Cultural Health Capital and Patient Partner Recruitment into Healthcare Improvement Work

Abstract (149 words)
A rising emphasis on patient involvement in clinical research and healthcare improvement has led to the steady incorporation of patient and family partners into this work. However, interactional factors shaping recruitment processes are not well understood. We conducted interviews with twenty-six patients, family members, engagement staff and healthcare providers at three Collaborative Learning Health Systems (CLHSs). We found that expressions of and judgments about partners' cultural health capital (CHC) shape decisions to recruit. We show that healthcare providers, engagement staff, and partners attend to different aspects of CHC when accounting for why they extended or received a recruitment pitch. We also find that participating in healthcare improvement work leads to a further increase in CHC for partners, and we examine the implications of CHC-based recruitment practices. Our findings extend current conceptualizations of cultural health capital beyond the clinical encounter to reveal factors shaping patient recruitment into healthcare improvement work.

Cultural Health Capital and Patient Partner Recruitment into Healthcare Improvement Work

Cultural health capital (Shim 2010) is a concept that grants insight into how interactions between patients and healthcare providers unfold, adapting Bourdieu's (Bourdieu 2011) idea of cultural capital to describe the interpersonal dynamics of a healthcare encounter. Cultural health capital (CHC) is "the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviors, and interactional styles, cultivated by patients and healthcare providers alike, that, when deployed, may result in more optimal health care relationships" (Shim 2010:1). As a concept, cultural health capital is crucial for understanding how social inequalities are reproduced through the mundane interactions of patients and medical providers. In healthcare encounters, patients may display CHC through having advanced biomedical knowledge and the ability to convey information that providers regard as relevant. Additional forms of CHC can include whether patients' attitude towards managing their health, self-discipline, self-efficacy, and even resilience to adversity match healthcare providers' expectations for patient behavior (Shim 2010). In an individual clinical encounter, providers play an important role in judging, making relevant, and cultivating patients' cultural health capital, and so cultural health capital can be understood as a "collective achievement" in clinical interactions (Shim 2010:4).

While past research has theorized how CHC affects the individual clinical encounter, this is not the only healthcare setting where patients and providers come into contact. In recent decades, a rising emphasis on patient participation has led to the steady incorporation of patients and caregivers into clinical research. Stakeholder involvement in research has become so prominent in modern science that Community-Based Participatory Research (CBPR) comprises a prominent body of scholarship and applied work that has been used to develop the area of patient-centered outcomes research (PCOR) (Kwon et al. 2018). Along with this newer focus on patient engagement in research, increasing attention has been directed on how to identify and recruit patients that are hard to reach for better diversity and representation and to address health disparities (Epstein 2007). Recently, Shim and colleagues (2023) found that upstream decisions in community-based participatory research (CBPR) recruitment practices affect the quality of community engagement. In line with previous research on cultural health capital, Shim and colleagues (2023) found that researchers considered several criteria when recruiting community members to partner with, including personal characteristics, perceived capacity to participate, and even prior experience in the field. Research in this area helps identify common social processes that infuse hierarchically-organized medical spaces. Displays and judgments of cultural health capital as an interactional phenomenon appear to bridge the clinical encounter and research recruitment encounter. In this paper, we dive into the action, interviewing members of various stakeholder groups about how they decide to extend, solicit, and accept invitations to participate in patient engagement work. Our findings complement the work of Shim and colleagues (2023), who have mapped the landscape of different rationales for community engagement in scientific work (precision medicine research) and their effects. Our case, however, differs. We take up the case of patient and family member engagement in healthcare improvement collaboratives that are explicitly structured around multi-stakeholder engagement and infused with an "all teach, all learn" mentality: the Collaborative Learning Health System (CLHS).

The CLHS (Seid, Hartley, and Margolis 2021) is a type of continuously learning healthcare system that uses data aggregation, informatics, implementation science, and quality

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improvement techniques to systematically improve health outcomes and organizational processes for a group of people affected by a health condition or health disparity (Friedman 2022; Institute of Medicine (US) Roundtable on Evidence-Based Medicine 2007). The CLHS model is explicitly designed to create multi-stakeholder collaboratives where patients and family members can work together with researchers and clinicians on healthcare improvement initiatives. These types of multi-stakeholder collaboratives embrace patient participation in ways that were previously taking place outside of the formal bounds of healthcare, such as in online patient support groups (Barker 2008), and embrace empowered patients in ways that providers may find inconvenient or challenging in the context of the clinical encounter (author cite). While criteria for recruitment have been shown to affect the quality of community engagement work (Shim et al. 2023), this insight has yet to be applied to healthcare improvement work.

Healthcare improvement organizations are often uniquely centered around missions and a shared purpose that produce strong, long-term relationships between community members (author cite), increasing the importance of interpersonal dynamics, relationships, and social inequalities. Clinical research often faces obstacles to community engagement such as the finite duration of the study, the driving focus of the scientific work, the professional benefits of completing research, and financial constraints (Shim et al. 2023). Healthcare improvement organizations offer an alternative case for examining patient recruitment practices; they are less constrained by the standards and practices of research projects and the pressures to recruit a heterogeneous participant population (Epstein 2007). Additionally, our research on CLHSs has allowed us to investigate the recruitment experiences of patients and family members as a social process that complements our understanding the factors shaping whether a provider or engagement staff member extends an invitation to participate in the work of the CLHS. Patients' perspectives are necessary for this research to reveal biases in the recruitment process, assumptions about the patients' eligibility and readiness, and inclusion and exclusion criteria. As centering the patient and stakeholder perspective is a key value of the CLHS, and CLHSs have long-term patient-provider relationships, they provide a valuable case to research the topic of inequalities in patient recruitment: who becomes recruited to participate in healthcare improvement work and why. We focus on how judgments and displays of cultural capital shape who is invited to participate in the central work of a CLHS, which includes quality improvement, patient engagement, and other central network roles and committees.

By taking up the case of patient participation in healthcare improvement work, and drawing on the insights of cultural health capital, we develop a theory of how judgments and displays of cultural health capital contribute to reproducing inequalities in patient recruitment into healthcare improvement work. Our findings allow us to extend the notion of cultural health capital as an interactional achievement in the provider-patient relationship to flesh out the role of cultural health capital in shaping invitations to participate in Collaborative Learning Health Systems. Based on the qualitative analysis of interviews with patients, caregivers, engagement staff and healthcare providers at three Collaborative Learning Health Systems (CLHS), we find that providers' estimations of patients' and caregivers' cultural health capital shape whether patients are invited to participate in CLHS work. We also show that participating in CLHS activities offers patients and caregivers opportunities to develop significant amounts of cultural health capital and opportunities to produce transmissible cultural health capital for less centrally involved patients and caregivers. In what follows, we describe our study. In the analysis we highlight the backstage judgments and discussions that prefigure whether a given patient or caregiver will be invited to join the Learning Health Network's activities, focusing on how

providers and support staff implicitly and explicitly assess patients' CHC. In the discussion, we offer both theoretical and policy implications of our work on equitable patient engagement in healthcare improvement initiatives.

Background

With the rising authority of patient stakeholders' embodied knowledge, regulations requiring patient involvement in research, and even funding contingent on stakeholder participation, the role of patients in medical research has grown considerably over several decades (Kirwan et al., 2017; Misa-Hebert et al., 2019; Epstein 2008). The different levels of intensity and forms of patient engagement work have led to a proliferation of terms such as that are used to describe intentional inclusion of patients and family members in healthcare improvement work and research, such as patient engagement, involvement, and participation. Specifically, patient engagement has been used to refer to involvement with research, devising clinical practice guidelines, sharing lived experiences in online communities, recommending policy changes, and more (Barker 2008; Concannon et al. 2019; Domecq et al 2014; Hansen, Draborg, and Kristensen 2011; Mikdashi 2022). Through this work, patients' lived experience has gained a cultural authority as embodied knowledge, building on the work of health-related activists to establish that knowledge as credibility for their involvement in medical decision-making (Brown and Zavestoski 2004). However, questions about which patient partners become involved in clinical research efforts remain present for both sociologists and practitioners.

Previous sociological research has identified processes of inclusion in healthcare improvement work, where selection for healthcare improvement work is a function of a patient partner's race, class, and perceived ability to participate in biomedical research. Often, patients are recruited to these efforts because of the unique perspective their lived experience affords or because of their trusted connections to communities of interest (Epstein 1995). However, these initiatives have had mixed results. While incorporating individuals with lived experience has no doubt enriched these initiatives, questions remain about whether the right stakeholders have been recruited into these initiatives, especially when the stakeholders represent only a portion of the broader affected population. Steven Epstein (Epstein 1996) highlighted this in the case of AIDS activists recruited to participate in clinical trials, finding that the activists who were able to participate tended to be white, financially well-resourced, and well enough to participate.

Questions of inclusion, however, also raise questions of exclusion. Indeed, research on exclusion in healthcare research has shown that populations that are deeply affected by health conditions—and that might have valuable input for addressing these conditions—can be left out of healthcare improvement work. For example, Kevin Moseby's (Moseby 2017) work has highlighted who was excluded from AIDS activism, finding that even highly impacted groups, such as African Americans, were not included in patient advocacy groups during the first decade of AIDS activism and the search for its cause. While this body of research has identified race and class as factors that facilitate inclusionary and exclusionary processes in clinical research at the group level, additional research can identify interactional processes within groups that lead to individual members' inclusion and exclusion in clinical research and other similar settings that consider patient involvement in research and other forms of healthcare work to be of at least prima facie importance (cf. Shim et al. 2023, "pantomime community engagement"). Understanding *how* recruitment takes place on an interactional level is also a first step toward improving recruitment, and we seek to motivate both theoretical and practical work in equitable patient and family member engagement in healthcare improvement work.

To identify factors shaping the extension of recruitment invitations, we identified a setting where a high emphasis is placed on patient inclusion in healthcare improvement work: the Collaborative Learning Health System. Over the past 15 years, a new structure for healthcare improvement has been emerging called the Learning Health System (LHS) (Institute of Medicine (US) Roundtable on Evidence-Based Medicine 2007). The LHS utilizes technology, data, and quality improvement science to 'learn' rapidly—producing insights into population level health that can be rapidly implemented as changes to organizational care processes and individual treatment (Friedman 2022; Platt, Raj, and Wienroth 2020). A subset of these organizations is the Collaborative Learning Health System (CLHS), which centers multi-stakeholder engagement as the foundation for healthcare innovation and improvement (Seid et al. 2021). In CLHSs, stakeholders collaborate on healthcare improvement activities, revolving around a shared mission that is often focused on a geographic location or health condition (Ong et al. Forthcoming; Seid et al. 2021). One such stakeholder group is patients and family members, whose roles vary by CLHS but can include advisory roles for projects and committees, participation in research design and production, advising network priorities, influencing organizational policies, creating patient resources, and holding leadership roles (David et al. 2021).

The CLHS model is explicitly designed to create multi-stakeholder collaboratives where patients and family members can work together with researchers and clinicians on healthcare improvement initiatives. Sociologists have begun to study the features of CLHS as a social group, theorizing the CLHS as an example of what Erik Olin Wright (2020) has called a 'real utopia' (author cite). Real utopias are created when a group of people harnesses a spirit of experimentalism to re-envision familiar social institutions with the aim of creating a more just world (Wright 2020). The CLHS is a strong case for studying the involvement of patients and family members in clinical research because patient engagement is central to the stated mission of the CLHS. A stated commitment to patient engagement is so central to the CLHS structure that it is used as an indicator of a network's success on frameworks like the Network Maturity Grid (Lannon et al. 2021). The CLHS literature has sought to understand the relationship between patient engagement and improved outcomes, better patient-provider relationships, and cost-effectiveness (Hartley et al. 2020; Institute of Medicine (US) 2011). The CLHS model seeks to challenge conventional relations in healthcare by leveling patient-provider hierarchy through an emphasis on collaboration. As a result, engagement in CLHSs requires individual stakeholders to buy into the shared values of rejecting the traditionally limited role of patients in healthcare and centering the patient voice; it applies to all healthcare stakeholders involved in engagement work (Seid, Margolis, and Opipari-Arrigan 2014).

To study patient and family (hereafter "partner") engagement, we identified a common starting point for partner engagement: recruitment via the clinical encounter. Although we began our study with the broad aim of investigating who becomes involved in CLHSs and what these activities entail, it rapidly became apparent that recruitment practices were of central importance. CLHSs used different kinds of recruitment practices and these had different downstream effects on who became involved (cf. Shim et al. 2023). Most commonly, CLHSs used closed recruitment, or recruitment by direct invitation (author cite). One key sensitizing concept, developed to describe interactional dynamics in the clinical encounter and to trace their impact on care provision, helped us interpret our findings: cultural health capital. Cultural health capital is a set of cultural skills, competencies, and behaviors that explains how social inequality can occur interpersonally by creating more optimal patient-provider relationships (Shim 2010).

These notions of cultural capital and cultural health capital are dependent on what is valued by dominant groups and can both reflect and reproduce social stratification—certain forms of cultural capital are valued while others are devalued (Yosso 2005).

Although CHC is normally displayed without conscious intent, it can also be employed deliberately (Dubbin, Chang, and Shim 2013; Shim 2010). Similar to the reproduction of cultural capital in other domains (Armstrong and Hamilton 2013; Calarco 2018; Lareau 2011), patients accumulate and develop cultural health capital as a result of their exposure to knowledge and practice in settings such as education and the family. Because CHC is acquired through embeddedness in particular contexts, existing social inequalities can be reproduced through differential access to valued forms of CHC. The amount of CHC patients and family members possess and display leads to variation in experiences with the healthcare system, experiences that are also shaped by a patient's or family's class, race and access to social and economic capital (Dubbin et al. 2013; Gage-Bouchard 2017; Gengler 2014).

Cultural health capital also shapes how healthcare is delivered. Patient-centered care has been increasingly recognized as an ideal model for care delivery (Tzelepis et al. 2015) and reflects a general shift from overt medical paternalism to patient participation and empowerment. An emphasis on patient-centered care can promote healthcare providers to customize their care to their patients, which means that providers need to be attentive to patient needs and interactional styles (Dubbin et al. 2013; Epstein and Street 2011). Indeed, patients often have better experiences when their provider shares some identity and subsequently similar forms of cultural health capital (Greenwood, Carnahan, and Huang 2018; Shim 2010; Tsugawa et al. 2017). For example, past experiences of racial discrimination lead some patients to prefer providers of the same race, suggesting that matching cultural health capital between patients and providers could benefit their relationship and subsequently improve quality of care and outcomes (Malat and Hamilton 2006; Olaisen et al. 2020; Takeshita et al. 2020).

However, healthcare providers may value, but not always achieve, the ideals of patient-centered care. This can mean that inequalities are reproduced because interactional aspects of the healthcare encounter fail (or succeed) in ways that harm or benefit patient care. For example, when the patient has high levels of cultural health capital matching their provider, it can give the provider a "good feeling" to work with them (Sointu 2017). Eeva Sointu (2017) defines the different experiences and characteristics of "good" and "bad" patients. "Good" patients uphold medical authority, match their provider's interactional style, follow instructions, and generally provide a good feeling to work with due to their compliance and relatability. Characteristics of "bad" patients often include lack of adherence, missing appointments, or other factors that are often entrenched in social inequalities and personal barriers. As good patients give a "good feeling" to providers, they may receive better care, have better relationships with their physician, and even experience improved outcomes which perpetuates inequality in healthcare delivery and outcomes. Additionally, good patients are perceived to be more engaged in their care, knowledgeable about medicine and their condition, and holding proactive and self-disciplines attitudes. These perceived traits could lead good patients to be disproportionately selected for healthcare improvement and/or patient engagement work, as they may be considered "ready" to participate due to their status as good patients (Fleming et al. 2017). Since notions of the "good patient" are fundamentally shaped by patients' existing social inequalities and barriers to healthcare, selecting good patients for engagement work could increase marginalization for less engaged patients.

Drawing these concepts into an analysis of recruitment into healthcare improvement work helps us demonstrate how judgments about cultural health capital mediate the decision to recruit patients into healthcare improvement work. Our analysis fleshes out the mechanisms of inclusion and exclusion in healthcare improvement work, and by extension other forms of clinical research that engage patients and family members. In so doing, we extend the concept of cultural health capital beyond the individual clinical encounter to describe its role in shaping who becomes involved in healthcare improvement work. In uncovering these processes in the context of collaborative learning health systems (CLHS), a fledgling model for multi-stakeholder healthcare improvement and clinical research, we also develop a conceptual basis for intervening in existing CLHS recruitment processes.

Data & Methods

In order to learn about how patients and family members are recruited into healthcare improvement activities, we interviewed stakeholders from three Learning Health Networks (LHNs), a type of Collaborative Learning Health System (CLHS). Two of these networks are disease-specific and one is formed around a geographic area. The LHNs were selected because they are three of the oldest and most mature (cf. (Lannon et al. 2021) LHNs to be developed by the Anderson Center for Health Systems Excellence, a LHN incubator located at Cincinnati Children's Hospital Medical Center. The disease-specific networks represent the most common way CLHSs are formed and help us understand the typical aspects of our case. The third network, formed around a geographic area, represents a special case that helps us represent promising recruitment practices beyond the norm in this group of networks.

This research was approved by the IRB at [institution removed for peer review] and all interviewees provided written consent to participate, with parental consent and participant assent obtained for three participants under age 18. Each member of the author team comes to this work through personal and/or professional engagement with CLHSs. In addition to leading the study, Author 1 is a patient partner with leadership experience in patient engagement. Author 2 is a sociologist working to develop the science of learning health systems.

Interviews were conducted with 26 participants from three pseudonymous CLHSs. To identify interviewees, we sent open calls for participation via email, social media and network gatherings to each network with the aim of recruiting members who were highly engaged in LHN work at the individual care center and national leadership levels. During the data collection period, some participants suggested additional LHN members to recruit, leading us to incorporate snowball sampling to better address our research questions. Participants from each network included representatives from multiple stakeholder groups, allowing us insight into various stakeholder perspectives. Overall, interviews were conducted with pediatric patients, adult patients, parents, providers, quality improvement staff members, engagement staff leaders, and network leaders, some of whom occupied multiple stakeholder roles (e.g. parent and quality improvement staff member). Participants from Network A included pediatric/young adult patients, providers, parents, and engagement staff/network leaders. Network B's participants were adult patients, parents/caregivers, quality improvement coordinators, and engagement staff/network leaders. Participants from Network C were engagement staff members only; one limitation of our study was not being able to recruit community members through Network C. Semi-structured interviews were guided by questions developed for each stakeholder group: patient, provider, or engagement staff. A common interview guide was used for the parents, caregivers, and patients, and the engagement staff guide was also used in interviews with

network leaders and center-level quality improvement specialists. Interview guides were flexibly modified for participants occupying multiple roles in their CLHS. Interviews were conducted by Author 1 over Zoom and were recorded and transcribed using the Zoom application with additional manual corrections by the interviewer.

The interview transcripts were coded using Dedoose (SocioCultural Research Consultants, LLC 2023). We used a three-pass iterative process to code the interviews and met frequently to discuss coding progress and code application. We collaborated to determine relationships between the codes and generate themes, using a generic qualitative analysis process that incorporated memoing and idea mapping. Following coding, participants' responses were de-identified and each was provided a pseudonym. Networks were also provided with pseudonyms. Additional words and phrases have been removed from the data based on the research team's evaluation of them as potentially identifying.

Findings
Displays and Judgments of Cultural Health Capital

When patients or family members are recruited to be partners with a disease-specific network, the most common form of recruitment described by interviewees was a personal invitation from a medical provider during a healthcare appointment. In interviews, we found that providers could account for why they invited certain people and not others and that partners also had ideas about what experiences and attributes qualified them for inclusion in healthcare improvement work. However, we found that providers and partners tended to account for their recruitment invitations in different ways: providers focused on a subset of CHC that included attitudes, behaviors and interactional styles while partners focused on the subset of CHC that included cultural skills and (non)verbal competencies. As a provider explained:

> There are definitely times where I'm in an office visit with someone, and it kind of--something about the way that the visit is going, or the way that the person is…something they share with the patient and sharing with me or the way they're behaving or acting or questions they're asking makes me think oh, man, this person would be an amazing member. (Stephanie_Provider)

This provider was also able to recognize some of the downsides of this approach:

> I have a colleague who has [network-specific condition], she's an adult now, and she said when I was a teenager like you would never have recruited me. I was like, you know, like hated coming to the doctor, it was awful, like I didn't want to take my meds, you know all this stuff, and now she's a, you know, an excellent advocate, a medical professional, a leader in the field. You know. So, I'm curious about those people who might not be the classic example of a, you know, primed engaged patient.

Another provider told us how he makes the decision to recruit:

> The decision to invite them to join is very subjective. How the parents and patients are tackling their disease, how engaged they are, how involved they are, do they have a desire to really participate and make a shared decision…with me that affects their child's care or the patient's care. (Stephen_Provider)

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These providers describe what they look for when recruiting new partners, including attributes like health literacy, self-management, receptiveness to medical advice, and a proactive approach to care. Generally, these indicators reflect when the patient/caregiver is acting and behaving in ways that match the provider's expectations for fit as an engaged partner, in other words, forms of cultural health capital that are being demonstrated in clinic encounters.

While these displays of CHC may be identified by providers as a sign of readiness to participate in healthcare improvement work, they may emphasize different kinds of CHC than partners consider to be valuable for recruitment into LHNs. Indeed, when asked about how they become involved in their LHN, many of the partners shared their relevant advocacy experiences, such as working with their care center or similar medical organization, or even professional experience gained in their career. The skills partners gained through these professional and advocacy experiences correspond with CHC displays that fall under cultural skills and (non)verbal competencies (Shim 2010). For example, multiple partners described their progression of working with their care center first before advancing to the national network level:

> I worked first at the center level, so I was participating with my care center on local engagement projects. I did some resource creation for my center, I did some quality improvement initiatives. And then, probably six months after doing that, I expressed interest in getting involved in patient community. (Lola_Patient)

In addition to relevant advocacy work, some partners shared their career paths and associated professional skills that could be transferred to LHN work. For example, Maria also shared that her job, which allowed her to gain deep expertise in public insurance programs, was one reason why she was invited to participate in LHN work: "…one of our providers, said, she's like, you've answered every question I ever had about insurance and she's like, I feel like you're huge add value for that factor." This partner considered her professional job to have transferable skills for LHN work and considers her recruitment to be largely attributable to it. During interviews, many of the partners identified these cultural skills and (non)verbal competencies gained via relevant advocacy and professional experience as qualifications for their recruitment into LHNs.

While partners tended to identify cultural skills and (non)verbal competencies as forms of CHC that serve as qualifications for recruitment, providers more consistently selected for patients who demonstrated desirable attitudes and behaviors or interactional styles. Multiple providers shared that patients' proactive, self-disciplined attitude indicated recruitment readiness, such as one provider who told us: "Sometimes it is someone who you can already tell has a ton of self-management skills. You know, like they're leading their appointment already. They are asking the questions." Providers also took account of the patient's approach to medical treatment, identifying adherence to a treatment plan as an additional sign of patients to recruit. For example, one provider explained, "So you know, if they're the type of folks that show up and, you know, do what is recommended […] essentially good role models, like what kind of parent will be able to model, you know, actions and behaviors." Another team member emphasized interest in partners who "fit" with their team and felt comfortable speaking up:

> Um, so we did want somebody that we thought would feel comfortable kind of speaking up. So, we have like I said, we work on these projects, but we really,

> really value the patient and family input. So, we wanted somebody that was like feeling comfortable to kind of say, hey, this is how I feel about of things, and not be intimidated that, you know, that they're having to speak up in front of the whole care team. So, somebody that was like—that felt good about that. And then also somebody that just was kind of really excited about QI [quality improvement] and potentially throwing out some new project ideas and things like that. So, we just wanted somebody that was—that would kind of fit in with the team and also feel comfortable giving their input. (Nancy_Engagement Staff)

Partners may expect advocacy and professional qualifications to indicate their recruitment readiness, but providers more frequently shared anecdotes about partner's behavior and attitudes, indicating that they may place a stronger emphasis on the interpersonal presentation of partners—what one partner described as the "vibe." Providers often described the following hallmarks of Shim's (2010) CHC when considering recruitment: self-surveillance, consumption and expression of acquired medical knowledge, patient adherence, self-management, self-efficacy, attitude, feelings of competency, "medical sophistication". In clinic encounters, these hallmarks of cultural health capital in patients are described by providers in LHNs as having "self-management skills," "the ability to manage their disease," "good adherence," "good grasp" of the disease and treatment, and transferable skills from career. Cultural health capital was also described as patients who are "asking the questions," "leading their appointment," "acting as an adult patient," mature, "not too bashful," agreeing with the recommended care plan, who "show up" and are "doing what is recommended," who are educated and are "comfortable speaking up…and giving input." Some providers did identify relevant advocacy and professional experiences of partners as valuable characteristics for the LHN, but they more frequently considered attitudes and behaviors as well as interactional styles as more significant determinants for extending the LHN invitation.

An explanation for this rationale is suggested by Eeva Sointu (Sointu 2017), who explains the phenomenon of "good" and "bad" patients. Sointu explains that a "good patient" engages with medical professionals in a way that "upholds medical knowledge," supports their expertise, and aligns with their cultural skills and values (2017:72). This latter component may be most relevant for explaining why providers may prioritize interpersonal dynamics when considering recruitment into LHNs. Providers may identify "good patients" whose proactive mindset and agreeable attitude make the professional's job easier. For example, another provider shared that receptiveness to their care plan was important for involvement with LHNs, stating: "it becomes difficult for them to agree or participate if they are already not receptive to what I'm telling them about care or medications and other things." Good patients who adhere to medical recommendations, agree with their doctors, and are "on top of" their care may give healthcare professionals a good feeling to work with them.

"Good patients" also strike healthcare providers as the type of patients who will model being a "good patient" to other patients, and this can shape whether healthcare providers elect to elevate some patients into mentor roles for patients and parents who are newly diagnosed or less centrally involved with the LHN:

> I think I would tend to recommend people who have pretty good adherence, you know, like they seem to have a good grasp of what [the disease] is, and what treatment their child is on, and why they're on that treatment. And you know, they show up for their

> follow up visits and part of that too, is if we're gonna recruit a mentor, we want to make sure that they're going to be there for their mentees, too. So you know, if they're the type of folks that show up and, you know, do what is-is recommended, and, you know, ask questions if they've-they …essentially good role models, like what kind of parent will be able to model, you know, actions and behaviors that are productive to help them, help their child be healthy, and help them kind of navigate the system well. So that that's probably one of the biggest things. What else…? Yeah, I think that would be the big one. (Stephanie_Provider)

Positive feelings that providers associate with "good patients" are an important factor shaping recruitment into LHN work. These perspectives also frame "good" partners as those who reinforce healthcare providers' recommendations, while also being able to transmit cultural health capital to other patients by helping them navigate the healthcare system.

Increasing CHC once people are involved in LHNs
Although they attended to different aspects of it, partners and providers both identified cultural health capital (CHC) as a reason for recruitment into healthcare improvement work. However, our interview findings also suggested that CHC is further developed *through involvement* with the LHN. The cultivation of CHC in partners happens through training resources and activities provided by the LHN, tailored interpersonal skills developed through collaboration with others working on healthcare improvement projects, and increasing health literacy and self-management skills through exposure to the "back end" of healthcare. Consequentially, the CHC that partners and engagement staff described developing through their engagement in LHNs tended to match those that the providers reported prioritizing in recruitment, as well as more static indicators of privilege, such as adherence to treatment plans and attending regular medical appointments.

LHNs offer training for partners to build knowledge and skills
The contributions of partners vary based on each network's mission and organizational structure, but those in the disease-specific LHNs shared participating in projects to improve clinical practices using their lived experiences and quality improvement (QI) science. In interviews, partners and engagement staff from all three LHNs shared that that they provided or participated in different types of formal training for these forms of engagement, including quality improvement training, coaching in office job skills, and structured onboarding processes. These activities allowed partners to develop CHC for participating in healthcare improvement work, which in LHNs is distinguished by its location in an academic medicine environment that requires having typical "office job" skills. For example, engagement staff from Network C, a community-based LHN that supports neighborhood residents' involvement in improvement projects, shared some strategies to help members learn technology-related skills to participate in LHN activities:

> …the coaching phase with families helps them to feel more comfortable. And you know if you're not able to figure out even how to reply to an email or like how to copy and paste something, you have to like start from scratch. So like, then to them it seems like it's way more work. But if you show them little tricks around

things with the computer or you know, even with their phone.
(Marlene_Engagement Staff)

And even with like when we first started with, because of Covid with Zoom, like
no one knew how to zoom. So, we just broke down an instruction. We had
practice days, you know. (Marlene_Engagement Staff)

One partner from Network B described how LHN engagement staff also provided training in
quality improvement during the onboarding of new partners:

That was more structured because we had an official onboarding with the learning
network itself as part of one of their waves of standing up new facilities. So we
went through an actual couple sessions [of] training on quality improvement, the
basics of like KDD [key driver diagram] work--everything, I mean, just literally.
It was like quality improvement 101. (Maria_Patient)

Providing extensive materials for both clinicians and partners to facilitate the onboarding process
allows new partners to develop the knowledge and skills necessary to carry out their role. Giselle
explained why such detailed training is necessary:

We just came up with a checklist of all the things that partners need to know. This
is like in the last two months. And it's a pretty massive checklist of all the things
partners need to know, and we heard from the clinicians who were gonna give this
to their partners. They're like, "Wow! We didn't even know the partners needed to
know—like we didn't have any clue they needed to know this much information."
[…] Because how do you know what they need to know early on? They don't. So
it's […] this long, to be very clear: this is what a partner needs to be onboarded
with. (Giselle_Engagement Staff)

This onboarding guide, which acts as a repository of accumulated knowledge from other
partners, can be passed on to new partners as a source of CHC that is relevant to participating as
a partner in healthcare improvement work. Interestingly, Giselle mentioned that both partners
and providers alike were surprised at how much partners needed to learn, and this onboarding
guide makes that explicit, thereby facilitating the transmission and acquisition of CHC pertaining
especially to (non)verbal competencies, interactional styles, and cultural skills. This network
onboarding process assumes that CHC needs to be developed in the partners even after
recruitment and provides extensive resources to do so.

Similarly, an engagement staff member from Network A highlighted the learning that
patients and parents do after becoming involved with network committees:

There's a lot to learn. And so more than looking for patients or parents who
understand it, we're looking for folks who are just willing to learn and excited
about it, because that's what the work comes down to is are you willing to listen
and learn and try new things. When you get into some of the more clinical
committees, they do tend to look for patients and parents who are familiar with
medical terms. But they offer onboarding, they offer transparency training, and

folks are looking at data and don't know quite how to handle--not handle, but how
to interpret the information. But [the network] really does a great job of making
sure that it's more about the enthusiasm than about the previous knowledge.
(Maeve_Engagement Staff)

Prioritizing the ability of partners to acquire CHC ("are you willing to listen and learn and try
new things") rather than already having it emphasizes how partners develop their CHC through
involvement in LHNs. While providers and partners still recognize that CHC heavily influences
their recruitment into LHNs, engagement staff and partners also emphasize the importance and
value of using training to develop CHC in newly recruited partners.

Partners can develop interpersonal skills that match repertoires of academic medical work
 Providers, engagement staff, and other partners can also provide opportunities and
resources for the development of communication skills, another relevant form of cultural health
capital, through involvement in LHNs. Partners develop communication skills tailored to
academic medical settings through immersion in medical information and working with
healthcare professionals, which increases their ability to adapt their interactional styles to
medical providers. Some interviewees shared anecdotes about building interpersonal skills with
LHN members through engaging with other partners and healthcare professionals on group
meetings or projects. For example, two patient partners shared:

 My speaking skills and communication skills have gotten much better. I definitely
 am still very awkward, but I feel like I can definitely communicate and get my
 point across in a better manner than I was before. (Maya_Patient)

 And now, being in leadership, has made me feel more socially confident in this
 space, which I think has translated to other spaces of like feeling like I can
 develop friendships and get to know people and be a leader. (Kevin_Patient)

Partners can develop confidence with speaking as well as develop and incorporate social skills
that fit the "good patient" expectations of physicians. These social skills can be utilized in
encounters with healthcare professionals and other stakeholders. For example, multiple providers
identified that they look for partners who feel comfortable "speaking up" when determining who
to recruit. Clear and concise communication, friendliness, and comfort speaking up are examples
of the adapted interactional styles category of CHC emphasized by providers for recruitment.
These largely build upon interactional styles that "vibe" with providers as well as behaviors that
may give a good feeling to those working with the patient (Sointu 2017). Similar to other forms
of CHC, this interactional style valued by providers can be both something that a partner already
displays and something that is further developed by partners after recruitment. Indeed, as the
second quote implies, developing cultural capital through learning field-specific ways of
interacting can also support the development of social capital. This is one mechanism by which
individuals can "cash in" one form of capital for another, deepening their embeddedness in the
field of healthcare improvement work.
 Gaining cultural health capital can also include acquiring and displaying specialist
medical information about one's own condition or other similar health conditions. Having this
type of knowledge can improve how someone manages their health, and several partners

reported that being part of a LHN allowed them to substantially expand their knowledge of their condition. Interviewees described acquiring cultural health capital through attending academic conferences, having opportunities to speak with doctors outside of their own medical encounter, carrying out healthcare improvement projects, and writing research articles:

> I feel like honestly my years of experience going to conferences, speaking with doctors, and, you know, putting together you know, projects and everything, articles; it really taught me more professionally than I thought. Like, you know, I kind of went in thinking it was a support group, and I ended up leaving with a lot more than just like support, confidence, and friends. It was, you know, incredible, educational for healthcare in general, but also [medical] stuff, like I feel like a little expert in how it all runs because of learning it all through the conferences and everything. (Gianna_Patient)

In addition to developing knowledge, health literacy, and efficacy to better manage their own disease, partners described a rapid learning process to gain relevant biomedical information for healthcare improvement activities. For example, a patient from one of the networks discussed learning from her participation in LHN committees and projects like the network work groups and educational resources:

> And academically, I-I think… so being on… the different committees, like I'm on the steering committee for the [network initiative], and doing other like larger network initiatives where I'm kind of thrown in to these… they're a little bit above my-my head a little bit, like I don't exactly understand what's going on, but I can learn. I think those are-that's a good example of how I can grow academically. (Lola_Patient)

This patient considers that while the information and level of knowledge for the LHN initiatives is initially at more advanced level than she is familiar with, she feels confident in her ability to learn. This reflects the capacity of LHN resources and staff to build field-specific cultural health capital in partners that facilitates these partners' participation in healthcare improvement work.

Partners convert their CHC into more cultural and social capital

Not only do partners build (non)verbal competencies, self-management behaviors, and interactional styles suited for healthcare settings through their LHN work—all markers of cultural health capital—they are also able to increase their social capital by establishing professional connections that can unlock access to new career opportunities and increase their access to healthcare. Thus, the development of CHC that occurs when someone becomes an engaged partner in LHN work is intertwined with increases in social capital and cultural capital. As their careers progress, partners who are centrally engaged in LHN work are able to translate both their CHC and their social capital into increased professional and personal opportunities. For example, one patient partner described getting a job in another CLHS based on her patient engagement experience in her own CLHS: "they counted it as if it was like a job, almost." Other partners shared how their work in their LHN connected them to center-level opportunities and chances to publish research. Yet other partners described developing closer relationships with their own personal physicians through collaborating on CLHS work. These are examples of how

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involvement in an LHN can increase CHC and other forms of cultural capital in partners, and these professional opportunities often occur in healthcare settings, which can allow for further development of CHC.

In addition to professional opportunities, partners shared that they developed personal relationships with medical providers through LHN activities that could increase their access to healthcare:

> I would like to hope that because I am helping my center out, If I were to need something from them, whether it be--I don't know--help filling out paperwork, or-or needing to discuss something medical, I kind of would hope that they would…be more willing to help me with that because I am helping them with the patient family partner stuff. (Penny_Patient)

Increased CHC from LHN involvement may also extend beyond the acquisition of medical knowledge, proactive self-management attitudes, and access to professional opportunities. Especially for younger partners, the effect of increased CHC through LHNs could be more heavily applicable to their career goals. For example, one provider described a trend of very engaged partners going into healthcare professions after their time in the LHN. This provider identified that the partners from the network that went into healthcare professions were highly engaged: either in patient leadership or otherwise very actively involved in LHN activities. He described these partners as "high functioning, involved, engaged people" indicating that the most actively engaged partners tend to be those who are able to build the most CHC and translate it into significant benefits for their career pathways.

Overall, LHNs provide trainings and resources that can increase partners' CHC. Additionally, partners reported improving their medical knowledge, proactive stance towards health, self-management behaviors, professional connections, and professional opportunities. These increases in CHC can be mapped to the four categories of Shim's (2010) concept of cultural health capital: cultural skills (medical knowledge), (non)verbal competencies (communication), attitudes and behaviors (being proactive and having self-efficacy), and interactional styles (pro-social medical encounters). Partners reported growth in CHC that can overwhelmingly contribute to their medical knowledge and efficacy, which can lead to the proactive and self-managed attitudes and behaviors valued by providers for recruitment. Additionally, partners also discussed learning to communicate in ways that were tailored to prevailing norms and provider expectations in healthcare settings and creating personal relationships with healthcare professionals, enabling them to develop very strong abilities to adapt their interactional styles for medical providers.

Creating Transferable Forms of Cultural Health Capital

Cultural health capital (CHC) can be transmitted from partners with more to patients and families with less. Toolkits and other resources by partners represent these transmissible forms of CHC due to inclusion of information derived from partners' lived experience and lessons learned. Moira explained how knowledge can be passed down to other patients through partners:

> …having that ability to reflect and look back about how those experiences could have gone better, you know. Like with some of the older members thinking through oh, for myself, making the college toolkit was a lot of reflection about,

> this was kinda a disaster in some ways, and I've heard from a lot of folks with [disease] other chronic conditions that college can be a really tough time. And so having that ability to use your experience kind of reflect back, and then be like oh, here's some tips that would have been really helpful for me to know.

This streamlines lessons learned about navigating the disease and healthcare system to recipients, increasing their CHC without the same longevity and need for direct experience. This transmission of CHC can also be facilitated by LHN activities. As another patient partner, Sarah, shared:

> I am in the [work group]. […] So that has been another thing like bringing the patient experience to the table, and just how to get more like [network] things out there for people. And how like make sure that patients and parents or anyone, like understands what's happening, and how our resources can help.

Commented [AHV7]: Becky, can we live without this?

LHN partners with high CHC transmitting their knowledge to other patients and families can improve the distribution of CHC. A provider, Stephanie, described this beneficial effect for other patients:

> And you know what it's like, and you've had you know good experiences and bad experiences, and many in between I'm sure, and can share and learn from each other. I think that's really, really powerful and I know I can tell you for sure that it helps patients directly who interact with you guys.

LHN partners can share their high levels of CHC, which is acquired through personal experiences and advancement through LHN involvement. LHN initiatives like toolkits and other resources that are infused with insights and insider knowledge from patients and family members can distribute CHC from these partners to other patients and families.

Discussion

When asked about how they decide on which people to invite into healthcare improvement activities in Learning Health Networks, providers tended to identify hallmarks of cultural health capital that are most often associated with attitudes, behaviors, and interactional styles. This emphasis on interpersonal dynamics as a recruitment proxy is different than partners' own focus on their backgrounds and qualifications. The providers' determination for recruitment appears less dependent on qualifications like professional and advocacy experiences and more on interpersonal dynamics; this suggests that providers consider partners' interactional style and how well they get along as more important factors shaping a decision to recruit. Ironically, while partners and providers both identified aspects of cultural health capital as a reason for recruitment into healthcare improvement work, our findings suggest that partners' cultural health capital is substantially developed through involvement with the LHN. The cultivation of cultural health capital in partners results from training resources provided by the LHN, interpersonal skills developed through collaboration in an academic medicine environment, and increasing health literacy and self-management skills.

These sharp increases in CHC reflect the forms of CHC that providers expressed selecting for in recruitment. However, if partners rapidly develop the forms of CHC that

providers look for when recruiting, this insight may allow LHNs and other CLHSs to reduce the importance of CHC as a criterion for recruitment. The recruitment process could be opened to partners with less CHC, and this approach could increase the representation of partners. Sociological research on representativeness and heterogeneity in medical research has tended to examine this in the context of clinical trial recruitment, but this context differs markedly from the involvement of patient and family stakeholders in healthcare improvement work. Healthcare improvement work is made better by the inclusion of those with varying experiences in the healthcare system, as these individuals can focus efforts on unintended variation in care and health outcomes, making them an object of improvement work. Healthcare improvement organizations should consider recruitment strategies that do not rely on cultural health capital to avoid reproducing social inequality in their work. Network C, the geographical area-based CLHS, which seeks to work within a low-income neighborhood context to improve health outcomes, offers potential best practices for the intentional cultivation of cultural health capital to enable participation of community members in healthcare improvement work.

The findings of this research have important implications for helping innovative organizations like LHNs achieve their potential. First, because provider assessments of partners' cultural health capital mediate recruitment into LHNs, there are good reasons to employ open recruitment methods that are not dependent on a provider invitation. Second, because we found that engaged partners' cultural health capital increases as a result of involvement in LHNs, we advance the point that there is no substantive reason to avoid engaging partners via open recruitment methods. Open recruitment processes may help CLHS members identify stakeholders who are ruled out (who "fail" assessments of cultural health capital) but who may be able to provide important input about where the health system is lacking. A shift in recruitment practices may have a big impact on health systems by easing the entry of precisely those stakeholders who do not have adequate support or cultural health capital to navigate the healthcare system, and who may best suited to identify areas for improvement.

The limitations of this study suggest areas for future research. Although relatively small, this study uses strategic sampling for LHN heterogeneity in order to learn about a wide range of recruitment practices. The richness of qualitative interviews allows us to investigate how and why actors use recruitment processes and to understand the factors shaping partners' experiences. Although we were not able to directly understand the perspectives of community members who collaborate with the geographically-based CLHS (Network C), we were able to understand in depth how engagement staff from this network facilitate the participation of community members, helping them to transmit or gain relevant cultural capital in the domain of LHN work. Finally, in order to understand the experiences of those who had been recruited into LHNs, we recruited people who are centrally involved in these groups. Thus, the selection bias in our study is a product of the selection bias present in LHN recruitment processes. This means that while we can understand the experiences of those who were invited to participate and accepted the invitation, we cannot speak to the experiences of people who were not recruited or did not accept an invitation to participate. Further work will be required to identify whether cultural health capital is salient to non-recruited individuals as a reason for why they were not recruited, or if they identify other reasons. These remaining gaps in our understanding motivate our future work in this area.

As the number of multi-stakeholder healthcare improvement networks steadily increases, more and more patient partners are recruited to participate in this work. We have sought to investigate the boundary between involvement and non-involvement in healthcare improvement

work by investigating recruitment practices into healthcare improvement organizations called Learning Health Networks, with the larger aim of fostering equitable patient engagement practices. By showing that expressions and judgments about patient partners' cultural health capital mediate providers' decisions to offer recruitment pitches, our findings extend current conceptualizations of cultural health capital beyond the immediate clinical encounter. Our findings also help us apply key concepts from medical sociology in the context of an organizational form that strives to be a transformative organization, the Collaborative Learning Health System. Understanding the role of cultural health capital in recruitment processes can help us surface best practices or ways to improve that, if implemented, can help this transformative organization achieve its potential.

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