



Eliminating health disparities, ensuring that patient and family advisory councils (PFACs) and PFA programs are representative of the communities served and engaged meaningfully in improvement of health care, and reestablishing family presence and participation in all settings were priorities in 2023 and will continue to be our major areas of focus in 2024.

SUPPORT THE INCLUSION OF FAMILIES AS ESSENTIAL CARE PARTNERS

IPFCC continued critical work on our Better Together campaign, which recognizes the importance of families and trusted friends as essential care partners in all care settings. We provided education and new resources to help [hospitals](#), health systems, and [long-term care communities](#) ease restrictions on family presence and participation established during the COVID-19 pandemic. With funding from the Patient-Centered Outcomes Research Institute (PCORI), we collaborated with patients, residents in long-term care, staff, clinicians, and administrative leaders in hospitals and long-term care to learn about family presence and participation during the COVID-19 pandemic. The resulting lessons learned and themes for future research reinforce the important roles of patient, resident, and family advisors and can help better inform decision-making in future public health crises.

ADVANCE PFCC PRACTICE AND STRENGTHEN PATIENT AND FAMILY PARTNERSHIPS

IPFCC staff and faculty served as consultants to hospitals, health systems, and provincial health authorities, providing education and support for the implementation of PFCC best practices to bring about transformational change. We worked with multiple health care organizations to help them move forward following the pandemic, using an appreciative inquiry approach coupled with comprehensive [organizational assessments](#) of current policies, programs, and practices to advance PFCC and foster healing among the workforce.

BUILD CAPACITY FOR DIVERSITY, EQUITY, AND INCLUSION IN PFAC AND PFA PROGRAMS

Building on our [national survey of children's hospitals](#), IPFCC and Cincinnati Children's Hospital Medical Center completed an 18-month project funded by the Lucile Packard Foundation for Children's Health to identify and share best practices for strengthening PFAC diversity and representativeness and advancing the role of PFAs in DEI work. The [key learnings and opportunities](#) identified in this project will serve as the foundation for a new grant to develop tools and resources and form a learning collaborative of children's hospitals who share goals to advance PFAC DEI.

STRENGTHEN PATIENT, FAMILY, AND COMMUNITY PARTNERSHIPS IN RESEARCH

IPFCC contributed to multiple projects funded by PCORI and led by the American Institutes for Research (AIR) to support [partnerships in research](#). IPFCC supported the collaborative development of engagement guidance to foster the meaningful inclusion of all partners in patient-centered outcomes research. We assisted with the development of guidance to support small organizations in applying for PCORI funding and build capacity for new grantees. We also supported learning networks to advance the implementation of evidence-based interventions, engagement practices, and the measurement of engagement practices and outcomes.

DEVELOP NATIONAL STRATEGIES FOR COMMUNITY ENGAGEMENT

As part of the [INSPIRE](#) project, IPFCC is working with the Camden Coalition, Commonwealth Care Alliance, the Center to Advance Consumer Partnership, Community Catalyst, and PFCCpartners to develop a national strategy to advance partnerships between healthcare organizations and people with lived experience. The INSPIRE project aims to advance community engagement on a national scale by identifying best practices for community engagement and developing a roadmap that includes tools, resources, and learning and coaching models to support implementation.

SUPPORT PARTNERSHIPS TO BUILD TRUST IN THE HEALTH SYSTEM

Through a Cooperative Agreement with the Centers for Disease Control and Prevention (CDC) and the Association of American Medical Colleges (AAMC), IPFCC is supporting stronger collaboration between teaching hospitals and local public health and community organizations. As consultants to the AAMC, IPFCC developed a [4-part video series and several new guidance resources for ambulatory clinics](#) to increase understanding of ways to partner with families and youth from diverse communities to build trust in vaccines and other aspects of health care.

ENHANCE QUALITY IMPROVEMENT FOR MATERNAL HEALTH CARE AND NEWBORN INTENSIVE CARE

IPFCC is helping to integrate a patient-centered approach to improve health equity via a CDC-funded initiative of the Texas Collaborative for Healthy Mothers and Babies. As part of an effort to ensure that all infant care is neurodevelopmentally protective and appropriate in neonatal settings, IPFCC staff is also serving as expert faculty for the Vermont Oxford Network NICQ All Care is Brain Care Collaborative, facilitating partnerships with families in care and quality improvement.

SHARE KNOWLEDGE TO GUIDE PFCC PRACTICE, EDUCATION, AND RESEARCH

IPFCC staff co-authored a recent article in the *Patient Experience Journal* that described approaches for fostering partnerships with patient and family advisors in research studies, titled [Meaningful Engagement of Patients and Families in a Complex Trial of Advance Care Planning in Primary Care](#). Staff also contributed to *The Beryl Institute's Patient Experience* publication, [Listening Organizations: Elevating the Human Experience in Healthcare through the Lived Experience of Patient & Families](#) that explores what is needed to evolve the role of PFAs in healthcare improvement strategies. IPFCC also continued to provide collaborative learning opportunities, hosting bi-monthly PFCC.Connect Informal Conversations to leverage the knowledge and expertise of the participants. Through robust discussions, peers shared experiences, ideas, and resources on specific topics, including strengthening, and evaluating family presence, evaluating PFACs, and PFACs and DEI initiatives. (Recordings are available on [PFCC.Connect](#)).

BUILD UNDERSTANDING OF HOSPITAL LEADERS' PERCEPTIONS OF FAMILY-CENTERED CARE

IPFCC is partnering with the new Ronald McDonald House Charities® Center at the University of California San Francisco to conduct a global survey of hospital leaders' perceptions of family-centered care knowledge, attitudes, and practices in their children's hospital or general hospital with pediatric specialty care. Findings from the survey, which will be available in 2024, will help build awareness and understanding of family-centered pediatric care and facilitate adoption and improvement of family-centered practices.

COLLABORATE WITH GLOBAL ORGANIZATIONS IN SUPPORT OF THEIR FAMILY-CENTERED CARE EFFORTS

Serving as a consultant for RMHC® Global and collaborating with the RMHC® Chapter in Hungary, IPFCC presented "Advancing the Practice of Family-Centered Care in Pediatrics" to the Hungarian Society of Pediatricians congress. In addition, working with the RMHC® Chapter in Ukraine, IPFCC presented "Advancing the Practice of Family-Centered Care and the Education of the Interdisciplinary Team" virtually for its 6th country-wide FCC conference. IPFCC also has assisted the RMHC Curaçao Chapter in working with its partner hospital to change restrictive visiting hours to more support for family presence and participation.



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