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## The intersection of diversity, equity, and inclusion with pediatric Patient and Family Advisory Councils

Ndidi I. Unaka

*Cincinnati Children's Hospital Medical Center*

Mindy Hoang

*University of Cincinnati College of Medicine*

Jesse Hsu

*University of Cincinnati College of Medicine*

Pam Dardess

*Institute for Patient and Family Centered Care*

Carlos T. Casillas

*University of Cincinnati*

*See next page for additional authors*

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### Cover Page Footnote

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### Authors

Ndidi I. Unaka, Mindy Hoang, Jesse Hsu, Pam Dardess, Carlos T. Casillas, Meghan Fanta, Deborah L. Dokken, and Andrew F. Beck

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Ndidi I. Unaka, *Cincinnati Children's Hospital Medical Center; Department of Pediatrics, University of Cincinnati College of Medicine, ndidi.unaka@cchmc.org*

Mindy Hoang, *University of Cincinnati College of Medicine, hoangmd@mail.uc.edu*

Jesse Hsu, *University of Cincinnati College of Medicine, hsujs@mail.uc.edu*

Pam Dardess, *Institute for Patient and Family Centered Care, pdardess@ipfcc.org*

Carlos T. Casillas, *University of Cincinnati, carlos.casillas@cchmc.org*

Meghan Fanta, *Cincinnati Children's Hospital Medical Center; Department of Pediatrics, University of Cincinnati College of Medicine, meghan.fanta@cchmc.org*

Deborah L. Dokken, *Institute for Patient- and Family-Centered Care, ddokken@ipfcc.org*

Andrew F. Beck, *Cincinnati Children's Hospital Medical Center; Department of Pediatrics, University of Cincinnati College of Medicine, andrew.beck1@cchmc.org*

### Abstract

Patient and family advisory councils (PFACs) advance patient- and family-centered care within children's hospitals but may not reflect the diversity of the communities they serve. We sought to assess PFAC diversity among children's hospitals and explore barriers, drivers, and enablers of recruitment, retention, and engagement of patient and family advisors (PFAs) with diverse perspectives and backgrounds. We performed a mixed methods study to evaluate structure, composition, recruitment, and engagement strategies of children's hospital PFACs. Individuals likely to have knowledge of or responsibility for PFACs at each Children's Hospital Association (CHA) member hospital were asked to complete an electronic questionnaire. A subset of respondents from hospitals varying in size and region participated in 1-hour virtual interviews. We received valid responses from 166 (73%) of 228 CHA member hospitals. Eighty-eight percent reported having at least one PFAC. Only 21% selected "definitely true" when asked if their PFACs reflected the racial and ethnic diversity of the community served. Twelve respondents from various children's hospitals participated in qualitative interviews. Five themes emerged: 1) Importance of Diversity in PFAC Membership; 2) Targeted, Personalized Recruitment and Engagement Strategies Facilitate Diverse PFACs; 3) Importance of Supporting PFAs from Diverse Backgrounds; 4) Ample Opportunities to Engage PFAs in Institutional Diversity, Equity, and Inclusion Efforts; and 5) External Factors as Drivers for Change within PFACs. Many PFACs are working to increase diversity, equity, and inclusion, but opportunities to close gaps remain. Findings may inform strategies to promote diversity, equity, and inclusion within PFACs across hospital systems.

### Keywords

Patient and family advisory councils; diversity equity and inclusion, family centered care; patient engagement; patient and family engagement

### Background

The National Academy of Medicine identified family centeredness and equity as core tenets of quality healthcare.<sup>1</sup> Additionally, the National Quality Forum highlights patient and family engagement as one of six national priorities seen as necessary to eradicate disparities, reduce harm, and decrease healthcare spending.<sup>2</sup> As a result, healthcare systems have implemented several initiatives, and used a variety of methods, to amplify and incorporate voices of patients and families. One key example is the creation of patient and family advisory councils (PFAC).<sup>3</sup> PFACs engage numerous stakeholders

such as organizational leaders, clinicians, allied health professionals, and patient and family advisors (PFA) to promote active collaboration and address pressing issues affecting patients and families within healthcare systems. PFAs contribute by sharing insights and perspectives from their points of view and providing recommendations for changes to, and improvements in, care delivery and/or institutional initiatives.<sup>4-6</sup>

Despite the significant benefits of diverse representation and a culture of inclusion in providing patient- and family-centered care, healthcare systems – including children's hospitals – still largely fail to reflect the varied

backgrounds and perspectives of patients and communities they serve, particularly those who have been historically excluded and marginalized.<sup>6</sup> Furthermore, children from marginalized communities are disproportionately affected by health disparities across conditions and phases of care, making the void of their experiences and perspectives in shaping healthcare delivery decisions all the more egregious.<sup>7-10</sup> To close equity gaps, healthcare systems must actively engage patients and families from historically marginalized groups to understand their care experiences and co-produce interventions aimed at improving care delivery and, ultimately, health outcomes.<sup>11</sup>

Little is known about how children's hospitals (or healthcare organizations more generally) ensure that their PFACs include the perspectives of historically marginalized groups. Studies examining the impact of PFACs on a range of institutional decisions have identified limitations in PFACs' ability to reflect the diversity of the patient populations served.<sup>12</sup> Barriers to diverse representation have included timing of PFAC meetings and lack of access to interpreters.<sup>13</sup> While organizations like the Institute for Patient- and Family-Centered Care (IPFCC) outline best practices for the creation of diverse and inclusive PFACs, with published guidelines informing recruitment and engagement practices, it is unclear whether and how these guidelines are utilized.<sup>4-6, 11</sup>

To address these gaps, we developed a research team with representatives from IPFCC and Cincinnati Children's Hospital Medical Center (CCHMC). Together, we first sought to assess the extent to which PFACs in children's hospitals across the United States (US) reflected the populations they serve with a keen focus on racial, ethnic, and socioeconomic diversity. Then, we sought to explore the barriers, drivers, and enablers of recruitment, retention, and engagement of patients and families with diverse perspectives and backgrounds.

## Methods

We conducted a mixed methods study of PFACs in US children's hospitals. Study components included an online survey of individuals within children's hospitals who had knowledge about the implementation of PFACs or patient- and family-centered care policies and practices in their respective institutions, and semi-structured, qualitative interviews with a small subset of respondents. The work presented in this paper focuses on the diversity, equity, and inclusion (DEI) strategies of PFACs and is part of a larger study that more fully evaluated PFAC function, structure, and engagement strategies.<sup>14</sup>

### *Study Population*

We recruited respondents from member hospitals of the Children's Hospital Association (CHA). As of August

2020, CHA included 228 hospitals, representative of approximately 90% of all children's hospitals in the US.<sup>15-16</sup> Hospitals were included in the study if they were self-governing children's hospitals; independent specialty hospitals, including those with clinical specialization in rehabilitation or chronic diseases; and pediatric units within adult hospitals. Hospitals were excluded if they did not provide care for children or were outside of the US.

### *Quantitative Data Collection and Analysis*

Quantitative data elements were collected via a survey questionnaire that was adapted from a questionnaire used in a previous study of PFAC presence and operational characteristics in New York adult hospitals.<sup>3</sup> Adaptations to the survey were made to customize the items to be most applicable to PFACs in children's hospitals (see Appendix). We also included items to explore emerging issues such as PFAC diversity and PFAC operations in the face of the COVID-19 pandemic. A link to the electronic survey was distributed to participants via email. IPFCC, in conjunction with CHA, created a contact list of individuals from each children's hospital expected to have specific knowledge and/or significant engagement with PFACs. A personalized link to the electronic survey was subsequently distributed to each contact via email. Survey responses were collected between October 2020 and January 2021. Our previous work includes a full description of data collection and analysis of survey results.<sup>14</sup> Here, we focused on responses related to recruitment, retention, and engagement strategies of PFACs, as well as diversity of PFACs. We used descriptive statistics to quantify such factors.

### *Qualitative Data Collection and Analysis*

We complemented quantitative data with qualitative data, obtained via virtual, in-depth, semi-structured interviews of a select subset of survey respondents. We conducted interviews to elucidate factors that affect PFAC performance as well as the unique barriers, drivers, and enablers of diverse PFACs. An interview guide was developed and piloted with a subset of respondents. Certain questions were designed to obtain a more in-depth understanding of PFAC practices related to DEI. Survey participants who responded in the affirmative to be contacted for the qualitative portion of the study were purposely sampled to achieve heterogeneity in hospital location based on US Census Region (Northeast, South, Midwest, and West), hospital type, hospital size based on number of beds, number of hospital PFACs (range = 1 to 14), and PFAC age (range from less than one year to 30+ years). One-hour interviews were completed between June 2021 and August 2021. Information about participants (e.g., job title, length of employment, responsibilities) was collected via a pre-interview online survey. Each interview was facilitated by two study team members, followed by a debrief session to review learnings and emerging themes.

**Table 1: Children’s hospital characteristics**

Characteristics (survey respondents)		n (%)			
Type of children’s hospital					
Independent and self-governing		72 (43%)			
Pediatric unit in larger adult hospital		79 (48%)			
Specialty or psychiatric		15 (9%)			
Characteristics (qualitative interview respondents)					
Region	Hospital Size	Hospital Type	# PFACs	PFAC Type (Unit/ Dept. based, Hospital-wide)	PFAC Age (years)
Midwest	344	Independent	1	Hospital-wide	≥ 10
Northeast	208	Independent	2-3	Both	≥ 10
Northeast	51	Ped unit	2-3	Both	≥ 10
South	392	Independent	≥10	Both	≥ 10
Northeast	103	Ped unit	1	Hospital-wide	≥ 10
South	288	Independent	4-5	Both	≥ 10
Midwest	244	Independent	≥10	Both	≥ 10
Midwest	34	Specialty	1	Hospital-wide	6-9
West	138	Ped unit	2-3	Unit-based	<1
West	381	Independent	6-9	Both	≥ 10
South	185	Independent	6-9	Both	6-9
West	131	Ped unit	2-3	Hospital-wide	6-9

Interviews were audio-recorded and transcribed using Otter.ai transcription software (Otter.ai, 2021, Los Altos, CA). Interview transcripts were uploaded to Taguette, an open-source research tool that assists with qualitative data management and analysis. Three members of the research team generated a thematic coding scheme corresponding to our research questions, interview guide topics, and after an initial review of transcripts. Interview text was systematically coded into themes using an inductive qualitative content analysis approach.<sup>17</sup> All interview data were independently coded, with discussion among coders clarifying code application. A senior research team member prepared summary tables with emergent themes and verbatim, illustrative quotes. Finally, we utilized an integrated analytical approach of quantitative and qualitative data and merged quantitative and qualitative results.

## Results

### *Quantitative Survey Findings*

Respondents from all 228 CHA affiliated hospitals were invited to complete the electronic questionnaire. We received valid responses from representatives of 166 hospitals, corresponding to a 73% response rate (Table 1). A total of 88% of respondents reported having at least one PFAC. Patients and families comprised the majority membership in most PFACs (83%). Just 21.6% of respondents selected “definitely true” when asked if their PFACs reflected the racial and ethnic diversity of the community served (Table 2). These quantitative findings

were confirmed and bolstered by qualitative findings, illustrative of real gaps PFAC DEI across US children’s hospitals.

### *Qualitative Interview Findings*

A total of 12 respondents subsequently completed qualitative interviews, all of whom were employed at their hospital for at least five years and reported having a high degree of familiarity with hospital and PFAC operations (Table 1). Respondents represented the variability in hospitals in several domains including geographic region, hospital size, hospital type, number of PFACs, PFAC type (e.g., hospital-wide, unit-based or specialty, or both), and age of PFAC(s). In addition, we selected for variability in PFAC performance, based upon survey responses indicating level of implementation of PFAC best practices. Overall, we had representatives from 4 regions in the US (Midwest, Northeast, West, and South). Table 2 shows the characteristics of selected interviewees. All respondents had attended a PFAC meeting and/or were familiar with the structure and function of PFACs at their respective institutions.

Qualitative interviews generated 5 themes related to barriers and facilitators of DEI initiatives within PFACs: 1) Importance of Diversity in PFAC Membership; 2) Targeted, Personalized Recruitment and Engagement Strategies Facilitate Diverse PFACs; 3) Importance of Supporting PFAs from Diverse Backgrounds; 4) Ample Opportunities to Engage PFAs in Institutional DEI Efforts; and 5) External Factors as Drivers for Change

**Table 2: Quantitative survey results**

PFACs Reflect Diversity of Communities Served in Terms of:					
		Limited English Proficiency n (%)	Gender n (%)	LGBTQ+ n (%)	Race/Ethnicity n (%)
Response Choices	Definitely not true	67 (49.3)	18 (13)	31 (23.5)	19 (13.7)
	Somewhat not true	37 (27.2)	24 (17.4)	45 (34.9)	35 (25.2)
	Somewhat true	20 (14.7)	54 (39.1)	42 (31.8)	55 (39.5)
	Definitely true	12 (8.8)	42 (30.4)	14 (10.6)	30 (21.6)
	Total Number of Responses	136	138	132	139

within PFACs. Table 3 (see Appendix) includes representative quotes from interview participants for each theme.

**Theme 1: Importance of Diversity in PFAC Membership:**

Respondents varied in the ways in which they defined diversity. Most respondents discussed diversity in the context of race and ethnicity. However, a variety of diversity dimensions beyond race and ethnicity were noted by respondents including religion, gender identity, sexual orientation, socioeconomic status, geographic location, primary language, disability, and medical condition. One respondent said, “When I say diversity, we’re talking about everything, right, like disabilities or special needs?” Another respondent noted, “We have a very diverse Council. But we take diversity in its entirety from inpatient, outpatient, religion, faith.” The variability in how diversity was defined among respondents highlighted the wide range of what respondents considered to be DEI initiatives and approaches.

Despite the varied diversity dimensions mentioned, all respondents articulated a desire to increase diversity on their respective PFACs to reflect their patient populations more accurately and to explicitly enhance representation of historically marginalized populations. Most respondents (11 out of 12) noted that their PFACs currently lacked sufficient diversity and were not representative of the communities they served. Many agreed that their PFACs were more representative of those from affluent and privileged backgrounds and lacked representation from, and perspectives of, those from racial and ethnic minority groups. One respondent stated, “The majority of our patient family advisors...look like me. They are women in their 30s, 40s, 50s, who are white, who don’t speak other languages. So, it’s a really tough thing that we have

grappled with for quite a while.” Another respondent noted, “I wish that I could say that we mirror our patient population to a T. That would be a lie... We do have some diversity on our councils, but the percentage of our population is not what is represented in our councils. We’re working toward that.” And another respondent stated, “I would be shocked if we had even a single member on our board [PFAC] that had Medicaid. Our board is all college-educated people, some who are retired, some who don’t have to work because of their place in life. We have a very privileged board.” Respondents also recognized that having conversations with PFACs about DEI sans diverse representation was an exercise in futility: “We actually intentionally waited to start the conversation [about DEI] until we had a little bit more diversity on the council. It felt like it wasn’t necessarily productive for us to have 10 white people sit around the table talking about diversity.”

**Theme 2: Targeted, Personalized Recruitment and Engagement Strategies Facilitate Diverse PFACs:**

Respondents noted that developing recruitment and engagement strategies to achieve a more representative PFAC was an ongoing effort with many challenges. Respondents noted that their current strategies for PFAC recruitment largely relied upon staff or clinician referral. These traditional recruitment strategies were viewed as inadequate for recruiting and engaging with representative councils. Although respondents expressed awareness of these challenges, they also described uncertainty in how to approach developing newer, improved strategies: “We just kind of did a recruitment push in the last six months. And we were really specific when we were asking about recruitment with the provider team, like this is what we’re looking for, this is what we’re hoping to capture. They

were great, and the people they recruited, they're lovely. They're just not diverse."

Additionally, respondents noted difficulties associated with building rapport and trust with specific patients and families, especially those from marginalized communities. More specifically, respondents reported challenges engaging and building relationships with those with time constraints, those from rural communities, and those with transportation and financial challenges. "Our close-by people are the people that we recruit because it was easy and convenient for them to come on site and come to meetings. We have this very affluent bubble that the hospital's located in, when in fact, the rest of [location] is rural, and has extraordinary socioeconomic diversity, and limited access to good bandwidth and varying comfort with technology." Respondents cited the lack of pre-existing trust between hospitals and the community as well as poor communication – including use of medical jargon – as factors that make invited family members feel out of place.

Respondents highlighted several recruitment and engagement strategies that their hospitals have employed with reported success. For example, some described an overhaul of recruitment and decision-making practices to promote more diverse and inclusive PFACs, "We've done things like try to improve the application. The previous application asked for education, experience, and things that could be seen as off-putting. And quite frankly, your education background has no impact on your ability to be a patient and family advisor... we were trying to shift that culture as much as we can."

Another respondent described leveraging other allied health professionals with the direct ask of recruiting patients and families from diverse backgrounds: "I send nomination forms to all nurses now... all child life specialists, all social workers... I now very specifically say..., 'We very much value input from parents that reflect our population. So, as you're making your nominations, please do keep diversity in mind.'" Another respondent highlighted the power of reaching out to patients and families from diverse backgrounds who have had suboptimal healthcare experiences: "A better strategy that we have started is when we actually have someone who expresses a concern about diversity, we invite them to the council. And that has worked better for us."

Some respondents noted the importance of parent-to-parent recruitment, especially when attempting to engage patients and families from marginalized communities, "I think it's going to take our diverse advisors to recruit with us. I think it has to come from their voice. They have to reach out to somebody that will reach out to somebody... We can talk about it as much as we can, but I believe they need a personal invitation. And I believe that it's critical

that first meeting, that they feel welcomed... And we better act upon it fast. So that they see a difference." Another respondent spoke about recruitment of families to their Spanish-language PFAC: "They are fantastic at connecting, they are the best. We haven't had as big of a problem with recruitment... I think because of the language, those moms will find other Spanish speaking moms, even during this time. Because I've heard from them, they feel so isolated, because of the language barrier. So, they'll find somebody who speaks the language. And through that experience, they will bring in new people."

Respondents also mentioned the importance of digital media in the recruitment of individuals who are traditionally underrepresented on PFACs. Many interviewees reported success posting content on websites and sharing information via social media platforms (e.g., Instagram and Facebook). One example: "I spent a big portion of this year beefing up our Patient Family Advisory Council page on our website. And so it goes, all councils then have their own page. And they have a story... We asked a parent to share their story kind of a testimonial on their pages." Others commented on leveraging local media outlets for recruitment.

### Theme 3: Importance of Supporting PFAs from Diverse Backgrounds:

Respondents highlighted the importance of integrating historically marginalized patients and families into existing PFACs by providing appropriate support and mechanisms to promote engagement and inclusion. At the same time, respondents reported a lack of infrastructure and/or resources as significant barriers to supporting PFAs from diverse backgrounds. For example, respondents noted challenges overcoming communication barriers when integrating PFAs with limited English proficiency into larger PFACs. While interpreters were seen as helpful, respondents worried about not fully capturing experiences of PFAs whose primary language was not English. After initially inviting Spanish-speaking patients and families into general council meetings with the use of a headset interpreter, another respondent received feedback that developing a separate PFAC specifically for monolingual Spanish speakers would be more effective and achieve a more comfortable environment.

While several respondents expressed a desire to develop PFACs for specific groups as a way of helping PFAs feel more comfortable sharing their perspectives, one respondent shared how staffing and time constraints made the development of a council for Spanish-speaking families elusive: "We've thought about the Spanish-speaking council. I know some of my peers have those, but truthfully, it's a huge scope with not a lot of people and not enough time." Relatedly, respondents also reported the challenges associated with the length of time needed to gain approval for the establishment of a new council, "A

lot of times, we have a lot of processes and procedures and things that we want to do, they just take really long to implement, and you have to go through so many processes, and so many people have to approve it.”

Additionally, effective use of technology emerged during the pandemic as a promising tool for improving PFAC diversity, inclusion, and engagement. Respondents noted that virtual meetings minimized barriers related to travel time and cost and allowed PFAs to participate while being at home with other family members: “Just seeing that everyone in the house was involved in the meeting, the cousin who was staying with them, because his family was quarantining from COVID, and he was sleeping in the spare bedroom on the floor. Everybody was involved in contributing. That is a visual to me that whenever I think about treating our Spanish families and what we need to provide... It’s not about one person making a decision. It’s everyone.”

Virtual meetings also facilitated engagement of PFAs with diverse perspectives. Most respondents did not cite access to the internet as a major barrier to PFA participation in virtual meetings; toolkits were developed to assist with navigation of virtual platforms and/or the network of PFAs were able to assist those who were less familiar with virtual platforms. “We developed a virtual toolkit for all of the PFACs to use, and that helped them understand how to conduct meetings in a virtual environment. From there, we went and talked to each of the PFACs to see...how much help they may have needed from us. And we...made sure that everybody had the support they needed. We used family advisors that were savvy with technology [to help]. The first meeting, I had one advisor [who] did a whole tutorial showing [PFAs] how to navigate virtually.”

#### Theme 4: Ample Opportunities to Engage PFAs in Institutional DEI Efforts:

Respondents noted that hospital-wide DEI efforts in strategy and planning were largely a recent endeavor. One respondent noted, “At the moment, I happen to be the lead person for DEI. It’s an area that we’re currently working on, and I’m the person for DEI because, frankly nobody else was doing it. I’m filling the gap.” Moreover, respondents articulated that PFACs would likely be engaged more consistently by institutional leaders to advance nascent DEI efforts as more time and resources become available for these initiatives. Several respondents reported the recent establishment of DEI committees and newly identified DEI leaders within the past year: “And then we have a new director of diversity. She has now probably been with us about four or five months. We now have one of our VPs [vice president] also over I, D, and E [inclusion, diversity, and equity] but again, that was just a year ago that we finally did that. I mean, how sad is that? That it took us that long to get administrators in those roles.” Opportunities identified by respondents included

expanding patient and family engagement in DEI initiatives by including PFAs on various organizational committees and amplifying the voices of patients and families from diverse backgrounds by having PFAs play a role in educating clinicians and other staff.

Respondents commented on the types of DEI activities in which PFACs and PFAs are now engaged, including providing DEI education/training for PFAs and sharing experiences and providing feedback on institutional DEI initiatives. One respondent shared that one PFA was a trained DEI facilitator and, with some of her colleagues, led “...about a 30 minute to an hour session of one of our meetings, looking at diversity and identities, how all of our identities change. And then that will continue doing more over time.” Another respondent highlighted the impact of Spanish-speaking PFAs on improving written communication with other patients and families who speak Spanish: “One of the members on our Hispanic Family Advisory Council is with our media and communications department. So that has hugely impacted, getting things translated into Spanish... A lot of our website now is translated into Spanish. And part of that was our Hispanic Advisory Council, went through our whole website and said, ‘this is where you need to prioritize this is where the most valuable information is.’ Our Hispanic Advisory Council was responsible for a lot of the change that we’ve seen. And I think they’ve played a big part.” Furthermore, some respondents discussed DEI initiatives in general and highlighted ways in which hospitals can become more engaged.

#### Theme 5: External Factors as Drivers for Change within PFACs:

A few respondents noted that the racial justice movement, ignited in 2020 by the murder of George Floyd and underscored by the disproportionate COVID-19 morbidity and mortality experienced among Black, Hispanic, and Native American children and adults, pushed leadership at many institutions to think about their own approach to DEI: “We actually formed kind of a DEI subcommittee in the Fall, as we saw what was happening around the country, we realized that it’s long overdue... We’ve always talked about it as a goal. But never really put pen to paper, or really something actionable, like a list of ‘this is what we should be doing.’” Another respondent noted, “We created an Office of Diversity, Equity, Inclusion, and Belonging when everybody else did... It’s a joint effort to do better in our community. But we also, as a children’s hospital, have, in one of our strategic priorities, really acknowledged that with systemic racism within healthcare, we can’t help kids be healthy. We have to fix that to be able to do better.” Hospital leadership, specifically those involved in or accountable for DEI efforts, were shown to be a driver for PFA involvement in institutional efforts: “We’ve had our Director of diversity now over the last year. We’ve also hired a medical director

of equity. And she is a huge advocate, she makes sure that there is a parent on the committees where they really need to hear parent voice.”

## Discussion

PFACs are a bedrock of healthcare quality. This mixed methods study sought to elucidate barriers, drivers, and enablers of recruitment, retention, and engagement of patients and families with diverse perspectives and backgrounds onto PFACs. Our work adds to the body of literature that characterizes DEI-related strategies and activities of PFACs. We provide quantitative information from a large swath of children’s hospitals and qualitative information from a representative few. Several themes emerged, including a clear focus on the importance of increasing PFAC diversity, the effectiveness of personalized approaches to recruitment, and the challenges associated with meaningful engagement of historically marginalized patients and families. The findings also underscore how the call for racial justice exposed woefully inadequate DEI efforts at children’s hospitals and spurred intentional, action-oriented work with and within hospital PFACs.

Despite the significant and progressive growth of racial and ethnic minority groups that comprise the US population, healthcare systems are plagued by the lack of a diverse workforce from executive leadership to frontline staff who provide care to patients and families.<sup>18-20</sup> A recent survey conducted by the American Hospital Association found that individuals who identify as racial and ethnic minorities accounted for only 14% of hospital board members and 11% of executive leadership.<sup>21</sup> This results in the propagation of processes, policies, and systems informed nearly exclusively by those with privilege, resources, and influence. Our findings indicate that PFACs are no exception and, nearly across the board, fail to reflect the diverse populations served by various hospitals.<sup>22-23</sup> These findings complement results from a cross-sectional study of council members of PFACs at a large Midwestern healthcare system which noted that their council did not reflect the population it served. In that study, most council members identified as white (70% of teen members, 84.3% of adult members), female (83.9%), reported English as their preferred language (100% teen, 91.6% adult), had at least an undergraduate degree (78.3%), were married (90.4%), had an annual household income of at least \$100,000 (56.6%), had a child with special healthcare needs (91.6%), and reported having private insurance for their children (80.7%).<sup>23</sup>

While respondents recognize the importance of diverse PFACs, challenges abound in reaching this desired end-state. Challenges included a lack of clarity regarding how diversity is defined as well as what diversity dimensions should be prioritized for recruitment. For example,

respondents noted efforts that targeted individuals from various racial groups, ethnic groups, those with limited English proficiency, and those who identify as LGBTQ+. Other efforts targeted those patients with special health care needs and their families – a population that tends to be overrepresented on PFACs.<sup>23</sup> Respondents noted that they, and hospital leadership, recognized the pressure to create inclusive environments that cultivate a sense of belonging for individuals from marginalized communities; they also recognized that this vital task was a difficult one. In identifying potential paths forward, many articulated the push-pull of developing PFACs for specific groups (e.g., Spanish-language PFAC). On the one hand, specialized PFACs may foster inclusion and contribute to a sense of comfort among PFAs. And yet, the creation of specialized PFACs can contribute to marginalization and othering.

Respondents described additional obstacles and potential opportunities regarding recruitment of individuals from diverse backgrounds. Our findings add to previous work that describes barriers and facilitators of recruitment and inclusion of diverse PFAs on councils.<sup>22,24</sup> Though organizations supporting and promoting PFACs have published toolkits for increasing inclusion of diverse voices,<sup>4,6</sup> organizations remain challenged by recruitment efforts that largely rely on word of mouth, personal connections, and individuals already involved in PFACs. A PFAC devoid of individuals from diverse backgrounds begets a homogenous PFAC. On the other hand, individuals who are a part of a diverse PFAC are more likely to refer and/or recruit individuals who add to the diversity of the PFAC. Such intentional recruitment, however, is not easy. Respondents shared multiple recruitment challenges, including: 1) application questions that lacked relevance (e.g., level of completed education) that can be demeaning and exclusionary; 2) inefficient processes, lack of time and/or resources to create PFACs that meet the unique needs of specific populations; and 3) lack of rapport and trust between hospitals and patients and families from historically marginalized communities.

Though such challenges should not be minimized, the COVID-19 pandemic forced hospitals to assess and adapt longstanding practices and, in some cases, develop new ways of recruiting and engaging patients and families. Respondents highlighted the importance of a multimodal approach to communication (i.e., websites, social media, local media outlets), soliciting patient and family referrals from a variety of healthcare professionals, and adaptability based on emerging or evolving needs as critical recruitment strategies which are aligned with previously published work.<sup>24,25</sup> Respondents also pointed to virtual meetings as a way of providing flexibility to families who otherwise may not be able to easily attend in-person meetings. More importantly, respondents recognized the opportunity to intentionally seek out and recruit patients

and families who have expressed concerns about DEI to hospitals.

More recently, healthcare systems have recognized the importance of patient and family involvement in research, quality improvement, patient safety, and DEI initiatives; the value of such engagement is reinforced by various policies and regulatory requirements.<sup>26-28</sup> PFACs are critical mechanisms by which patients and families can connect and partner with hospital leadership to advance these efforts. Furthermore, hospitals must optimize engagement and partnerships with patients and families from marginalized communities with lived experience as a key part of their efforts to address equity gaps in health outcomes. Hospitals eager to make improvements must be focused on reducing and eliminating disparities, and diverse representation on PFACs is a crucial step toward quality, safe, and equitable care.

Our study was not without limitations. First, we conducted 12 interviews for the qualitative portion of this study, which may impact the generalizability of the findings. However, we were intentional in recruiting respondents representing hospitals that varied in size, location, and populations served. Second, our results may have been affected by social desirability, especially given the focus on DEI. However, based on our findings, respondents clearly identified significant deficiencies in the diversity of PFACs, the historical lack of intentional focus on DEI initiatives, and the obstacles that exist in efforts related to the recruitment, retention, and engagement of diverse PFACs. Third, respondents who participated in the study may have been from hospitals that are either primed for or are more actively engaged in DEI efforts. Finally, PFAs were not study team members or study participants, hence our findings reflect the perspectives of only one key stakeholder group.

## Conclusion

As hospitals increasingly and appropriately strive to partner with patients and families on institutional improvement efforts, representation on PFACs must mirror communities that those hospitals serve – especially those communities that have been historically marginalized. Our study identified barriers, drivers, and enablers to recruitment of diverse PFACs as well as opportunities for promoting increased representation and participation of historically marginalized patients and families. Next steps include understanding the experiences of patients and families from diverse backgrounds who serve on PFACs at children's hospitals to inform delineation of best practices for recruitment, retention, and engagement of diverse PFACs. Additionally, respondents shared potential strategies for increased impact of PFACs, with a focus on institutional DEI efforts; assessing the

relationship of PFAC diversity and institutional DEI initiatives should be a focus of future work.

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## Appendix

Table 3. Qualitative Findings

Themes	Summarized Findings	Key Quotes
Importance of Diversity in PFAC Membership	Respondents had varying definitions for diversity and noted that their advisory council was not reflective of their patient population.	<p>“So the people who were able to come up here for meetings are upper SES [socioeconomic status]. They’ve got the reliable cars. They’ve got the time, they got the money to pay for gas, they have the job that is probably a nine to five, and they can come in the evening and they can pay for a babysitter to keep their kids. I mean, kids were always able to come to our playroom and be with our child life specialists, we welcomed them. So that wasn’t a barrier. But still, sometimes you don’t want to bring your child and have your child at home late that night.”</p> <p>“It’s a continuing challenge across the board... We have 25 members on our big Council, and three of those members are African American, and the rest are Caucasian. And three of those members are male, and the rest are women. We’re a pretty white middle class Council.”</p> <p>“I think we could do better. I think we’re on our way, but we could definitely do a little more recruiting. And well, when I say diversity we’re talking about everything, right, like disabilities or special needs. Most of our families have pretty complex kids. So we usually get families that have significant healthcare issues. Right now, we just recruited a couple more that actually don’t have really complex needs, but have had challenges in accessing certain services like mental health. So that’s been good. So I feel like we’re getting there. But we do have work to do. We recognize that.”</p> <p>“We’re getting there, but we are not where we need to be. We have a very diverse Council. But we take diversity in its entire lives from inpatient, outpatient, religion, faith. But we do not have a family that is support for an individual that is transgender or supporting LGBTQIA forums, experiences. We are learning and creating bonds for that. We do have several Black, African American members who have experience in different units. We have some that have older children, some that have younger children. I look very carefully at it.”</p>
Targeted, Personalized Recruitment and Engagement Strategies Facilitate Diverse PFACs	Most reported using staff or clinician referral to recruit, while a much smaller proportion recruited through other parents and community outreach. Many PFAC leaders acknowledged that traditional recruitment strategies are inadequate and noted the value of digital media.	<p>“I think word of mouth of the current PFAs [facilitates diversity]. I would like to think that our wonderful recruitment plan is but when it comes down to it, it’s the parent network, they all know each other.”</p> <p>“I would say within the hospital community, PFAs are well known and valued and sought after. I bet if I went into our local grocery store and said, ‘Hey, do you know what a PFA is?’ Nobody would know. So we could definitely do better with that.”</p> <p>“I’m interviewing with the news anchor to Telemundo, which is our Hispanic news station this afternoon to serve on our PFAC. So she’s assured me because I’ve talked to her that she is more than willing to get families on TV and to interview, our manager of language services, to talk about our PFACs and to recruit for us.”</p>

**Appendix (cont'd.)**

**Table 3. Qualitative Findings (cont'd.)**

Themes	Summarized Findings	Key Quotes
Importance of Supporting PFAs from Diverse Backgrounds	Respondents highlighted the lack of infrastructure and/or resources to support PFAs from historically marginalized communities. The COVID-19 pandemic highlighted the utility of virtual meetings as a means of removing barriers and increasing engagement of PFAs from diverse backgrounds.	<p>“They [Hispanic PFAs] also said that how we advertise is critical and key, because they don’t understand the medical lingo. They don’t know what this council is going to be about. So are they going to feel, as they said in quotes, ‘dumb,’ because they won’t speak in fear of they don’t understand what’s being asked.”</p> <p>“We have been trying to develop the LGBTQ family advisory council for about three or four years. And we finally got the approval about a year ago.”</p> <p>“Previously, we were not inviting a lot of families to participate on the PFAC because they were traveling from hours away to our facility, but now they are able to be introduced and involved in the PFAC because of the virtual option.”</p> <p>“It’s a family centered community. And just seeing that everyone in the house was involved in the meeting, the cousin who was staying with them because his family was quarantining from COVID, and he was sleeping in the spare bedroom on the floor. Everybody was involved in contributing.”</p>
Ample Opportunities to Engage PFAs in Institutional DEI Efforts	Although PFA involvement in institutional committees, including those focused on DEI, varied, few hospitals reported having families and patients on committees other than PFACs	<p>“One of the goals of our medical center Family Advisory Council in 21-22 is to work with our staff in the area of [DEI]. So we have two parents that are serving on the [DEI] hospital wide committee.”</p> <p>“Another reason that our PFACs are successful is that we have parent advisors sitting on multidisciplinary committees – patient safety, patient experience, home health. When parents are in those roles, staff realize the value of their input.”</p> <p>“So doing things like the support events where we recognize other significant holidays or months that haven’t necessarily been brought to the forefront as often as they should. Looking at ways that we can provide more diverse support events, so that we’re not just covering Halloween and Valentine’s Day in the winter holidays, but things like Black History Month, Earth Day, women’s history, you know, things that matter.”</p>
External Factors as Drivers for Change within PFACs	Racial justice movement in 2020 pushed hospitals to think about their own approach to DEI and the inclusion of patient and family voice in key institutional initiatives.	<p>“That [the push for formation of committees for DEI] came directly from the leadership from, you know, across the organization, and so seeing the needs to push DEI as one of our priorities and goals for our organization. And so that’s why across the health system, we have made that a priority for each of the departments to be a part of.”</p> <p>I think we’ve had three meetings in the past year that were either exclusively, or primarily dedicated to DEI. One, this most recent one, we actually told all our hospital representatives, and even myself, we all recused ourselves from the meeting because we brought in this consultant. We wanted the families to feel comfortable speaking objectively and freely about their experience with our health system from that standpoint.”</p>

## Appendix (cont'd.)

### Supplemental File 1: Children's hospital PFAC survey questionnaire

#### Screening questions

1. What is the name of your children's hospital?
2. What kind of children's hospital is it?  
Independent and self-governing children's hospital  
Specialty (e.g., rehabilitation) or psychiatric children's hospital that is self-governing and independent  
Pediatric unit (designated as a children's hospital) within a larger adult hospital
3. Is there at least one PFAC within your children's hospital? {Yes; No; No, but we have one in development}
4. Is that PFAC primarily {Check all that apply}:  
Hospital-wide  
Specialty, departmental, or unit-based  
Both

#### For hospitals that have a PFAC:

5. Please specify which PFAC you will answer the following questions about: {Open-ended}
6. How long has the PFAC been in existence?  
Less than 1 year  
1 to 5 years  
6 to 9 years  
10 years or more
7. Our PFAC has: {Check all that apply}  
A charter or bylaws  
Annual written goals or plan  
An annual budget, designated specifically for the PFAC  
A patient (teen or youth) or family/parent advisor as either the chair or co-chair  
A senior hospital leader who serves as an executive champion for the PFAC  
A designated staff liaison  
A defined place on the organizational chart of the children's hospital, showing the relationship to hospital leadership and operations
8. Prior to the COVID-19 pandemic in March 2020, our PFAC met on average:  
1-4 times per year  
5-9 times per year  
10 or more times per year
9. Since the start of the COVID-19 pandemic in March 2020, has the PFAC met virtually via video or conference call?  
{Yes; No; Don't know}
10. Compared to before the pandemic in March 2020, our PFAC is meeting:  
More frequently than before  
As frequently as before  
Less frequently than before  
Our PFAC has not met since March 2020
11. Compared to before the pandemic, attendance at PFAC meetings has been:  
Better (more members attending)  
About the same  
Less (fewer members attending)

## Appendix (cont'd.)

### Supplemental File 1: Children's hospital PFAC survey questionnaire (cont'd.)

12. Our PFAC supports meeting participation by providing: {Check all that apply}
  - Language/interpreting services
  - Honoraria or stipend
  - Virtual participation
  - Other (please specify)
13. What percentage of PFAC members are parents, family members, or patients (teen or youth)?
  - 50% or less
  - More than 50%
  - Don't know
14. Our PFAC membership reflects the diversity of the community served by the hospital in terms of: {Definitely true, Somewhat true, Somewhat not true, Definitely not true, Not seeking this diversity}
  - Gender
  - Race/ethnicity
  - Socioeconomic status
  - Disabilities
  - Sexual orientation
  - Limited English proficiency status
15. Our PFAC uses the following strategies for recruiting new PFA members: {Check all that apply}
  - Referrals from staff or clinicians
  - Referrals from other PFAs
  - Social media, hospital website, or hospital publications
  - Outreach to community resources or organizations
  - Other (please specify)
16. We have a specific strategy aimed at the recruitment of a PFAC that reflects the diversity of the community served by the hospital. {Definitely true, Somewhat true, Somewhat not true, Definitely not true, Not seeking this diversity}
17. Our PFAC uses a selection process for PFAs that includes: {Check all that apply}
  - A written or online application
  - An interview or discussion
  - Background checks
18. PFAC members are provided with: {Check all that apply}
  - A formal orientation for new members
  - Mentoring
  - Opportunities for continuing education (e.g., conferences, webinars, training)
  - Additional training for special PFA placements (e.g., quality/safety committees, educators of health professionals, research committees)
  - Other (please specify)
19. PFAC PFAs and other PFAs serve on committees, teams, and task forces of the children's hospital such as: {Check all that apply}

Patient experience	Diversity and inclusion
Quality and safety	Community relations
Health information technology	Pandemic planning and response
Patient and family education	Other (please specify)
Staff and clinician education	None
Research	

**Appendix (cont'd.)****Supplemental File 1: Children's hospital PFAC survey questionnaire (cont'd.)**

20. In our children's hospital: {Yes; No; Don't Know}  
 PFAC PFAs or other PFAs serve on the hospital Board of Trustees.  
 PFAC PFAs or other PFAs serve on Board-level committees.  
 When PFAs serve on committees, teams, or task forces, there are typically two or more PFAs represented.
21. Does your children's hospital have paid family partners on staff (that is, family members who serve as staff and are tasked with representing the family's voice and promoting partnership with patients and families)? {Yes; No; Don't know}
22. Our PFAC regularly discusses data about the performance of the children's hospital. {Yes; No; Don't know}
23. Our PFAC: {Yes; No; Don't know}  
 Conducts an annual evaluation to review the process and effectiveness of the PFAC  
 Develops an annual report
24. The work of our PFAC and other PFAs is tracked and measured in the following ways: {Check all that apply}  
 Number of PFAs who serve on the PFAC or in other ways  
 Number and/or value of hours contributed by PFAs  
 Documentation of initiatives, activities, and committees on which PFAs are involved  
 Number of staff and students who received training from PFAs  
 No measurement or tracking done currently  
 Other
25. The outcomes of PFAC activities/initiatives are reported to: {Check all that apply}  
 Board of Trustees  
 Hospital leadership  
 Hospital staff  
 Community via hospital website or newsletters  
 Don't know  
 Other (please specify)
26. What percentage of PFAC activities and initiatives within the last year were initiated by the PFAC itself?  
 None or almost none  
 Less than half  
 About half  
 Most or almost all  
 Don't know
27. When the PFAC makes recommendations to leadership and staff of your children's hospital, how often is feedback about changes/outcomes/results provided? {Always; Usually; Sometimes; Never}
28. In your opinion, what were the three most important accomplishments of your PFAC in the three years prior to the COVID-19 pandemic in March 2020? {Open ended response boxes}
29. In your opinion, what are the three most important accomplishments of your PFAC since March 2020? {Open ended response boxes}

## Appendix (cont'd.)

### Supplemental File 1: Children's hospital PFAC survey questionnaire (cont'd.)

30. In your opinion, what were the three most significant challenges or barriers experienced by your PFAC prior to the COVID-19 pandemic in March 2020? {Check three options}
- Difficulty recruiting new PFAs
  - Difficulty recruiting and/or retaining diverse PFAs
  - Hospital leadership not committed to the PFAC as a priority
  - Transitions of key leaders or staff involved with the PFAC
  - Lack of resources (staff time, finances)
  - Limited understanding on the part of staff about the potential role and impact of PFACs
  - Lack of knowledge/experience about how to develop an effectively functioning PFAC
  - Other
31. In your opinion, what have been the three most significant challenges or barriers experienced by your PFAC **since** March 2020? {Check three options}
- Difficulty recruiting new PFAs
  - Difficulty recruiting and/or retaining diverse PFAs
  - Hospital leadership not committed to the PFAC as a priority
  - Transitions of key leaders or staff involved with the PFAC
  - Lack of resources (staff time, finances)
  - Limited understanding on the part of staff about the potential role and impact of PFACs
  - Lack of knowledge/experience about how to develop an effectively functioning PFAC
  - Other
32. Prior to the COVID-19 pandemic in March 2020: Our PFAC influenced the leadership, strategy, and operations of our children's hospital. {Definitely true; Somewhat true; Somewhat not true; Definitely not true}
33. Since the COVID-19 pandemic in March 2020: Our PFAC has influenced the leadership, strategy, and operations of our children's hospital. {Definitely true; Somewhat true; Somewhat not true; Definitely not true}
34. Prior to the COVID-19 pandemic in March 2020: {Definitely true; Somewhat true; Somewhat not true; Definitely not true}
- Our PFAC had an influence on improving quality and safety
  - Our PFAC had an influence improving patient experience
35. Since the COVID-19 pandemic: {Definitely true; Somewhat true; Somewhat not true; Definitely not true}
- Our PFAC has had an influence on improving quality and safety
  - Our PFAC has had an influence improving patient experience