Diversity, Equity, and Inclusion in Patient and Family Advisory Councils: Advancing Best Practice in Children's Hospitals

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Introduction: This qualitative research study explored practices that support and advance diverse membership in Patient and Family Advisory Councils (PFACs) in children's hospitals and the involvement of PFACs in organization-level diversity, equity, and inclusion work.

Method: This study consisted of a focused literature review and 17 key informant interviews. The study sought to identify important learnings about (1) recruiting and supporting patient and family advisors (PFAs) from historically marginalized populations and (2) ways to develop and sustain meaningful partnerships with PFAs and PFACs in diversity, equity, and inclusion work.

Results: The study findings highlighted a number of best practices for hospitals to adopt, including more actively reaching out to communities served, addressing barriers to participation through

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approaches and structures such as specialty PFACs and "tiered" options for participation by PFAs, and co-creation of inclusive environments.

Discussion: To move forward with this work, additional research, true commitment from health care organizations, and shared guidance and tools for the field are needed. J Pediatr Health Care. (2024) *38*, 184−193

INTRODUCTION

Patient- and family-centered care (PFCC) is a model that promotes active collaboration and mutually beneficial partnerships between patients, families, and health care professionals (Institute for Patient- and Family-Centered Care, n. d.). PFCC is an approach promoted by the Joint Commission, National Academy of Medicine, and other organizations to optimize health care delivery, quality, and experience in ways that align with patients' and families' preferences, needs, and values (Committee on Quality of Health Care in America, 2001; "NAPNAP Position Statement," 2016; The Joint Commission, 2010). PFCC is built on the core concepts of respect and dignity, information sharing, participation, and collaboration (Institute for Patient- and Family-Centered Care, n.d.). The pursuit of PFCC includes (1) practicing cultural humility and honoring the diverse backgrounds and experiences of patients and families, (2) ensuring flexibility in policies, practices, and processes that take into consideration the diverse backgrounds, beliefs, and experiences of patients and families, (3) sharing health information in an honest, unbiased, and affirming manner that promotes strong therapeutic relationships between care team members and patients and families, (4) providing patients and families support as they navigate the health care system and various stressors across phases of care, (5) collaborating with patients and families at all levels of the health care system, and (6) identifying and building on patient and family strengths in a manner that empowers them to make health care−related decisions (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012). Embodied within the model of PFCC is the duty of those working within the health care system to partner with patients and families who are wholly representative of the populations they serve (Merner et al., 2023).

A common mechanism for implementing partnerships at the organizational level is Patient and Family Advisory Councils (PFACs), which are formal groups consisting of patients and family members (i.e., patient and family advisors [PFAs]), clinicians, administrators, and other staff that collaborate to enhance the patient experience and quality of care (Santana et al., 2018). PFACs serve as a platform for patients and families to provide feedback, share their perspectives, and actively participate in the development, implementation, and evaluation of organizational policies and processes that support PFCC (Minniti & Abraham, 2013). Within pediatric health care systems, PFACs are commonplace; previous studies highlight their widespread prevalence and deep history in children's hospitals. Our preliminary work, a mixed-methods study that surveyed PFAC leaders at 228 children's hospitals, showed that 88% of survey respondents had at least one PFAC at their children's hospital. Of these hospitals, 51% had PFACs that had been in existence for at least 10 years (Unaka et al., 2022).

Despite the rich history of PFACs at children's hospitals and the desire for meaningful partnerships with patients and families, PFACs within children's hospitals often are not fully reflective of the diverse populations and communities served (Unaka et al., 2022). Although many hospitals have strategies for recruiting PFAs across a variety of diversity dimensions, PFAC membership tends to demonstrate less gender, racial, ethnic, education, and income diversity than hospitals' broader patient populations (Harrison et al., 2019a; Jones & Potter, 2019; Montalbano et al., 2021). There also are significant opportunities to further advance PFAC involvement in diversity, equity, and inclusion (DEI) initiatives. Many children's hospitals have created and bolstered leadership structures, strategic plans, and initiatives to advance health equity (Knight, 2022); at the same time, engagement of PFAs in DEI-related work varies and is often limited (Dokken et al., 2021).

As a result, children's hospitals may be at significant risk of not obtaining input and perspectives from individuals, groups, and communities that have historically been underrepresented and/or marginalized, including individuals who self-identify as racial/ethnic minorities, have low socioeconomic status, have a primary language other than English, have disabilities, and/or are lesbian, gay, bisexual, transgender, and queer. These populations and communities experience unacceptable health inequities at disproportionate rates (Huang et al., 2022). Failure to include a diversity of individuals in PFACs may therefore entrench inequities by impeding the ability of health care organizations to plan, implement, and evaluate health services in ways that address and explicitly recognize the diversity of patients served (Snow, 2022). Recognizing this challenge, PFAC leaders at children's hospitals have articulated a clear need for additional information, resources, and support to guide their path forward (Unaka et al., 2022).

This paper presents findings from an exploration of practices that support and advance PFAC DEI. Our primary objectives were to identify and share learnings about (1) recruiting, preparing, and supporting PFAs from historically marginalized populations; and (2) developing and sustaining meaningful partnerships with PFAs and PFACs in DEI work.

METHODS

We developed questions to guide our exploration of PFAC DEI practices, as shown in the Box.

BOX. Project guiding questions

Guiding Questions

1. How do children's hospitals define and set goals for PFAC DEI?
2. What are the best practices for developing, supporting, and sustaining partnerships with historically marginalized populations?
3. How have children's hospitals and other organizations engaged patients, families, and community members in DEI work?

We used a research design consisting of a focused literature review and individual interviews. We selected these methods given the exploratory nature of the project, which necessitated the inclusion of evidence from a variety of sources. We conducted the literature review and interviews simultaneously. The study was reviewed by the Cincinnati Children's Hospital Medical Center Institutional Review Board and deemed exempt. All participants consented to participate. The Lucile Packard Foundation for Children's Health provided funding for the project (grant no. 2022-07139).

Focused Literature Review

We conducted a focused literature review between January and March 2023 to identify best practices for developing, supporting, and sustaining partnerships with historically marginalized populations and collect examples of partnerships with patients and families in DEI work. Our search strategy was informed by the project guiding questions and focused on the dual concepts of (1) partnerships with patients and families and (2) DEI, combined with settings and populations of interest. We developed keywords (see Table 1) and created searches in PubMed to identify articles. We also used the same keywords in Google searches to maximize the retrieval of potentially relevant tools and resources. We also searched the websites of selected organizations specializing in the development of patient and community

partnerships, solicited recommendations for resources from Project Advisory Committee members, and reviewed the reference list of all documents to identify other potentially relevant articles and resources.

We limited searches to English-language articles and resources published since 2010. To enable a broad exploration of project topics, we included a variety of documents in the literature review (e.g., research studies, case studies, white papers, guidance resources, presentations, webinars, and podcasts). Our inclusion criteria prioritized documents that addressed recruiting, developing, and/or sustaining partnerships with historically marginalized populations. We excluded documents if they were not in English, not available in full text without a subscription, or referenced the need for DEI and partnerships with patients and families without providing additional details. Searches were conducted from January through March 2023.

We conducted an initial screening of retrieved document titles and reviewed the abstracts of 152 documents deemed potentially relevant. We flagged 65 documents for full review and data extraction. To record information from relevant documents and resources, we charted the following using a standardized Microsoft Excel template: document/resource type (e.g., research article, presentation, guidance document), document purpose and objective, setting (e.g., hospital, community-based, research), population of focus, and key findings. We generated an initial coding scheme on the basis of project goals and refined codes using topics that emerged from the interviews (see below).

Interviews

We conducted 17 one-hour, individual video interviews from February through April 2023 to learn how organizations that partner with PFAs define DEI, identify practices that support the recruitment of and partnership with PFAs from historically marginalized populations, and collect examples of how patients and families have been engaged in DEI work. Individual interviews were selected as a methodology for the purpose of obtaining insights that may not

TABLE 1. Literature review search concepts and terms

Concept: partnership	Concept: diversity, equity, and inclusion	Setting/population[a]
Patient/Family Advisory Council (PFAC/FAC)	Health equity	Health care
Patient/family advisor	Health disparity	Children's hospital
Patient and family advisory board	Diverse/underserved/ underrepresented/vulnerable/marginalized populations or communities[a]	Hospital
Consumer Advisory Committee/Council	Diversity equity inclusion (DEI/D&I/E&I)	Clinic
Community Advisory Board	Anti-racist/anti-racism	Social service
Patient/family partner/leader		Youth/adolescent
Patient/family partnership		Education
Patient/family engagement		
Community engagement		

[a]As needed, we also searched for information about partnering with specific populations including, but not limited to the following: Black/African Americans, Asian Americans, Hispanics/Latinos, and other racial/ethnic groups; individuals with disabilities; children with special health care needs (CSHCN); lesbian, gay, bisexual, transgender, queer or questioning, or another diverse gender identity (LGBTQ+) individuals; individuals from lower socioeconomic backgrounds; and non-English speaking individuals.

have been captured in the literature because of the emerging nature of this topic. In addition, interviews allowed the team to collect specific implementation examples and details of efforts to support and advance PFAC DEI. We used a grounded theory approach for interviews, allowing for the iterative generation and development of themes and continual team consideration of how and where data collection could be refined to address gaps and further explore emerging ideas.

We developed a semistructured interview protocol to guide the interviews. Interview topics, which were informed by the project guiding questions, included organizational infrastructure to support PFCC and DEI, strategies for recruiting and supporting PFAs and patient partners from historically marginalized populations, practices for establishing equitable and inclusive partnerships, and PFA/patient partner involvement in organizational DEI work. The interview guide was shared with Project Advisory Committee members and revised on the basis of their feedback to improve clarity.

Eligible interview participants were individuals involved in DEI initiatives and partnerships working at children's and adult hospitals, academic research centers, and community-based and advocacy organizations. We identified interview participants from children's hospitals via a participant pool established during our previous survey of children's hospitals (Dokken et al., 2021). Specifically, we reviewed survey responses to identify organizations that reported having the diversity of PFAs, a strategy for PFAC diversity, and/or PFACs focused specifically on historically marginalized populations (e.g., Transgender, Black/African American). We identified additional participants on the basis of web-based searches and recommendations from members of the Project Advisory Committee, which included individuals leading PFAC and DEI work at children's hospitals, pediatric health care delivery experts, and PFAs. We purposively selected 18 interview participants, aiming to reflect variation in organization type, geographic location, and populations served. Participants received an email invitation to participate from interviewers that included an introduction to the research team along with a description of the project purpose and research activities. Of the 18 initially selected participants, 16 agreed to participate, and an alternate participant was identified for one individual. Information about interview participants (e.g., position title and responsibilities, demographics) was collected via an online survey and is shown in Table 2. All participants received an honorarium.

Two senior staff members conducted the interviews. Interviewers had the flexibility to ask additional probes and pursue topics of relevance as indicated by participants' experience and expertise. We audio-recorded all interviews and transcribed them verbatim using Otter.ai, which provides speech-to-text services. Interviewers reviewed each transcript for accuracy. We generated a thematic coding scheme on the basis of the project goals, interview guide topics, and an initial review of transcripts. Two trained qualitative researchers systematically coded interview transcripts, using Microsoft Excel to assist with qualitative data management and analysis. We reviewed coded text, developed themes and subthemes using an inductive qualitative content analysis approach (Patton, 2014), and validated themes and subthemes with interviewers and other project staff. The principal investigator then developed code summaries that described key messages, highlighting similarities and variations across interviews. The team developed a brief recorded presentation using Prezi to share themes with interview participants and invite additional input; one participant responded with feedback that amplified existing themes.

RESULTS

Below, we discuss findings organized by the project guiding questions. First, we present findings related to how children's hospitals conceptualize PFA diversity and the development of goals to advance progress. Second, we identify learnings about best practices for recruiting and supporting PFAs from historically marginalized populations. Third, we examine how children's hospitals have engaged PFACs and PFAs in DEI work. For each guiding question, we report findings from the literature and interviews separately, noting areas of overlap.

Guiding Question 1: Goals for PFAC Diversity in Children's Hospitals

Literature findings

The literature emphasized the importance of health care organizations having a clear understanding of their patient population before developing goals for diversity (Doupe Gaiser et al., 2016; National Institute for Children's Health Quality, n.d.). Diversity dimensions mentioned in relation to PFAs included race, ethnicity, age, health and disability status, gender identity, sexual orientation, and socioeconomic status (Dukhanin et al., 2020; Nandyal et al., 2021; Synnot et al., 2022). Intentional examination of data before developing

TABLE 2. Characteristics of interview participants	
Characteristics	n (%)
Organization type	
Children's hospital	9 (53)
Adult hospital	2 (12)
Community-based or nonprofit organization	4 (24)
Academic research organization	1 (6)
Advocacy organization	1 (6)
Length of time in current role	
< 5 years	5 (29)
> 5 years	12 (71)
Race	
White	11 (65)
Black	6 (35)
Ethnicity	
Hispanic or LatinX	3 (18)
Not Hispanic or LatinX	14 (82)
Gender	
Cisgender female	14 (82)
Cisgender male	3 (18)

goals for diversity mitigates the risk of making assumptions about who is underrepresented; further, data-driven goals can be used to inform the development of strategic plans that outline actions and required resources to achieve goals (Brostoff, Wiliamson, Raman, & Litterer, 2021).

Interview findings

Interview participants confirmed that, compared with their hospitals' patient populations, PFAs were more likely to be White, suburban, middle-aged, cisgender women of higher socioeconomic status. One participant shared that a system-wide examination conducted several years ago found that 82% of their PFAs were White, 65% had a master's degree or higher, and 73% had a household income of at least $150,000. Several participants reported that their hospitals had developed specific targets for PFAC diversity, with multi-year goals for progress. Interview participants considered PFAC diversity in terms of dimensions mentioned in the literature and also urged broad consideration of factors that can contribute to health inequities (e.g., language spoken, geographic location, employment, immigration status, health insurance type, and diagnosis or condition).

Guiding Question 2: Best Practices for Recruiting and Supporting PFAs from Historically Marginalized Populations

The literature and interviews provided highly consistent findings about best practices for recruiting and supporting partnerships with PFAs from historically marginalized populations. We have compiled best practices for recruitment in Table 3 and best practices for supporting sustainable partnerships in Table 4.

Literature findings

There is a dearth of literature about best practices for recruiting and supporting PFAs from historically marginalized populations that are specific to the children's hospital setting. However, literature from fields including community engagement, community-based participatory research, and education provided valuable information and insights (Cope et al., 2022; Harrison et al., 2019b). Best practices for recruitment include building authentic relationships in ways that acknowledge the deep-seated distrust that historically marginalized populations may have of the health care system. Relationship-building is a process that includes establishing a visible, ongoing, and mutually beneficial presence in the community (BC Patient Safety & Quality Council, 2022). Other important practices for sustainable partnerships include co-building safe spaces for collaboration and actively identifying and addressing potential barriers to participation (Doupe Gaiser et al., 2016; Riggs et al., 2015; Sayani et al., 2021).

Interview findings

Interview participants echoed best practices cited in the literature, further emphasizing the need to review and address aspects of existing systems that contribute to disenfranchisement. Interview participants also highlighted the importance of accompanying PFAC diversity efforts with work to ensure the PFAC itself is inclusive. Fostering inclusivity begins with a commitment to ensuring that everyone's perspective is

TABLE 3. Best practices for recruiting patient and family advisors (PFAs) from historically marginalized populations

Practice	Examples
Work with trusted community partners to develop ongoing relationships	• Partner with individuals and organizations that have a credible, ongoing, and stable presence in the community and that are well-positioned for effective partnerships, such as faith-based organizations, social service providers, schools, community centers, and local nonprofits (Harrison et al., 2019a; Nandyal et al., 2021; Snow et al., 2018)
Establish a visible, authentic presence in the community	• Create ongoing touch points, participate in community spaces, and show up for and invest in historically marginalized communities (BC Patient Safety & Quality Council, 2022) • Provide services of benefit to the community (e.g., health screenings and wellness events) and sponsor local community events (Ceasar et al., 2017; Health Quality Ontario, 2017)
Engage individuals within the hospital as partners in increasing PFA diversity	• Share goals for increasing PFA diversity with clinicians and staff to address misconceptions or assumptions about the types of patients that can serve as PFAs (Bougrab et al., 2019; Health Quality Ontario, 2017) • Partner with clinics that serve patients from historically marginalized populations to share information about the Patient and Family Advisory Council (PFAC) and opportunities for PFAs • Reach out to staff who may not traditionally be engaged in PFA recruitment, such as environmental services staff, and ask them to support recruitment efforts
Develop PFAC recruitment messages and materials that reflect and support diversity	• Ensure PFAC marketing and recruitment materials are culturally sound, reflective of the diversity being sought, and literacy-friendly (Ceasar et al., 2017; Health Quality Ontario, 2017) • Ask patients from historically marginalized populations to review recruitment materials and identify opportunities for improvement • Develop recruitment materials in multiple languages
Identify and address aspects of the recruitment process that hinder efforts to improve diversity	• Ask individuals from historically marginalized populations for input about barriers associated with PFA recruitment processes • Revisit processes that may prevent individuals from completing the PFA application process (e.g., applications that are overly long or geared toward individuals with higher levels of literacy; the need for background checks)

TABLE 4. Best practices for supporting patient and family advisors (PFAs) from historically marginalized populations

Practice	Examples
Co-design and foster inclusive spaces	• Work with PFAs to co-create guiding principles for Patient and Family Advisory Council inclusivity • Develop ground rules for inclusive meetings, along with policies for addressing challenging situations that may arise (Harrison et al., 2019a) • Engage in reflexive practices, encouraging staff and others to examine personal experiences, values, interests, beliefs, assumptions, and understanding (Roche et al., 2020)
Provide diversity, equity, and inclusion training for PFAs and staff working with PFAs	• Provide education and training related to topics such as unconscious bias, cultural sensitivity, and respectful communication (Andress et al., 2020)
Create time for relationship-building	• Provide opportunities for PFAs to connect and learn about each other • Prioritize group activities that encourage relationship-building, such as sharing meals and providing opportunities for personal updates (Harrison et al., 2019b)
Examine and address factors that may prevent PFAs from historically marginalized populations from participating fully	• Hold meetings at times (e.g., at night or on weekends) and in locations (e.g., community spaces) that facilitate PFA attendance (Doupe Gaiser et al., 2016; Snow et al., 2018) • Provide virtual meeting options to mitigate the burden of travel • Cover costs associated with PFA participation (e.g., transportation, child care, food) and provide PFAs with honoraria or stipends whenever possible, but particularly for more intensive work such as participation on committees or workgroups (DeCamp et al., 2015; Grant et al., 2018) • Ensure PFAs have access to technology, if necessary, for participation (e.g., iPads, internet, hotspots; Plunk et al., 2022) • Provide translation of all written materials and interpretation during meetings (Thompson & Federspiel, 2018) • Support options for tiered and flexible participation that reflect varying levels of commitment and intensity of involvement (Homer, 2019)

equally sought and valued and that everyone experiences a sense of belonging. Finally, interview participants suggested that obtaining feedback from PFAs through regular evaluation and reflection activities demonstrates respect for PFAs' experiences and supports PFAs from historically marginalized populations in actively identifying opportunities for improvement.

Guiding Question 3: Engagement of PFAs in DEI Work

Literature findings

Overall, the literature emphasized the importance of providing historically marginalized communities with opportunities for partnership that reflect their priorities, needs, and preferences (Tremblay et al., 2020). However, existing literature lacked specific examples of PFA engagement in the development and implementation of hospital-based DEI initiatives. Developing partnerships requires a commitment to the value of lived experiences, inclusion of voices that are not traditionally heard (or sought), and a desire to learn from rather than "fix" marginalized populations (Roche et al., 2020). Engaging PFAs in meaningful—rather than tokenistic—ways that allow substantive contributions was stressed as important (Passmore et al., 2022). The literature also discussed factors that facilitate the engagement of PFAs in DEI work, most notably creating intentional connections between DEI and PFCC at the organizational level, developing DEI and PFCC teams that are representative of the communities being served, and allocating organizational

resources to support PFA engagement in DEI (Gilfillian et al., 2021; Roche et al., 2020).

Interview findings

Interview participants echoed the importance of connecting DEI and PFCC at an organizational level and including PFAs on hospital-level DEI task forces, workgroups, and committees. At the same time, participants indicated a strong tendency for DEI and PFCC to be siloed within hospitals and noted that patient and family voices are frequently excluded from organizational-level DEI structures. Several participants discussed their hospitals' efforts to improve connections between PFCC and DEI by developing specialty PFACs that serve as "safe spaces" for PFAs to elevate and discuss issues disproportionately affecting historically marginalized populations (e.g., Latino/LatinX, Black/African American, LGBTQ/Gender Proud, and Deaf Councils). Other interview participants had created or leveraged structures for engaging PFAs in DEI work that extended beyond the hospital and cited the importance of using structures that work for historically marginalized populations. For example, one hospital attended "Talking Circles" to learn about the health care experiences of community members from Indigenous populations. Another hospital was in the process of creating a community-based "Wisdom Council" that would bring together members of various community groups outside of the hospital setting to generate knowledge about health care needs.

Given their experience of working directly with PFAs, interview participants provided more robust examples of how their organizations had engaged PFAs in DEI projects

TABLE 5. Examples of diversity, equity, and inclusion (DEI) projects from interview participants

Project	Examples
Share experiences and perspectives to inform understanding of equity issues	• Meet with hospital leaders and staff to share personal stories about how patients, families, and community members perceive and experience equity at the hospital • Contribute to open conversations focused on specific issues (e.g., the impact of George Floyd's murder, mental health in Black and Latino communities)
Provide input into and feedback on DEI-focused policies, practices, programs	• Provide input into hospital DEI policies and feedback on specific services (e.g., language and interpretation) • Advise on programs for specific patient populations (e.g., lesbian, gay, bisexual, transgender, queer or questioning, or another diverse gender identity) • Participate in workgroups around DEI issues (e.g., respectful collection of race, ethnicity, and language data) • Serve as members of standing hospital committees to infuse DEI perspectives (e.g., culture council, patient education committee)
Participate in research projects	• Brainstorm project ideas to address disparities in experiences and outcomes and review data on existing projects • Serve as consultants on research projects related to DEI topics
Participate in DEI-focused education for clinicians and staff	• Assist in the development of case studies and materials to help medical students gain skills related to DEI • Participate in incorporating DEI-related topics into simulation and educational training • Co-design cultural awareness campaigns for clinicians and staff
Participate in community engagement and outreach to historically marginalized populations	• Assist with developing programs that address the needs of historically marginalized populations (e.g., outreach programs for children who screen positive for social risks or prioritized social needs) • Participate in outreach to historically marginalized communities through community forums, listening sessions, programs, and events
Contribute to public advocacy	• Support and participate in local and state-level advocacy related to historically marginalized populations (e.g., legislation related to the LGBTQ+ community)

and initiatives than are available in the literature. These projects flowed from data about health inequities, hospital-level DEI initiatives and goals, and PFA input about DEI priorities. Table 5 presents examples of specific projects undertaken by interview participants and their teams. Partnership in DEI projects has benefits for the hospital and for PFAs themselves, with one interview participant from a children's hospital observing, "Parents or patients get excited to actually participate in something that's going to have a direct impact on patient care."

DISCUSSION

Equity, like safety and patient and family experience, is core to the delivery of quality care (Committee on Quality of Health Care in America, 2001). Health care organizations across the United States have bolstered DEI initiatives, as reflected in evolving strategic plans, goals, and measures. This focus is reinforced by key entities like the Commission on Magnet Recognition, which incorporated DEI initiatives into the 2023 Magnet application (Bryant et al., 2022), and US News and World Report, which incorporated health equity measures into their ranking methodology (Binger et al., 2023; Lobo et al., 2023). Strategies that support DEI are of fundamental importance as health care organizations work to improve access, engage individuals and communities, achieve better outcomes, and improve experiences for employees and patients alike. At the same time, there are no standardized solutions for improving DEI; health care organizations must consider the populations served,

community needs and resources, organizational structures and capacity, and multiple other factors.

PFACs exist to ensure that the perspectives and experiences of patients and families are heard and considered in organizational decision-making processes. Diverse PFACs that truly reflect the populations served are better positioned to assist health care organizations in their quest to eliminate health inequities, promote social justice, and deliver quality health care. However, opportunities to partner with health care organizations and inform change through PFAC membership have not been equally available to all patients and families (Unaka et al., 2022). In some instances, the lack of PFAC diversity reflects the eroded trust between historically marginalized communities and health care institutions (Suite et al., 2007; Washington, 2006; Wells & Gowda, 2020).

To better understand opportunities to advance PFAC DEI, this study explored practices that support PFAC DEI through a focused literature review and key informant interviews. Our work called attention to best practices for recruiting and supporting PFAs from historically marginalized populations and engaging PFACs and PFAs in DEI work. Overall, literature specific to PFAC DEI within the children's hospital setting was limited. However, literature from adjacent fields that emphasized partnership with community members, including community-based participatory research, education, and community engagement, provided helpful insights and practices—particularly related to the recruitment and inclusion of historically marginalized populations—that can be translated to health care settings. In addition, interviews with individuals working "on the

ground" in children's and adult hospitals, as well as community-based and advocacy settings, provided valuable learnings about recruitment and the development of meaningful and sustainable partnerships with PFAs from historically marginalized populations.

Our study suggests that recruitment methods long-used in community engagement and community-based participatory research offer promising practices for increasing PFAC diversity. Historically, many health care organizations have reported challenges engaging individuals from underrepresented and marginalized populations, characterizing these populations as "hard to reach" (Harrison et al., 2019a) when, in reality, they may be overlooked. Recruitment approaches that include community partners and emphasize longitudinal; relational interactions may offer greater promise for developing meaningful, effective, and sustained partnerships.

Similarly, our findings underscored the importance of intentionally creating inclusive spaces, which requires understanding the challenges experienced by PFAs from historically marginalized populations. Traditional practices that center on the needs of health care organizations (e.g., holding PFAC meetings during work hours and at hospital locations) or that overlook challenges experienced by PFAs (e.g., related to transportation, language access) disproportionately disadvantage PFAs from historically marginalized populations. Practices that emphasize inclusion as a dynamic process—one that requires cultural humility and a mentality of being "other-oriented" (Foronda et al., 2016)—can help cultivate a sense of belonging. Moving engagement opportunities outside of the health care setting and into the community (e.g., by holding meetings in the community with clinicians and staff as "guests") can shift dynamics, creating spaces in which all individuals feel welcome.

Our targeted literature search demonstrated a dearth of studies that highlight examples of engaging patients and families as partners in advancing DEI initiatives. However, by actively including individuals from diverse social identities, backgrounds, and communities, PFACs can call attention to the unique challenges faced by individuals from historically marginalized communities and drive progress toward the development of equitable and inclusive processes, procedures, and practices. At the same time, the responsibility for DEI initiatives is not solely within the purview of individuals from historically marginalized populations; health care organizations need to fully own, commit to, and invest in the work.

Limitations

Our study had several limitations. First, we limited our literature search to published work from 2010 and beyond and articles written in English. We may have missed pertinent articles from before 2010 or that were written in other languages. Second, we conducted interviews with 17 key informants; their perspectives may not fully encompass the range of experiences and perspectives of health care and community organizations. That said, our analysis reached thematic saturation. Third, key informant responses may have been susceptible to recall bias.

CONCLUSIONS

PFACs provide health care organizations with a valuable opportunity to partner with individuals from diverse backgrounds and social identities to understand and address the unique challenges faced by individuals from historically marginalized communities. The work to ensure that PFACs are diverse and truly representative and to develop meaningful partnerships with PFAs requires true commitment from health care organizations accompanied by actions that demonstrate to those with lived experiences how much their presence and voices matter. This requires structures for partnership that promote meaningful engagement, a strong sense of community, and connections to organizational initiatives.

The next steps in our efforts include qualitative work with PFAs from diverse backgrounds to understand their experiences within children's hospitals and other health care organizations. In addition, because organizations are in different places with this work, there is a need to support them in the implementation of PFAC DEI by developing and sharing guidance, approaches, and examples from a range of health care organizations. We hope that these findings can serve as a scaffold for furthering this work.

CONFLICTS OF INTEREST

None to report.

AUTHOR CONTRIBUTIONS

P. D., D. L. D., N. I. D, C. A. C., L. R., U. P., A. F. B. conceptualization; P. D., D. L. D., L. R., U. P. data collection; P. D., analysis; D. L. D., N. I. D., C. A. C., L. R., U. P., A. F. B. analysis review; P. D. and D. L. D. funding acquisition; P. D., D. L. D., N. I. D. writing-original draft; C. A. C., L. R., U. P., L. R. R., A. F. B. writing-review and editing.

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