



IPFCC Webinar



December 14, 2021
12 - 1 PM ET

Presenters:
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Strengthen the Future of PFACs and PFAs in Your Organization!



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Helpful Tips

- All participants are muted upon entering
- Please use the **chat box** for all questions (not the Q&A function)
- Download handouts using the link provided in chat
- A recording will be available and posted to IPFCC's website after the webinar (www.ipfcc.org)
- Closed captioning is available

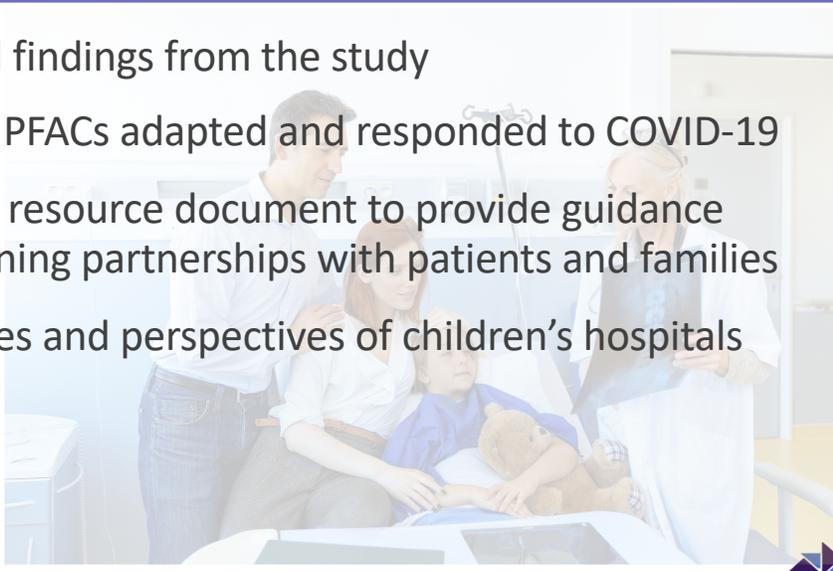




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Our Time Together

- Present selected findings from the study
- Summarize how PFACs adapted and responded to COVID-19
- Introduce a new resource document to provide guidance about strengthening partnerships with patients and families
- Share experiences and perspectives of children's hospitals
- Q&A



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Acknowledgements

- Support for this research was provided by the Lucile Packard Foundation for Children's Health, Palo Alto, CA
 - Thank you to Allison Gray and Ly Nguyen, LPFCH project officers
- Additional partners
 - Cincinnati Children's Hospital Medical Center
 - Children's Hospital Association
 - Children's Healthcare Canada



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Thank you: National Project Advisory Committee

TjaMeika Davenport	Children's National Hospital
Kori Jones	Michigan Medicine
Sunnah Kim	American Academy of Pediatrics
Linda McAleer	Upstate Golisano Children's Hospital SUNY
DeeJo Miller	Children's Mercy Hospital of Kansas City
Donna Provenzano	Children's Specialized Hospital
Latoshia Rouse	CD(DONA), American Board of Pediatrics
Sara Toomey	Boston Children's Hospital, Harvard Medical School
Karen Wayman	Lucile Packard Children's Hospital
Nora Wells	Family Voices



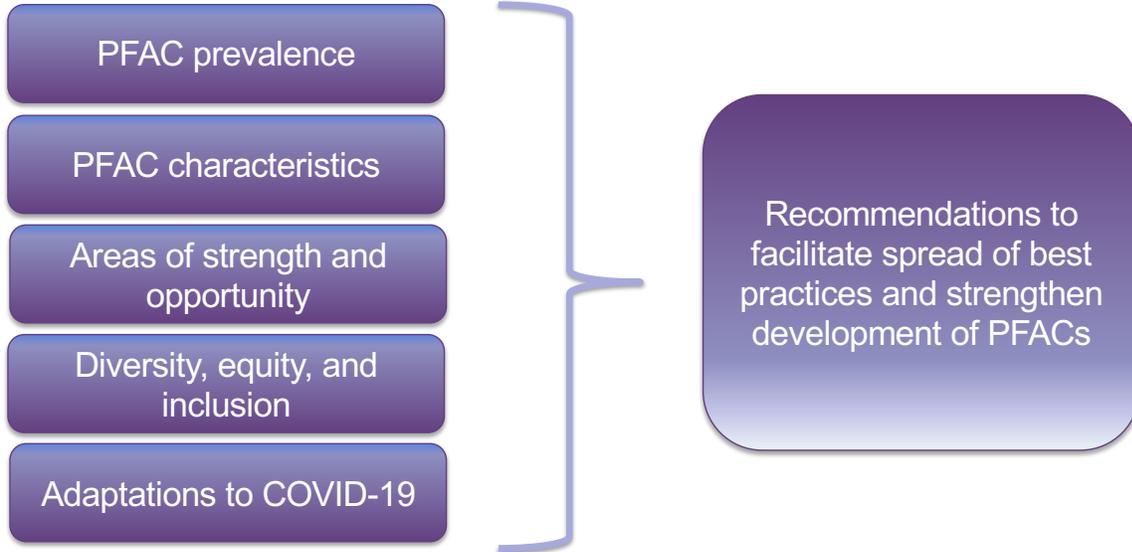
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Thank you: Children's Hospital Study Participants



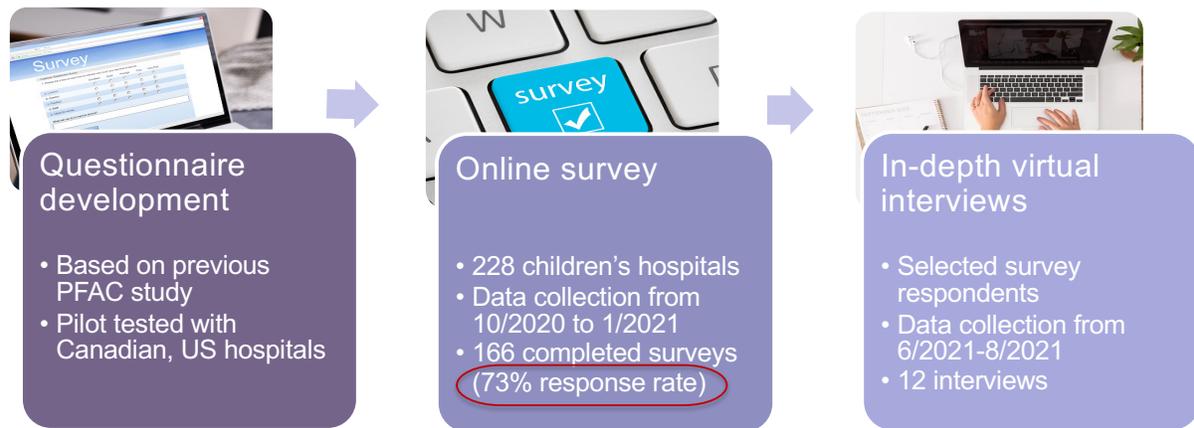
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Study Goals



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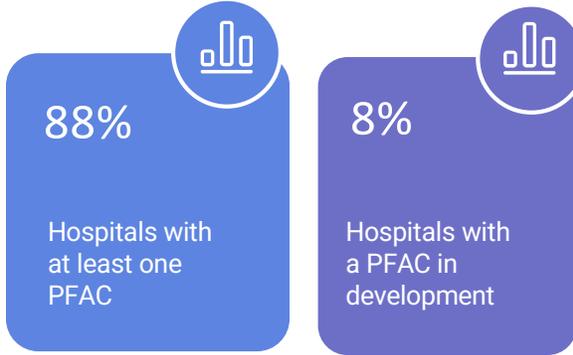
Study Methods



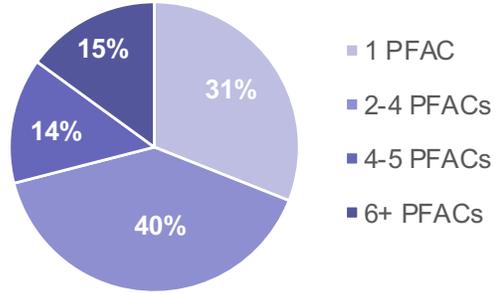
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PFAC Prevalence

The majority of children's hospitals have at least one PFAC



Many hospitals have multiple PFACs



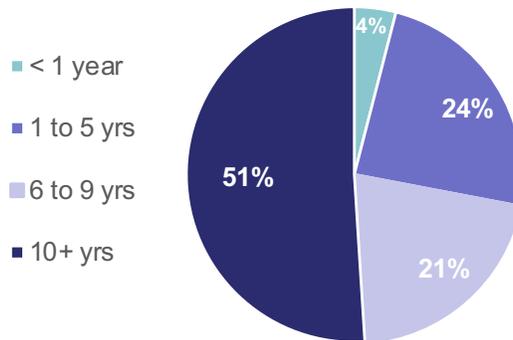
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PFAC History

Many children's hospitals have a long history with PFACs

In interviews, specific influential leaders often cited as forces behind PFAC development

Years PFAC has been in existence



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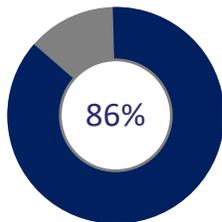
PFAC Areas of Strength

- Structures in place to support PFACs
 - Charter/bylaws
 - Executive champions
 - Staff liaisons
- Membership and recruitment
 - At least 50% patient/family members
 - Strategies for recruitment
 - Written/online application
 - Interview/discussion as part of selection process
 - Formal orientation for new members
- Adaptions during COVID-19



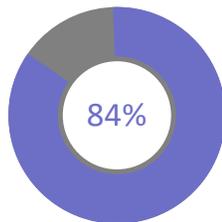
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PFAC Adaptations Due to COVID-19



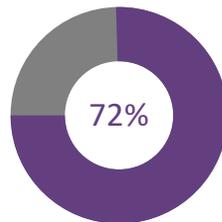
Meeting virtually

86% of PFACs had met at least once since March 2020



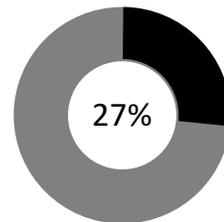
Meeting frequency

84% of PFACs anticipated meeting as frequently as before the pandemic



Meeting attendance

72% of PFACs reported attendance at meetings was the same as or better than before the pandemic



PFA involvement in COVID committees

27% of hospitals involved PFAs on pandemic planning and response committees



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PFACs and COVID-19

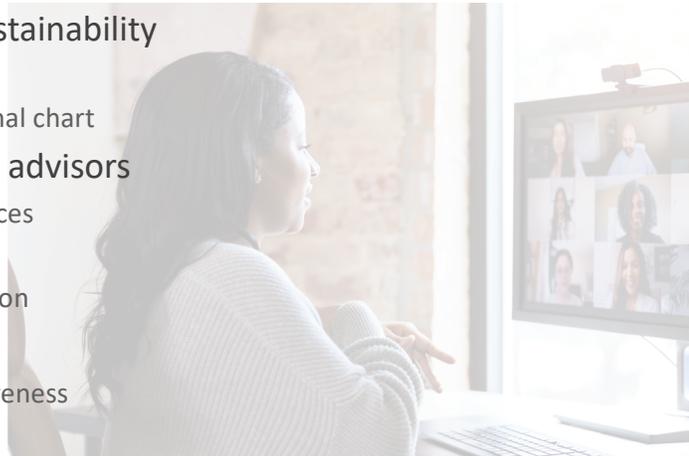
- Rapid adaptations were needed
 - Some PFACs experienced temporary disruptions
 - Others had begun thinking about virtual meetings pre-pandemic; positioned to adapt quickly
- Preparation was key for successful transitions
 - Training and providing PFAs with support for technology, virtual interactions
 - Training for staff liaisons about how to run virtual meetings
- Virtual meetings came with benefits
 - Improved ability for some PFAs to attend
 - Increased comfort with participation
 - Improved ability to recruit PFAs who reflect diversity of patients and families served



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PFAC Areas of Opportunity

- Structures to support PFAC sustainability
 - Annual PFAC budget
 - Defined PFAC place in organizational chart
- Support for patient and family advisors
 - Language and interpretation services
 - Honoraria or stipends
 - Mentoring and continuing education
- Measurement and evaluation
 - Annual evaluation of PFAC effectiveness
 - Tracking number/value of hours
 - Reporting PFAC outcomes to Board of Trustees, hospital staff, community
- PFAC diversity and representativeness



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PFAC Representativeness

62% of respondents identified “difficulty recruiting or retaining PFAs who reflect the diversity of the patient/family population served” as one of their 3 most significant challenges

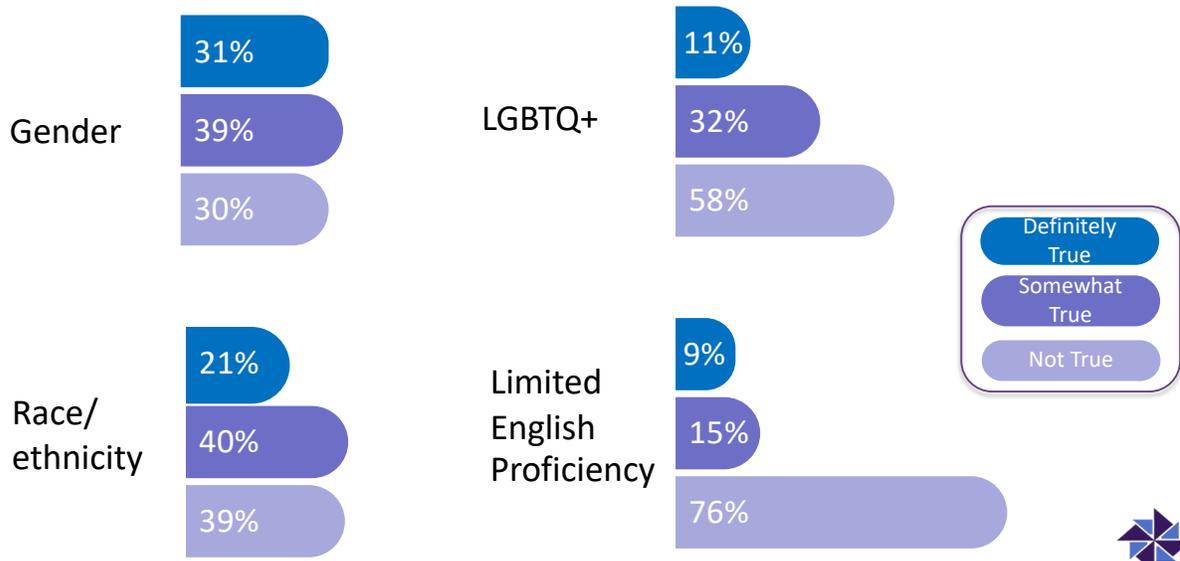
Challenges

- Lack of trust between underserved communities and healthcare system
- Time and/or costs required of PFAs to participate
- Lack of necessary supports for PFAs (e.g., stipends, language translation)



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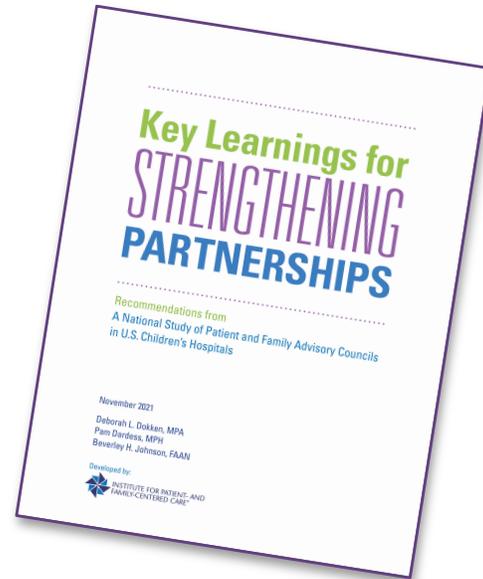
PFACs Reflect Diversity of Communities Served in Terms of:



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Key Learnings for Strengthening Partnerships

- Provide practical guidance and recommendations for the field
- Intended for a broad audience, from newly-formed to more experienced PFACs
- Share and discuss with leaders, staff, patient and family advisors



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Key Learnings

- 1 Leadership commitment and support is important for success
- 2 Successful PFACs develop and expand progressively over time, with sustained attention to relationship and trust-building

"The only way the PFAC grows is having support from our leadership, endorsing the importance of partnering with families and the value of the input that we get."



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Key Learnings

- 3 Having a defined infrastructure facilitates and sustains PFAC development
- 4 Organizations need a specific recruitment strategy to sustain and expand PFAC membership and ensure representativeness

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



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Key Learnings

- 5 Expanding involvement of patient and family advisors beyond the PFAC reflects growth and organizational commitment
- 6 Investing in onboarding, mentoring, continuing education, and training for specific roles supports patient and family advisor involvement

“Another reason 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.”



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Key Learnings

- 7 As the number of PFACs grows, it is beneficial to have mechanisms to ensure coordination and synergy of efforts
- 8 Successful PFACs adapt to and are integrally involved in organizational decision-making about emerging issues

“We have a coordinating council with co-chairs from each of our PFACs. We’re currently up to 13 PFACs across our health system.”



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Key Learnings

- 9 Measurement, evaluation, and reporting highlight the PFAC’s importance and provide a rationale for expanded engagement of patients and families
- 10 Effective use of technology has the potential to increase PFAC membership, diversity, and effectiveness



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Children's Hospital PFAC Experiences Panel

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DeeJo Miller

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In the Future

- More information on the link between PFAC characteristics and PFAC performance and influence
- Published articles summarizing research findings
- Additional PFCC.Connect conversations around aspects of PFCC and advancing PFACs



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Resources available at www.ipfcc.org



▶ PFCC and COVID-19

IPFCC recognizes the enormous and tragic impact that COVID-19 is having on the health care system across the world. We remain firmly committed to advancing patient- and family-centered approaches that also adhere to the safest guidelines and pose the least burden on health care professionals.



In direct care, maintaining connections between patients and their families is vital to health and healing. Yet, to prevent the spread of the virus, health care facilities have understandably restricted the physical presence of families and others. The words used and the tone of communications related to COVID-19 are important to conveying the essential role of families and care partners. Many organizations are creatively establishing ways to connect patients, their families, and care partners and continue to support the concept that families are key partners for safety.

- ▶ **Spotlights**
- ▶ **Helpful Resources**

In this section of our website, we provide examples from the field and resources. If you want to share a best practice or resource, please email us at institute@ipfcc.org

PFCC Best Practices: PFCC and COVID-19



▶ Patient and Family Advisory Programs

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

Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals



Patient and Family Advisors

Patient and Family Advisory Program Annual Reports

PFCC Best Practices: Patient and Family Advisory Councils



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Thank You for Joining Us!

For questions/more info about the study:

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