

Strengthening the
DIVERSITY
AND ROLE
of Patient and Family
Advisory Councils

Opportunities for Action



INSTITUTE FOR PATIENT- AND
FAMILY-CENTERED CARE®
Transforming health care through partnerships

BACKGROUND

Patient and Family Advisory Councils (PFACs) can help create meaningful partnerships with patients and families, bringing their voices into the planning, delivery, and evaluation of health care. A common challenge facing many health care organizations is the lack of diversity among PFAC members compared to the broader patient population. Patient and family advisors (PFAs) are more likely to be White, female, more highly educated, and of higher socioeconomic status. Likewise, while many health care organizations have developed structures, plans, and initiatives to advance health equity, partnership with patients and families in diversity, equity, and inclusion (DEI) work is limited.

These challenges place health care organizations at significant risk of not obtaining input and perspectives from individuals, groups, and communities that experience health inequities at disproportionate rates. PFACs that are reflective of the patient population served and engaged in DEI initiatives are better positioned to help health care organizations:

- ▶ address health inequities and social determinants of health;
- ▶ improve health care quality, safety, and experiences of care;
- ▶ promote social justice; and
- ▶ foster community engagement.

ABOUT THIS RESOURCE

This document highlights opportunities for action in **six key areas** to help hospitals strengthen the diversity of PFACs and the role of PFAs in DEI initiatives. In developing this resource, the project team conducted a focused review of the literature; interviews with individuals working in children's and adult hospitals and other health-related settings; and focus groups with PFAs from historically marginalized populations. This work builds on [key learnings](#) from a 2021 study of U.S. children's hospitals that provided guidance to the field for strengthening partnerships with patients and families and identified a clear need for additional information to guide PFAC DEI forward.

Suggested citation: Institute for Patient- and Family-Centered Care. (2023). *Strengthening the diversity and role of patient and family advisory councils: Opportunities for action*. Institute for Patient- and Family-Centered Care.

USING THIS RESOURCE

PFAC coordinators, hospital DEI leads, staff who work in positions related to DEI and patient- and family-centered care (PFCC), and PFAC members can review, share, and discuss the information in this document to identify organizational areas of opportunity and develop initial goals for improving PFAC DEI.

Following are definitions for key terms used in the document:

► Diversity

The representation of individual and collective identities (including but not limited to factors such as race, ethnicity, ability, gender identity, sexual orientation, and socioeconomic status) with particular consideration of those who have been historically marginalized or underrepresented.

► Equity

The understanding of systems that contribute to differential access to opportunities, information, resources, and power.

► Inclusion

The active practice of intentionally creating space for diverse perspectives and voices. Inclusion requires acknowledging unequal power in relationships and providing accommodations to ensure all people can participate in meaningful ways.

► Patient and family advisors (PFAs)

Patients and families who partner with health care professionals to improve health care by sharing their insights and perspectives and offering suggestions for change and improvement.

► Patient and family advisory council (PFAC)

A formal group of PFAs and hospital staff members that meets regularly to improve hospital programs, policies, and processes.

OPPORTUNITIES FOR ACTION

1

Define Goals for PFAC Diversity, Equity, and Inclusion

- Obtain data to understand the diversity needed on the PFAC
- Develop goals and plans for PFA diversity and inclusion
- Create connections between the PFAC and hospital DEI work

2

Recruit to Increase PFA Diversity

- Increase PFAC visibility and make PFA diversity a shared goal of the institution
- Build authentic relationships between the hospital and community
- Identify and address barriers in the PFA recruitment and application process
- Develop recruitment materials that promote diversity and inclusion

3

Explore and Use Structures that Facilitate PFA Participation

- Offer varied options for PFA participation
- Explore opportunities for specialty PFACs
- Develop approaches to meet community needs

4

Support Inclusive and Equitable Practices

- Identify and address barriers that prevent full participation from PFAs
- Develop and implement guidelines for inclusion
- Provide training related to DEI practices for staff and PFAs
- Create opportunities for relationship-building

5

Partner with PFACs in Hospital DEI Initiatives

- Engage PFAs as partners on all DEI projects, workgroups, and committees
- Actively seek input from historically marginalized patients and families
- Share DEI data and brainstorm opportunities to eliminate inequities

6

Sustain PFAC Progress

- Provide opportunities for meaningful participation and feedback about results
- Conduct formal and informal assessments of the PFAC
- Increase diversity in PFAC leadership

1. Define Goals for PFAC Diversity, Equity, and Inclusion

Obtain data to understand the diversity needed on the PFAC

Data about a hospital's patients and their health outcomes can provide a better understanding of the diversity that needs to be reflected among PFAs. Collecting and reviewing data about current PFAs can highlight potential gaps. Most commonly, children's hospitals have considered PFA diversity based on dimensions of race, gender identity, sexual orientation, and socioeconomic status. Additional dimensions for hospitals to consider include ethnicity, culture, language, geographic location/place of residence, type of insurance, disability status, immigration status, health care experiences, and other factors that may affect health outcomes.

Develop goals and plans for PFA diversity and inclusion

Establishing intentional goals for PFA diversity encourages progress. Goals are most helpful when customized to an organization's patient population, connected to broader hospital DEI work, and accompanied by strategies and specific action items. Setting intentional goals can also help prevent tokenism, that is, making changes that give the appearance of diversity without committing to substantive progress. Embedding DEI into the PFAC's annual goal setting process facilitates the development and periodic review of a PFAC-driven plan for diversity and inclusion that captures accomplishments, key priorities, challenges, and next steps.

Create connections between the PFAC and hospital DEI work

DEI is most effective when it is aligned throughout the organization. Establishing connections between patient- and family-centered care (PFCC) and DEI work helps create a robust partnership. Connecting PFCC and DEI teams through organizational structures—like offices of DEI and DEI councils, advisory committees, workgroups, and task forces—provides guidance, internal support, and visibility for both PFAC and DEI work.

EXAMPLE FROM THE FIELD

In late 2019, the Family Advisory Council (FAC) at Boston Children's Hospital committed to a strategic Equity, Diversity & Inclusion (ED&I) goal: "Our goal is to ensure that our membership reflects the diversity of the patients and families we are privileged to serve. That diversity includes such things as race, ethnicity, nationality, LGBTQ+, ability, and care and services received here at Boston Children's." In 2020, FAC members wrote their own ED&I plan and worked with organizational leaders to align FAC goals with those of the hospital. Since implementing the ED&I plan, the FAC has enhanced membership diversity in three key areas: primary language spoken, racial/ethnic identity, and location of residence. The FAC is committed to recruiting a diverse membership to ensure that there are representative voices on the council.

2. Recruit to Increase PFA Diversity

Increase PFAC visibility and make PFA diversity a shared goal of the institution

Making information about the PFAC visible to clinicians and staff helps create shared responsibility for increasing PFA diversity. Opportunities to increase PFAC visibility include publicly sharing PFAC information via intranet and staff portals, monthly newsletters, huddle boards, and departmental meetings and by connecting with individuals within the hospital who interact with populations of interest (e.g., physicians, child life specialists, nurses, social workers, unit clerks, caseworkers, and environmental services staff). Sharing information about the PFAC directly with patients, families, communities, and neighborhoods via social media, flyers in public spaces, and family-to-family newsletters is also helpful for increasing PFAC visibility.

Build authentic relationships between the hospital and community

Hospitals benefit from developing sustained relationships with trusted community partners who work with historically marginalized populations. Cultivating a visible presence in the community helps hospitals meet potential PFAs in their environment. Opportunities include outreach to community- and faith-based organizations, social service providers, schools, local government agencies, and others working in community engagement. Offering beneficial services (e.g., health screenings, wellness events) and participating in community-led events can help hospitals build trusting relationships that demonstrate sustained commitment to communities.

EXAMPLE FROM THE FIELD

The University of Rochester Medical Center (URMC) saw a critical need to add an African American/Black PFAC to their network of existing PFACs. They engaged several members of the local Black community as consultants. Working with the Office of Equity and Inclusion, the first step was listening to the consultants' input and advice. URMC moved forward after agreement that there was a compelling need for the PFAC and with assurance of leadership's commitment to change based on PFAC input and feedback.

Identify and address barriers in the PFA recruitment and application process

A supportive application process for PFAs facilitates engagement and signals that the hospital is serious about improving diversity and inclusion. Feedback from PFAs can identify potential barriers associated with recruitment, such as overly long applications, the need for internet access, requirements for in-person interviews, background checks, and limited application options for individuals with lower levels of literacy or those who do not speak English.

Develop recruitment materials that promote diversity and inclusion

PFAC marketing and recruitment materials should reflect the diversity of patient and family populations served, be available in languages that address the organization's patient demographics, and promote inclusion by:

- using plain language, a conversational tone, and text that is easy to translate;
- incorporating culturally-inclusive images and examples;
- describing expectations along with resources available to support PFA participation; and
- highlighting what PFAs from historically marginalized populations have shared about the benefits of participation (e.g., the opportunity to improve care for underserved communities).

3. Explore and Use Structures that Facilitate PFA Participation

Offer varied options for PFA participation

Creating structures that offer flexible opportunities for participation outside of the PFAC can make serving as a PFA more accessible. Some hospitals use a tiered approach, reflecting a spectrum of opportunities that range in time commitment, intensity, and requirements. At one end of the spectrum, PFAs may serve as e-advisors, reviewing materials and messages or providing input via surveys. This type of participation requires less time commitment, and PFAs usually do not have to complete required volunteer trainings, adhere to vaccination requirements, or undergo background checks. At the other end of the spectrum, PFAs may participate in work that includes in-person volunteering, education, simulations, mentoring, or committee-level work, with greater time involvement and the need to follow all hospital requirements for in-person volunteers.

Explore opportunities for specialty PFACs

Specialty PFACs are those in which membership is defined by specific, shared characteristics. These PFACs can be helpful in establishing a shared experience and providing a space where PFAs feel more comfortable speaking up, raising concerns, and suggesting solutions. Opportunities for specialty councils should be explored with input from the populations that would be represented. Examples include:

- Youth or kids' PFAC
- Black/African American PFAC
- LGBTQ+/Gender Proud PFAC
- Deaf PFAC
- Latino/LatinX/Hispanic PFAC (bilingual or Spanish-speaking)
- Condition-specific PFACs (e.g., Spina Bifida)

EXAMPLE FROM THE FIELD

At Children's Mercy Kansas City, *El Consejo de Familias Latinas/Hispanas* focuses specifically on the needs of Spanish-speaking patients and their families, who represent 18-20% of the hospital's patient population. El Consejo's primary goal is promoting a relationship between families and professionals from Children's Mercy to ensure that the right services are being delivered to children and families. El Consejo is chaired by a parent, with a membership of approximately 10 families whose children receive care at Children's Mercy. Monthly meetings are conducted in Spanish.

Develop approaches to meet community needs

A PFAC may not always be the best structure for hearing from patients and families. Tailoring opportunities to meet the needs of specific populations can help hospitals learn from people through the structures and settings with which they are most comfortable. For example, a children's hospital in Canada attended "Talking Circles" with Indigenous communities in eight locations to listen and learn from the stories of community members.

4. Support Inclusive and Equitable Practices

Identify and address barriers that prevent full participation from PFAs

Obtaining input from community partners, PFAs, and reviewing data from community health needs assessments can highlight potential challenges to PFAC participation experienced by historically marginalized populations. Examples of how to address potential barriers include:

- holding PFAC meetings in the community to increase access and comfort;
- offering options for virtual meetings to ease travel burden;
- scheduling meetings on days and at times that are convenient for PFAs, which may mean holding meetings outside of traditional working hours;
- covering expenses associated with participation, including travel, child care, and meals;
- paying PFAs an honorarium or stipend, particularly for more intensive work such as participation on committees;
- providing language access services, including translation of written materials and interpretation during meetings; and
- providing access to technology to facilitate collaborative work (e.g., iPads, laptops, internet access).

Develop and implement guidelines for inclusion

Creating safe spaces for sharing experiences and perspectives begins with a commitment to an equitable environment in which everyone's voice is valued, respected, and heard. It is important to talk with PFAs about the need to have challenging or uncomfortable conversations as part of the learning process, and provide support for members during and outside of PFAC meetings. PFAs should be partners in co-developing ground rules for PFAC meetings, group agreements for interactions, and processes for how the group will approach and negotiate challenging conversations and situations.

EXAMPLE FROM THE FIELD

At Children's National Hospital, guiding principles for inclusivity in meetings are included on every agenda and reviewed at the beginning of every meeting. These principles include treating everyone with respect, assuming best intentions, staying on topic, suggesting solutions, and making space for everyone to participate.

4. Support Inclusive and Equitable Practices (cont.)

Provide training related to DEI practices for staff and PFAs

Training can help staff and PFAs develop a better understanding of issues related to DEI and create a more supportive environment. For staff, training can help learn how to best support PFAs from diverse backgrounds and be open to hearing what PFAs from historically marginalized backgrounds have to share. For PFAs, training can help understand important topics (e.g., social determinants of health), work with diverse groups of people, and be more effective partners in working toward health equity.

Create opportunities for relationship-building

Providing opportunities for PFAC members to get to know each other on a personal level helps build an inclusive environment. It is helpful to set aside time before or during meetings for building relationships using culturally respectful and inclusive activities. Creating space for personal connections is especially important when new PFAs join an existing PFAC, particularly one that has not had diverse membership.

GUIDING CHANGES TO ESTABLISHED PFACS

Making changes to established PFACs can be challenging. If there is significant resistance to change, consider pausing, restructuring, and relaunching the PFAC with a clear focus on diversity. In the meantime, learn about and bring in other perspectives, for example, by partnering with community-based organizations and advocacy groups to hold listening sessions in the community. Practices to intentionally guide changes to established PFACs include:

- educating current PFAs about the importance of diversity and representativeness;
- working with current PFAs to develop goals and a collaborative plan for creating a more diverse, representative, and inclusive PFAC; and
- looking for natural transitions and opportunities to bring in new PFAs.

5. Partner with PFACs in Hospital DEI Initiatives

Engage PFAs as partners on all DEI projects, workgroups, and committees

Engaging a diverse group of PFAs in all DEI-focused projects, workgroups, committees, and programs ensures that patient and family perspectives and needs are well represented. Strengthening connections between PFAC programs and hospital-based DEI work facilitates the engagement of PFAs in ways that enable them to contribute to and affect meaningful changes.

Actively seek input from historically marginalized patients and families

Working with a diverse group of PFAs or community members can help identify ways in which hospital policies, practices, and programs differentially affect marginalized populations. PFAs can provide suggestions to better address the needs of patients and families—e.g., related to electronic medical records, signage, family presence at the bedside, language access services, physical and electronic accessibility, and other areas.

Share DEI data and brainstorm opportunities to eliminate inequities

Sharing data with PFAs (e.g., about inequities in outcomes, quality, safety, and experience of care) engages them as partners in improvement. Discussing potential gaps helps identify opportunities for the PFAC to support the hospital's broader DEI priorities. PFAs can help generate DEI-related ideas, issues, and projects, and develop goals for PFAC DEI efforts that are aligned with hospital-level goals.

EXAMPLES FROM THE FIELD: ROLES FOR PFAS

<p>Provide input for hospital policies, practices, programs</p>	<ul style="list-style-type: none"> • Provide feedback on hospital DEI policies. • Share perspectives on how patients, families, and community members perceive equity at the hospital. • Work on policies and changes to improve physical and virtual accessibility to services. • Advise on programs and policies for specific patient populations (e.g., LGBTQ+). • Collaborate on cultural awareness initiatives for staff and patients.
<p>Participate on hospital-level workgroups and committees</p>	<ul style="list-style-type: none"> • Participate on workgroups for topics related to DEI (e.g., respectful collection of race, ethnicity, and language data). • Serve as members of standing hospital committees (e.g., culture council, patient education committee).
<p>Provide input for and review patient materials</p>	<ul style="list-style-type: none"> • Provide input to ensure materials are understandable to and resonate with members of specific communities. • Advise on culturally-inclusive messaging for patients and families.
<p>Participate in clinician and staff education</p>	<ul style="list-style-type: none"> • Contribute to Grand Rounds presentations on DEI. • Assist in the development of case studies and materials to help medical students develop skills related to DEI. • Participate in simulations and trainings, incorporating DEI-related topics through intentional education.
<p>Participate in community forums or listening sessions</p>	<ul style="list-style-type: none"> • Meet with hospital leaders and staff to share stories and highlight issues related to equity. • Contribute to open conversations on current issues (e.g., mental health in Black and Hispanic/Latino/LatinX communities).
<p>Engage in community programs and outreach</p>	<ul style="list-style-type: none"> • Help develop programs that address the needs of historically marginalized populations (e.g., outreach programs for children who screen positive for social risks). • Partner with community groups to understand their concerns and obtain input about hospital programs and services.
<p>Participate in research projects</p>	<ul style="list-style-type: none"> • Serve as consultants on DEI-related research projects. • Review data and help develop projects designed to address disparities in outcomes.
<p>Contribute to public advocacy</p>	<ul style="list-style-type: none"> • Participate in local and state-level advocacy related to historically marginalized populations (e.g., legislation affecting the LGBTQ+ community).
<p>Provide input for PFAC improvements to address DEI</p>	<ul style="list-style-type: none"> • Review PFAC processes to provide feedback on potential issues for historically marginalized populations (e.g., related to the PFAC application and onboarding process).

6. Sustain PFAC Progress

Provide opportunities for meaningful participation and feedback about results

Being honest with PFAs about the organization's DEI journey and providing opportunities to contribute to meaningful changes establishes an environment for partnership. It is important to listen to PFAs' ideas with an open mind and take action based on their feedback when possible. Sharing information with PFAs about how their contributions have resulted in changes is also important. When changes are not possible, share this information as well. Providing this feedback contributes to an environment in which PFAs feel valued and respected.

Conduct formal and informal assessments of the PFAC

Creating an environment for sustained partnership requires an understanding of PFAs' experiences. Assessments can be formal in nature (e.g., standardized yearly surveys of PFAC members) or more informal (e.g., debrief discussions at the end of PFAC meetings, informal surveys, or individual discussions). Obtaining feedback through regular evaluation and reflection activities can help PFAs feel supported and heard and highlight opportunities for improvement. For example, PFAs from historically marginalized groups have shared the experiences of:

- feeling as though they have been included primarily to address quotas for diversity;
- feeling sole responsibility for representing diverse voices and bringing the "DEI" perspective; and
- perceiving unspoken expectations around their behavior, participation, and sharing.

Increase diversity in PFAC leadership

Increasing representativeness in PFAC leadership positions sends the message to potential PFAs that they are valued by the organization. Look for opportunities to create pathways for PFAs from historically marginalized populations to move into leadership roles within PFACs and committees (e.g., chair, co-chair, facilitator).

EXAMPLE FROM THE FIELD

The Family Advisory Council (FAC) at Boston Children's Hospital asks members to complete an annual assessment survey to gauge member experience and satisfaction. In 2020, as part of the hospital's ED&I plan, the annual assessment survey was expanded to include questions about how members perceive the FAC's commitment to diversity and inclusiveness of the FAC environment.

ABOUT THE PROJECT

This resource was developed by the [Institute for Patient- and Family-Centered Care](#) (IPFCC) in partnership with [Cincinnati Children's Hospital Medical Center](#) (CCHMC) as part of a project to identify promising practices for improving PFA diversity and partnering with PFAs on DEI initiatives.

Information in the document is based on learnings from:

- ▶ a focused literature review;
- ▶ interviews with children's and adult hospitals, academic research centers, community-based organizations, and advocacy organizations; and
- ▶ focus groups with PFAs at children's hospitals that self-identified as members of historically marginalized populations.

This work builds on a [previous study](#) conducted by IPFCC and CCHMC that examined the prevalence and functioning of PFACs in U.S. children's hospitals and that highlighted ten key learnings for strengthening partnerships.

Support for this work was provided by the Lucile Packard Foundation for Children's Health. The views presented here are those of the authors and do not reflect those of the Foundation or its staff. The Foundation's Program for Children with Special Health Care Needs invests in creating a more efficient and equitable system that ensures high-quality, coordinated, family-centered care to improve health outcomes for children and enhance quality of life for families. Learn more at lpfch.org/CSHCN.

ACKNOWLEDGEMENTS

We are grateful to the patient and family advisors, staff, and clinicians who participated in interviews and focus groups and so generously shared their experiences related to PFACs and DEI.

Thank you also to the individuals on our project Advisory Committee and to our program officers at the Lucile Packard Foundation for Children's Health, Allison Gray (Senior Program Officer) and Hannah Au (Program Associate). Without the expertise, insights, and commitment of these individuals, this project could not have happened.

PROJECT TEAM MEMBERS

IPFCC

Pam Dardess, MPH
Vice President, Strategic Initiatives and Operations

Deborah Dokken, MPA
Senior Specialist, Patient and Family Partnerships

Ushma Patel, MSPH
Director, Special Projects and Educational Programs

LaToshia Rouse, CD/PCD (DONA)
Consultant and Family Leader

CCHMC

Ndidi Unaka, MD, MEd
Associate Professor, Division of Hospital Medicine

Andrew F. Beck, MD, MPH
Professor, Divisions of General and Community Pediatrics and Hospital Medicine

Carlos A. Casillas, MD, MPH
Pediatric Hospital Medicine Fellow

Laura Rangel Rodriguez, MD
Categorical Pediatrics Resident