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
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

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
Thank you: National Project Advisory Committee

<table>
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<th>Name</th>
<th>Institution</th>
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<tbody>
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<td>Nora Wells</td>
<td>Family Voices</td>
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Thank you: Children’s Hospital Study Participants

You build a community with bricks and mortar but most of all with people.
Study Goals

PFAC prevalence
PFAC characteristics
Areas of strength and opportunity
Diversity, equity, and inclusion
Adaptations to COVID-19

Recommendations to facilitate spread of best practices and strengthen development of PFACs

Study Methods

Questionnaire development
• Based on previous PFAC study
• Pilot tested with Canadian, US hospitals

Online survey
• 228 children’s hospitals
• Data collection from 10/2020 to 1/2021
• 166 completed surveys (73% response rate)

In-depth virtual interviews
• Selected survey respondents
• Data collection from 6/2021-8/2021
• 12 interviews
**PFAC Prevalence**

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

- **88%**
  - Hospitals with at least one PFAC

- **8%**
  - Hospitals with a PFAC in development

Many hospitals have multiple PFACs

- **31%**
  - 1 PFAC
- **14%**
  - 2-4 PFACs
- **15%**
  - 4-5 PFACs
- **15%**
  - 6+ PFACs

**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

- **51%**
  - < 1 year
- **24%**
  - 1 to 5 yrs
- **21%**
  - 6 to 9 yrs
- **4%**
  - 10+ yrs
PFAC Areas of Strength

• Structures in place to support PFACs
  o Charter/bylaws
  o Executive champions
  o Staff liaisons

• Membership and recruitment
  o At least 50% patient/family members
  o Strategies for recruitment
    o Written/online application
    o Interview/discussion as part of selection process
    o Formal orientation for new members

• Adaptions during COVID-19

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
PFACs and COVID-19

• Rapid adaptations were needed
  o Some PFACs experienced temporary disruptions
  o Others had begun thinking about virtual meetings pre-pandemic; positioned to adapt quickly

• Preparation was key for successful transitions
  o Training and providing PFAs with support for technology, virtual interactions
  o Training for staff liaisons about how to run virtual meetings

• Virtual meetings came with benefits
  o Improved ability for some PFAs to attend
  o Increased comfort with participation
  o Improved ability to recruit PFAs who reflect diversity of patients and families served

PFAC Areas of Opportunity

• Structures to support PFAC sustainability
  o Annual PFAC budget
  o Defined PFAC place in organizational chart

• Support for patient and family advisors
  o Language and interpretation services
  o Honoraria or stipends
  o Mentoring and continuing education

• Measurement and evaluation
  o Annual evaluation of PFAC effectiveness
  o Tracking number/value of hours
  o Reporting PFAC outcomes to Board of Trustees, hospital staff, community

• PFAC diversity and representativeness
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)

PFACs Reflect Diversity of Communities Served in Terms of:

<table>
<thead>
<tr>
<th>Category</th>
<th>Definitely True</th>
<th>Somewhat True</th>
<th>Not True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>31%</td>
<td>39%</td>
<td>30%</td>
</tr>
<tr>
<td>LGBTQ+</td>
<td>11%</td>
<td>32%</td>
<td>58%</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td>21%</td>
<td>40%</td>
<td>39%</td>
</tr>
<tr>
<td>Limited English Proficiency</td>
<td>9%</td>
<td>15%</td>
<td>76%</td>
</tr>
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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

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.”
Key Learnings

3. Having a defined infrastructure facilitates and sustains PFAC development

"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.'"

4. Organizations need a specific recruitment strategy to sustain and expand PFAC membership and ensure representativeness

5. Expanding involvement of patient and family advisors beyond the PFAC reflects growth and organizational commitment

"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."

6. Investing in onboarding, mentoring, continuing education, and training for specific roles supports patient and family advisor involvement
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.”

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.
Children’s Hospital PFAC Experiences Panel

TjaMeika Davenport
Parent Navigator and PFAC Advisor
Children’s National Hospital (Washington, DC)

DeeJo Miller
Program Manager, Patient and Family Engagement
Children’s Mercy Kansas City (Kansas City, MO)

Donna Provenzano
Director, Family-Centered Care
Children’s Specialized Hospital (New Brunswick, NJ)

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
PFCC Best Practices: PFCC and COVID-19

PFCC Best Practices: Patient and Family Advisory Councils

Resources available at www.ipfcc.org

Thank You for Joining Us!

For questions/more info about the study:

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