

Pediatric Experience
Collaborative



2024 Annual Report

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Preparer

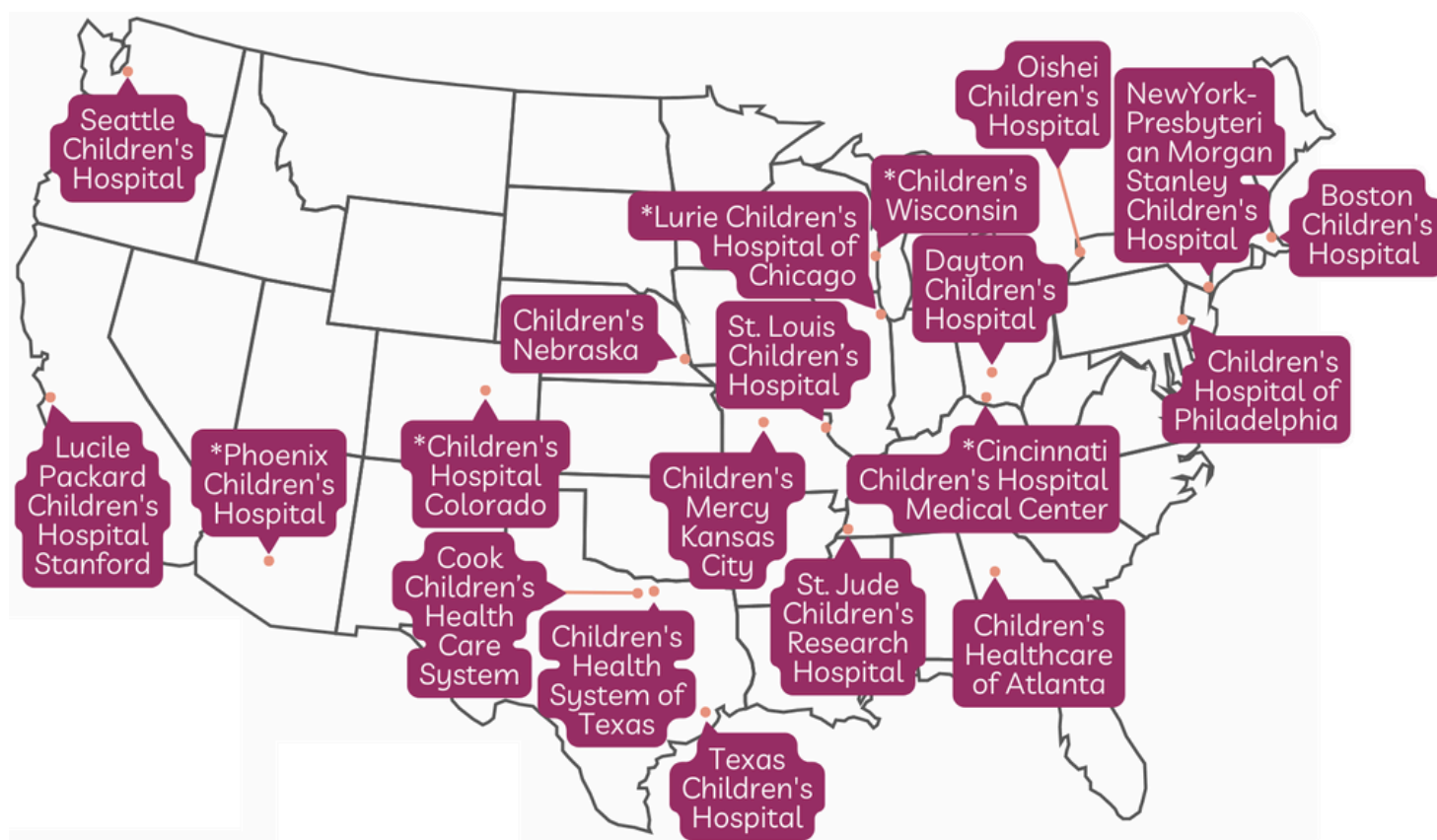
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Collaborative Members



*2024 Steering Committee Members

Welcome Letter

Dear Members of the Pediatric Experience Collaborative,

What a truly monumental year 2024 has been! Inspired by our Spring and Fall Summits, we advanced our efforts through two committees, sustained timely and vital discussions in our monthly calls and subcommunities, and challenged ourselves to lead the way in shaping a better future for pediatric healthcare.

We extend heartfelt gratitude to every member of our Pediatric Experience Collaborative. Each of you brings unique perspectives, skills, and a shared passion for improving the pediatric experience.

The commitment of our leaders and members serving on the Experience Improvement Committee and the Education & Communication Committee continues to drive greater impact. Their leadership, teamwork, passion, and dedication are the cornerstone of our collective achievements.

Our Collaborative has been strategically guided by the expert leadership of our Steering Committee. Their vision and efforts have created a strong foundation that enables us to flourish. Thank you to the dedicated teams at Colorado Hospital Children's, Phoenix Children's, Children's Wisconsin, and Cincinnati Children's for their invaluable contributions. We also extend a special thank you to Lurie Children's Hospital of Chicago for their service on the Steering Committee and offer a warm welcome to Oishei Children's Hospital.

We owe a debt of gratitude to our Collaborative Manager, Bri Combs. We are blessed to have her passion, integrity, compassion, and courage driving us toward our mission. As Dr. Sam Hanke's prepares to conclude his term as Hospital Co-Chair, we are thrilled to welcome Shelby Chapman as Hospital Co-Chair Elect. Shelby brings a wealth of experience and expertise, and we are confident the future is bright under her leadership.

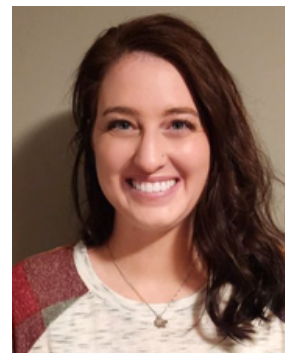
As you will read in this report, the Collaborative is strong, and we have accomplished a great deal over the past year. Together, we are making a profound difference in the lives of children, their families, and the dedicated staff who care for them. Please take the time to read and share these impactful stories across your institution.

Thank you for your partnership and for the friendships we have forged along the way. Let us continue collaborating to bring tangible value to our institutions through consistently better experiences for our patients, families, and staff. We will always believe in better.

*With appreciation and anticipation,
Dr. Sam Hanke and Molly Warneke*



Dr. Sam Hanke
Hospital Co-Chair
Jan '23 - Dec '25
Cincinnati Children's



Molly Warneke
Family Co-Chair
Jan '24 - Dec '26
Children's Nebraska

Pediatric Experience Collaborative Overview

Mission Statement: The Pediatric Experience Collaborative (PEC) leverages the advantages of scale by collaborating and sharing expertise, data, and experiences amongst participating children's hospitals to optimize patient, family, and care provider experiences.

History

2016

- PFE leaders from 10 pediatric hospitals gather to collaborate with one another

2017

- The Pediatric Experience Collaborative is established with an official charter

2019

- Dr. Sara Toomey of Boston Children's Hospital appointed as first Hospital Co-Chair
- Anika Mian of Boston Children's Hospital hired as Project Manager

2020

- Tiffany Messer of Cincinnati Children's hired as first Parent Co-Chair

2021

- Dr. Harris Baden of Seattle Children's Hospital appointed as next Hospital Co-Chair

2022

- Leadership and funding transferred from Boston Children's Hospital to Cincinnati Children's
- Bri Combs of Cincinnati Children's hired as first full-time Collaborative Manager
- Enjoli Harris of Seattle Children's hired as next Parent Co-Chair
- Family Scholarship introduced for Fall Summit
- LinkedIn page created

2023

- Dr. Sam Hanke of Cincinnati Children's appointed as next Hospital Co-Chair
- Launch of website
- Launch of subcommunities for counterparts across the nation to connect
- Conclusion of the Optimizing Diverse Voices Workgroup and Race & Ethnicity Framework Workgroup, including their respective projects
- Creation of Experience Improvement Committee and Communication & Education Committee

2024 Highlights

- Lurie Children's Hospital of Chicago ended term as Steering Committee Member
- Children's Wisconsin joined the Steering Committee
- Molly Warneke of Children's Nebraska hired as next Family Co-Chair
- Virtual Spring Summit: *Improving Mental Healthcare Experiences in Pediatrics*
- Hybrid Fall Summit hosted by St. Jude Children's Hospital in Memphis, TN: *Designing for the Family, the Feasible, and the Future*
- Addition of Cook Children's Hospital and Oishei Children's Hospital as new members
- Donna Murray hired as Strategic Consultant

2023-2025 Strategic Plan Progress

Strategy 1: Increase our Collaborative's capacity to establish evidence-based best practices to improve the pediatric experience



OBJECTIVE #1: Establish Quality Improvement Infrastructure

- Create Experience Improvement (EI) Committee led by an inclusive triad of hospital, clinical and family co-leads

Progress

- Created (Experience Improvement) EI Committee lead by leadership triad:
 - Carlee Doss, Family Co-Lead, Cincinnati Children's
 - Bridget Albani, Hospital Co-Lead, Children's Mercy Kansas City
 - Dr. Taylor Sewell, Clinical Co-Lead, NewYork-Presbyterian Morgan Stanley Children's Hospital
- 10 participating hospitals represented in membership: Dayton Children's Hospital, Children's Hospital Colorado, Cincinnati Children's, Children's Mercy Kansas City, St. Jude Children's Research Hospital, Children's Health System of Texas, Boston Children's Hospital, NewYork-Presbyterian Morgan Stanley Children's Hospital, Cook Children's, St. Louis Children's Hospital
- Support of Strategy Consultant (Donna) and Quality Improvement (Annette)
- Revised charter
- In process of contracting with Dennis Deas, Quality Improvement Specialist to lead Collaborative-wide quality improvement project and capacity-building



OBJECTIVE #2: Drive Collaborative-Wide QI Projects

- Identify priority outcomes meaningful to patients, families and staff
- Provide resources to execute projects
- Share improvement internally and externally

Progress

- Surveyed member hospitals to identify their strategic priorities for improving pediatric experience
- Identified effective inpatient communication between care team members and families as the most common institutional priority.
- Surveyed Family Advisors within the Collaborative about their inpatient communication experiences, analyzed the feedback, and identified "drivers" of satisfaction when communicating with inpatient care teams.
- Identified which member hospitals were asking, *"Was there good communication between the different doctors and nurses?"* on their patient and family experience surveys.
- Interviewed clinical leaders at select member sites to learn who they considered to be part of the child's care team, how care teams communicate with families, any pain points or areas of communication breakdown, what improvements they have tried, and ideas for improvement.
- Analyzed survey and interview responses to revise SMART AIM.
- Began drafting a Key Driver Diagram, filling in the Global Aim, SMART Aim, and key drivers from the survey and interview responses.



OBJECTIVE #3: Compile Quality Improvement Education Resources for Collaborative Members

- Compile educational resources for Quality Improvement basics (concepts, tools and methods)

Progress

- Annette Bonjour, Clinical Quality Specialist from Cincinnati Children's recorded didactics on QI terminology for Experience Improvement Committee and Collaborative members
- Created preliminary list of potential quality improvement educational trainings
- Reframed Committee's pilot quality improvement project to build quality improvement capacity at participating sites, as well as within Committee membership

2023-2025 Strategic Plan Progress

Strategy 2: Elevate the pediatric experience standard for patients, families, and staff



OBJECTIVE #1: Establish Education and Communication Infrastructure

- Create Education and Communication Committee led by an inclusive triad of hospital, clinical and family co-leads

Progress

- Created Experience Improvement Committee lead by leadership triad:
 - Nancy Netherland, Family Co-Lead, UCSF Benioff Children's Hospital, transitioned in July 2024 to Maureen Hoff, Family Co-Lead, Children's Hospital Colorado
 - Jana Rojas, Hospital Co-Lead, Children's Mercy Kansas City
 - Dr. Dana Williams, Clinical Co-Lead, Phoenix Children's
- 9 participating hospitals represented in membership: Cook Children's, Phoenix Children's, Children's Mercy Kansas City, Children's Wisconsin, Dayton Children's Hospital, Cincinnati Children's, Boston Children's, Children's Hospital Colorado, Children's Nebraska
- Revised charter



OBJECTIVE #2: Establish Best Practices Library for Members to Contribute to Regularly

- Draft template form for members to contribute QI project processes and outcomes
- Invite members to contribute best practices
- Develop an enhanced online platform for searching and identifying best practices

Progress

- Identified desired operational and design features for library
- Vetted many potential external platforms to host our best practices and resource library
- Chose to hire Jessica Haines Design, an Australian web developer to create a customized page within our existing website
- Once Steering Committee approved design proposal, Committee leaders scheduled design days with developer
- Identified potential categorization of content to host in library
- Drafted form for member hospitals to submit practices and resources into library
- Began taking inventory of existing practices and resources previously shared by members



OBJECTIVE #3: Increase Awareness and Legitimacy of the Pediatric Experience Collaborative

- Increase awareness and visibility of PEC
- Share what we know about pediatric experience

Progress

- Resource Bundle
 - Surveyed Collaborative members to learn their priorities – landed on improving experience through communication in pediatric emergency departments as the focus for our first resource bundle
 - Identified common features in successful resource bundles from other national networks to model after
 - Began taking inventory of existing practices and resources previously shared by members
- Papers
 - Identified writing team: Dr. Harris Baden, Dr. Taylor Sewell, Dr. Dana Williams, Dr. Sam Hanke, Lauren Hamilton, Bri Combs, Molly Warneke, Trenton House
 - Wrote perspectives paper, *The Pediatric Experience Collaborative: Paving the Way in Pediatric Experience*, and submitted to the *Journal of Patient Experience* for publishing
 - Lauren Hamilton presented paper at Fall Summit

2023-2025 Strategic Plan Progress

Strategy 3: Expand & strengthen national pediatric experience community of patients, families and staff



OBJECTIVE #1: Increase Participation in our Pediatric Experience Collaborative

Progress

- Contracted with Donna Murray, Strategy Consultant
- Welcomed Oishei Children's Hospital and Cook Children's Hospital as new members
- Grew by 180+ patients, families and staff from member hospitals



OBJECTIVE #2: Increase Accessibility and Inclusivity of Membership and Leadership to More Accurately Represent each Member Hospital's Patient Population

- Establish leadership triad from each member hospital
- Develop compensation model for family engagement
- Increase opportunities of engagement for patients and culturally diverse families

Progress

- Worked toward identifying leadership triads at each member hospital to ensure representation from families, nonclinical staff and clinical staff from each institution
- Began identifying potential members for focus groups to begin sharing best practices and strategizing how to increase engagement opportunities for Patient Advisors, as well as those who do not speak English as their primary language

Fiscal Year 2024 Financial Statement

(July 2023 -June 2024)

Beginning Balance: \$295,249

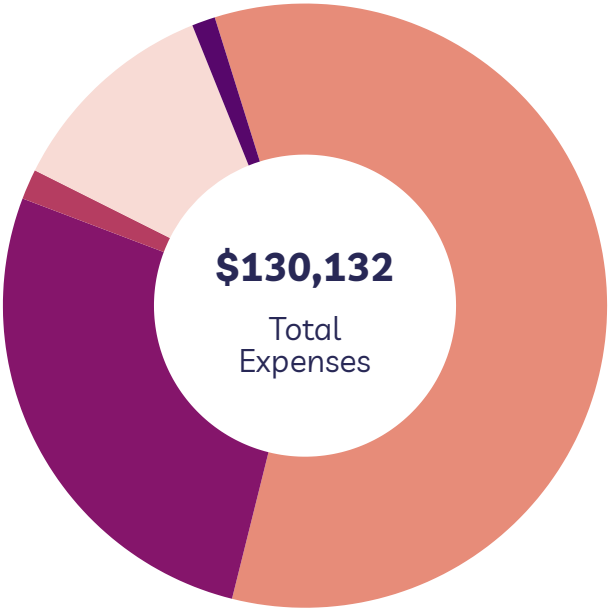
Revenue: \$197,999

- 2023 Membership Dues
- 2022 Fall Summit Registration

Expenses: \$130,132

- Salaries, Benefits & Stipends
- Conferences
- Software
- Contracted Services
- Miscellaneous

Year-End Balance: \$363,116



Virtual Spring Summit

Beyond Beds & Waitlists: Improving Mental Healthcare Experiences in Pediatrics

Friday, April 26th

Description

Our 2024 Spring Summit was focused on improving the pediatric mental healthcare experience in two parts: 1) How youth experience the mental healthcare system before, during and after mental health crises or diagnoses, and 2) How mental health challenges can stem from the traumas and stresses of the medical healthcare journey. We discussed how we understood these varied experiences, how different mental health service models improved access, and best practices for supporting patients and families during the wait for services.

Agenda

Understanding the Mental Healthcare Experience

- Patient Advisor shared his experience with familial and cultural barriers that made it difficult for him to access essential mental health care
- Data Analyst reviewed of how we learn about these experiences through feedback surveys, what we are learning, and what challenges exist with the collection and measurement of that data

Improving Access and Wait Experiences

- Services Models and Best Practices: Community partnership on the prevention/identification side of youth mental healthcare; behavioral health urgent care model has improved access to youth mental healthcare
- Supporting Families in the Wait: Implementation and growth of enrichment groups for patients boarding from the Emergency Department to a higher level of psychiatric care' Mental Health Family Advisory Council has improved supports for patients and families waiting for mental health services.

Managing and Mending Trauma

- *Patient & Family Story*: Mother and daughter shared how their medical journey had impacted their mental health. They shared key takeaways for staff to implement in every visit, across all disciplines of medicine.
- *Wellbeing and Resilience Among Patients & Families*: The Roadmap Project shared resources and best practices used to support the emotional health of families and patients with chronic conditions.

Presenting Hospitals

Boston Children's Hospital, Children's Hospital Colorado, Children's Wisconsin, Cincinnati Children's, Dayton Children's Hospital

- **171** attendees
- **Over 20%** Patient & Family Advisor attendees
- **3** Patient Advisor presenters

The patient story about seeking care from a teen and immigrant family perspective was very impactful.
Family Member and Nonclinical Staff

I was delighted that you brought in the patient and family coping experience around medical conditions, as often mental health and emotional/behavioral health are in different silos -- but whole people are not. Moving stories.
Clinician

The family stories are always the most impactful, but I also valued the real world examples of ways organizations are trying to address the huge demands for mental health care.
Family Member and Nonclinical Staff

Fall Summit at St. Jude Children’s Research Hospital

Designing for the Family, the Feasible, and the Future

Wednesday, October 16 - Friday, October 18

Description

At our 2024 Fall Summit, we learned how pediatric hospitals across the nation are leveraging the feedback and personal narratives of patients and families to initiate experience-based improvements while balancing the hospital’s operational needs and restraints. Our host, St. Jude Children’s Research Hospital, shared (and showed!) us how the human-centered design approach led to the creation of a floor dedicated to meeting the non-clinical needs of their patients and families. We heard from experts in the fields of Innovation and Design Thinking on how to balance the desire of the patient with the hospital’s business parameters, while assuring the solution was technically and practically feasible.

Wednesday Agenda

- Mojo Memphis Tour
- Duck March at Peabody Hotel
- Welcome Dinner & Tour of Family Commons

Thursday Agenda

- Welcome & State of Collaborative
- The Patient Experience at St. Jude
- The Patient Voice
- Keynote: Human-Centered Design
- Centering People in Design: Understanding the Role of Human Factors Engineering
- Refueling Improvement Interest with Elements of Design Thinking
- Enhancing Hospital Wayfinding through Human-Centered Design
- Exploratory Learning Data Debate
- Social Hour
- Patient & Family Adviser Dinner

Friday Agenda

- Tour of St. Jude Children’s Research Hospital
- PEC Experience Improvement Committee Report
- PEC Communication & Education Committee Report
- The Patient Voice

The human centered design presentation provided lots to consider as it relates to intentionality and how to frame and re-frame questions to get to the heart of improving systems. Virtual Nonclinical Staff Attendee

I loved how accepting and open everyone was to hearing new ideas and opinions. Everyone held a great respect for one another. It is such a fresh and inspiring thing to witness... In-Person Family Attendee

It was very affirming to see how many disciplines are working on the patient experience together. Virtual Nonclinical Staff Attendee

I thoroughly enjoyed the networking aspect and being able to talk with others to hear their perspectives and how things look similar or different at their hospital. In-Person Family Attendee

What a strong and fun community!! In-Person Clinical Attendee

We had a total of 178 attendees virtual in-person

Hospital staff	69			47				
Patients & Families	25		25					
Clinicians	6	6						

There was a positive atmosphere and...I felt included, respected and engaged. In-Person Family Attendee

I was really inspired by St. Jude and their commitment and manifestation of co-design. They really are committed to excellence in everything they do. Their evident pride in their work was palpable and justified and inspiring. In-Person Clinical Attendee



I truly enjoyed hearing how all our hospitals are working cohesively to elevate the patient and family experience at every level! Virtual Family and Nonclinical Staff Attendee

Discussion Topics

Open Forums

Our monthly Open Forums are for our members gather for an hour of open discussion. In this meeting, we share a variety of questions, current projects, and hot topics related to pediatric experience.

- End-of-life care and supporting grieving families
- Therapy dogs
- Trainings for Family Advisors
- Social determinates of health
- Compensation for family feedback
- Improving wait time experiences
- Incorporating patient and family experience in employee orientation
- Surveying patients with behavioral health needs
- Experience coaching for clinicians
- Getting physicians to buy into experience work
- Educational resources for clinical teams to improve communication with families who speak languages other than English
- Reducing stigma of mental healthcare in pediatrics
- Supporting staff and caregivers of patients with mental health needs
- Artificial Intelligence in patient experience
- Survey vendors
- Leadership rounding with families
- Staff recognition
- Collaborative tools for PFACs
- Inpatient Sleeping Arrangements for Infant Siblings
- Celebrating heritage days/months
- Long-term visitor badging

Membership Calls

Our monthly Membership Calls are where our members gather for business updates and best practice presentations from member hospitals.

January: *NRC Patient Experience Toolkit Pilot*, presented by Children's Mercy Kansas City

February: *Price Transparency*, presented by Children's Hospital Colorado

March: *ReSetting, ReFreshing, ReVitalizing our Patient Advisory Council (PAC)*, presented by Cincinnati Children's

April: *Shift Happens! Using Data to Drive PFE Experience*, presented by Children's Healthcare of Atlanta

May: *Patient & Family Reflections from Spring Summit*

June: *Children's Health Reese-Jones Center for Foster Care Excellence: Center Partnerships & Surveying*, presented by Children's Health System of Texas

July: *The Parent Mentor Learning Collaborative*, presented by Lucile Packard Children's Hospital Stanford

August: *Managing Agitation with De-escalation in the Pediatric Inpatient Setting*, presented by NewYork-Presbyterian Morgan Stanley Children's Hospital

September: *Spanish Family Advisory Councils*, presented by Children's Hospital Colorado and Children's Mercy Kansas City

October: *E-Visits in Primary Care*, presented by Children's Wisconsin

November: *Improving the Emergency Room Experience through Team-Based Care*, presented by St. Louis Children's Hospital

December: *Supporting Patient, Family and Workforce through the Complaint and Grievance Process*, presented by Seattle Children's Hospital

Basecamp Message Board

Basecamp is our Collaborative members' communication and project management hub. On this platform is a Message Board, a space for members to post questions and keep the conversation going in between Collaborative-wide meetings.

- The Joint Commission - Grievance Committee
- Surveying Patients with behavioral health needs
- Child advocacy/non-accidental trauma billing
- Patient experience survey questions
- Wayfinding signage in languages other than English
- Leader rounding in ambulatory/clinic setting
- Compensating Family Advisors
- Supporting staff in caring for disruptive families
- Shadowing & coaching to improve bedside manner
- Paid parent position
- Family Seal PFAC's
- Urgent Care translation
- Service dogs for families
- Primary Care clinic surveys
- Patient Relations operations
- Inpatient leader rounds
- Family Resource Centers
- Care teams and schools partnering to support mutual patients/students
- Reviews on 3rd party sites

Subcommunity Reports

These groups are designed as additional spaces for counterparts across the country to connect, share ideas and work through challenges with those who are doing similar work. There is no agenda or objectives that these groups need to accomplish.

Analyst Subcommunity

- 19 individual members from 10 member hospitals
- Created educational presentation for PFACs on how survey data is collected, used, etc.
- Presented data training to PEC's Family & Caregiver Subcommunity
- Discussed new methodology for comment analysis; and using patient and family feedback data for storytelling and visualization design to drive meaningful change within our organizations

Chaplains & Spiritual Care Subcommunity

- 7 individual members from 6 member hospitals

Child Life Subcommunity

- 16 individual members from 9 member hospitals

Clinician Subcommunity

- 18 individual members from 13 member hospitals
- Partnered with PEC's Communication & Education Committee to author perspectives paper about the PEC to be submitted to the *Journal of Patient Experience*

Diversity, Equity & Inclusion Subcommunity

- 26 individual members from 12 member hospitals
- Discussed potential ramifications of policy changes no longer requiring diversity, equity and inclusion programs and the hope that pediatric institutions will still be held accountable to providing equitable healthcare; film *Everybody's Work: Healing What Hurts Us All*; and film *Nurse Unseen*

End-of-Life Subcommunity

- 26 individual members from 11 member hospitals

Subcommunity Reports continued

Family & Caregiver Subcommunity

- 35 individual members from 14 member hospitals
- Developed a Welcome Packet for Patient and Family Advisors on how to join the PEC
- Compiled list of commonly used acronyms in pediatric healthcare
- Discussed the PEC's Communication and Education Committee's perspectives paper draft and writing process; and the PEC's Experience Improvement Committee's survey for Family Advisors preparing for their Collaborative-wide quality improvement project

Family Relations Subcommunity

- 21 individual members from 9 member hospitals

Interpretation & Translation Subcommunity

- 14 individual members from 10 member hospitals
- Discussed streamlining document translation with Microsoft SharePoint; privacy concerns associated with limited availability of translators for small, tight-knit communities; new regulation requiring accessibility kits, updating nondiscriminatory fliers, etc.; the challenge of hosting a hospital tour without an in-person interpreter or reliable wi-fi. Solution: three-way call with interpreter, tour guide, and family.

IT/IS Subcommunity

- 7 individual members from 4 member hospitals

NRC Subcommunity

- 9 individual members from 6 member hospitals
- Discussed benchmarking with other hospitals using magnet questions; what courtesy and respect means from the patient family perspective; adding survey questions around language translation services; composite scoring; leader rounding; editing process around survey questions, set up, and logistics; and translation/interpretation of experience survey
- Compiled wish list for NRC to add capabilities for connecting leader rounding feedback with patient family survey responses
- NRC representative joined a meeting to answer subcommunity members' specific questions

Patient & Family Advisory Staff Subcommunity

- 37 individual members from 17 member hospitals
- Worked on orientation parents facilitating orientation rounds to new families on inpatient units
- Discussed involving families in PEC; providing stipends for Family Advisors; recruiting diverse Advisors to ensure representation of the communities they serve; participation in a trial advisory council with the Institute for Patient- and Family-Centered Care to increase diversity; and including patient/family voices in staff and clinician orientation to ensure family-centered care

Patient & Family Experience Directors Subcommunity

- 13 individual members from 12 member hospitals

Press Ganey Subcommunity

- 21 individual members from 7 member hospitals
- Discussed strategies for improving response rates; how to better understand responses by race, ethnicity, language, and interpreter needs; sharing data with providers; provider scorecard customization; self-service dashboards; displaying data to leadership; sharing the correlations between employee experience and patient/family experience
- Press Ganey representative attending upcoming meeting to address shared pain points and newly discovered survey features/offers identified in subcommunity discussions



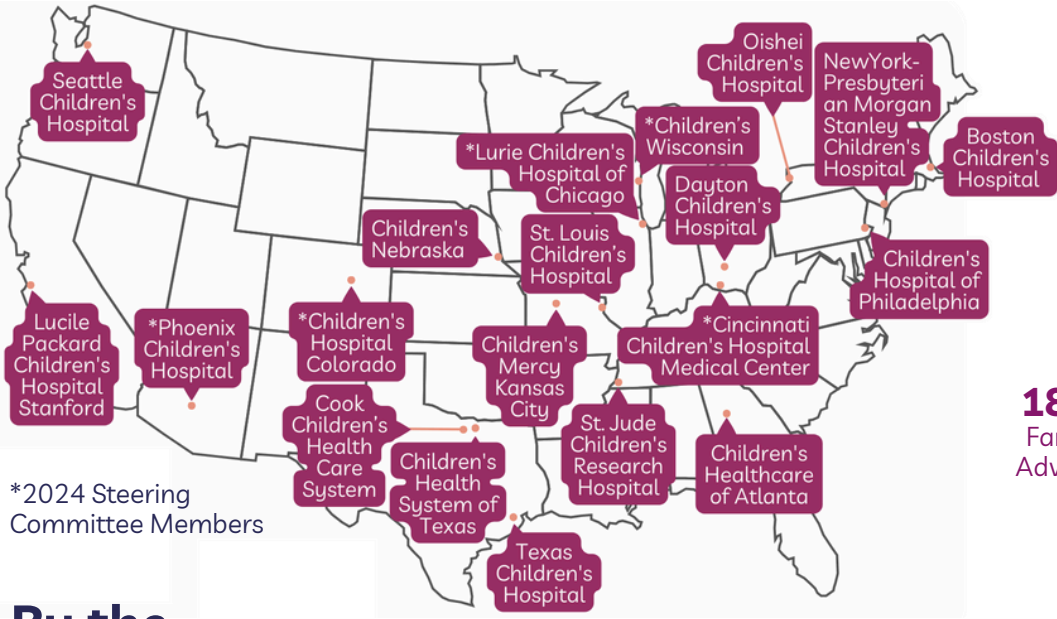
Pediatric Experience Collaborative

2024 A Year In Review

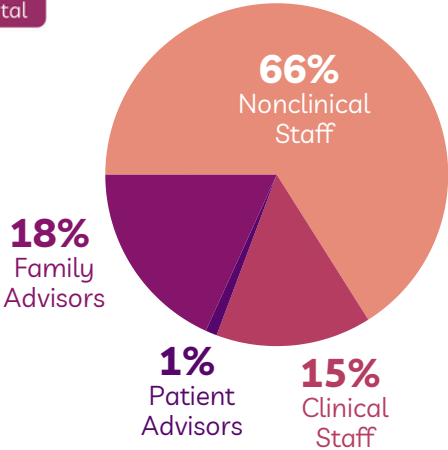
Testimonial

Participating in the Pediatric Experience Collaborative has been an incredibly empowering journey for me...I've learned that my insights and experiences can significantly contribute to developing best practices, not only at my local children's hospital but across pediatric hospitals nationwide...I am grateful for the opportunity to be part of a movement that strives to improve care for children and families everywhere.
Family Advisor, Cincinnati Children's

Member Hospitals



Individual Members



By the Numbers

349 Total Attendance of both Summits	\$363,116 Year-End Balance	30 Average Open Forum Attendance
54 Average Membership Call Attendance	20 Member Hospitals	120 Discussions & 357 Responses on Basecamp Message Board
1st Paper submitted for publishing, <i>The Pediatric Experience Collaborative: Paving the Way in Pediatric Experience</i> , and submitted to the <i>Journal of Patient Experience</i> for publishing		

Testimonial

The Pediatric Experience Collaborative has been an invaluable resource...The ability to collaborate with peers from children's hospitals across the country and learn from each other has directly improved the experiences for our patients, families, and staff. Based on these shared learning opportunities we have made changes to our survey methodology, identified new ways to visualize experience data, enhanced the experience in our ED waiting rooms, implemented ambulatory and inpatient quality improvements, and much more. We frequently use the PEC...as a quick and efficient way to get input on projects or challenges that we encounter.
Shelby Chapman, Director of Patient-Family Experience, Children's Hospital Colorado