experimented with best practices for engaging members to foster a collaborative and diverse group of patient advocates. In 2018, the Advocacy TF implemented new methods of engagement, such as "onboarding" calls to meet new members and better understand their interests. Adding this personalized form of connection boosted engagement, with increased retention, due to the electronic nature of most PAC communications.

While onboarding new members via call was effective, it was not time efficient nor sustainable. Advocacy TF leads began distributing monthly surveys to gage interest in ongoing projects and learn more about members' skills and availability. These surveys allowed Advocacy TF leads to more successfully match members with projects that fit interests and schedules, additionally increasing involvement.

Lastly, the PAC has had success incorporating social "PAC Chats" and Facebook chat groups. PAC Chats occur a few times monthly and are opportunities to virtually spend time together. The PAC's Facebook chat groups include medical conversations, project brainstorming, official PAC updates, and informal conversation. New members can be immediately welcomed by experienced members. These connection opportunities fulfill a crucial ingredient to engagement: fostering and building community.

3.4 | Toolkit generation

The main goal across PAC toolkits is to improve the quality of care and daily life for pediatric patients living with IBD, while addressing patient/family needs that are unmet in pediatric IBD care due to limited accessible resources[11]; consequently patient-driven toolkits likely serve a valuable function for patients/families and providers alike. Patients may share their experiences and perspectives for different reasons—to validate their own stories, provide guidance for others, educate providers, or feel active in their healthcare journey. PAC toolkits are generated using QI methodology.[11,12] Generally, there are

five main stages of PAC toolkit development: brainstorming, establishing a team, collecting content, assembling, and reviewing. These stages are detailed in Table 1, utilizing clarifying examples from prior PAC projects.

In early PAC years, toolkit generation was fairly individualized. A member would recognize a need and create a resource—often developing, formatting, and authoring the toolkit him/herself. PAC leadership was involved in a limited capacity to offer relevant assistance or information. While the generation process varied based on the creator, they would often (a) choose a topic, (b) generate surveys to obtain qualitative information from other PAC members, (c) consolidate responses, (d) add relevant commentary, (e) submit the toolkit for review within ICN (process described later in this paper), and (f) formally publish the toolkit on the ICN website.

In recent years, the Advocacy TF has begun overseeing toolkit development to standardize processes and encourage contributions from other PAC members. Toolkit development begins with a toolkit proposal submitted by a PAC member, later reviewed by the Advocacy TF. A toolkit team is recruited, members meet to delegate tasks, brainstorm ideas, and create the toolkit. This current structure allows the Advocacy TF to oversee and support toolkit production, while the creator manages the project, allowing more PAC members to lead and co-produce resources. As the PAC has grown increasingly interested in co-producing resources, a wider range of stakeholders from ICN are involved, such as dietitians, psychosocial professionals, physicians, and parents. Most recently, the PAC began experimenting with a variety of toolkit formats (eg, interactive websites) to increase impact and accessibility.

3.5 | Reviewing resources within ICN

Because several of the ICN patient-created toolkits include clinically relevant content, it was critical for the LHS to develop a collaborative and efficient system for key stakeholders to review and approve resources. The process for toolkit review begins before the project is created; when PAC members propose a project and a staff liaison is informed and shares information with stakeholders in the ICN network. They may recommend clinicians within the network, who can be consulted throughout the project.

Once the project is completed, a draft is shared with the ICN staff liaison. The draft is initially reviewed by a specified group within ICN (the "Engagement Group"), who may raise questions or concerns about content/formatting. The toolkit is then shared with ICN's clinician networks (physicians, nurses, nutritionists, or social workers), who review the toolkit's clinical aspects. The draft is then posted to ICN's online platforms, to elicit feedback from the broader LHS community.

One challenge that inevitably arises from this process is timeliness of the review, particularly in cases in which the toolkit includes a significant amount of clinical content. While all toolkits contain a standard disclaimer stating that the toolkit content does not constitute medical advice, the review process is crucial to avoid any misinformation. It is important to ensure that both LHS staff and patient leaders agree upon the review and approval process to ensure ongoing collaboration.

4 | RESULTS

4.1 | Review of current toolkits

A summary of current toolkits is provided in Table 2. CIRCLE is ICN's newsletter, which individuals 13 years of age and older can sign up for biweekly emails and voluntarily identify their stakeholder group (eg, patient). This table displays data from CIRCLE and non-CIRCLE sources regarding resource accessibility within the ICN community. Data from CIRCLE sources represents the number of downloads from individuals clicking the hyperlinks in CIRCLE emails. Click rate data, as the term suggests, represents the percentage of email recipients who clicked on a given hyperlink. Click rate data presented for patients and parents represents the percentage of patients and parents, self-identified when signing up for CIRCLE, who clicked on a given hyperlink. Non-CIRCLE sources represent the number of downloads where an individual accessed the resource outside of CIRCLE, such as engaging in a web search that directs the individual to an ICN resource. The average number of CIRCLE downloads was 135.17 with a range of 86 to 160 downloads, and the average number of non-CIRCLE downloads was 256 with a range of 109 to 412 downloads. The average overall CIRCLE click rate was 2.78%, while the average CIRCLE click rate for patients and parents was 42.59%. Notably, since its creation in 2017, the average rate of CIRCLE emails being opened is 20.62% and the average click rate for any link in the CIRCLE email is 2.13%.

5 | DISCUSSION

While the PAC's primary role is resource creation, patients are also involved in projects in the larger ICN network. Alongside provider partners, PAC members serve in both short- and long-term initiatives. Patients may contribute to QI initiatives, serve as representatives on ICN committees, and present at national conferences. Patient representation on high-level committees, such as the Board of Directors, helps to address certain challenges that arise (eg, patients need to understand clinical language and QI terms). While, historically, PFAC involvement in organizational decision making is limited, ICN's comprehensive incorporation of patient/family partners recognizes the immense value of PFAC expertise. A visual of the PAC's structure and toolkit generation process, which summarizes the processes described above, is included (Table 3).

ICN's PAC represents a novel type of PFAC: one that allows infrastructure to evolve as community engagement needs arise. As outlined previously, the PAC directed its own structural evolution by identifying community needs (ie, need for toolkits) and making intentional change (eg, the toolkit generation process outlined in Table 1), enabling sustainable production of these resources. This ability to

TABLE 1   Overview of PAC toolkit generation

Section	Description	Example
Brainstorming	PAC toolkit ideas reflect topics that patients and families deem important. Toolkit topics are often developed through group brainstorming, such as during monthly PAC calls, through group chat, or PAC surveys. Past topics have included ostomy surgery, body image, nutrition, transitioning to college, academic and workplace accommodations, and travel. Decisions regarding which topic(s) will be developed into a toolkit are made by consensus among PAC leadership. PAC leadership takes into consideration available tools within and outside ICN to broaden the scope of topics addressed. Typically, the PAC is working to build one to two resources at any point in time. By consistently identifying important topics and generating novel resources, the PAC works to address the patient experience and perspective in real time	As one example, the initial idea for the IBD and Disordered Eating Toolkit was generated at an ICN conference. At the conference, PAC members discussed the ways IBD has impacted their thoughts and behaviors regarding food, weight, and body shape. This led to the proposal of an IBD and Disordered Eating Toolkit, as many PAC members felt this would be a meaningful addition to available resources
Establishing a team	After a topic is established, the Advocacy task force leads assess interest within the PAC via survey. Any member of the PAC may participate, either in a leadership role or as a contributor. Toolkit leadership is generally one or two PAC members who oversee the design, data collection, synthesis of the resource content, and review process. If a member with no previous leadership experience is selected for this role, a member with prior experience joins as co-lead and mentor. Once identified, the toolkit leadership invites contributors to join a toolkit "team," with a specific role. Each team is in charge of a different aspect of the toolkit: developing surveys, conducting interviews, or doing graphic design, among other things. The toolkit team connects through virtual meetings and online communication, facilitated by the toolkit lead or co-leads. The frequency of toolkit team meetings, as well as the development schedule, varies by project	For example, the Lifestyle and IBD Toolkit (a current project) schedules weekly team meetings to monitor progress. The Disordered Eating and IBD Toolkit team met once a month over the course of 4 months, and then transitioned to email communication on a weekly basis
Collecting content	Once a team is established, the content for the toolkit is collected. When creating resources, the PAC aims to include all relevant perspectives and experiences, such as that of the patient and medical professionals, which the PAC's ICN liaison helps to facilitate. The toolkit team develops surveys to distribute to the PAC to gather patient experience. These surveys often include a mix of quantitative and qualitative data. The toolkits also contain insights from professionals involved in the ICN community. In addition to content gathered through surveys, some toolkits include data from other credible sources, such as the Crohn's and Colitis Foundation website, or academic literature	For example, the IBD Nutrition Toolkit team collaborated with nutritionists and registered dietitians within ICN to get a provider perspective. Similarly, the Disordered Eating and IBD Toolkit partnered with GI Psychology fellow and former PAC member, Dr. Jennie David
Assembling content	After sufficient content is collected, the assembly process begins. The team of PAC members arranges patient stories, professional insights, and research into a format that is easily accessible to the reader. While the PAC generally follows a toolkit template created by ICN, content is organized logically to best convey information. Historically, some toolkits have been organized in a slide (presentation) format, and others in document format	Newer toolkits, such as the Lifestyle and IBD Toolkit (currently in development), have begun to branch out in design, utilizing an interactive website format

TABLE 2 Overview of PAC toolkits

Toolkit	Toolkit summary	Toolkit members	Year published	CIRCLE downloads	CIRCLE overall click rate	CIRCLE patient/ parent click rate	Non-CIRCLE overall downloads
The Transfer Toolkit	This toolkit describes notable skills and considerations for adolescents approaching transition and transfer to adult care	Patients, psychologists, dietitians, social workers, physicians, nurses	2018	118	3.71%	31.36%	-
Travel Toolkit	This toolkit describes experiences and considerations for individuals with IBD to make travel comfortable and easier	Patients	2018	-	-	-	172
Crohn's and Colitis Storybook	This toolkit describes various perspectives from individuals with IBD on diverse topics, such as self-care and relationships	Patients	2017	-	-	-	109
Ostomy Toolkit	This toolkit describes the experiences of individuals who underwent temporary or permanent ostomy surgery	Patients, parents	2015	-	-	-	151
Nutrition and IBD Toolkit	This toolkit describes perspectives of individuals with IBD on various nutritional therapies	Patients, dietitians	2019	152	4.18%	51.97%	333
Disordered Eating and IBD Toolkit	This toolkit describes experiences of individuals with IBD on disordered eating behaviors	Patients, psychology provider	2020	160	3.6%	41.88%	-
College and IBD Toolkit	This toolkit describes resources of interest to adolescents with IBD transitioning to college	Patients	2019	155	4.6%	45.16%	412
Body Image and IBD Toolkit	This toolkit describes experiences of individuals with IBD on body image concerns	Patients	2018	86	2.72%	-	-
Accommodations for IBD Toolkit	This toolkit describes various educational and occupational accommodations for individuals living with IBD and perspectives from individuals with IBD	Patients, social workers	2018	140	3.81%	-	359

flexibly adapt a PFAC structure to meet identified community needs is essential for genuine integration of a PFAC into an LHS. While the PAC has previously published on individual patient-driven co-produced resources,[11,12] this paper aims to summarize the larger sustainable mechanism that turns patient experiences and needs into resources, by and for patients. Other patient/parent-driven innovations, like the emergence of the Genetic Alliance, are powerful, but may engender concern because innovations that depend on a single individual may not be sustainable.

One of the most notable strengths of ICN is the opportunity for collaboration between patients, families, physicians, and care providers. These mechanisms allow strong partnerships to form, crucial for the co-production of resources. While this LHS has successful

mechanisms in place to develop resources, integrating these co-produced resources into medical care has proved challenging.

5.1 | Challenges integrating resources into care

Traditional healthcare places the responsibility for patient education on providers with specialized expertise. The PAC represents complementary expertise of lived experience. The benefits of patient-physician collaboration have been previously published,[2,9,11,12,16] but efforts to integrate patient expertise are stymied by barriers, such as the challenge of having a patient expert available. Within ICN, co-production of toolkits is one solution that addresses gaps in care.[11,12]

TABLE 3   Visual of PAC structure and toolkit generation flow
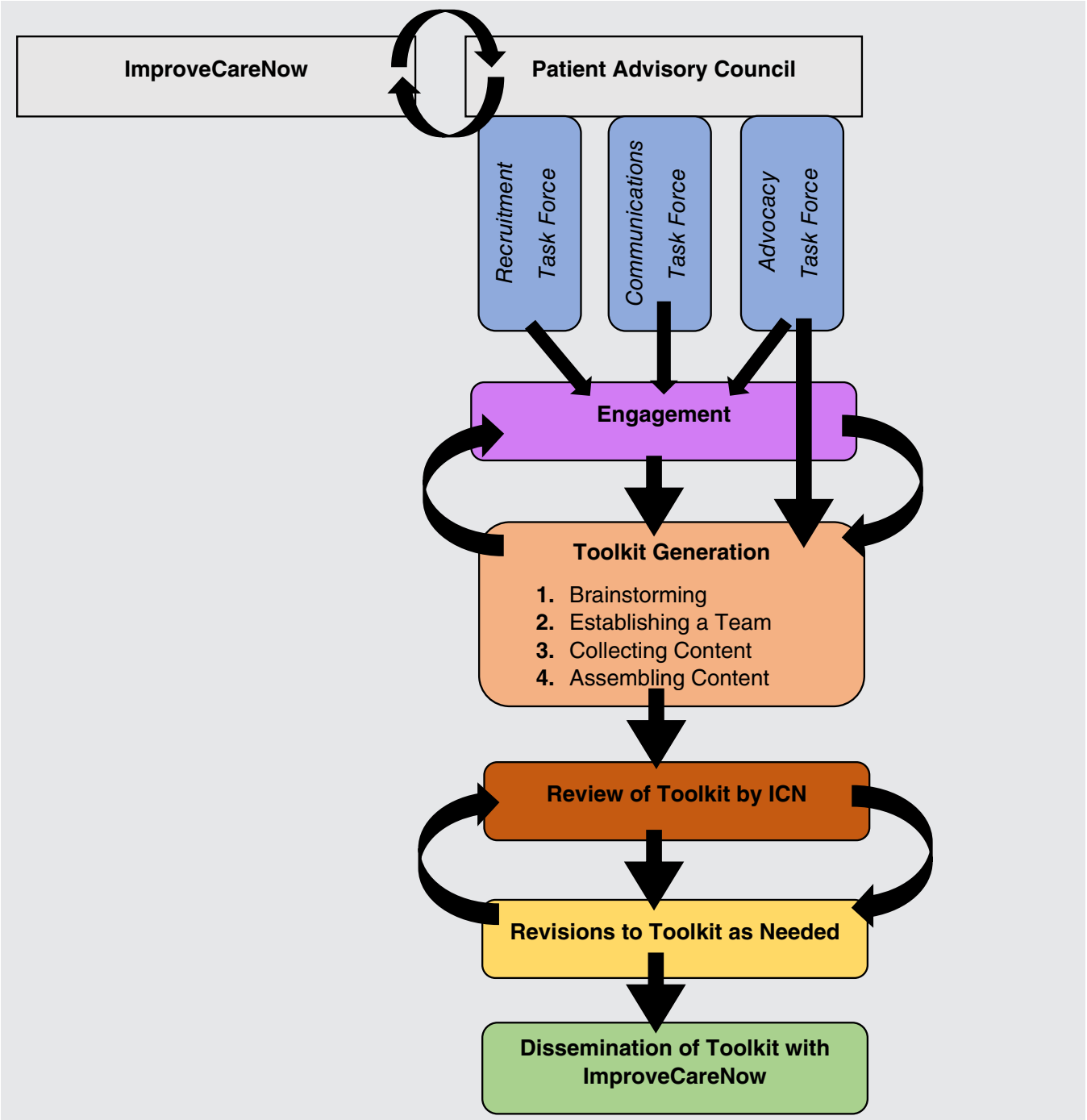
However, these resources are wasted if they cannot be easily integrated into care. When surveyed regarding one PAC resource, providers reported several reasons for limited use, including competing clinical demands.[12]

Despite challenges, resources derived from patient expertise have benefits to children and adolescents with IBD. To balance maintaining clinic efficiency while incorporating new clinical resources, one ICN clinic used a "scale-up" approach, starting with one PAC toolkit and then expanding to other clinical settings and other toolkits. Another ICN site has included a list of PAC toolkits in the After Visit Summary

for all IBD outpatient visits. Ongoing work to use QI methodology to pilot, track, and evaluate mechanisms to integrate resources into care is needed. Additional work is also needed in evaluation of these co-produced resources, such as understanding how patients/families come to receive toolkits (eg, by medical providers), perceived utility and satisfaction of toolkits by patients/families, and possible changes in patient/family levels of anxiety or stress upon engagement with toolkits.

In addition to challenges integrating co-produced resources into clinical care, emerging data (Table 1) demonstrate difficulties in

making resources accessible within the larger ICN community. Overall click rates suggest a very low figure of less than 5%. Interestingly, the click rate appears to increase among patients/parents, ranging from approximately 31% to 52%. Compared to average click rates for all links in CIRCLE emails, which was just over 2%, the click rate on toolkits is notably higher. This exploratory data suggests higher engagement among patients/parents compared with the larger ICN community. While this is encouraging that patients/parents are interested in these resources, it also presents concerns regarding the limited engagement of other ICN stakeholders, such as physicians.

As previous qualitative work from ICN posits that patients/families prefer receiving information from their clinicians,[17] this poses a challenge for disseminating resources. For example, a patient/family who learns about a patient-led resource from a CIRCLE newsletter may be less receptive than if their gastroenterologist (GI) provider had shared this resource. While all PAC toolkits were vetted by medical providers, there may be limited awareness about the toolkits among ICN providers and, consequently, limited awareness among their patients/families. Future QI efforts should focus on engaging ICN providers to improve the reach of these valuable resources.

Notably, while this paper discusses the novel structure of the PAC within an LHS and its ability to sustainably generate patient-driven resources, questions remain related to the broader issue of sustainable use and implementation of these resources within the LHS. These questions go beyond the current scope of this paper, while also producing an essential need for further research and understanding of if and how these resources can be sustainably integrated into care delivery.

5.2 | Limitations

While we wish to share these strategies to support other PFACs, it is important to address some potential limitations of our findings. First, different diseases (or disease communities) may have varied needs. It is possible that our experiences working within an LHS focused on pediatric IBD are distinct from another disease community, and our processes may require adaptations. As such, our work should be considered as a case study for co-producing resources.

While ICN's PAC has grown and diversified significantly in the past few years, our group cannot possibly represent the voices of all patient experiences. Since these patient-driven resources were largely informed by the experiences of PAC members, patients outside of the PAC (or in other disease communities) may express different opinions or methods for patient involvement. It is our hope that with continued efforts to diversify the PAC, our resources will continue to highlight even more diverse patient voices.

Lastly, we wish to draw attention to the lack of current academic literature capturing present patient/parent-driven innovations. For example, a paper summarizing the ostomy toolkit was published in 2018, which represents a 3-year time delay from when the resource was finalized in 2015. A delay in publishing may mean that literature searches are not up to date on innovations in the fields of PFACs and co-production in healthcare. These delays also likely represent the

barriers and challenges of publishing academic work, and patient advocates may not have expertise in this domain. Lastly, at present there is limited systematic evaluation of these ICN PAC resources following distribution, and their impact (eg, on psychosocial coping) is unknown. While these limitations are critical in understanding the context of this paper, the innovations led by ICN's PAC are emblematic of a larger and notable shift in the sustainable development of patient resources. These limitations also serve as a call to action to improve the translation of patient/family innovations into the academic literature to allow for timely knowledge and understanding of such innovations.

5.3 | Implications

The sustainable generation of patient-driven resources described here can serve as a case report for co-produced patient-driven innovations. Virtually all toolkits developed by ICN's PAC were driven directly by patient experience and needs. The evolving structure, scope, and support from ICN has provided a sustainable mechanism to translate the patient community's needs into tangible and sharable resources. This serves as a reminder that patients have the capacity, passion, and ability to lead and co-produce meaningful resources. When provided with opportunities for collaboration, patients and families can bring incredible advancements to the healthcare field.

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