
Key Learnings for STRENGTHENING PARTNERSHIPS

Recommendations from

A National Study of Patient and Family Advisory Councils
in U.S. Children's Hospitals

November 2021

Deborah L. Dokken, MPA

Pam Dardess, MPH

Beverley H. Johnson, FAAN

Developed by:



BACKGROUND

While many children’s hospitals have long and expanding histories with Patient and Family Advisory Councils (PFACs),¹ to date there has been no national research on the prevalence and functioning of PFACs and other advisory roles in children’s hospitals.

Building on its 2018 study of PFACs in New York State,² the Institute for Patient- and Family-Centered Care (IPFCC) led a study, in collaboration with Cincinnati Children’s Hospital Medical Center, exploring the prevalence and characteristics of PFACs in children’s hospitals as well as factors contributing to their effectiveness. The study consisted of a national online survey sent to all children’s hospitals in the U.S. that were members of the Children’s Hospital Association (n=228). The survey was conducted between October 2020 and January 2021; it yielded 166 valid responses (73% response rate). Eighteen interviews were also conducted with individuals selected for their knowledge of PFACs and who represented different hospital locations, types, and sizes.

PURPOSE OF THIS DOCUMENT

Based on a synthesis of the findings³ from both the online survey and the qualitative interviews, this document highlights key learnings and recommendations for practice to provide practical guidance to the field for strengthening partnerships with patients and families.

The document is intended for hospitals that are developing PFACs—and also for those with well-established councils that might benefit from new “wisdom” from the field. Hospital leaders, PFAC coordinators, and other staff who work in positions related to patient- and family-centered care (PFCC) and patient experience and engagement as well as PFAC members themselves will benefit from the guidance provided.

¹ Children’s hospitals may use different terminology for these groups, e.g., Family Advisory Council, Parent Advisory Board. Some may also have Councils or Boards on which teens or youth serve.

² Institute for Patient- and Family-Centered Care. (June 2018) Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals. Available at: https://www.ipfcc.org/bestpractices/NYSHF_2018_PFAC_Online_v3.pdf

³ More detailed data from the study will be available in future published articles.

KEY LEARNINGS

1

Leadership commitment to and support of partnerships is important for the success of PFACs.

Interview respondents noted that leaders play a key role in setting expectations related to the involvement of patient and family advisors (PFAs) and to the infusion of PFCC throughout hospital activities and culture. For the small number of hospitals in the survey who reported having a PFAC in the past but not currently or who had tried unsuccessfully to start a PFAC, the absence of leadership support was a common reason cited for lack of success.

*“Because we have key senior leaders who attend PFAC meetings every time, families have the appropriate impression that this PFAC **does** matter – that it makes a difference.”⁴*



⁴ All quotations are excerpted from the qualitative interviews conducted as part of the study.

KEY LEARNINGS

2

Successful PFACs develop and expand progressively over time and focus ongoing attention on relationship- and trust-building among PFAs, staff, and the community.

Slightly more than half of the PFACs that responded to the survey had been in existence 10 years or longer. Hospitals with larger numbers of PFAs tended to have more well-established PFACs. In the interviews, several respondents mentioned that their hospitals had started with one PFAC and then expanded to others. When identifying factors that help sustain partnerships with PFAs, interview respondents mentioned the importance of building relationships, “keeping in touch,” and visibly acknowledging the value of the PFAC and its members.

“In the beginning, our PFAC was more of a group that provided feedback about what was brought to it. Over the last 10 years, we’ve grown to take on different and more active roles. We actually have our own initiatives. We are more of a partner!”

3

A defined infrastructure, including staff coordination and an allocated budget, facilitates and sustains PFAC development.

Most hospitals in the survey (90%) reported having a staff liaison responsible for facilitating the work of the PFAC. In addition to coordination responsibilities, the liaisons who participated in the interviews described their role as “supporting forward momentum” of PFAC work. However, the majority of survey respondents (64%) noted that their hospitals lack an annual budget designated to support the PFAC and less than one-third reported having paid family leaders.

“Initially, the PFAC didn’t get any traction because we didn’t have the right structure in place to have someone who’s committed to [the belief that] ‘these committees are my job.’”

KEY LEARNINGS

4

Organizations need a specific recruitment strategy to sustain and expand patient and family membership on PFACs and to ensure that populations served are represented.

The majority of responding hospitals (97%) reported using staff or clinician referral for recruiting PFAs. A much smaller percentage recruit PFAs through outreach to community resources or organizations. When asked about diversity of PFAC membership, only 20% of hospitals in the survey indicated that it was “definitely” true that members reflected the diversity of the community in terms of race/ethnicity. Recruiting and retaining a diverse group of PFAs was identified as a significant challenge. While there was a desire to improve diversity, most hospitals did not indicate having a clear recruitment strategy for doing so.

“We are a regional referral center and we get kids from all over the state. How do you ensure that you’re hearing the voice of everybody who is receiving services here?”

“It’s exciting to see that we are going from a more narrow diagnosis-specific or experience-specific focus to really looking at our community and looking at populations that have special needs or cultural considerations.”

5

Expanding involvement of PFAs beyond PFAC membership (e.g., organizational workgroups and committees) reflects growth and organizational commitment to patient and family engagement.

Survey results showed that it is most common for PFAs to serve on quality and safety committees (72%), patient experience committees (69%), and patient and family education committees (55%). Fewer than one-third of hospitals reported having families and patients on other committees, including staff and clinician education, health information technology, community relations, research, diversity and inclusion as well as pandemic planning and response.

“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.”

KEY LEARNINGS

6

Patient and family advisors need planned opportunities for onboarding, mentoring, and continuing education as well as specific training for roles on workgroups and committees.

While the majority of hospitals (81%) in the survey provide formal orientation for new PFAC members, only 49% provide PFAs with mentoring or opportunities for continuing education.

“Involvement on the front end – making sure we have the right people at the right time – has been really important. And, then, setting expectations and investing in the training and coaching of advisors.”

“The key to our longevity is the fact that we’ve worked really hard to implement specific training for patient and family advisors. We’ve created a mentor program to make sure that onboarding is more seamless and that advisors can jump in and get to work.”

7

As the number of PFACs grows within an organization, it is helpful to design a mechanism to ensure coordination and synergy of efforts.

The majority (almost 70%) of survey respondents indicated that their hospital has more than one PFAC; more than 20% reported having between six and nine PFACs. Interview respondents described different models used to provide coordination across multiple councils; the most common is having a larger coordinating council or periodic meetings of council chairs.

“We’re trying to make sure that we don’t have multiple PFACs working on the same thing and to create some synergy and leverage learning from one PFAC to another.”

“The staff liaison and the parent PFAC chairs attend leadership meetings every other month. Our goal is that they will report back to their own council about what other councils are doing.”

KEY LEARNINGS

8

Successful PFACs adapt to emerging issues (e.g., the COVID-19 pandemic) and are integrally involved in organizational decision-making about them.

More than 85% of surveyed hospitals reported that their PFAC had met since the start of the COVID-19 pandemic; the majority (78%) anticipated that the PFAC would continue to meet as frequently as it did prior to the pandemic. In response to an open-ended question about PFAC accomplishments since March 2020, more than 40% of the responses mentioned the PFAC's successful transition to virtual meetings and involvement of the PFAC in COVID-related projects and activities.

“Throughout COVID, when a policy or procedure was beginning to be developed, we utilized the PFACs, together with health system leadership.”

“We definitely used our family advisors to help us navigate the communication challenges with COVID. When we rolled out vaccines for 12-year-olds and up, the advisors helped us with creating the message and pushing it out in a really positive way.”

9

Measurement, evaluation, and reporting of PFAC impact on key initiatives highlights the PFAC's importance within the organization and provides the rationale for expanded engagement of patients and families.

Although many hospitals document initiatives and activities in which PFAs are involved, fewer than half of survey respondents reported conducting an annual review focused on the process and effectiveness of the PFAC. In the interviews, respondents affirmed the importance of measuring impact but talked about the lack of time to plan and implement measurement and evaluation approaches.

“The measurement is more around ‘How much did we participate, What did we do’ rather than what difference did this intervention make? We haven’t really figured out how to measure the work that the advisors do.”

KEY LEARNINGS

10

Effective use of technology has the potential to increase PFAC membership, diversity, and effectiveness.

During the interviews, some hospitals reported exploring virtual meetings prior to March 2020 but without great frequency or effectiveness. However, as a result of their experience during COVID, respondents highlighted the promising potential offered by technology to increase PFAC membership, to diminish disparities (e.g., due to the inability of some PFAs to attend in-person meetings) and, therefore, to increase the diversity of PFAC members. In providing information about ways in which their hospital partners with PFAs outside of the PFAC, more than half of survey respondents (55%) indicated that PFAs serve as virtual or e-advisors.

“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.”



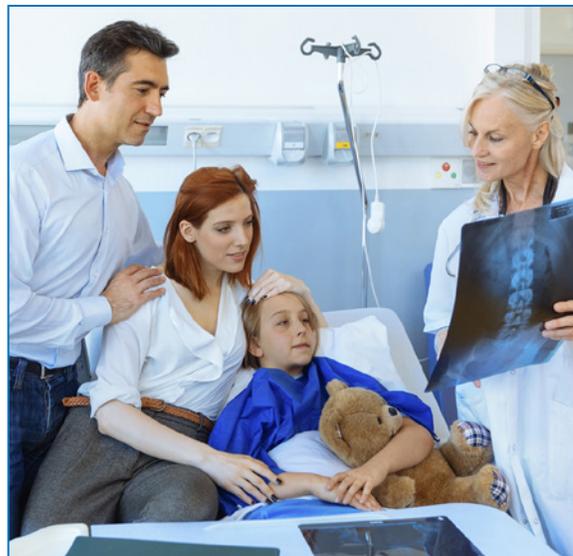
IN CONCLUSION

Since their inception more than three decades ago, PFACs have been an important mechanism for engaging families and patients as partners in change and improvement in pediatric health care. With this recent study of PFACs in U.S. children's hospitals that includes data collected during the time of a public health crisis, findings are available to further guide the development and expansion of PFACs. Reviewing this document and its key learnings with a multidisciplinary team, including patient and family advisors, will further the development of strategies for strengthening partnerships within your hospital or health system.



©2021 Institute for Patient- and Family-Centered Care®

The Institute for Patient- and Family-Centered Care grants permission to duplicate this publication for education and planning purposes. This material may not be distributed for any commercial use.



ACKNOWLEDGEMENTS

Support for this research was provided by the Lucile Packard Foundation for Children's Health, Palo Alto, California. The views presented here are those of the authors and not necessarily those of the Foundation or its directors, officers, or staff.

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. We also wish to thank the Children's Hospital Association for their partnership with the online survey and Children's Healthcare Canada for their assistance with piloting the survey. Finally, we are grateful to the members of our National Project Advisory Committee for their contributions and thoughtful input.

