

Conceptualizing and redefining successful patient engagement in patient advisory councils in learning health networks

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Abstract

Introduction: Patient engagement has historically referenced engagement in one's healthcare, with more recent definitions expanding patient engagement to encompass patient advocacy work in Learning Health Networks (LHNs). Efforts to conceptualize and define what patient engagement means—and what *successful* patient engagement means—are, however, lacking and a barrier to meaningful and sustainable patient engagement via patient advisory councils (PACs) across LHNs.

Methods: Several co-authors (Madeleine Huwe, Becky Woolf, Jennie David) are former ImproveCareNow (ICN) PAC members, and we integrate a narrative review of the extant literature and a case study of our lived experiences as former ICN PAC members. We present nuanced themes of successful patient engagement from our lived experiences on ICN's PAC, with illustrative quotes from other PAC members, and then propose themes and metrics to consider in patient engagement across LHNs.

Results: Successful patient engagement in our experiences with ICN's PAC reaches beyond the “levels of engagement” previously described in the literature. We posit that our successful patient/PAC engagement experiences with ICN represent key mechanisms that could be applied across LHNs, including (1) personal growth for PAC members, (2) PAC internal engagement/community, (3) PAC engagement and presence within the LHN, (4) local institutional engagement for those who participate in the LHN, and (5) tangible resources/products from PAC members.

Conclusion: Patient engagement in LHNs, like ICN, holds significant power to meaningfully shape and co-produce healthcare systems, and engagement is undervalued and conceptualized dichotomously (eg, engaged or not engaged). Reconceptualizing successful patient/PAC engagement is critical in ongoing efforts to study, support, and understand mechanisms of sustainable and successful patient engagement. Having a modern, multidimensional definition for successful patient engagement in LHNs can support efforts to increase underrepresented voices in PACs, measure and track

Madeleine Huwe and Becky Woolf are Co-first authors.

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successful multidimensional patient engagement, and study how successful patient engagement may impact outcomes for patients and LHNs.

KEYWORDS

learning health networks, patient advisory council, patient engagement

1 | INTRODUCTION

Patient engagement often references involvement within one's healthcare¹; however, recent discussions about patient engagement have grown to encompass patient and family member involvement at local hospitals in the form of advisory groups, like Patient Family Advisory Councils (PFACs).² In the last fifteen years, Learning Health Systems (LHSs) have brought forth a new way to conceptualize and define patient engagement.^{3,4} A subset of LHSs are Collaborative Learning Health Systems or Learning Health Networks (LHNs) like ImproveCareNow (ICN),⁵ which center stakeholder collaboration on the organization's mission of healthcare improvement.⁶ Within LHNs, patient engagement occurs on an organizational level for healthcare improvement work, with applications varying widely and are explored further in this paper. These LHN patient groups, who refer to themselves under many different names, such as ICN's Patient Advisory Council (PAC), are engaged with defining the network's priorities, practices, and projects at a level far above participation in individual healthcare.

While there is extensive literature on traditional patient engagement,⁷ it lacks a nuanced discussion of PACs in LHNs and the community and cultural drivers that explain *why* patients become—and remain—engaged in LHNs. In this paper, we seek to expand upon “levels of engagement”³ by integrating a review of the extant literature with the lived experiences of ICN PAC members. We propose a shift in the conceptualization of what successful patient engagement means in LHNs. Additionally, we propose particular metrics to more fully encompass how multidimensional successful patient engagement can be, consider how access and infrastructure to patient engagement opportunities impact patients' abilities to be meaningfully engaged when and how they wish to be,⁸ and offer recommendations to other LHNs on how to use proposed metrics of patient engagement in their systems and foster sustainable and successful patient engagement.

As former PAC members in ICN ourselves (MH, BW, JD) who have experienced the rich, transformative power of successful patient engagement in an LHN, we feel compelled to share mechanisms we have observed across our collective ICN PAC terms and how this may benefit other LHNs in their patient engagement work. Based on our multigenerational PAC experiences, we believe that successful patient engagement in a PAC in an LHN is an active process that requires key elements to create and sustain success, as well as data that can be captured and tracked. We also believe that PACs in LHNs can be invaluable to improving healthcare, promoting patient-centered care, and shaping a patient-centered and humanistic culture of healthcare and medical research. By considering and implementing the proposed

ideas and structures in this paper, we anticipate that leaders of other LHNs will be more empowered to facilitate sustainable, meaningful, diverse patient engagement that is valuable to the participating patients, stakeholders, and healthcare systems. We hope our writing can serve as a groundwork for future PACs across LHNs and future research.

1.1 | What do we know about patient engagement in LHNs in the extant literature?

While the medical and health sciences field often considers patient engagement regarding proactiveness with the patient's own healthcare, this term has been redefined by the more recent shift to include patients as advisory partners in healthcare improvement work. These patient advisory groups, often called “PACs or PFACs,” are common at clinics and hospitals, and more recently, are also key components of LHNs. PACs in healthcare settings are groups of patient advocates who partner with healthcare staff to identify and address opportunities for improvement in healthcare systems.⁹ PFACs perform similar functions but include multidisciplinary perspectives of patients, caregivers, and family members. A primary goal of PACs/PFACs is patient and caregiver engagement that represents the diversity, values, and perspectives of their patient population, as well as incorporating these perspectives and priorities into care. PACs/PFACs can be effective structures and mechanisms to promote patient-centered care and improve the function of healthcare from the perspective of patients/families. They may promote discussion of systemic issues and encourage healthcare quality improvement (QI). PACs/PFACs also create space to collaborate with healthcare providers, researchers, and institutions, and allow others to learn from patients' and families' lived experiences.¹⁰

Despite the many benefits of patient and family engagement, PACs/PFACs are not always used optimally. Previous research on PACs/PFACs outside of LHNs has spoken to their positive perception, positive and empowering experiences for patients/families, providers, and the system/institution, resources or policies that are shaped by these councils, and the role of an inclusive culture to sustain such councils.^{2,11-16}; as Niehaus¹³ succinctly wrote, PAC/PFACs have unique perspectives and abilities to identify the “blind spots” and can harness the power of personal narratives in effecting change in the systems for other patients and families. The lived experiences of patients and families allow them to *see* and *feel* things in their care that providers may not be sensitive to and therefore may remain overlooked and unaddressed. The level of involvement of these

PACs/PFACs, however, varies and can result in less significant claims of patient approval; in some medical settings, PACs/PFACs are used to greenlight initiatives that do not represent patient perspectives or address the needs truly felt by diverse patient populations.¹⁷

As an emerging area of interest and discussion, PACs/PFACs within or outside LHNs also allow positive interpersonal growth and empowerment for the patients and families that comprise PACs/PFACs.^{12,13,17} The majority of existing research done on PACs/PFACs indicates that implementation of PACs/PFACs has positive effects on healthcare initiatives and promotes more patient-centered care.¹⁸ The research that has been conducted suggests that PACs positively impact patient safety.¹⁶ There is, however, limited literature on how PACs/PFACs impact the functioning of LHNs and even less on the impact they can have on PAC/PFAC members themselves.

Another likely barrier to the successful implementation of PAC/PFACs in LHNs is that no current standard guidelines exist to shape the structure, maintenance, or integration of PAC/PFACs into LHNs. Establishing standardized guidelines for PAC/PFACs would create a blueprint around how to initiate, implement, and maintain PAC/PFACs, which can promote the growth of and engagement in PAC/PFACs.¹⁹ A detailed discussion of the sustainable structure of ICN's PAC as one example is discussed in David et al.¹⁷ The extant literature on PAC/PFACs, taken together, is limited, with even less work examining PAC/PFACs within LHNs. Current research overall highlights the importance and potential of PAC/PFACs, with limited guidance about how to fully conceptualize, define, and measure successful patient engagement.

1.2 | What we learned via a case example of ImproveCareNow's Patient Advisory Council

In exploring the conceptualization, definition, and measurement of successful patient engagement within LHNs, the authors propose a careful examination of ICN's PAC. Founded in 2011, the PAC has experienced tremendous changes to its infrastructure, role within ICN, community, and resource production over the past decade.¹⁷ As former and current members of the PAC, we have personally felt, observed, and participated in this evolution and revolution of how patient engagement in an LHN is significantly more than a dichotomous variable of engaged or not engaged. Based on our experiences in ICN's PAC, the authors of this paper hypothesize that PAC demographics often include members with increased disease severity since these patients have had more encounters with the healthcare system and may therefore feel more motivated for advocacy. We have also noted that patients with prior leadership experience (eg, student council) translate this into PAC engagement. Therefore, PAC members' illness experiences and personal involvements can be harnessed and used to improve the PAC.

Instead of "engaged" or "not engaged," we began to ask ourselves what it truly means for patient engagement of a PAC/PFAC to be successful, and how do we define that success in an LHN? While there is a growing interest in the standardized implementation of

PAC/PFACs in LHNs, it is essential to first conceptualize what successful patient engagement for PAC/PFACs in an LHN looks and feels like beyond the ladder/levels of engagement.^{3,20} The definition of success is likely diverse and relative to the PAC/PFAC and LHN it is operating within (eg, disease type), as the LHN's missions and needs vary widely. Additionally, the authors understand from our collective lived experiences in ICN's PAC that there is a strong positive correlation between the investment of LHN leaders in PAC/PFACs and the engagement of patients within that LHN. More research is needed on the successful patient engagement of PAC/PFACs in LHNs: Does the success of a PAC/PFAC predict integration of PAC/PFACs in LHNs? Does successful patient engagement help to sustain and/or grow PAC/PFACs within LHNs? How does successful patient engagement increase support from administration/executive leaders within LHNs? Does the use of engaged PAC/PFAC perspectives in QI initiatives within LHNs help improve healthcare outcomes?

The PAC's 10-year tenure identifies several key areas that we feel are vital in conceptualizing, defining, and measuring success for patient engagement in ICN's PAC that we describe in detail as (1) personal growth for PAC members, (2) PAC internal engagement/community, (3) PAC engagement and presence within the LHN, (4) local institutional engagement for those who participate in the LHN, and (5) tangible resources/products. Current and former ICN PAC members were approached to solicit qualitative data about their lived experiences on ICN's PAC and what successful engagement meant to them, and responses received are integrated into this case example.

1.2.1 | Personal growth for ImproveCareNow Patient Advisory Council members

The mechanisms of community-building translate into substantial benefits for ICN PAC members, which has been echoed in the larger PAC/PFAC literature.^{11,12,15} Many ICN PAC members report emotional growth from their engagement. ICN's PAC fosters a supportive community of young people who can provide and receive support related to shared experiences living with chronic illnesses. PAC members do this in many ways (eg, monthly all-PAC calls, social chats). PAC members informally teach each other how to advocate for themselves, prepare for the transition to adult care, how to balance work/school/life/illness, and even health literacy related to IBD (eg, insurance). ICN PAC members provide opportunities for vulnerability and validation of others' experiences, which experientially has supposed PAC members to improve their relationship with their own illnesses. ICN PAC members are continuously learning while also teaching each other, creating mutual benefits in every encounter.

One PAC member reflects on her emotional growth: "Before joining the PAC, my IBD carried a negative connotation, and I was not able to use my experiences to benefit others. The PAC allowed me an outlet by which to use my negative experiences with IBD for good. Being able to advocate for other patients gives meaning to my IBD diagnosis... Additionally, the PAC

has provided me a community of IBD patients I did not have access to prior. I have made long lasting friendships because of my engagement with the PAC, and feel less alone in my IBD diagnosis.”

A repeated sentiment within ICN's PAC is how advocacy work gave meaning to their IBD experiences. A previous PAC member reflects on this:

It [PAC] helped me shift my perspective on my own experience with IBD into a narrative not just about me, but a narrative about how I fit into a community. As I continue to grow with IBD, that sense of belonging and responsibility has been a blessing.

In addition to emotional growth, many PAC members expressed enthusiasm about how the PAC and ICN influenced their professional development.

A PAC member explains: “My time with the PAC has impacted me immensely. Without the PAC, I don't believe I would have truly found my interest in medicine or been able to attend medical school. The PAC not only gave me a community, but also provided me with an outlet to advocate surrounding IBD... My time with the PAC also significantly impacted my professional development. Being able to present at ICN conferences... and have a term as co-chair of the PAC facilitated my maturation and professional life post-college. Being in the PAC gave me significant networking opportunities that allowed me to engage in research and quality improvement projects. I feel more able to advocate for myself in professional settings due to my experiences in the PAC.”

There is a common theme in ICN's PAC that many members have preexisting goals of pursuing a career in healthcare, and many still form and/or affirm these career desires via ICN PAC engagement and engagement in the LHN. The PAC and ICN create many opportunities for PAC members to explore their professional interests, receive professional development and mentorship, and network opportunities surrounding research, quality improvement science, leadership, and engagement. Within ICN, there are many opportunities for PAC members to specialize in their interests. PAC members have been involved with numerous ICN initiatives: ICN's Board of Directors, Research Committee, Diversity, Equity, and Inclusion (DEI) Committee, Learning Lab leadership teams, Executive Search Committee, Transition Committee, Social Work and Psychology Group, and more. As ICN's community culture is centered around the importance of patient engagement and the inherent value of listening to and learning from those with lived experiences, many ICN members have strong interests in helping PAC members develop their professional careers and offer mentorship, guidance, connections, and even opportunities or work experience.

1.2.2 | ImproveCareNow's Patient Advisory Council internal engagement/community

ICN PAC's internal engagement and sense of community are at the heart of successful patient engagement, as described in a recent paper about ICN's PAC and outlining how the unique mechanism of the PAC has allowed for the sustainable generation of patient-driven resources.¹⁷ Generations of ICN's PACs have focused on how to grow and sustain meaningful community connections to catalyze other engagement efforts.¹⁷ The authors emphasize that a sense of community and internal engagement is a key variable that is likely both a precursor and facilitator of successful patient engagement for ICN's PAC.

ICN's PAC also provides professional networking and mentorship within itself.¹⁷ More experienced ICN PAC members, often in college, help provide opportunities within the group to newer or less experienced PAC members who may be in middle or high school. Those in leadership positions are encouraged to “train themselves out of their role” by delegating tasks to more junior PAC members, creating opportunities for them and mentoring their emotional and professional growth; this also allows for built-in succession planning to foster the longevity of ICN's PAC.¹⁷ There is a strong, persistent culture of mentorship across all levels of ICN's PAC that mirrors such a culture within ICN: general PAC members are mentored by task force PAC leads, who are assisted and mentored by the PAC Co-Chairs, who, in turn, receive coaching from ICN members. A common route to the PAC Co-Chair position is a general PAC member being coached into leading a toolkit, then being encouraged to become a task force PAC lead that is mentored by the current PAC Co-Chairs, and then filling the role themselves. ICN's PAC leadership intentionally creates and delegates opportunities to other PAC members, oftentimes doing so based on understanding these PAC members' career interests. For example, a PAC Co-Chair observed many PAC members were interested in mental health and then collaborated with ICN's Social Work and Psychology group to advocate for and create opportunities for PAC members to get more experience working on the topic with a network of psychosocial providers. Not only is this mentorship useful for accelerating ICN PAC members' professional growth, but it is also an extremely successful mechanism to ensure leadership sustainability within ICN's PAC.

Another previous ICN PAC member, now a pediatric physician, shared her career journey with the PAC:

My time in the PAC was a stepping stone into my career as a physician. Being in the PAC taught me advocacy and QI skills that I still use on a daily to monthly basis. More importantly though, I really found myself in the PAC. I discovered my identity as a leader and that being able to facilitate connections among others is something I really enjoy.

In summary, the success of patient engagement within ICN's PAC would be significantly understated and under-valued to conceptualize success dichotomously and cannot be measured without considering the emotional, personal, and professional growth that we call *community success*.

1.2.3 | ImproveCareNow Patient Advisory Council engagement and presence within the LHN

The engagement and presence of ICN's PAC within ICN is another important benchmark of successful patient engagement in an LHN from our lived experiences. ICN provides a platform and space for patient voices to reverberate across the LHN. ICN's PAC and ICN have accomplished this in several ways, including a trend of increasing patient attendance at ICN conferences for the PAC to address the network within the formal conference agenda, which empirically appear to be highly sought-after presentations across all conference attendees (eg, providers, patients). Additionally, the PAC has been invited to sit on vital boards and committees across the network, including the Board of Directors, the DEI Committee, ICN Research Committee, ICN Executive Search Committee, Learning Lab Leadership, ICN Pathway to Mastery Steering Committee, and the ICN Community Council. As discussed in the recent publication on ICN's PAC, ICN has also committed various resources to the PAC to support and foster this integration into the network.¹⁷ Measuring this type of successful patient engagement in ICN may include capturing the presence of PAC perspectives at ICN events, integration in ICN boards and committees, and ICN resource allocation to the PAC.

As Vinson⁸ proposes, the culture of an LHN is integral to its success and functions as the infrastructure to its operations and achievements. Likewise, the culture of community acts as the infrastructure with which ICN's PAC operates both inside the PAC and in the larger ICN community. ICN members join together to improve IBD pediatric care under a core set of values that are reinforced through ICN community conferences, impactful "Ignite" talks by community members at these ICN conferences, and even interpersonal interactions between ICN conferences. There is a deliberate, consistent effort to level the playing field between providers and stakeholders, such as patients in ICN, with a shared understanding that all stakeholders bring uniquely valuable expertise to the discussion of improving healthcare. This intentional erosion of the provider-patient hierarchy creates an enthusiastic learning perspective that is at the heart of a successful LHN like ICN, the appreciation for the diversity of thought and experiences, and the intentional implementation of these varied perspectives on improvement initiatives.

In summary, the culture of ICN is an essential ingredient to successful patient engagement for the PAC. As Vinson⁸ states, there is the socialization of norms and beliefs within ICN, which creates a strong community culture of support and shared values and provides the basis that allows the PAC such successful patient engagement.

1.2.4 | Local institution engagement for those who participate in ImproveCareNow

Several ICN PAC members are actively engaged in their respective local institutions, which reflects another component and metric of localized patient engagement success with ICN. This type of patient engagement is important to capture and measure as it likely integrates

the patient perspective into a given local institutional community (eg, the patient perspective of receiving care at a rural hospital) and increases awareness and energy around patient engagement that may positively contribute to more patient engagement on local and ICN network-levels. Additionally, patients who are engaged in improvement efforts at their local ICN care center may have more detailed insights about how care might improve and may represent an under-represented cohort of the local pediatric IBD community to share with the broader ICN network. Engaging patients with ICN center-level initiatives also strengthens the care center's integration with the network and helps disseminate the benefits of ICN patient-involved initiatives.

1.2.5 | Tangible resources/products from ImproveCareNow's Patient Advisory Council

Additionally, another important component of successful patient engagement in an LHN that ICN's PAC exemplifies are tangible resources/products that harness patient perspectives, patient expertise, quality improvement knowledge, and support from ICN to generate patient-driven toolkits housed on ICN's website, ICN blog posts, the novel PAC podcast, and academic publications co-authored by PAC and ICN members. Further, as described by David et al.,¹⁷ these products also become accessible resources and salient examples of successful patient engagement for stakeholders across ICN. Measurement of this success includes capturing the number of existing resources for patients and families within ICN, the number of resources in development for patients and families within ICN, resources for providers/other stakeholders in ICN, medium/format of these resources (eg, written, audio, video), usage and accessibility of these resources by ICN, and the number of academic presentations and publications. These authors feel strongly that successful patient engagement work, co-authored and led by ICN PAC members, is integral to the academic recognition that patient engagement in ICN matters and to document the inherent power patient advocates contribute to improving ICN. Future work should seek to explore and understand how these resources may impact outcomes (eg, quality of life, health outcomes).

2 | WHAT IS NEXT: A CALL TO ACTION IN CONCEPTUALIZING AND MEASURING PATIENT ENGAGEMENT IN LHNS

There are many ways to think about and measure the successful patient engagement of a PAC/PFAC within LHNS, which makes the question of *what* to define, *how* to define it, and *who* gets to define successful patient engagement essential questions to answer. What successful patient engagement looks like is likely highly related to and reflective of the LHN itself: the target patient population; the composition of patients in the PAC/PFAC; and the mission, goals, values, and social norms of the LHN, which makes metrics of successful

patient engagement of PAC/PFACs nuanced and individualized. Successful patient engagement metrics will need to be modifiable and tailored based on the factors specific to different LHNs, but this work aims to provide a blueprint for conceptualizing and measuring successful patient engagement informed by the experiences, lessons learned, and achievements of ICN's PAC to jumpstart the broader conversation across LHNs. We also present a summary from the extant literature, our lived experiences as ICN PAC members, and the lived experiences of our ICN PAC colleagues in Table 1.

There are currently no clearly defined metrics of successful patient engagement for PACs/PFACs in LHNs. Researchers, therefore, have a limited ability to effectively and rigorously study PAC/PFACs and their impact(s) within and on LHNs, and beyond. An understanding of nuanced successful patient engagement is proposed to be an important discussion in the ongoing study of PAC/PFACs within LHNs, such as for sustainable implementation of PAC/PFACs across LHNs. Additionally, there is a limited understanding of how to promote diverse patient representation and sustainable implementation of successful, representative patient engagement within PAC/PFACs

in LHNs. The authors believe that PACs/PFACs are critical tools that hold immense potential for improving care in LHNs, and we have felt the gravity of this work in our own time with ICN's PAC for ourselves (Madeleine Huwe, Becky Woolf, Jennie David).

How we define successful patient engagement has implications for how LHNs structure, create, perceive, and measure patient engagement. The implications can also be expanded to health equity approaches, although this is a topic that needs more research to better understand. PACs/PFACs may also fail to meet the needs of some patient populations as it is likely that they are not all fully representative of the diversity of the patient population and/or geographical region. Existing case studies suggest that this occurs because the patients and caregivers in PACs/PFACs are often composed of patients with greater access to healthcare, resources, and support; this may partially be attributed to assumptions, likely fueled by systemic issues like implicit bias, that may deter providers from asking patients/families to consider joining PAC/PFACs.^{21,22} These barriers may create and contribute to vicious cycles where minority/underprivileged patient and family perspectives are excluded from PACs/PFACs and

TABLE 1 Overview of successful patient engagement components for patient advisory councils.

Overview of successful patient engagement of PACs	
Extant Literature	<ul style="list-style-type: none"> • Promote patient-centered care¹⁸ • Facilitate discussion of issues that matter to patients and families¹⁰ • Allow for multistakeholder collaborations¹⁰ • Identify “blind spots” in the delivery of health services¹³ • Facilitate positive interpersonal growth for patients^{12,13,17} • Positively impact patient safety¹⁶ • Can be a positive/empowering experience for patients/families if culture is inclusive^{2,11-16} • Influenced by the culture of the LHS⁸ • Often measured dichotomously (ie, engaged or not engaged); more nuanced measures include the “ladder of engagement”^{3,20} • Patients with perceived traits such as treatment adherence, proactivity, timeliness, or compliance may disproportionately be recruited for PACs by providers²¹
Our [MH, BW, & JD] Experiences in ICN's PAC	<ul style="list-style-type: none"> • Pervasive LHN-wide culture of “leveling the playing field” • The majority of the ICN's PAC population appear to be patients with more severe disease and preexisting leadership skills • More detailed insights on ICN PAC structure and how it has impacted the PAC's culture and processes are discussed in David et al.¹⁷ • Metrics of “engaged” or “not engaged” are inadequate to describe patient engagement in ICN's PAC • There appears to be a strong positive association between the investment of ICN leaders in PAC and patient engagement in ICN • Patients with preexisting leadership skills (eg, student council) can translate these to ICN's PAC • Culture of delegation, mentorship, and “training out of the role” are used in ICN's PAC to promote longevity and sustainability • Local patient engagement at ICN centers offers insights on how to improve care for specific patient populations
ICN PAC Interviews	<p>Experience in ICN's PAC facilitated/promoted:</p> <ul style="list-style-type: none"> • Emotional growth from community support • Improved positive conceptualization of their own IBD diagnoses • Appreciation of PAC and ICN community • Decreased feelings of isolation related to living with IBD • Professional development • Leadership identity • Engagement in research • QI knowledge and skills • Improved skills in advocacy

QI initiatives. Perhaps the most concerning, minority/underprivileged patients may also be excluded from diversity and equity initiatives. Further research is needed to identify if and where gaps in engaging underrepresented populations exist and how these barriers can be addressed.

It can, however, be suspected that engaging populations that are underserved, underrepresented populations in medicine within LHNs' PACs may work towards increasing diversified perspectives and the future workforce of medical professionals in generations ahead. If underrepresented populations were involved in an LHN's PAC as a patient advocate, they have access to the informal education, mentorship, professional skills, and experience that are beneficial for medical/graduate school and their applications. More investigation should be done on the relationship between this community success and career development, but it is reasonable to suggest that a beneficial relationship likely exists and would extend to underserved populations involved in PACs.

Taken from our experiences on ICN's PAC and being steeped in the emerging academic literature, we propose LHNs use the following metrics to conceptualize successful patient engagement: (1) personal growth for PAC/PFAC members, (2) PAC/PFAC internal engagement/community, (3) PAC/PFAC engagement and presence within the LHN, (4) local institutional engagement for those who participate in the LHN, and (5) tangible resources/products generated by the PAC/PFAC. As described in detail above in the case example of ICN's PAC, these metrics hold promise to capture the multidimensional and dynamic factors of successful patient engagement in a LHN. These proposed metrics for other LHNs to use in assessing and supporting patient engagement are also likely sensitive to strengths of an LHN's PAC/PFAC (eg, the PAC/PFAC internal community) and areas of growth (eg, local institutional engagement) for personalized support to optimize and sustain meaningful patient engagement. Continued discussions of PAC/PFAC members' experiences and research on patient engagement in an LHN will help to grow this work and build custom tools to capture the incredible efforts of patients engaged in these LHNs and support the long-term viability of such engagement.

The long-held belief that patient engagement was dichotomous—engaged or not engaged—is an antiquated construct that undervalues the immense potential of patient engagement in an LHN and is vital to redefine, as evidenced by the case example of ICN's PAC. With the extant literature and our own experiences as current and former ICN PAC members (Madeleine Huwe, Becky Woolf, Jennie David), these authors strongly believe there are diverse and meaningful ways to define and measure the successful patient engagement of PAC/PFACs in LHNs. Characterizing the nuance of successful patient engagement in ICN—from a sense of community to representation across ICN to tangible resources—provides a richer understanding of the potentially tremendous scope of successful patient engagement in all LHNs. Further, reconceptualizing and measuring successful and dynamic patient engagement in LHNs across the metrics outlined above may provide opportunities for engagement with QI science in real-time to understand potential outcomes associated with

successful patient engagement at the LHN level, individual site level, and patient level. Future work should seek to apply our lived patient engagement experiences in ICN's PAC to other LHNs, understand and support diverse voices in patient engagement in LHNs, continue to examine and update metrics proposed in this paper to help measure, study, and sustain meaningful and successful patient engagement. And so, the question is no longer whether to engage or not engage patients but how will you meaningfully, sustainably, and successfully engage patients in your LHN?

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