

Adapting and responding to a pandemic: Patient and family advisory councils in children's hospitals during COVID-19

Pam Dardess

Institute for Patient- and Family-Centered Care

Deborah L. Dokken

Institute for Patient- and Family-Centered Care

Ndidi I. Unaka

Cincinnati Children's Hospital Medical Center

Jesse Hsu

University of Cincinnati College of Medicine

Mindy Hoang

University of Cincinnati College of Medicine

See next page for additional authors

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Other Medicine and Health Sciences Commons](#), [Pediatrics Commons](#), and the [Quality Improvement Commons](#)

Recommended Citation

Dardess P, Dokken DL, Unaka NI, Hsu J, Hoang M, Beck AF, Johnson BH. Adapting and responding to a pandemic: Patient and family advisory councils in children's hospitals during COVID-19. *Patient Experience Journal*. 2022; 9(1):62-71. doi: 10.35680/2372-0247.1661.

This Research is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

Adapting and responding to a pandemic: Patient and family advisory councils in children's hospitals during COVID-19

Cover Page Footnote

Support for this research was provided by the Lucile Packard Foundation for Children's Health. The views presented here are those of the authors and not necessarily those of the Foundation or its directors, officers, or staff. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm The authors wish to thank the project officers from the Lucile Packard Foundation for Children's Health, Allison Gray and Ly Nguyen, for their support. The authors also wish to thank the Children's Hospital Association for its partnership with the online survey and Children's Healthcare Canada for assistance with piloting the survey. Finally, we are grateful to the members of our National Project Advisory Committee (NPAC) for their contributions and thoughtful input.

Authors

Pam Dardess, Deborah L. Dokken, Ndidi I. Unaka, Jesse Hsu, Mindy Hoang, Andrew F. Beck, and Beverley H. Johnson

Adapting and responding to a pandemic: Patient and family advisory councils in children's hospitals during COVID-19

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

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

Ndidi I. Unaka, *Cincinnati Children's Hospital Medical Center*, Ndidi.Unaka@cchmc.org

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

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

Andrew F. Beck, *Cincinnati Children's Hospital Medical Center*, andrew.beck1@cchmc.org

Beverley H. Johnson, *Institute for Patient- and Family-Centered Care*, bjohnson@ipfcc.org

Abstract

This mixed-methods study investigated the effects of the COVID-19 pandemic on Patient and Family Advisory Councils (PFACs) within children's hospitals in the United States. Specifically, the study sought to understand how PFACs adapted operations as a result of the COVID-19 pandemic, how patient and family advisors (PFAs) were engaged in the response to COVID-19, and the intersection of the COVID-19 pandemic with PFAC diversity, equity, and inclusion. The study consisted of a survey distributed to 228 children's hospitals, with a 73% response rate, and in-depth interviews with selected survey respondents (n=12). While COVID-19 temporarily disrupted PFAC operations and forced rapid adaptations, most children's hospital PFACs transitioned successfully to virtual meetings, with 86% reporting that their PFAC met at least once from March to December 2020 and 84% indicating that their PFAC planned to meet as frequently or more frequently than before the pandemic. The majority of respondents (72%) reported that attendance at virtual PFAC meetings was the same as or better than with in-person meetings. Interview participants reported benefits associated with virtual meetings, including the potential ability to recruit and engage PFAs who better reflected the diversity of the patients and families served by the hospitals. Children's hospitals are well-positioned to be leaders in the field, contributing to the development of new approaches, lessons learned, and best practices moving forward. This is especially true as hospitals continue to navigate the evolving realities of the COVID-19 pandemic, and as PFACs address challenges associated with maintaining diverse, equitable, and inclusive councils.

Keywords

Patient-centered care, patient- and family-centered care, patient engagement, patient and family engagement, COVID-19, patient and family advisory councils, mixed methods research, healthcare

Introduction

Patient and Family Advisory Councils (PFACs) are a well-established approach for engaging patients and families as partners in change and improvement of processes and procedures within a health care organization or system.¹ PFACs emphasize partnership with patients and families in the planning, delivery, and evaluation of health care to ensure that it is responsive to patients' and families' priorities, preferences, and values. Within the pediatric setting, PFACs have a long history; some children's hospitals have family, youth, or child advisory councils that have been in existence for more than 20 years.²⁻⁴ In recent years, children's hospitals without PFACs have sought to add them, while those with PFACs have expanded and adapted their use. In both cases, PFAC growth aligns with an evolving evidence base that increasingly highlights their benefits.^{5,6}

Despite their impressive growth in both number and scope, many PFACs currently face challenges to advancement and sustainability.⁷ The COVID-19 pandemic emerged in the Spring of 2020 as a significant disruptor to the health care system. As hospitals faced an evolving situation and as restrictions on in-person gatherings went into effect, questions arose regarding if and how PFACs should continue meeting, how PFACs could inform the response to COVID-19, and what the impact of the COVID-19 pandemic would be on the future of PFAC programs. The COVID-19 pandemic also highlighted pre-existing and worsening racial, ethnic, and socioeconomic disparities in health care provision, and health outcomes more generally. This reality, alongside the renewed push for racial justice in the wake of the murder of George Floyd, amplified the need to reflect on the composition of PFACs and the inclusion of perspectives from marginalized populations in the work of PFACs.⁸⁻¹⁰

In late 2019, prior to the onset of the COVID-19 pandemic, teams from the Institute for Patient- and Family-Centered Care (IPFCC) and Cincinnati Children’s Hospital Medical Center (CCHMC) began planning for a mixed-methods study to better understand the prevalence and functioning of PFACs in United States (US) children’s hospitals and to identify the extent to which PFACs at children’s hospitals reflect the patient populations they serve. The timing of the study in relation to the pandemic afforded the opportunity to incorporate questions and learn more about how PFACs in children’s hospitals were affected by and responded to the pandemic. This article focuses on aspects of the study that relate to how PFACs adapted operations to the realities posed by COVID-19, the ways in which PFACs and patient and family advisors (PFAs) were engaged as partners in response to the pandemic, and the intersection with issues related to PFAC diversity, equity, and inclusion (DEI).

Methods

Study design

This study used a mixed-methods approach consisting of an online survey of representatives from US children’s hospitals and follow-up virtual interviews with selected survey respondents. The CCHMC Institutional Review Board (IRB) reviewed this study and deemed it exempt. All participants consented to participate.

Survey of US children’s hospitals

In the first part of the study, an online survey was sent to all children’s hospitals in the US that were members of the Children’s Hospital Association (CHA) (n=228).

The team drafted the survey questionnaire based on an instrument used in a previous study of PFACs in New York hospitals.¹¹ We adapted this instrument to reflect characteristics of children’s hospitals and to enable collection of information about PFAC operations in the face of the COVID-19 pandemic (Table 1). The draft survey was reviewed by a National Project Advisory Committee consisting of patient and family advisors and representatives from children’s hospitals, the American

A personalized link to the online survey was emailed to individuals likely to have knowledge of any PFAC within the hospital, including staff who worked in positions related to patient experience, quality and safety, and child life. These individuals were identified using CHA’s contact list, IPFCC contacts, and outreach to hospitals. Survey processes consisted of a pre-survey email, email with survey link, and up to three follow-up attempts via email and phone. Survey data collection occurred between October 2020 and January 2021.

Respondents to the survey were first asked questions regarding whether the hospital had a PFAC or worked with PFAs. If respondents indicated that their hospital had a PFAC, they were subsequently asked about the number and type of PFACs as well as PFAC characteristics, operations, and functioning. Respondents also provided information about the characteristics of their hospitals, including location and hospital type (e.g., independent/free standing, specialty, children’s hospital within an adult hospital).

Of the 228 children’s hospitals invited to participate in the survey, valid responses were received from 166 hospitals, or 73% of the sample. Surveys were coded as complete if respondents formally submitted the questionnaire through Qualtrics (n=161) or progressed through at least 25% of the survey questionnaire (n=5) without formal submission.

Interviews with children’s hospital staff

For the qualitative portion of this study, twelve one-hour video interviews were conducted with selected survey respondents in June through August 2021 to obtain a more in-depth understanding of PFAC operations and best practices. Interview participants were identified from survey respondents who responded affirmatively to a survey question asking about willingness to participate in follow-up interviews. Interview participants were purposively selected to achieve heterogeneity in hospital location, hospital type, hospital size based on number of beds, and number of PFACs at the hospital.

Table 1. Children’s hospital PFAC survey items related to COVID-19

<ul style="list-style-type: none"> • Since the start of the COVID-19 pandemic in March 2020, has the PFAC met virtually via video or conference call? • Compared to before the pandemic, do you anticipate that your PFAC will meet (more, as, less frequently) than before? • Compared to before the pandemic, attendance at PFAC meetings has been (better, about the same, worse)? • PFAs serve on key committees, teams, and task forces of the children’s hospital (select all that apply, with pandemic planning and response committee as an option)

Academy of Pediatrics, and the CHA. The survey was pilot tested with four children’s hospitals in the US and ten in Canada.

A semi-structured interview guide was constructed and piloted, with a subset of questions focused on adaptations in operations made by the PFAC in response to the

pandemic, the process by which changes were made, and the role that PFAs or the PFAC played in the hospital's pandemic response. The interview guide also included a series of open-ended questions about PFAC composition and the relationship with ongoing DEI initiatives. Information about interview participants (e.g., position title, length of time employed at hospital, responsibilities) was collected via a pre-interview online survey. A team of two interviewers conducted each interview, debriefing afterwards to review learnings and identify emerging themes.

Data analysis

Quantitative data from the survey were displayed using descriptive statistics. Frequencies were calculated for all survey items using Stata version 16 (Stata Corp, 2020, College Station, Texas, USA).

Qualitative interviews were audio-recorded and transcribed verbatim using Otter.ai; project team members verified each transcript for accuracy. Interview transcripts were uploaded to Taguette, a software program that assists with qualitative data management and analysis. Three members of the research team generated the thematic coding scheme based on the interview guide and an initial review

with discrepancies resolved through discussion. A senior research team member prepared code summary tables to identify themes and verified these themes with members of the research team that had conducted the interviews.

An integrated analysis of the quantitative and qualitative data was conducted, merging results from the survey and interviews. Findings from the interviews were used to enhance understanding of quantitative data by providing context for and additional details related to survey results.

Results

Survey respondent characteristics

Valid responses to the online survey were received from 166 of 228 children's hospitals to whom the survey was distributed (73% of potential respondents). Table 2 displays characteristics of respondent hospitals based on survey response categories.

Interview participant characteristics

A total of 12 of the 166 survey respondents also participated in a qualitative interview. Table 3 displays characteristics of hospitals that participated in the qualitative interviews. All interview participants were

Table 2. Characteristics of hospitals and PFACs within the hospitals

Characteristics	Number of participants (%) (n=166)
Type of children's hospital	
Independent and self-governing	72 (43%)
Pediatric unit in larger adult hospital	79 (48%)
Specialty or psychiatric	15 (9%)
Presence of PFAC	
Yes	146 (88%)
No	13 (8%)
In development	7 (4%)
Number of PFACs in the children's hospital	
1	44 (30%)
2-3	59 (40%)
4-9	32 (22%)
10 or more	11 (8%)
Age of PFAC	
Less than 1 year	5 (4%)
1-5 years	35 (24%)
6-9 years	31 (21%)
10 years or more	75 (51%)
Types of PFACs	
Hospital-wide	50 (34%)
Specialty, departmental, or unit-based	14 (10%)
Both	82 (56%)

of the transcripts. Interview text was systematically coded into themes using an inductive qualitative content analysis approach.¹² All interview data were independently coded,

Table 3. Characteristics of hospitals participating in interviews

	Region*	Hospital Type	# of PFACs	PFAC Age	# of PFAs
1	Northeast	Pediatric unit in adult hospital	5	20-29 years	30-50
2	Northeast	Pediatric unit in adult hospital	1	15-19 years	100+
3	Northeast	Independent, self-governing	2	15-19 years	10-15
4	Midwest	Independent, self-governing	1	20-29 years	30-50
5	Midwest	Independent, self-governing	6	15-19 years	1000+
6	Midwest	Specialty	1	6-9 years	Not reported
7	South	Independent, self-governing	14	10-14 years	51-100
8	South	Independent, self-governing	5	20-29 years	200-300
9	South	Independent, self-governing	7	6-9 years	30-50
10	West	Independent, self-governing	9	30+ years	100-200
11	West	Pediatric unit in adult hospital	2	<1 year	<10
12	West	Pediatric unit in adult hospital	2	10-14 years	10-15

employed at their respective children’s hospital for at least five years and had a high degree of familiarity with hospital procedures and operations. Participants described their job responsibilities as facilitating PFACs and PFA initiatives, PFAC coordination and performance, and “supporting forward momentum” of PFAC work. The majority of hospitals (75%) with a participant represented in the qualitative interview sample had more than one PFAC. Over half (58%) had PFACs that were in existence for 15 years or longer; only one had a PFAC that was in existence for less than one year. The number of total PFAs at the hospitals in the interview sample ranged from six to over 1000. Hospitals with larger numbers of PFAs were more likely to have PFACs in existence for a longer period and/or had structured programs to work with PFAs as virtual or e-advisors.

Survey Results

Survey responses provided information about PFAC meeting frequency, attendance, and PFA involvement on pandemic planning and response committees, as shown in Table 4.

The majority of survey respondents (86%) reported that their PFAC had met at least once in the time period of March to December 2020. In an open-ended survey question asking about PFAC accomplishments since March 2020, many respondents noted the transition to virtual PFAC meetings as their most important accomplishment. Nearly three-quarters of respondents (72%) reported that attendance at PFAC meetings after

transitioning to virtual meetings was the same as or better than before. Most respondents (84%) indicated that their PFAC planned to meet as frequently or more frequently than before the pandemic; prior to March 2020, 52% of PFACs met at least ten times per year.

Only a quarter (27%) of hospitals reported that PFAs were engaged in pandemic planning and response committees. In responses to an open-ended survey item, hospitals reported several challenges to partnering with PFAs from March to December 2020, including COVID-19 causing “interruptions” for the PFAC, the need to make decisions rapidly, and hospitals and staff being “overwhelmed.”

Qualitative Interview Findings

Qualitative interviews generated key themes related to the effect of COVID-19 on PFAC meetings, the timeline for transitioning to virtual meetings, challenges and opportunities associated with changes to PFAC operations, and how PFAs and PFACs contributed to the pandemic response. Themes are described below; Appendix 1 provides additional quotes from interview participants for each theme.

Theme 1: COVID-19 temporarily disrupted PFAC operations for many hospitals, forcing rapid adaptations.

Multiple interview participants noted that COVID-19 temporarily paused their PFAC meetings due to the inability to continue meeting in-person. Only three PFACs in the interview sample were able to transition immediately to a virtual environment and did not miss any of their

Table 4. Survey responses: COVID PFAC operations

Survey item	Yes	No
PFAC met virtually March to December 2020	120 (86%)	20 (14%)
PFAC will meet as frequently or more frequently than pre-pandemic	113 (84%)	22 (16%)
PFAC meeting attendance is the same as or better than pre-pandemic	91 (72%)	35 (28%)
PFAs serve on the pandemic planning and response committee	38 (27%)	105 (73%)

regularly scheduled meetings; two of these PFACs had started planning for or had implemented virtual meetings prior to the pandemic. During the pause in PFAC meetings, hospitals worked rapidly to understand the potential impact of COVID-19 on hospital operations and resources, identify appropriate virtual technology platforms, develop a plan for virtual meetings, and contact PFAs about their interest in continued participation.

Further contributing to delays were challenges associated with staffing. As COVID-19 infection rates increased in the Spring of 2020, some hospitals experienced staffing shortages due to furloughs and redeployment. This sometimes meant that a PFAC was left temporarily without a staff member to support its work. As one interview participant described, “We had a lot of people that left positions; we had a reduction of staffing of 25% across the health system at that time. So not only did we have to check with each of the PFACs to see if the same people were leading those efforts, those people may not even be in the organization anymore.” Despite these challenges, most interview participants indicated that their PFACs were holding regular virtual meetings by Summer of 2020.

Theme 2: Preparation of PFAs helped support participation in virtual PFAC meetings. Many interview participants reported providing support to PFAs for virtual participation. Several hospitals began with outreach to their PFAs to determine whether they had internet access and the ability to join a video conference. Interview participants noted that the majority of PFAs had access to the technology needed for virtual participation, with one stating, “I think everybody either has a laptop or is using a portable device of some sort, and even our families that don’t necessarily have the means have a cell phone that they can use.” However, access was an issue for some. Solutions included sending webcams to PFAs and offering phone dial-in options for PFAs without internet access. Several hospitals also prepared toolkits and guides for PFAs that included information about logging on to virtual platforms, using cameras, and participating in a virtual environment. Some hospitals provided tutorials to PFAs to assist them with questions and virtual access. Individual outreach was also important for PFAs who needed support with technology, with one interview participant sharing, “I have a Spanish-speaking Child Life specialist who is phenomenal with the parents. We have about eight parents on that council. If they were at a clinic visit, she met individually with these folks to show them how to log into Zoom, because most of them had never done it before. And she sat with them, walked them through it, had a practice session with all of them. And when they all signed on for that evening meeting, I almost cried.”

Theme 3: There were demonstrable benefits associated with virtual PFAC meetings, despite initial skepticism. All interview participants mentioned that, prior to the COVID-19 pandemic, both PFAs and staff viewed virtual meetings as vastly inferior to in-person meetings. PFACs that previously had the option for virtual meetings reported that they were not used with great frequency or effectiveness. One participant reported, “A couple of years ago, I wanted to try Zoom with our general council. And they were very against it, they did not like that idea at all. They felt like it was very important for people to come and be on-site. They were adamant about that.” Despite this prior skepticism, participants reported successful implementation of virtual meetings during the pandemic with several unanticipated benefits. First, similar to survey results, over two-thirds of interview participants reported better attendance by PFAs with the transition to virtual meetings. The remaining interview participants indicated that attendance was approximately the same as pre-pandemic. This was attributed to convenience—particularly related to eliminating the burden of travel and the time associated with it—and removing the need for childcare.

A second observed benefit of virtual meetings was improved PFA engagement, as demonstrated through more active participation in PFAC meetings. Some hospitals found that PFAs, particularly those who were not as vocal in-person, were more comfortable sharing thoughts and perspectives openly in a virtual meeting. As described by an interview participant, “When I meet with the PFAs, they are probably more open to me on Zoom than if I was sitting face-to-face with them in-person.” While reasons for this were unclear, interview participants speculated that being able to participate in meetings from home added a degree of inclusiveness and comfort.

Finally, multiple interview participants observed that having virtual PFAC meetings led to an improved ability to recruit and engage PFAs, with one stating, “We were able to receive a couple new PFAC members who weren’t invited initially... just because of their distance from the hospital. But now they are able to be re-involved because of the virtual option.” Interviewees also noted the potential for virtual participation to assist in recruiting PFAs who better reflect the diversity of patients served by the hospital, noting the removal of barriers to participation for PFAs who lack transportation or childcare, have constraints on their time, are geographically distanced from the hospital, or have medically complex children. Virtual PFAC meetings also enable PFAs to participate in ways that feel comfortable, with one interview participant explaining, “When we do the Spanish meetings, oftentimes it’s not just the parent on the council who is involved, the whole family is sitting in the living room and the whole family participates, including the patient. The family is

sitting on the couch with them and listening and commenting, and it's really beautiful.”

Theme 4. As they plan for the future, hospitals are exploring hybrid models that include the flexibility of virtual PFAC meeting options. Slightly over half of interview participants had discussed plans for future meetings; all reported plans to adopt a hybrid model for PFAC meetings, with a combination of virtual and in-person meetings when safe to do so. Providing continued options for virtual participation was seen as important for facilitating PFA attendance and helpful for recruiting a more diverse and representative group of PFAs, with one interview participant explaining, “When we think about wanting to be more representative of our patient population, we have to consider that not everyone can drop everything and get to [the hospital] at 6 pm on a Wednesday. There’s childcare, there’s jobs, there’s a lot of things.”

Despite the benefits of virtual meetings, interview participants also spoke about the important role of in-person gatherings, explaining that informal interactions, conversations, and celebrations were difficult to replicate in a virtual environment. In-person interactions also were noted as important for PFACs that engage in peer support and outreach, with one interview participant explaining, “Some parents, I think more in the NICU PFAC, expressed that they really want to meet in-person more. But the things that they do are a little bit different. They do a lot of family support...and so that one-on-one, face-to-face, they really value that.”

As an overarching principle to guide future planning, interview participants noted the importance of considering PFAs’ needs and preferences in terms of meeting frequency, format, time, length, and structure. One interview participant explained, “How do you structure a committee meeting, and at a time so that it meets the needs of the parents that you want to have participating? It may be a weekend meeting; it may be an evening meeting to be able to reach the most people. I think we’re going to learn going forward that we have to be more flexible.”

Theme 5. Despite pauses in PFAC meetings, many hospitals found ways to engage PFAs during the pandemic. Some hospitals noted challenges integrating PFAs into pandemic planning and response as PFACs paused meetings and priorities around COVID-19 shifted. In the early days of the pandemic, efforts focused on providing PFAs with information and updates about COVID-19, with one interview participant explaining, “A lot of our first couple of meetings, they [PFAs] wanted to know what was going on. Our PFAC is a family. And so of course we were concerned, and they were concerned for us.”

Ultimately, the majority of interview participants reported successfully engaging PFAs in the response to COVID-19 in multiple ways. For example, many interview participants reported that their hospitals partnered with PFAs to understand how patients and their families were experiencing COVID-19. This included experiences with care provided by the hospital, gaps, and unmet needs. As hospitals grappled with controlling the spread of COVID-19, PFAs provided input for revised family presence policies and communications around these policies.

Hospitals also engaged PFAs in COVID-related messaging and communications to the broader patient population and community (e.g., infection prevention, vaccine roll-out). Additionally, PFAs contributed to staff and leadership appreciation efforts, with one interview participant describing, “Our PFAC developed a video of parents and families saying thank you to our leadership that was sent to our president and CEO. And I heard that our president said, ‘Did you see what the PFAC sent us?’ And he broadcasted it throughout the hospital for all employees to see.” Finally, while less frequently mentioned, some PFAs also provided support for inpatients and their families in the form of virtual visits and connections.

Theme 6. COVID-19 amplified issues regarding PFAC diversity, equity, and inclusion. Multiple interview participants noted that PFAC DEI activities increased during the time of the pandemic as national events and conversations amplified issues of racial inequity and injustice. Work centered on DEI included providing PFAs with DEI education and training, holding conversations about the needs of specific populations, and engaging PFACs in providing input. For example, one hospital worked with its Hispanic family advisory council to provide information that was important for families during the pandemic, asking the council to review the hospital’s website and identify information that was a priority for translation. While indicating PFACs’ increased attention to DEI issues during the pandemic, all interview participants also acknowledged that their own PFACs were not fully reflective of the diversity of patients and families served by the hospital. Many interview participants noted this as a priority area for improvement while also noting that the hospital lacked a clear implementation plan for recruiting a more diverse group of PFAs.

Discussion

To our knowledge, this is the first large-scale examination of the impact of the COVID-19 pandemic on PFACs in either a pediatric or adult setting. The results demonstrate that PFACs continue to be foundational to bringing the voices and perspectives of families, and increasingly, pediatric patients themselves, into children’s hospitals. Despite the COVID-19 pandemic emerging as a

significant disruptor in health care, we observed that many PFACs were able to successfully navigate many of the challenges. With different histories, systems, supports, and norms, the processes for adaptation unfolded differently. However, many children's hospitals with PFACs were able to transition to virtual meetings and adapt to new ways of interacting. Previously-held negative views about virtual PFAC meetings appear to be shifting as hospitals observed sustained—and in some cases increased—PFA participation and engagement.¹³

While the extent to which PFACs were engaged in pandemic planning and response varied across children's hospitals, those that did so successfully confirmed that PFAs can serve as important partners in ensuring safety, communicating credible and understandable information, and facilitating outreach to communities.¹⁴ Interview responses suggest that hospitals with longer histories of partnership may have been in a better position to integrate PFAs into COVID-19 planning and response. PFACs and PFAs are a valuable resource for hospitals and an important link to communities served. There are opportunities to further elucidate their role and the impact of their contributions during a time when health care organizations are increasingly overburdened but needing a closer connection and understanding of the communities they serve. Continued efforts to engage PFAs can support the development of a group of PFAs who are positioned to partner not only in future pandemic planning but also in responses to other emerging public health issues.¹⁵

The forced acceleration around virtual PFAC interactions also highlighted opportunities, particularly related to increasing PFAC diversity. The National Academy of Medicine defines equity as a core tenet of quality health care.¹⁶ However, many PFACs struggle to recruit PFAs who are representative of the full spectrum of patient and family populations. As health care organizations look for ways to better understand and address the needs and perspectives of patients and families, engaging a more diverse group of PFAs, particularly from historically underserved populations, is essential for improving health care and addressing disparities.¹⁷ Known barriers to more diverse PFAC representation are similar to those that limit the ability to access care, including timing of appointments or meetings, the time and resources required to attend, and the types of support provided (e.g., language translation services).¹⁸ As hospitals focus on addressing health disparities amplified by the pandemic, the ability to participate virtually may be an important tool for recruiting PFAs who reflect the range of patients and families served.

Virtual participation could also prove to be a tool to build relationships, develop recruitment channels, build trust, and ensure that all PFAs feel welcomed and valued. As such, there is growing recognition that virtual meetings will continue to be an important part of hybrid PFAC models

moving forward. At the same time, simply offering virtual options for PFAC meetings will not address all issues associated with increasing PFAC diversity, and concerted strategies are needed, along with dedicated resources, to ensure that PFACs more fully reflect and include the populations served. In addition, for virtual meetings to truly serve as a mechanism for engaging a more diverse group of PFAs, attention needs to be paid to the supports and structures capable of facilitating inclusion and meaningful participation. PFAs will need equitable access to technology and the internet. Meetings, with both in-person and virtual participation, will need to be structured to ensure equitable opportunities for all PFAs to contribute and to feel included and respected.

Limitations

There are several limitations to the current study. First, the study was limited to children's hospitals that are members of the CHA. CHA's membership reflected 228 hospitals at the time the survey was conducted; however, there may be hospitals that were not accounted for in the survey. Second, while we obtained a robust response rate, we do not have information that allows us to compare the characteristics of non-responders with our survey sample; therefore, we are unable to identify potential non-response bias. Given the topic of the survey, it is possible that hospitals without PFACs were less likely to respond. Third, our information about PFACs' involvement in pandemic planning and response came largely from the qualitative interviews; that sample was more heavily weighted to hospitals with well-established PFACs that generally had a longer history of integrating PFAs. In addition, the survey included an item asking about PFA involvement on pandemic committees, but the wording of the question was such that it did not capture information about how PFACs themselves were involved in pandemic planning and response. Finally, while asking about the experiences of PFACs during the COVID-19 pandemic, we did not obtain information from PFAs themselves. PFAs' perspectives on experiences during COVID-19 and the adaptations and response of PFACs are a topic for future exploration.

Conclusion

Historically, children's hospitals have been leaders in patient- and family-centered care and in developing partnerships with patients and families. Partnering with patients and families in ways that reflect meaningful, collaborative partnership at the organizational level may accelerate learning,¹⁹ allow for meaningful progress towards the provision of true patient- and family-centered care and improve health care safety and quality.²⁰ The novel nature of the COVID-19 pandemic meant that there was no blueprint or existing best practices for hospitals to follow with their PFACs and PFAs during this time. As

children's hospitals continue to develop operational models for PFACs that navigate the realities of the COVID-19 pandemic, and as PFACs address challenges associated with DEI, children's hospitals are well-positioned to be leaders in the field, contributing to the development of new approaches, lessons learned, and best practices moving forward.

References

1. Minniti M, Abraham M. Essential allies—patient, resident, and family advisors: a guide for staff liaisons. Published 2013.
2. Haycock C, Wahl C. Achieving patient and family engagement through the implementation and evolution of advisory councils across a large health care system. *Nurs Adm Q.* 2013;37(3):242-6.
3. Wynn J. The transforming power of patient advisors. *NC Med J.* 2015;76(3):171-3.
4. Tuller D. Gaining family input at a children's medical center. *Health Aff.* 2021;40(5): 698-701.
5. Chadwick S, Miller D. The impact of patient and family advisory councils in one hospital system. *Pediatr Nurs.* 2019;45(1):42-46.
6. Cunningham R, Walton MK. Partnering with patients to improve care: The value of patient and family advisory councils. *J Nurs Admin.* 2016;46(11):549-551.
7. Wayman K. Creating and sustaining effective hospital family advisory councils: findings from the California patient and family centered care network of pediatric hospitals. https://www.lpfch.org/sites/default/files/field/publications/creating_and_sustaining_effective_hospital_family_advisory_councils.pdf. Published September 2015. Accessed November 10, 2021.
8. Jones K, Potter T. A toolkit to improve diversity in patient and family advisory councils: a new method to advance health equity. *Creat Nurs.* 2019;25(2):176-181.
9. Jones K. Diverse voices matter: improving diversity in patient and family advisory councils. <https://www.ipfcc.org/resources/Diverse-Voices-Matter.pdf>. Published 2018. Accessed November 10, 2021.
10. Sharma A, Willard-Grace R, Willis A, et al. "How can we talk about patient-centered care without patients at the table?" Lessons learned from patient advisory councils. *J Am Board Fam Med.* 2016;29(6):775-84.
11. Strategically advancing patient and family advisory councils in New York state hospitals. https://www.ipfcc.org/bestpractices/NYSHF_2018_PFAC_Online_v3.pdf. Published June 2018. Accessed November 10, 2021.
12. Patton MQ. *Qualitative research and evaluation methods.* 3rd edition. Thousand Oaks, CA: Sage Publications, Inc.; 2002.
13. Chadwick S, Miller D, Taff K, Montalbano A. TeleBoard: the move to a virtual family advisory board. *Pat Exp J.* 2020;7(2):83-6.
14. Colimore SLC, Allen L, Lawrence Z, et al. Johns Hopkins Medicine responds to COVID-19: adjusting patient- family- and staff-centered care. *Pat Exp J.* 2020;7(2):118-24.
15. Patient- and family-centered care and partnerships with patients and families during COVID. https://www.ipfcc.org/bestpractices/covid-19/Partnerships_with_Patients_and_Families_During_COVID.pdf. Published February 2021. Accessed November 10, 2021.
16. Baker A. Crossing the quality chasm: a new health system for the 21st century. *BMJ.* 2001;323(7322):1192.
17. Richard J, Azar R, Doucet S, Luke A. Pediatric patient and family advisory councils: a guide to their development and ongoing implementation. *J Patient Exp.* 2020;7(6):1476-81.
18. Sharma A, Huang B, Knox M, Willard-Grace R, Potter M. Patient engagement in community health center leadership: how does it happen? *J Comm Health.* 2018; 43(6):1069-74.
19. Britto MT, Anderson JM, Kent WM, et al. Cincinnati Children's Hospital Medical Center: transforming care for children and families. *Jt Comm J Qual.* 2006;32(10):541-8.
20. Carman K, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff.* 2013; 32(2):223-231.

Appendix 1. Themes and Quotes from Qualitative Interviews

Theme	Quote(s)
<p>Theme 1: COVID-19 temporarily disrupted PFAC operations for many hospitals, forcing rapid adaptations.</p>	<p>We held our March [2020] meeting and then everything just kind of shut down. Suddenly hospital policies were changing what felt like hourly, it wasn't even daily. [The PFAC] did meet in June [2020] for a virtual...recognition of everyone's hard work, a few updates. Then we always do a hiatus in the summer. In September [2020] we pivoted fully to the virtual model.</p> <p>Some of our councils probably only missed one month. Out of the 14 councils, at least ten of them started meeting after about three or four months. Only two of our 14 councils ended up not meeting. [Those councils] have now regrouped and are now meeting. It took a little while for everybody to get on board.</p> <p>Maybe we should've already had a process developed on how to transition in-person to a virtual setting. We had to think on our feet very quickly, within a month or two, to decide how we were going to provide support and access to all our PFACs.</p>
<p>Theme 2: Preparation of PFAs helped support participation in virtual PFAC meetings.</p>	<p>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.</p> <p>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.</p>
<p>Theme 3: There were demonstrable benefits associated with virtual PFAC meetings.</p>	<p>We actually have significantly better parental participation with the virtual format. I think for parents, it's just plain easier, because we're in a rural setting. You don't have to travel, you don't have to find parking, you don't have to find childcare, you don't have to do any of those things.</p> <p>We found that we had actually a much higher participation rate via Zoom. Our hospital is in [urban area] and parents have to come in, get sitters for some of their kids, parking. It was a bigger commitment of time. It's so much easier now.</p> <p>It [virtual participation] has broadened our ability to bring diverse geography. Now we have members who live three, four, or five hours away who are able to participate, where they couldn't before when we were having in-person meetings.</p>
<p>Theme 4: As they plan for the future, hospitals are exploring hybrid models that include the flexibility of virtual PFAC meeting options.</p>	<p>What I would like is that there will always be a virtual option. My proposal will be three meetings in-person and seven via Zoom. What I would love is to have our January meeting in-person, our June meeting in-person. Then we break in July. We do subcommittees, any kind of catch-up work, August comes, and then we have our December year-end meeting in-person.</p> <p>When we give flexibility and allow for some sort of virtual participation, a lot of times people can balance it and be where they're needed—maybe at work or at home—but also participating actively as a PFA.</p>

Appendix 1. Themes and Quotes from Qualitative Interviews (cont'd.)

Theme	Quote(s)
<p>Theme 5: Despite pauses in PFAC meetings, many hospitals found ways to engage PFAs during the pandemic.</p>	<p>Our March and April [2020] meetings were specific to COVID. One of the two of them was just an open forum. We had some of the physicians that could speak to policy and keeping kids safe and how we were hearing that it wasn't a kid's disease, but how did kids with significant special needs and risk factors fit into that?</p> <p>In the NICU, we really looked at how to support parents who couldn't both be at the bedside at the same time...a lot of that was coordinated through the liaison in the NICU, but with the support of our PFAs who provided the additional push to say, you need to figure something out, and you need to figure out how to get parents at the bedside.</p> <p>Probably a month or so ago our hospital rolled out vaccines for 12 years and up. And the PFAs definitely helped us with creating that message and pushing it out in a really positive way to encourage families to get their children vaccinated. We will also go back to them when we start vaccinating younger children.</p>
<p>Theme 6: COVID-19 amplified issues regarding PFAC DEI.</p>	<p>We've had three PFAC meetings in the past year that were either exclusively or primarily dedicated to DEI. The most recent one, all our hospital representatives recused ourselves because we wanted families to feel comfortable speaking objectively and freely about their experience with our health system.</p> <p>More than 50% of our payer mix is Medicare and Medicaid. But I would be shocked if we had even a single member on our (Family Advisory) Board that had Medicaid.</p> <p>When we went to Zoom, it did level the playing field a little bit more because people are all in their own homes, they don't have to travel. We need to recognize that, if we want a true representation of the families we serve, we need to give them what they need to be at the table.</p>