

# 2023 Annual Report

Pediatric Experience  
Collaborative



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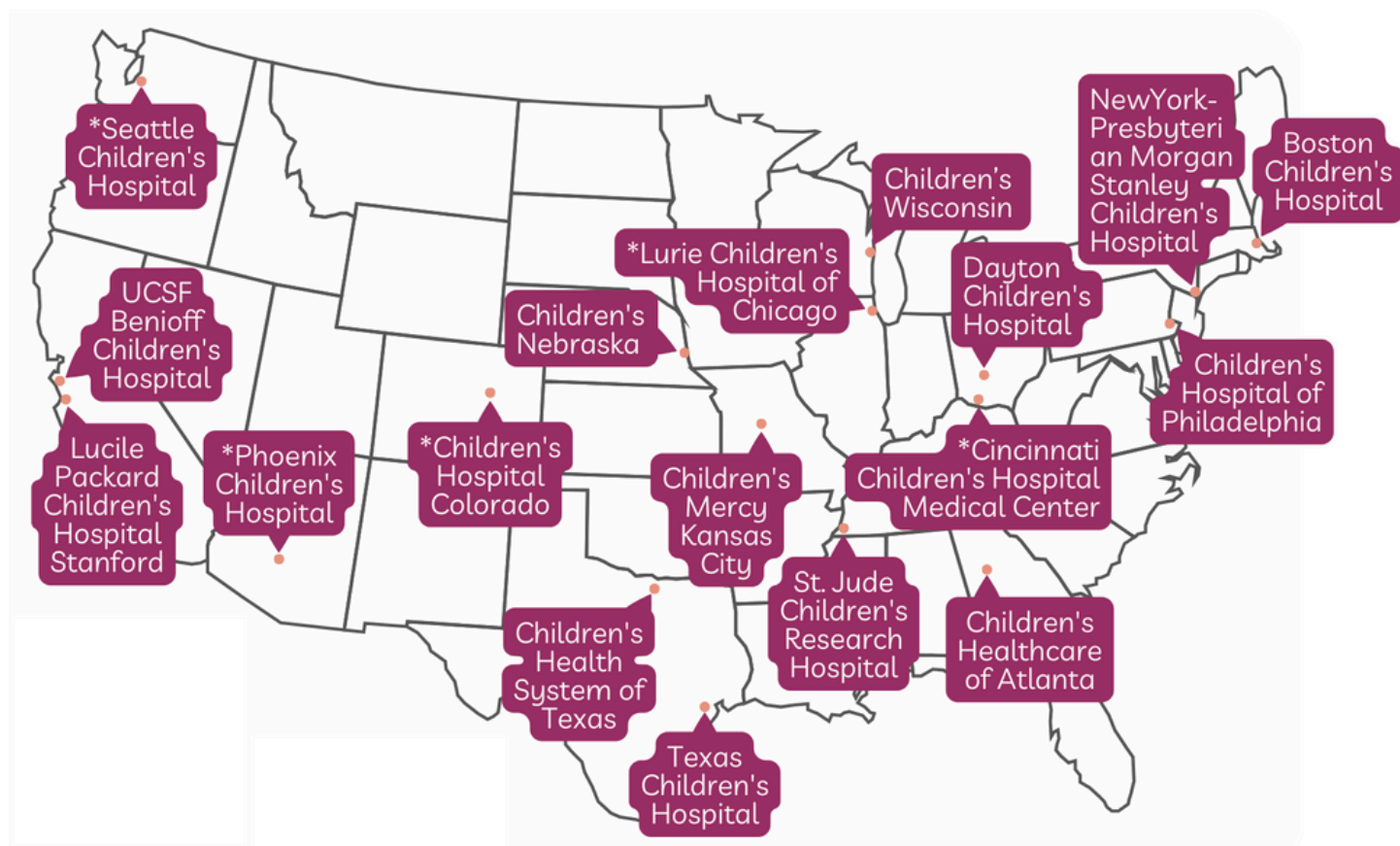
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## Collaborative Members



\*2023 Steering Committee Members

# Welcome Letter

*Dear Members of the Pediatric Experience Collaborative,*

*What a remarkable year 2023 has been for our Collaborative! From the warm welcomes extended to new members, to the launch of impactful committees, to thought-provoking discussions at our Fall Summit in Wisconsin, we've demonstrated the power of collaboration in driving positive change for pediatric healthcare.*

*I'd like to express my deepest gratitude to Enjoli Harris. Her leadership as Parent Co-Chair has been a true inspiration, and she continues to be in our thoughts as she prioritizes her health. I'm also grateful to Children's Wisconsin for their partnership and dedication in hosting a Fall Summit that explored the powerful intersection of technology and patient-centered care.*

*As we look back on the year, it's clear that our commitment to growth and improvement shines through in everything we do. The energy across our Collaborative is truly inspiring, and I'm excited by the promise that 2024 holds. Let's continue to push boundaries, amplify the voices of patients and families, and explore new ways to make a difference in the lives of children and those who care for them.*

*How can we further improve our Collaborative and bring even more value? Your ideas, your dedication, and your unwavering commitment to excellence are what make the PEC an exceptional force for good.*

*With sincere gratitude and unwavering optimism,  
Dr. Sam Hanke*



**Dr. Sam Hanke**  
Institutional Co-Chair  
Jan 2023 - Dec 2025  
Cincinnati Children's



**Enjoli Harris**  
Parent Co-Chair  
Jul 2022 - Dec 2023  
Seattle, Washington



**Bri Combs**  
Collaborative Manager  
Cincinnati, Ohio

# 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.

**Overarching Objective:** Above all, we are committed to collaborating - not competing - with one another to optimize the experiences of patients, families, and staff through transparent sharing, learning from one another, and developing best practices.

**Who We Are:** patients, families, caregivers, hospital staff and clinicians.

## 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: Anika Mian of Boston Children's Hospital hired as part-time Project Manager
- 2020: Tiffany Messer of Cincinnati, Ohio hired as first Parent Co-Chair
- 2022
  - Leadership and funding transferred from Boston Children's to Cincinnati Children's
  - Bri Combs of Cincinnati, Ohio hired as first full-time Collaborative Manager
  - Enjoli Harris of Seattle, Washington hired as next Parent Co-Chair
  - Scholarship created to support the attendance of family members at Fall Summit
  - LinkedIn page created

## 2023 Highlights

- Children's Hospital Colorado joined Steering Committee
- Dr. Sam Hanke began term as Institutional Co-Chair
- Launch of ten subcommunities for counterparts across the nation to connect
- Steering Committee Retreat resulted in the creation of our *2023-2025 Strategic Plan*
- Virtual Spring Summit, *Navigating Surges*
- Hybrid Fall Summit, *Centering Humanity in the Evolution of Healthcare Technology* at Children's Wisconsin
- Launch of website, [www.pediatricexperiencecollaborative.org](http://www.pediatricexperiencecollaborative.org)
- Addition of UCSF Benioff Children's Hospital, Lucile Packard Children's Hospital Stanford, and Children's Health System of Texas as new members
- Conclusion of the Optimizing Diverse Voices Workgroup and Race & Ethnicity Framework Workgroup, including their respective projects
- Creation of two new committees: the Experience Improvement Committee and the Communication & Education Committee
- Enjoli Harris ended year-and-a-half term as Parent Co-Chair
- Seattle Children's Hospital ended term as Steering Committee Member

# 2023 Strategic Plan

## 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 Committee led by a triad of family, hospital, and clinical co-leads
- Identify committee members
- Finalize committee charter



### OBJECTIVE #2: Drive Collaborative-Wide QI Projects

- Identify priority outcomes meaningful to patients, families and staff
- Experience Improvement Committee identifies several possible quality improvement project topics

## 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 a triad of family, hospital, clinical co-leads
- Identify committee members
- Finalize committee charter



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

- Needs and requirements for resource and best practice library platform have been identified



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

- Pediatric Experience Collaborative white paper has been outlined

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



### OBJECTIVE #1: Increase Participation in our Pediatric Experience Collaborative

- A job description has been written for PEC intern
- Compensation is being discussed for intern role with CCHMC finance department
- We are engaging with prospective members



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

- Leadership triad (hospital, clinical, and family co-lead) roles and descriptions have been drafted and are being finalized
- Compensation system and written agreement for family engagement has been established



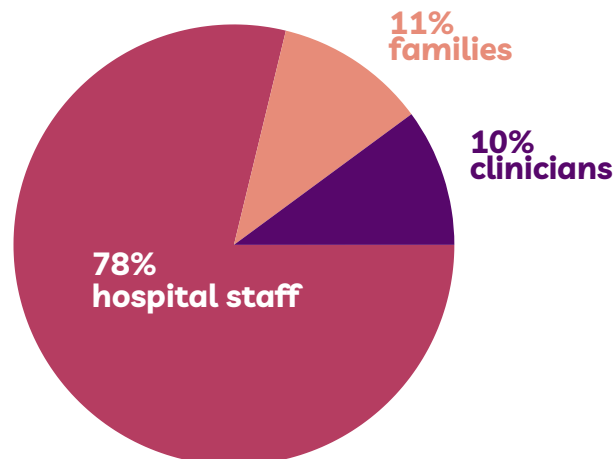
# Virtual Spring Summit: Navigating Surges

Thursday, May 11th

## Description

The theme for this year's Spring Summit was *Navigating Surges* and featured panel discussions with hospital leadership and families on their experiences and lessons learned during recent hospital surges, including the 2022 fall respiratory illnesses, the current youth mental health crisis, and Covid. The full spectrum of the experience was covered - from disparities exposed, to innovative ways in which we cared for our children during some of the most challenging healthcare moments of our time.

## Attendance



## Agenda

- Hospital Leadership Panel, sharing their experiences, lessons learned, and innovative practices/resources implemented to meet demands
- Family Panel, sharing their experiences, lessons learned, and innovative practices/resources they saw implemented, and what they hope will continue
- Discussion on comparing parallel experiences between clinicians, hospital staff, and families during surges; as well as best practices to implement during future surges to provide the best possible experiences for all.
- Networking Session
- Family Session to discuss how to improve resource navigation, engagement, and advocacy.

## Insights that attendees planned to implement upon their return to practice after this Summit:

- Keep families abreast of the predicted wait time before being seen.
- Always stopping to be sure I "see a patient and family member".
- Slowing down and being intentional.
- The focus on remote monitoring doesn't replace the face-to-face interactions with a family. Efficiency isn't always what is needed.

***It was incredibly valuable to hear from the family panel about their experiences with the pandemic/surge.***

Staff Attendee

***I appreciated the ideas shared by the various hospitals of ways both clinical and non-clinical employees helped out during the surge. I liked the tangible examples that were provided such as the sibling support area, workforce appreciation month, alerts when ED was surging, comfort cart, etc.***

Staff Attendee

# Fall Summit at Children's Wisconsin: Centering Humanity in the Evolution of Healthcare Technology

Wednesday, November 1 - Friday, November 3

We had a total of 134 attendees

■ virtual ■ in-person



***This is the warmest group of people I have ever had the opportunity to collaborate with.***  
In-Person Staff Attendee

***The passion is evident in the staff engaging in these discussions...they really want to learn and do better and make active changes.***  
In-Person Family Attendee

***The use of technology is growing and the need to engage families in providing insight to solutions is imperative.***  
In-Person Staff Attendee



***I feel validated that we are working on the right things at our hospital, and that we are not alone in our struggles and challenges.***  
In-Person Staff Attendee

***I appreciated the virtual breakout rooms and being integrated via chat, QR codes, etc. I appreciate your work in creating a meaningful hybrid session for those unable to travel.***  
Virtual Staff Attendee

***Thank you for the sweet care package with the book, notebook, and shopping bag even though I was not there in person. Very thoughtful!***  
Virtual Staff Attendee

***Can't wait to get more patients involved in the work, and was honored to be a part of this!***  
In-Person Patient Attendee

## Wednesday Agenda

- Milwaukee walking tour
- Networking dinner

## Thursday Agenda

- State of the Collaborative
- Family Story: An overview of EPIC from the family perspective
- Patient Story: *My Experience with Technology and Why it Matters*
- Family and staff breakout sessions: *Identifying Problems & Gaps in Technology*
- Keynote : Co-designing experiences using the Sprint improvement model with John Zeratsky
- Networking Lunch
- Family and staff breakout sessions: *Current Experiences and Technology Implementation*
- Race & Ethnicity Framework Workgroup Report
- Optimizing Diverse Voices Workgroup Report
- Happy Hour
- Family Dinner

## Friday Agenda

- Experience Improvement, and Communication & Education Committee interest meetings
- Family Story: *How Technology Changed the Game*
- Breakout reflections: *Improving Experience Using Technology throughout the Healthcare Journey*
- Hospital tour of Children's Wisconsin

# Optimizing Diverse Voices Workgroup Report

Timeframe: 2021-2023

## Co-Chairs

- Mary Rodriguez, Family Engagement Specialist, Children's Hospital Colorado
- Bart Bailey, Parent, NewYork-Presbyterian Morgan Stanley Children's Hospital

The objective of this workgroup was twofold: first, to identifying best practices for amplifying diverse family voices within the work of improving the pediatric experience, and second, standardizing the process for implementing these successful methods across Collaborative member hospitals.

## Ways in which member organizations are connecting with their communities to better understand and communicate with the diverse populations they serve.

- Partnering with school districts to provide health screenings, education, resources and services
- Establishing a specific division, institute, center or office dedicated to community engagement
- Allotting employees service hours to engage with local nonprofits
- Supporting community efforts with philanthropy and volunteering
- Executive leadership hosting "listening sessions" for community members to share experience feedback in conversational format to restore trust and reconcile relationships
- Recruiting diverse patients and families to serve on Patient and Family Advisory Councils
- Sponsoring the majority of the larger community events in underrepresented communities
- Partnering with community organizations, specifically those serving populations most affected by social determinants of health, to offer insurance, immunizations and resources to members
- Running community-based care clinics
- Hosting parent groups
- Homeless outreach

## Trainings offered or required for staff and volunteers to better connect with, understand, and provide equitable care to the diverse populations they serve.

- |  |   |                    |
|--|---|--------------------|
| • Bystander-to-Upstander Inclusive Workplace | • Inclusive Leadership                    | • Implicit Bias    |
| • LGBTQ+ Awareness, Allyship and Care        | • Respectful Workplace                    | • De-escalation    |
| • Systemic Racism and Healthcare Disparities | • Anti-Racism                             | • Data Inclusivity |
| • Intercultural Conflict Communication       | • Emotional Intelligence                  | • Health Literacy  |
| • Social Determinants of Health              | • Psychological Safety                    |                    |
| • Intimate Partner Violence Prevention       | • Communicating with Cultural Sensitivity |                    |
| • Immigrant & Refugees Diversity Awareness   | • Mitigating Microaggressions             |                    |
| • Religious Diversity Awareness              | • Cultural Competency                     |                    |

## Best practices for connecting with, and listening to, the diverse populations we serve.

- Moving justice, diversity, equity and inclusion into all aspects of hospital-wide strategies
- Working closely with Employee Resource Groups
- Mandating diversity equity and inclusion trainings for all employees and volunteers
- Empowering patients, families, staff, and volunteers to recognize and address concerns of discrimination, harassment, bullying and disrespectful behavior
- Shifting diversity, equity and inclusion efforts from a special topic to one inherent to success
- Cultural competency training follow-up assessments
- Health Equity Rounds to help foster a culture committed to belonging.
- Sharing drafted organizational changes with the Family Advisor Council



# Race & Ethnicity Framework Workgroup Report

Timeframe: 2021-2023

## Co-Chairs

- Michael Ponti-Zins, Data Analyst, Cincinnati Children's Hospital Medical Center
- Marissa Jacobs, Parent, NewYork-Presbyterian Morgan Stanley Children's Hospital

The purpose of this workgroup was to create a shared organizational framework to define equity for patient and family experience (PFE) in pediatrics. The original objectives were to 1) outline common challenges when measuring equity in PFE, 2) to share current approaches towards organizational equity in PFE measurement, and 3) develop a shared common measures and learn from variation across hospitals to close equity gaps. They planned to meet these objectives by creating best practice guidelines and shared patient and family equity measures, share common measures across the Collaborative, and learn from variation across hospitals to close equity gaps.

However, due to differences in how demographic data was being collected and challenges around accuracy of data, this workgroup revised their deliverables to 1) providing a summary of processes for collecting and analyzing demographic data, 2) developing a roadmap to help hospitals take initial steps in developing and implementing this framework, and 3) identifying best practices for educating patients and families on the value of collecting demographic data.

The workgroup surveyed the Collaborative membership to understand how members were collecting and using demographic (race, ethnicity and language) data. The workgroup held forums to discuss each stage of the roadmap.

## Forum 1: Collecting Demographic Data with Cultural Competence

Demographic data paired with experience feedback helps hospitals determine if and how the patient and family experience is influenced by demographics. Then, we use this data to improve the experience through equitable care.

### Best practices:

- Develop scripts for employees to use when asking families for their demographic information, including an explanation as to why it is being collected and how it will be utilized
- Standardize who will ask the families and at what points along the patient journey (e.g. registration staff)
- Set demographic fields on patient forms to be required
- Standardize definitions for demographic terms (e.g. utilize census definitions for race, ethnicity)

Key Learning: Demographic data was often incomplete or missing due to staff discomfort around the ask, or family discomfort around the information's intended purpose.

## Forum 2: Analyzing Response Rates by Demographics

Eight member organizations shared response rates broken out by language, race and ethnicity.

Best practices:

- Ensure survey responses align with patient demographics.
- Identify disparities, response rates and comment rates.

Key Learnings:

- Spanish-speaking families respond more frequently than English-speaking families
- White, English-speaking families are more likely to leave comments than families of color or Spanish-speaking
- Families were more likely to leave comments when responding to email or text surveys versus phone surveys, which may exclude certain demographics

## Forum 3: Analyzing and Sharing Experience Scores

Once we learn about the variations in experience for different patient populations, we need to communicate the results across the organization. Awareness of these disparities is the first step to providing equitable care for all.

All organizations saw similar trends in experience scores when broken out by race, ethnicity and language.

Best Practices:

- Build awareness of disparities and engage teams to identify ways to close gaps
- Be aware of small N sizes
- Be transparent with data through use of shared reports and dashboards to communicate across organization

Key Learnings

- Spanish-speaking families scored higher for key metric
- Significantly lower for other questions (4-point scale)
- Asian families scored lowest for most questions
- Black families scored lower than White families for most questions

## Summary

There are significant differences in how our member hospitals are collecting demographic data, analyzing experience feedback in relation to this demographic data, and sharing these learnings across their hospitals. Our experience feedback may not be representative of our patient populations due to incomplete data collection and/or inherent biases. However, from the limited data we were able to collect and analyze, we learned that similar patterns of disparities in experience scores do exist in many of our hospitals. Therefore, our member hospitals collectively desire to better understand and share how we are studying inequities in patient and family experience.

# Discussion Topics

## Open Forums

Our monthly Open Forums are for our members gather for an hour of open discussion. This meeting has no agenda, so attendees cover a wide variety of questions, share current challenges, and discuss hot topics.

- Flu and RSV surges
- Mental health crisis
- Improving the ED wait experience
- Staff and provider training
- Mental health and supports for clinicians
- Influences & impacts of provider ratings
- Wayfinding
- Rounding Compliance Targets
- Patient and Family Experience Week
- Safety Concerns and Measures
- Patient Passport
- Discharge Education
- Root Cause Analyses
- Resources to help families remember care team members
- Codesigning with Patient and Family Advisory Councils
- Combating health disparities to improve access
- Interpretation and translation for families
- Importance of individualized care
- Patient and family feedback surveys
- Improving communication between providers and families
- Grief throughout the healthcare journey

## Membership Calls

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

January: *Data & Transparency within the Collaborative*

February: *Goal Setting for PX Teams*, presented by Seattle Children's Hospital

March: *PEC Annual Report Overview*

April: *Optimizing Survey Questions*, presented by Dayton Children's Hospital

June: *Inpatient Communication Technology*, presented by Children's Hospital Colorado

July: *Increasing Parent Participation*, presented by Children's Mercy Kansas City

August: *Creating Safe & Nurturing Environments for All*, presented by Cincinnati Children's

September: *Getting Back to Basics*, facilitated by Boston Children's Hospital

October: *Best Practices When Designing Spaces for Optimal Pediatric Experiences*

December: *Follow-Up from Fall Summit: Centering Humanity in the Evolution of Healthcare Technology*

## 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.

- |                                  |   |                 |
|----------------------------------|---|-----------------|
| • Hospital App for Families      | • PFE Team Organizational Structure               | • OAS CAHPS     |
| • Patient Experience "Playbook"  | • Meal Ordering & Outside Food Delivery           | • Accessibility |
| • Language Services/Interpreters | • Code of Conduct/Behavior Expectations           | • Facility Dogs |
| • Child Life Metrics             | • Policies Following Patient Deaths               |                 |
| • Badging Families               | • Resident Fellow Education on Patient Experience |                 |
| • Peer Mentor Program            | • Communicating Masking Requirements              |                 |
| • Renaming of Chapel             | • Electronic Communication Board                  |                 |

# Finances

January 1st Balance: \$221,143.74

Revenue: \$180,600

- 2023 Membership Dues
- Summit registration fees

Expenses: \$106,138.67

- Salaries & Benefits
- Conferences
- Software
- Miscellaneous

Year-End Balance: \$295,605.07

# Many Thanks

## **Enjoli Harris, Parent Co-Chair (July 2022 - December 2023)**

We would like to express our gratitude to Enjoli Harris for serving as our Collaborative's second-ever Parent Co-Chair. Enjoli accepted this position in July 2022 and served until December 2023. During her time as Parent Co-Chair, Enjoli was an authentic and courageous presence. She advocated for children like her own, and caretakers like herself as she shared her lived experiences, expertise and perspective so beautifully and unashamedly. Life and health circumstances led Enjoli to step down from her position after a year and a half, but her guiding voice left an indelible impact on our Collaborative as she paved the way for other family members to also show up as their whole, authentic selves.