Hospital Diversity, Equity, and Inclusion Efforts: Perspectives of Patient and Family Advisors

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abstract

BACKGROUND AND OBJECTIVES: Patient and family advisory councils are common within children's hospitals. However, lack of diversity among patient and family advisors (PFAs) may result in exclusion of crucial perspectives and perpetuate inequities. We sought to understand PFA perspectives on how children's hospitals should approach: (1) recruitment and support of PFAs from groups at greater risk of health inequities; and (2) development of meaningful partnerships with PFAs or patient and family advisory councils on institutional diversity, equity, and inclusion (DEI) efforts.

METHODS: We conducted a qualitative study of PFAs of children's hospitals from communities at greater risk for health inequities based on self-identified race, ethnicity, gender, socioeconomic status, disability, language, or other factors. Focus groups were virtual and group discussions were recorded, transcribed, and analyzed using inductive qualitative analysis.

RESULTS: In total, 17 PFAs participated across 5 focus groups (4 in English, 1 in Spanish). We identified 6 themes: (1) PFA diversity is necessary to understand existing health inequities; (2) diversity needs to be considered broadly; (3) recruiting for diverse PFAs requires intentionality, visibility of PFACs within and outside of the hospital, and deliberate connections with families and communities; (4) efforts to increase PFAC diversity must be accompanied by work to develop inclusive environments; (5) diversity efforts require meaningful engagement and equity; and (6) diverse PFACs can enrich DEI efforts but require organizational commitment and follow-through.

CONCLUSIONS: Insights from our qualitative study of PFAs can be used by healthcare systems to foster diversity and inclusion in PFACs and advance hospital DEI efforts.

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Drs Casillas and Rodriguez collected data and drafted the initial manuscript; Drs Unaka and Beck conceptualized and designed the study; Ms Dardess conceptualized and designed the study and conducted the initial analyses; Ms Patel designed the data collection instruments, collected data, and condcuted the initial analyses; Ms Rouse collected data and conducted the initial analyses; and all authors critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

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WHAT'S KNOWN ON THIS SUBJECT: Patient and family advisory councils are common within children's hospitals; however, they often fall short of reflecting the diversity of the surrounding communities they serve. As a result, the perspectives of populations at greater risk of inequities have been overlooked.

WHAT THIS STUDY ADDS: Our study illuminates barriers and facilitators for diverse and inclusive patient and family advisory councils, insights generated from the voices of patient and family advisors from underrepresented communities, including the perspective of those who speak a language other than English.

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Patient and Family Advisory Councils (PFACs) foster collaboration among patients, families, clinical and operational staff, and administrators in hospitals and health systems.[1] Rooted in principles of patient- and family-centered care, PFACs directly seek the guidance of patients and families to inform the development, implementation, and evaluation of organizational policies, programs, and services.[2,3] PFACs can have broad institutional impact across areas including research, patient safety, and patient family experience.[1,4]

Over three-quarters of children's hospitals in the United States report having at least 1 PFAC.[5] However, studies reveal a lack of diversity among patient and family advisors (PFAs).[6–9] Although many hospitals have explicitly sought to increase diversity in PFAC membership, many do not reflect the population served based on race, ethnicity, gender, socioeconomic status (SES), disability, and languages spoken other than English (LOE).[10] PFACs are also not typically engaged in diversity, equity, and inclusion (DEI) initiatives at the hospital level.[11] Without a concerted focus on expanding PFAC diversity and inclusion and involving PFAs in DEI initiatives, hospitals risk excluding crucial perspectives from communities at greater risk for health inequities.[10,11]

In response, hospitals are exploring intentional strategies to engage diverse communities and explore opportunities for partnership on organization-level DEI initiatives. Previously, we conducted a literature review and interviews of organization leaders to (1) to identify best practices for developing, supporting, and sustaining partnerships with populations who have been historically marginalized, and (2) identify examples of partnerships with patients and families in DEI work.[11] Through this current study, we sought to build on these insights and elevate the voices of PFAs from groups disproportionately impacted by health inequities. We used qualitative methods to learn directly from PFAs how children's hospitals can approach: (1) recruiting, preparing, and supporting PFAs from communities at greater risk for health inequities; and (2) developing and sustaining meaningful partnerships between PFACs and hospital and health system efforts related to DEI.

METHODS

Study Design

We conducted a qualitative study of PFAs who represented PFACs from free standing children's hospitals and children's hospitals within adult healthcare systems. Between February and May 2023, we facilitated 5, 1-hour virtual focus groups (FGs) with current PFAs at children's hospitals from communities at greater risk for health inequities to better understand their experiences and perspectives regarding DEI among PFACs and collaboration on institutional DEI initiatives.[12] We identified PFAs based on self-identified race, ethnicity, gender, SES, disability, LOE, or other self-identified factors.[13] We conducted 4 FGs in English and 1 in Spanish. Spanish-speaking FG participants identified as Hispanic/Latino individuals and were monolingual or bilingual Spanish-speakers. The Cincinnati Children's Institutional Review Board deemed the study exempt.

Recruitment

We used convenience and purposive sampling to recruit participants. We did purposive sampling through outreach to children's hospitals whose responses to a previously completed survey[5] noted having at least 1 specialty PFAC (membership defined by specific, shared characteristics such as race, ethnicity, sexual orientation, and/or medical condition).[5,14] Recruitment was also pursued through the Institute for Patient- and Family-Centered Care (IPFCC), Cincinnati Children's Hospital (CCHMC), and referrals from National Project Advisory Committee members inclusive of PFAC and DEI leaders from children's hospitals.

We developed an electronic recruitment survey containing sociodemographic questions including race, age, gender identity, sexual orientation, and length of time as a PFA. We also collected insurance status of the PFA as an imperfect proxy for SES and marker of factors linked to access to care.[15] We sent the survey to prospective participants before the FG session and results were used to guide participant selection; we prioritized individuals from communities at greater risk for health inequities, with an emphasis on racial and ethnic diversity. We limited participation to no more than 2 individuals from the same hospital. All participants received a $75 honorarium.

Analysis

We developed a semistructured FG question guide, prompting PFAs to reflect on: (1) their roles; (2) perceived barriers to and facilitators of consistent engagement in PFAC activities; (3) experiences and perspectives on recruitment and inclusion; and (4) awareness of and involvement in institutional DEI efforts. Trained facilitators conducted English-speaking FGs and 2 team members fluent in Spanish conducted the Spanish-speaking FG. We held all FGs via Zoom. We audio-recorded all FGs and used Otter.ai software to transcribe English-speaking FGs.[16] The Spanish-speaking focus group was transcribed and translated to English by qualified translators through CCHMCs language access services team. All transcripts were verified for accuracy.

The research team includes individuals from IPFCC and CCHMC with various roles and backgrounds. The principal investigator (P.D.) and FG task lead (U.P.) reviewed all transcripts. The task lead conducted an initial coding of comments into predefined project guiding questions (Fig 1 or paper by Dardess and colleagues [2023] for further discussion) using Microsoft Excel to assist with qualitative data management and analysis.[10,17] Our analysis was grounded in the data beginning with an open coding

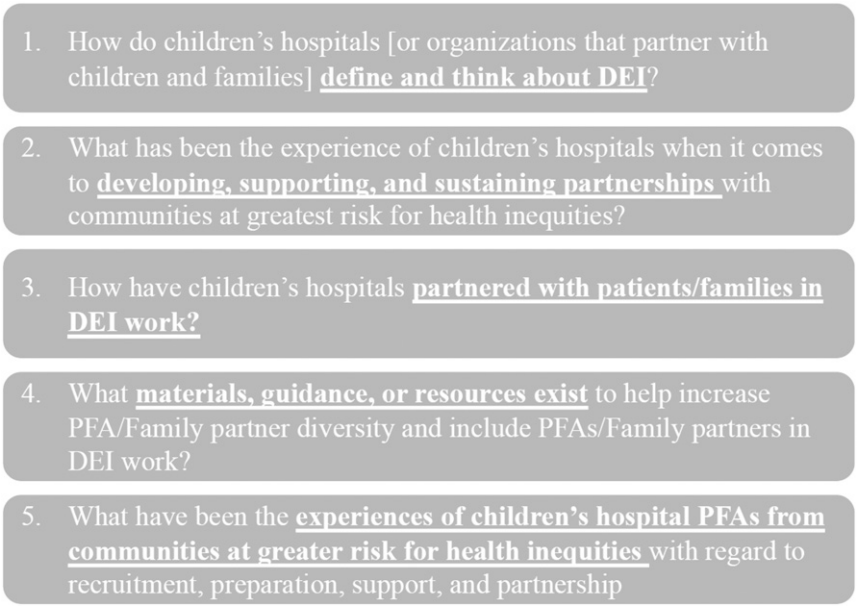

FIGURE 1
Guiding questions that informed the semi-structured interview guide and subsequent thematic analysis.

session in the initial review of the transcripts. P.D. and U.P. then systematically grouped FG data within the guiding questions, creating themes and subthemes, iteratively, using an inductive qualitative content analysis approach.[18] The team then developed overarching themes describing key messages, similarities, and variations across FGs. At the completion of the transcript reviews, we noted similar themes across all groups (including, the Spanish-speaking groups) with no new themes being generated. The team recorded a brief presentation in English and Spanish to share themes with participants and invite additional input; 2 participants responded, amplifying existing themes.

RESULTS

A total of 17 PFAs participated across 16 children's hospital sites. Table 1 includes the demographic characteristics of participants. Most participants identified as cisgender, female (88%). Furthermore, 41% identified as Black or African American, 35% Hispanic or Latino, and 35% white. Of the 6 participants who identified as white, there were additional dimensions of diversity captured, including gender identity, sexuality, presence in families with children insured by Medicaid, multicultural families, and families living in a rural area. Half of the participants had served as a PFA for at least 5 years. FG discussions generated 6 themes, see Table 2.

Theme 1: PFA Diversity is Necessary to Understand Existing Health Inequities

Participants noted that learning from the lived experiences of patients and families is necessary to fully understand the health inequities of a community. Without meaningful recognition of lived experiences, it is difficult for children's hospitals to identify how to best support patients with unique needs, resulting in overlooked communities. One participant noted, "I've met with a lot of minority families that have had certain suggestions or issues, but how are [hospitals] supposed to know these things are occurring if they don't have someone to represent?" Another participant shared that individuals with lived experience can help contextualize racial, ethnic, and language inequities in patient family experience data.

Theme 2: Diversity Needs to be Considered Broadly

Although many participants acknowledged engagement with diverse groups in terms of race and ethnicity as important, several participants discussed the need for broader diversity considerations tailored to the needs of those engaging with the hospital. This includes individuals with disabilities, fathers, and families with children with multiple complex medical and/or psychiatric conditions. One participant noted, "There are a lot of other groups that are not represented. I feel like the focus has to be on all inequities happening within the hospital." Many participants emphasized the importance of assessing the demographics of current PFAs, identifying gaps in diversity, and utilizing that data to inform recruitment.

Theme 3: Recruiting for Diverse PFAs Requires Intentionality, Visibility of PFACs Within and Outside of the Hospital, and Deliberate Connections With Families and Communities

Participants noted that improving diversity requires intentional recruitment. One participant described being

TABLE 1 Demographic Characteristics	
Characteristics	**Number (%)**
Age	
25–34	3 (18)
35–44	6 (35)
45–54	5 (29)
55+	3 (18)
Length of time as PFA	
Less than 1 y	1 (6)
1–2 y	5 (29)
3–5 y	2 (12)
More than 5 y	9 (53)
Race	
Black or African American	7 (41)
White	6 (35)
Asian	1 (6)
Native American	1 (6)
Middle Eastern	1 (6)
Other	1 (6)
Gender	
Cisgender female	15 (88)
Cisgender male	2 (12)
Ethnicity	
Hispanic or Latino	6 (35)
Sexual Orientation	
Heterosexual	13 (76)
Bisexual	1 (6)
Agender	1 (6)
Prefer not to say	2 (12)
Insurance status of PFA	
Medicaid, Medicare, or Medical Assistance	4 (24)
Insurance through employer or union	9 (53)
Insurance purchased directly from insurer	1 (6)
No health insurance	3 (18)

recruited by a friend who was a member of a PFAC looking for more "diverse voices," such as parents of children with disabilities. Participants also highlighted the importance of patients and families being aware of the existence and purpose of PFACs. One participant noted, "If we're trying to improve diversity [and] bring in more voices, more experiences, first we have to be visible to families." When families see themselves represented or see a need for their voice, they are more likely to get involved.

Some participants discussed the significance of relationship building beyond hospital walls to forge trust and relationships with surrounding communities and foster engagement. One participant highlighted their involvement in a food distribution program in partnership with the hospital; she was able to have candid conversations with families of patients about their experiences that led to PFA recruitment. Participants described the importance of relationship building rather than transactional outreach focused on PFAC recruitment.

Theme 4: Efforts to Increase PFAC Diversity Must be Accompanied by Work to Develop Inclusive Environments

To ensure equitable inclusion of PFAs, hospitals need to understand and address potential barriers to PFAC participation. Barriers cited included inconvenient meeting times, with one participant noting that meetings were held during working hours. Other participants noted that meeting times were often more convenient for hospital staff, resulting in "more employees invested as members on the council as opposed to patients and families." Requirements for in-person attendance were also noted as a barrier, although virtual participation options expanded because of the coronavirus disease 2019 pandemic, eliminating geographical constraints and increasing member attendance. Other barriers noted by participants included accommodations for members with developmental disabilities and for those who spoke a LOE.

In describing successful inclusive practices, many participants highlighted accommodations made on their behalf. One participant, who had a developmental disability, noted their PFAC provided early access to materials to allow additional time for review, along with the opportunity to provide postmeeting input. To address language access needs, participants noted variable access to translation and interpreter services for members who spoke a LOE. When interpretation was available, however, there were still logistical challenges. One participant mentioned that despite having an interpreter, the ability to follow real-time interpretation alongside the active conversation proved challenging.

Specialty PFACs were identified as a way for hospitals to foster more inclusive environments– especially among individuals who speak a LOE. One participant noted the lack of Latino voices among PFAs prompted her to advocate for the creation of a Spanish-speaking PFAC. Several hospitals have a similar model; 3 of the 4 participants in the Spanish-speaking FG belonged to a Spanish-speaking PFAC. Multiple participants in the Spanish-speaking group noted that the benefits were more than just language accessibility; the importance of shared cultural identity and experiences helped create a more inclusive PFAC environment. They also noted, "it is also about understanding our family and religious dynamics, especially in the area of health."

Theme 5: Diversity Efforts Require Meaningful Engagement and Equity

Although numerous participants noted efforts underway at their respective children's hospitals to enhance diversity, they articulated a fine line between meaningful engagement and feeling as though they were the "token" diversity member. One participant who identified as a member of a minoritized racial group explained that they did not feel welcome in their PFAC, describing a perceived unspoken expectation around conduct: "We want

TABLE 2 Themes and Quotes	
Themes	**Quotes**
PFA diversity is necessary to understand existing health inequities.	"I've met with a lot of minority families that have had certain suggestions or issues, but how are they supposed to know these things are occurring if they don't have someone to represent?" (English-speaking focus group)
Diversity needs to be considered broadly.	"I see this lack of representation of all of the different groups that need to be involved in DEI, that it is not just about racial and ethnic minorities, but there are a lot of other groups that are not represented. And I feel like the focus has to be on all of the inequities that are happening within the hospital." (English-speaking focus group)
Recruiting for diverse PFAs requires intentionality, visibility of PFACs within and outside of the hospital, and deliberate connections with families and communities.	"I feel like most families probably don't even know that the council exists … If we're trying to improve diversity, if we're trying to bring in more voices, more experiences, first we have to be visible to the families. And then maybe if they see themselves in us in some way, then they think, oh, wait, I can do that too. Or, oh, wait, this my experience isn't represented, but maybe there might be a place for me. So, that feels like a really important first step is actually finding a way for us to connect more directly with the families and some of that might just come naturally from that interaction." (English-speaking focus group)
Efforts to increase PFAC diversity must be accompanied by work to develop inclusive environments.	"[Our city] is still a city of first-generation immigrants. It's not like Maryland or Washington that already have 3 or 4 generations of Hispanic people. [In our city] many immigrants are still arriving. They don't have the freedom, or they don't have the ability to speak both languages. So, I know a lot of people who want to be engaged, but they don't know how. So, to have 1 in Spanish … Wow, that's a great idea!" (Spanish-speaking focus group)
Diversity efforts require meaningful engagement and equity.	"I don't feel like it was tokenist, actually. Because I know that the group has very actively tried to recruit and they think about ways of recruiting diverse advisory council members. So, I know it's something that they are truly invested in. And it's not like oh, here's our 1 person, she's off to the side. And whatever. Like it's something that in every facet of the way that they do things they think about these things. There are 3 moms now of color … so we are a minority [but] it doesn't feel tokenist." (English-speaking focus group)
	"There are just so many ways of collaboration and partnership building that I have not seen happen. And it's not from members like me being afraid. It's from hospital personnel. And people who look like you and others who don't really look at their own biases … So, I think a lot more education needs to be had and done. And I think there needs to be a form and good communication between PFACs and safe places where people of diversity, to know where they can go and communicate their needs and dislikes and disservice if they see it." (English-speaking focus group)
Diverse PFACs can enrich DEI efforts but require organizational commitment and follow-through.	"I'm a big advocate of you're doing things without the people that it affects. And there aren't a lot of adults that work for the hospital, or that are even on the DEI subcommittee that have these voices that they're trying to represent and trying to speak for. And that makes me seem like it's kind of shallow work that you can, you can't talk about a whole community of people. You can't talk about the whole community of heart, you know, deaf and hard of hearing community, and you don't have a representative there to voice their opinion." (English-speaking focus group)
	"[They] know my story, but how has that impacted the overall institution? Have you done anything differently when you engage with people of color? Have you done anything differently when you engage with somebody whose preferred language is something other than English? How is this translated to the family practice, to the emergency room? I couldn't tell you today, and I've been engaged with that institution for years. So, I don't know how it rolls out past that 1 hour meeting." (English-speaking focus group)

you to be articulate enough, but quiet and not share so much," and their perception that they "did not like for me to be too vocal." This experience was shared by other PFAs in that PFAC, resulting in the development of an "underground network of Black and Brown families." Reflecting on the lack of diversity in many PFACs, this participant further stated that, "a lot of healthcare systems really make it hard. I think, frankly, we're a showpiece." Another participant acknowledged similarly feeling "tokenized at first." However, this participant and others noted that this experience was mitigated when there was clarity from the PFAC about the need for more diverse perspectives and active and meaningful inclusion of PFA input. One participant noted that despite this concern of "tokenism," they represented a voice that needed to be included. They also suggested that, because of their involvement, other culturally and ethnically diverse PFAs eventually joined the council.

Bias training emerged as an important component of PFAC activities, albeit inconsistently implemented. Although some PFAs received formal training or presentations from the hospital's DEI department, others noted these opportunities were available only upon request. Participants underscored the necessity of comprehensive and consistent bias training as part of PFAC activities.

Theme 6: Diverse PFACs Can Enrich DEI Efforts, but Require Organizational Commitment and Follow-through

Participants expressed variable awareness about the overall DEI efforts of their respective hospital systems, reflecting a disconnect between PFACs and hospital-wide DEI work. A few participants noted deep engagement, with 1 participant citing their involvement with the DEI committee of their council. Others were engaged in systemwide DEI initiatives, outside of their PFA role. Some participants expressed concern about the superficial nature of existing DEI initiatives, attributing it to the lack of diverse voices shaping these efforts. One participant expanded on this, stating that their hospital was "doing things without the people that it affects. There aren't a lot of adults that work for the hospital, [or] on the DEI subcommittee, that have these voices that they're trying to represent." Another participant noted they were unsure whether their perspective and feedback resulted in any changes in care delivery. They noted that an important first step for hospitals is to "Be honest about where you are in your own journey as [an] organization before you start inviting families in, because you may cause more harm."

Participants recognized effective collaboration between hospitals and PFACs as pivotal in enhancing patient care. Numerous participants noted initiatives in which their PFACs partnered with the hospital to elevate patient voices and provide more inclusive care. For example, one participant noted their PFAC's work of introducing textured hair products and their availability to patients paired with nursing education on their uses. Other projects included improved interpretation for families who speak LOE in the emergency department, partnering with a local research study to perform a needs assessment resulting in interventions around food access and transportation, and sharing their experiences related to their identity to educate hospital employees. Although these initiatives were deemed significant, participants emphasized that they were initial steps, highlighting the need for larger systemic transformation.

DISCUSSION

Our study reveals the experiences of a group of PFAs from communities at greater risk for health inequities, engaged in efforts to diversify PFACs and/or contribute to institutional DEI efforts. To our knowledge, this is the first study to explore the qualitative experiences of PFAs from communities at greater risk for health inequities and explore this perspective in advisors who speak a LOE through a FG held in Spanish. Through this approach, we expanded on existing literature to further characterize facilitators and barriers to be representative of the patients, families, and communities served by the PFAC and elevate the voices of those from groups who have been historically underrepresented and medically underserved.

PFACs are potential catalysts for equitable care but fall short when their membership does not reflect the diverse patient populations served by children's hospitals. Recent analysis revealed a lack of diversity within PFACs, prompting increased focus on engaging individuals from communities at greater risk for health inequities.[5,13] With a growing number of organizations and accrediting bodies emphasizing the importance of DEI, institutions have increasingly engaged in strategic planning for effective partnership with underrepresented communities.[19–22] Some health systems have noted greater success than others.[10]

PFAs recounted contributions to initiatives that resulted in improved care delivery, more inclusive hospital environments, and greater interest from families of diverse backgrounds and lived experiences. However, limitations impact specific families, such as PFAs who speak a LOE. Several participants identified the development of specialty councils as a promising approach to cultivate inclusive environments.[10] Participants who served on a specialty council described them as safe spaces to communicate needs and issues, facilitate open dialogue, and in the case of language-specific PFACs, allow for meetings to be held in a shared LOE. Hospitals should consider implementing specialty PFACs based on the needs of their community. However, it is important to foster connections between specialty PFACs and general PFACs to ensure the ability to capture all voices and perspectives.

A common observation across all FGs was the time and effort expended by participants toward the goals of diverse recruitment and inclusive environments. Several commented on the tension that existed with the responsibility of serving as a minority in a group and representing the voice of their unique community. They commented on the perception, at times, of tokenism and feeling that their membership was an obligatory check box rather than a desire for meaningful engagement. This specific theme highlighted the concept of the "minority tax," which is commonplace among those who carry the disproportionate burden to advance DEI efforts solely based on their social identities.[23,24] We found that many participants felt a personal responsibility to broaden PFAC perspectives and diversify membership, to serve as cultural brokers of their community, and to ensure that important community voices would not be overlooked, by nature of being the sole voice in the group. Hospitals must acknowledge the unique challenges faced by specific PFAs, valuing them as important assets, while also ensuring that the responsibility for DEI efforts does not unfairly rest on the shoulders of a select few.[24]

Our study has several limitations. First, participants reflect a convenience sample; we recruited PFAs from several children's hospital contacts as well as network referrals, which may have introduced selection bias. Second, although participants were recruited from sites across the country,

our study's small sample size may limit the generalizability of findings in capturing the range of diversity that might be reflected among people who are from communities at greater risk for health inequities. Relatedly, although we were intentional in prioritizing participants who self-identified as belonging to communities at greater risk for health inequities, there is still a predominance of cis-gendered, heterosexual females who have served for greater than 5 years, both a product of our sampling and likely reflective of ongoing need for broader diversity in PFACs. Third, our demographic questionnaire did not capture information on education level, limiting our ability to characterize this demographic characteristic known to be linked to greater participation in PFACs. Lastly, our LOE FG only included Spanish speaking PFAs.

Despite these limitations, our study's findings provide important insights into the barriers and facilitators to achieving more diverse and inclusive PFACs and the potential for partnership on hospital DEI initiatives from the voice of PFAs across multiple centers, representative of groups often overlooked.

CONCLUSIONS

Although work to strengthen the representativeness of PFACs and to develop opportunities for collaborating with PFAs on DEI efforts are still in a nascent stage across children's hospitals, the future is promising. Insights from our qualitative study of PFAs will help inform engagement of communities at risk for health inequities; provide support for diverse, inclusive PFACs; and optimize DEI efforts of hospitals with the patient and family voice. Integration of DEI into the strategy and operations of PFACs can contribute to health systems' pursuit of improved patient experience, health care delivery, and outcomes for all patients.

ABBREVIATIONS

DEI: diversity, equity, and inclusion
PFA(s): patient and family advisor(s)
PFAC(s): patient and family advisory council(s)
PFE: patient and family experience
LOE: Language other than English

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