

2024 Patient and Family Advisory Council Annual Report Form

The survey questions concern PFAC activities in fiscal year 2024 only: (July 1, 2023 – June 30, 2024).

Section 1: General Information

NOTE: Massachusetts law requires every hospital to make a report about its PFAC activities publicly available by October 1 each year. Submitting the report to Betsy Lehman Center for inclusion on its website will fulfill that requirement.

1. **Hospital Name: Boston Children's Hospital**

2. **PFAC Name:**

2a. **Which best describes your PFAC?**

- We are the only PFAC at a single hospital – **skip to #3 below**
- We are a PFAC for a system with several hospitals – **skip to #2C below**
- We are one of multiple PFACs at a single hospital
- We are one of several PFACs for a system with several hospitals – **skip to #2C below**
- Other (Please describe): We are the hospital-wide FAC. Boston Children's has several other specialty-specific FAC's (that we do not govern) but we serve the entire population.

2b. Will another PFAC at your hospital also submit a report?

- Yes
- No
- Don't know

2c. Will another hospital within your system also submit a report?

- Yes
- No
- Don't know

3. **Staff PFAC Co-Chair Contact:**

3a. Name and Title: Jon Whiting DNP, RN, CCRN, Vice President and Associate Chief Nurse, Nursing/Patient Care & Clinical Operations

3b. Email: Jon.Whiting@childrens.harvard.edu

3c. Phone: 617-355-8564

Not applicable

4. **Patient/Family PFAC Co-Chair Contact:**

4a. Name and Title: Erin Poirier

4b. Email: erinmpoirier@gmail.com

4c. Phone: 508-468-8617

Not applicable

5. **Is the Staff PFAC Co-Chair also the Staff PFAC Liaison/Coordinator?**

- Yes – skip to #7 (Section 1) below
- No – describe below in #6

6. **Staff PFAC Liaison/Coordinator Contact:**

7a. Name and Title: Katie Litterer, Program Manager for Family Partnerships

7b. Email: Katherine.Litterer@childrens.harvard.edu

Not applicable

Section 2: PFAC Organization

7. This year, the PFAC recruited new members through the following approaches (check all that apply):

- Case managers/care coordinators
- Community based organizations
- Community events
- Facebook, Twitter, and other social media
- Hospital banners and posters
- Hospital publications
- Houses of worship/religious organizations
- Patient satisfaction surveys
- Promotional efforts within institution to patients or families
- Promotional efforts within institution to providers or staff
- Recruitment brochures
- Word of mouth/through existing members
- Other (Please describe): We leveraged our external website – we have a dedicated FAC page and a link to that page from our Patient & Family Resources external webpage.
- N/A – we did not recruit new members in FY 2024

8. Total number of staff members on the PFAC: 4

9. Total number of patient or family member advisors on the PFAC: 31: 22 “Active” members (attend all monthly meetings) and 9 “Emeritus” members (veteran members who attend up to three monthly meetings per year/serve on committees/workgroups)

10. The name of the hospital department supporting the PFAC is: Nursing/Patient Care & Clinical Operations

11. The hospital position of the PFAC Staff Liaison/Coordinator is: Program Manager for Family Partnerships

12. The hospital provides the following for PFAC members to encourage their participation in meetings (check all that apply):

- Annual gifts of appreciation
- Assistive services for those with disabilities
- Conference call phone numbers or “virtual meeting” options
- Meetings outside 9am-5pm office hours
- Parking, mileage, or meals
- Payment for attendance at annual PFAC conference
- Payment for attendance at other conferences or trainings
- Provision/reimbursement for childcare or elder care

- Translator or interpreter services
- Other (Please describe): Annual Appreciation event
- N/A

Section 3: Community Representation

The PFAC regulations require that patient and family members in your PFAC be “representative of the community served by the hospital.” If you are not sure how to answer the following questions, contact your community relations office or check “don’t know.”

3. Our hospital’s catchment area is geographically defined as:

- Don’t know

INPATIENT: Presently, approximately 76.8% of patients hospitalized at Boston Children’s Hospital are from Massachusetts. In addition, 13.8% of patients hospitalized at Boston Children’s are from New England excluding MA), 7.1% are from a national location (excluding New England), and 1.9% are from an international location.

OUTPATIENT: Presently, approximately 88.2% of outpatient patients at Boston Children’s Hospital are from children and families who live in Massachusetts. In addition, 7.6% of patients seen at a Boston Children’s outpatient clinic are from New England (excluding MA), 3.0% are from a national location (excluding New England), and .5% are from an international location.

**FY24 ends 9/30/2024 so we provide FY23 data because it is complete*

4. The racial and ethnic groups in these areas include (please provide percentages; if you are unsure of the percentages check “don’t know”):

	RACE						ETHNICITY	
	% American Indian or Alaska Native	% Asian	% Black or African American	% Native Hawaiian or other Pacific Islander	% White	% Other	% Hispanic, Latino, or Spanish origin	
14a. Our defined catchment area								<input checked="" type="checkbox"/> Don’t know
14b. Patients the hospital provided care to in FY 2024	0.3%	5.5%	9.0%	0.2%	54.4%	18.7%	11.9%	<input type="checkbox"/> Don’t know

14c. The PFAC patient and family advisors in FY 2024	0.0%	6.9%	3.4%	0.0%	75.8%	0.0%	13.8%	<input type="checkbox"/> Don't know
--	------	------	------	------	-------	------	-------	-------------------------------------

5. The languages spoken in these areas include (please provide percentages; if you are unsure of the percentages select "don't know"):

	Limited English Proficiency (LEP)	
	%	
15a. Patients the hospital provided care to in FY 2024	11.2	<input type="checkbox"/> Don't know
15b. PFAC patient and family advisors in FY 2024	3.4%	<input type="checkbox"/> Don't know

15c. What percentage of patients that the hospital provided care to in FY 2024 spoke the following as their primary language?

	%
Spanish	5.45
Portuguese	1.37
Chinese	0.54
Haitian Creole	0.42
Vietnamese	0.17
Russian	0.08
French	0.04
Mon-Khmer/Cambodian	0.03
Italian	0.01
Arabic	0.46
Albanian	0.02
Cape Verdean	0.24

Don't know

15d. In FY 2024, what percentage of PFAC patient and family advisors spoke the following as their primary language?

	%
Spanish	3.4%
Portuguese	3.4%
Chinese	0%
Haitian Creole	0%
Vietnamese	0%
Russian	0%
French	0%

Commented [ST1]: This would suggest that the number above should be 6.8%.

Commented [KL2R1]: Apologies - I'm not following. Esterlina is our Spanish speaker and Maria our Portuguese speaker. Can you help me understand where I'm getting confused, please?

Commented [LK3R1]: I understand now. It is deceiving BUT Esterlina speaks Spanish as her primary language. This said, she communicates proficiently in English - this leads to the difference between the percentages.

Italian	0%
Arabic	0%
Albanian	0%
Cape Verdean	0%

Don't know

6. The PFAC is undertaking the following activities to ensure appropriate representation of our membership in comparison to our patient population or catchment area:

Ensuring appropriate representation of our membership is an ongoing priority for our FAC. Our Family Partnerships team members are focused on building relationships with a diverse group of families, which includes families of varying races/ethnicities, socioeconomic status and hospital experiences. The FAC focuses recruiting efforts specifically on garnering voices that accurately represent the patients and families seeking care at Boston Children's. The FAC supplements the general call for FAC candidates each year with targeted efforts to staff who have strong working relationships with specific populations to solicit potential candidates. The FAC also leverages the E-Advisors Program on specific bodies of work where a broader perspective is beneficial. Our E-Advisors Program is made up of local, regional, national and international family members of current and former patients as well as current and former Boston Children's patients (ages 16+). Additionally, we have a part-time Family Partnerships Coordinator focused solely on providing support to our Latino families.

In late 2020, the FAC formally adopted a FAC-specific Equity, Diversity & Inclusion plan. The goals of this plan include creating an accessible, welcoming and sustainable membership experience for family members interested in lending their voices to the hospital through the FAC. Throughout FY21, FY22, FY23 and FY24, we have completed several action items to break down barriers for application and entrance to the FAC and to support an inclusive and welcoming environment for FAC members. In September 2023, we kicked off a formal refresh of our FAC-specific ED&I plan which will guide us through 2026 and in FY2024 we had great recruitment success, adding a number of new members starting in September 2024 who bring various aspects of diversity to our council.

Section 4: PFAC Operations

7. Our process for developing and distributing agendas for the PFAC meetings (choose):

- Staff develops the agenda and sends it out prior to the meeting
- Staff develops the agenda and distributes it at the meeting
- PFAC members develop the agenda and send it out prior to the meeting
- PFAC members develop the agenda and distribute it at the meeting
- PFAC members and staff develop agenda together and send it out prior to the meeting. (Please describe below in #17a)
- PFAC members and staff develop agenda together and distribute it at the meeting. (Please describe below in #17a)
- Other process (Please describe below in #17b)
- N/A – the PFAC does not use agendas

A formal FAC Steering Committee — comprised of volunteer family advisors and hospital staff — meets monthly to develop FAC meeting agendas together as a group. Members of this committee include our Senior Leadership Co-Chair, our Parent/Caregiver Co-Chair, FAC staff members, the Chief Safety & Quality Officer/Chief Experience Officer (who is an MD) and select Family Advisors who serve 1-2 years on the Steering Committee when our formal 3-year strategic plan aligns with having representation from a specific workstream present on the Steering Committee.

17b. If other process, please describe:

8. The PFAC goals and objectives for 2024 were: (check the best choice):

- Developed by staff alone
- Developed by staff and reviewed by PFAC members
- Developed by PFAC members and staff
- N/A – we did not have goals for FY 2024 – Skip to #20

Commented [ST4]: Why isn't our response this?

Commented [KL5R4]: Good catch! I mis-selected. Also, I need to do additional work on 19. Apologies for the oversight.

9. The PFAC had the following goals and objectives for 2024:

- Drive FAC strategic initiatives including: FAC-specific Equity, Diversity & Inclusion, continue to manage the Care Bundles Program (supporting families with limited support networks), Internal FAC culture, continue to drive 3-year FAC strategic plan (2023-2025)
- Track and measure family voice impact in engagement opportunities (quantitative and qualitative)
- Increase family engagement opportunities on hospital committees, etc., in a virtual setting
- Increase educational and training opportunities to bring patient/family voices to hospital employees/staff.
- Establish a new normal for hybrid operation and work with our FAC membership to identify creative ways to include every voice that wants to be heard during FAC meetings regardless of the nature of the meeting
- Identify and execute more ways to share the impact of FAC activities with members and the community

10. Please list any subcommittees that your PFAC has established:

- FAC Steering Committee: Plans all monthly agendas, addresses sensitive topics and strategic decisions.
- Care Bundles (formed Q1 2021): In partnership with social work, this group provides basic care and comfort items to patients and families receiving care at Boston Children's.
- FAC Equity, Diversity and Inclusion Committee: (formed in Q1 2020). This group created our FAC specific ED&I plan and oversees the plan's execution and maintenance.

11. How does the PFAC interact with the hospital Board of Directors (check all that apply):

- PFAC submits annual report to Board
- PFAC submits meeting minutes to Board
- Action items or concerns are part of an ongoing "Feedback Loop" to the Board
- PFAC member(s) attend(s) Board meetings
- Board member(s) attend(s) PFAC meetings
- PFAC member(s) are on board-level committee(s)
- Other (Please describe):
- N/A – the PFAC does not interact with the Hospital Board of Directors

N/A – We don't communicate through these approaches

Section 5: Orientation and Continuing Education

3. Number of new PFAC members this year: 6

4. Orientation content included (check all that apply):

- "Buddy program" with experienced members
- Check-in or follow-up after the orientation
- Concepts of patient- and family-centered care (PFCC)
- General hospital orientation
- Health care quality and safety
- History of the PFAC
- Hospital performance information
- Immediate "assignments" to participate in PFAC work
- Information on how PFAC fits within the organization's structure
- In-person training
- Massachusetts law and PFACs
- Meeting with hospital staff
- Patient engagement in research
- PFAC policies, member roles and responsibilities
- Skills training on communication, technology, and meeting preparation
- Other (Please describe below in #24a)
- N/A – the PFAC members do not go through a formal orientation process

24a. If other, describe:

5. The PFAC received training on the following topics:

- Concepts of patient- and family-centered care (PFCC) (new members)
- Health care quality and safety measurement
- Health literacy
- A high-profile quality issue in the news in relation to the hospital (e.g., simultaneous surgeries, treatment of VIP patients, mental/behavioral health patient discharge, etc.)
- Hospital performance information
- Patient engagement in research (FAC members who engage in research)
- Types of research conducted in the hospital
- Other (Please describe below in #25a)

☐ N/A - the PFAC did not receive training

25a. If other, describe:

As part of our ongoing FAC-specific EDI efforts, we partnered with two Boston Children's EDI leaders to bring a tailored, interactive educational experience focused on inclusion to the FAC. We had previously provided this type of experience in 2024. It was a wonderful experience for all and we have committed, as a FAC, to an annual EDI workshop for our council and small, bite-sized facilitated EDI exercises throughout the year to promote continuity and progress.

Section 6: FY 2024 PFAC Impact and Accomplishments

The following information concerns PFAC activities in the fiscal year 2024.

6. Please share the following information on the PFACs accomplishments and impacts:

26a. What were the three greatest accomplishments/impacts of the PFAC related to providing feedback or perspective?

Accomplishment/Impact	Idea came from (choose one)
Accomplishment/Impact 1: Project Mosaic Project Mosaic is the name for Boston Children's implementation of an electronic health record (EHR) platform from Epic. The FAC has played an integral role as one of many departments/groups collaborating to integrate the many parts of care Boston Children's provides to patients and families through a new EHR platform. From identifying patient/family priorities to validating efforts, to raising awareness about opportunities to further improve aspects of the care experience for patients/families AND workforce members through this new EHR, FAC voices have been woven throughout the process, from strategy and preparedness to optimizing the platform following its June 1, 2024 rollout. This partnership continues and family feedback is actively welcomed and actively sought out by hospital stakeholders.	<input type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input

Hospital-Acquired Condition partnerships

The FAC is committed to a partnership for safe and compassionate care here at Boston Children's. We have family voices represented on every safety committee dedicated to reducing/eliminating Hospital Acquired Conditions (HAC's). Family voices weigh in on potential reason for movement of the data, provide insights about how best to educate and/or include patient families in minimizing these types of events and bring a perspective to conversations about factors to consider and potential solutions or drivers of improvement.

Patient/family advisors of the PFAC

Department, committee, or unit that requested PFAC input

Accomplishment/Impact 3:

Phlebotomy Wait Times Improvement

In early 2024, patients wait times at the main Phlebotomy clinic were at an all-time high. To reduce wait times and improve experiences for both patients/families and staff, Laboratory medicine leadership partnered with the Enterprise Project Management Office (EPMO) and the Family Advisory Council (FAC). First, FAC members and E-Advisors surveyed electronically to understand the desired visit time goal, pain points, and other improvement ideas from patient families. With this information, the goal of having 80% of patients' visit times under 20 minutes was established. The project team then gathered front-line employees to identify current barriers to reducing patient visit times and brainstorm solutions. Solutions were categorized based on their implementation effort and impact

Patient/family advisors of the PFAC

Department, committee, or unit that requested PFAC input

from the FAC were categorized similarly and implemented. These included a more formal registration process and a method for patient families to communicate indirectly with the phlebotomists. With the help of both teams, the department was able to reduce the average visit time from 25.5 minutes (+ or - 14 minutes) to 15.8 minutes (+ or - 8.3 minutes). Before the change, 41% of patients had a visit time of under 20 minutes. Our most recent measurement captured that with these changes, 77% of patients are now in and out of the clinic under 20 minutes.

26b. What were the three greatest accomplishments/impacts of the PFAC related to influencing the institution's financial and programmatic decisions?

Accomplishment/Impact	Idea came from (choose one)
<p>Accomplishment/Impact 1:</p> <p>Patient, Family & Visitor Code of Conduct</p> <p>In partnership with Family Advisors, Boston Children's created and adopted a Patient, Family and Visitor Code of Conduct to provide clear communication and behavior expectations for those seeking care at or visiting Boston Children's. Signage will be at all public entrances, in all public waiting areas, in all ED and ambulatory exam rooms. The Code of Conduct is also accessible through our external website, in patient and family welcome materials and through the MyChildren's Portal. FAC members were engaged regularly during this project and the final document reflects very clear language recommended by FAC members.</p>	<p><input type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input</p>

Patient and Family Welcome Materials

Consistent patient and family welcome materials created to share key information with patients and families before their arrival/during their stay. Packets are tailored to Emergency Department, Inpatient and Ambulatory experiences. Each packet includes a welcome letter from Boston Children’s CEO, safety information, Patient, Family and Visitor Code of Conduct, available resources. Materials are available in our 6 core languages and are accessible both digitally and in print. They are accessible before a visit/stay through our external website and our MyChildren’s portal. During visits/stays they are accessible at ambulatory check in, ED check in/waiting area and on all inpatient units. FAC members weighed in on both the content and design of these materials, as well as how the materials are made accessible to patients and families.

- Patient/family advisors of the PFAC
- Department, committee, or unit that requested PFAC input

Accomplishment/Impact 3:

Education

FAC members are engaged in education content design and delivery for the following populations on an ongoing basis:

House Staff Orientation, Newly Licensed Nurse Orientation, Front Line Staff training, Call-Center Staff trainings, Medical Learner Education (Interprofessional Collaboration)

- Patient/family advisors of the PFAC
- Department, committee, or unit that requested PFAC input

26c. What were the three greatest accomplishments/impacts of the PFAC related leading/co-leading programs and initiatives?

Accomplishment/Impact	Idea came from (choose one)
-----------------------	-----------------------------

FAC EDI Programming

Following the success of our 2022 FAC-tailored EDI workshop, the FAC has established an ongoing relationship to bring education to the FAC as a group about equity, diversity, inclusion and belonging. Hospital EDI leaders will provide an annual workshop for FAC members on this topic and will visit FAC meetings quarterly to provide ongoing bite-size EDI education/connection opportunities for the group. This aligns with our FAC-specific EDI plan and promotes connection between members, cohesiveness and effectiveness of the group. It also will support individual members in more robustly supporting a broad base of patient families during committee work.

Patient/family advisors of the PFAC

Department, committee, or unit that requested PFAC input

Accomplishment/Impact 2:

Care Bundles

The Care Bundles Program is managed by the FAC. It provides small care and comfort items to staff who may access the inventory at any time. Staff select specific items that fit the needs of/are appropriate for individual patients/families.

Active management of the program includes maintaining and restocking the inventory, tracking usage of items and what groups are accessing those items. This is a successful and ongoing program that the FAC is proud of.

History of the FAC-managed Care Bundles Program:

In January 2021, based on a significant year-over-year increase in the basic human needs of our patient and family population,

Patient/family advisors of the PFAC

Department, committee, or unit that requested PFAC input

Department, the FAC embarked on a partnership with social work to provide basic personal care and comfort items to patients and families. BCH social workers provided a list of helpful items, ranging from hair- and toothbrushes to activity books, clean socks and soft blankets. FAC members procure, organize, package and deliver items to a dedicated storage area where BCH social workers can access needed items for specific patients/families. Family Advisors complete monthly inventory exercises and provide new stock for depleted items. Items are available individually or in “care bundles” which are packaged by FAC members and have a card from the FAC with a specific item list for each bundle attached. In 2022, the Care Bundles Program expanded to Primary Care and inpatient units across Boston Children’s and is intended to show our patients and their families that they are safe and cared for here at the hospital.

Accomplishment/Impact 3:

External website resources for patients and families

As one of our 2020-2022 FAC strategic initiatives, online support for patients and families is rooted in a long-term goal of bringing experience-based knowledge/mentorship to families seeking support at Boston Children’s.

To begin this process, we turned our focus to individual visitors to our Boston Children’s website. We offer a lot of information yet it’s not always easy to find, especially when a caregiver may be

- Patient/family advisors of the PFAC
- Department, committee, or unit that requested PFAC input

a child's medical status.

Since 2021, we have partnered with Family and Volunteer Services and the Marketing team managing our website. We have reviewed and prioritized both navigation and content based on the flow of a care experience. We have engaged FAC members and patients and families beyond the FAC in providing insights and feedback that have shaped our efforts and our progress to organize and present the helpful information in a way that is simple, accessible to all, and intuitive in navigation.

We are happy to share that the reorganization of this external website resource is complete. Our next steps include infusing family insights to tie users to relevant content and, hopefully, adding additional content to support families before, during and after their care experiences.

27. The five greatest challenges the PFAC had in FY 2024:

Challenge 1: Project Mosaic – Staff allocated elsewhere

As you may imagine, a complete overhaul of our EHR to an Epic-based platform, required (and still requires) a significant amount of time and manpower to prepare for, rollout and optimize. As such, FY2024 stood out as a year where the FAC needed to understand that this hospital-initiative needed to be prioritized over other bodies of work and that hospital stakeholders and partners who regularly seek out insights from our group were not seeking us out as much as they typically do. Now that we are in the optimization phase of our Epic transition, demand for FAC insights on other projects is returning to normal.

Challenge 2: Maintaining/enhancing internal FAC culture virtually

Internal culture and membership connections are a top priority for our council. We know that if we have a culture based on mutual respect and trust that we are a more cohesive, more effective working group. The 2020 shift to virtual-only operations served as a barrier against traditional methods that we had relied on to create and sustain connections between membership (in-person dinners/meetings/working group sessions).

This said, virtual engagement opened the door for our council to welcome more voices who are representative of those that we care for here at Boston Children's. Because of this, we have embraced virtual engagement, pairing it with hybrid meeting opportunities yet focusing on how to create and maintain those

interests in how they want to engage, if/how they want to communicate with other members, whether they are 100% virtual or attend hybrid meetings. So, each year we focus on optimizing our internal culture in a virtual environment because our membership is always evolving, as is our work.

Challenge 3: How to engage a new generation of FAC members effectively

Historically, FAC members were those with time and flexibility in their calendars. Post pandemic, however, we are finding that many people simply don't have the bandwidth in their days to commit time beyond our monthly FAC meetings. Additionally, we have worked hard to welcome a more representative body of voices to our council and we're no longer a group with lots of extra time on our hands. So, we must work smarter to engage our membership where each one of them are while maintaining our partnerships and reputation as a council who loves to say "yes" to partnership opportunities. This is doable yet not without thoughtful and deliberate creativity in our approach to partnership. This is an ongoing venture that we've had some good successes with, yet we believe this work will never be 'done.'

Challenge 4:

Challenge 5:

N/A – we did not encounter any challenges in FY 2024

8. The PFAC members serve on the following hospital-wide committees, projects, task forces, work groups,

or Board committees:

- Behavioral Health/Substance Use
- Bereavement
- Board of Directors
- Care Transitions
- Code of Conduct
- Community Benefits
- Critical Care
- Culturally Competent Care
- Discharge Delays
- Diversity & Inclusion
- Drug Shortage
- Eliminating Preventable Harm
- Emergency Department Patient/Family Experience Improvement
- Ethics
- Institutional Review Board (IRB)
- Lesbian, Gay, Bisexual, and Transgender (LGBT) – Sensitive Care
- Patient Care Assessment
- Patient Education
- Patient and Family Experience Improvement
- Pharmacy Discharge Script Program
- Quality and Safety
- Quality/Performance Improvement
- Surgical Home

research, government relations, facilities project planning, staff and employee recognition program
 N/A – the PFAC members do not serve on these – **Skip to #30**

9. How do members on these hospital-wide committees or projects report back to the PFAC about their work?

PFAC members sometimes bring committees that they are involved in to FAC meetings for broader group feedback.
Our “FAC Member Share” segment during select monthly FAC meetings provides a platform for one member to a meeting to share highlights of work they are involved in.
PFAC members provide quotes and testimonials about specific committees or projects that may be included in the annual report.

10. The PFAC provided advice or recommendations to the hospital on the following areas mentioned in the Massachusetts law (check all that apply):

- Institutional Review Boards
- Patient and provider relationships
- Patient education on safety and quality matters
- Quality improvement initiatives
- N/A – the PFAC did not provide advice or recommendations to the hospital on these areas in FY 2024

11. PFAC members participated in the following activities mentioned in the Massachusetts law (check all that apply):

- Advisory boards/groups or panels
- Award committees
- Co-trainers for clinical and nonclinical staff, in-service programs, and health professional trainees
- Search committees and in the hiring of new staff
- Selection of reward and recognition programs
- Standing hospital committees that address quality
- Task forces
- N/A – the PFAC members did not participate in any of these activities

12. The hospital shared the following public hospital performance information with the PFAC (check all that apply):

32a. Complaints and serious events

- Complaints and investigations reported to Department of Public Health (DPH)
- Healthcare-Associated Infections (National Healthcare Safety Network)
- Patient complaints to hospital
- Serious Reportable Events reported to Department of Public Health (DPH)

32b. Quality of care

- High-risk surgeries (such as aortic valve replacement, pancreatic resection)
- Joint Commission Accreditation Quality Report (such as asthma care, immunization, stroke care)
- Medicare Hospital Compare (such as complications, readmissions, medical imaging)
- Maternity care (such as C-sections, high risk deliveries)

32c. Resource use, patient satisfaction, and other

ICU patients)

- Patient experience/satisfaction scores (e.g. HCAHPS - Hospital Consumer Assessment of Healthcare Providers and Systems)
- Resource use (such as length of stay, readmissions)
- Other (Please describe): Data specific to Hospital Acquired Conditions (HAC) committees, HCAHPS data sliced by race/ethnicity. PCAC shares all safety data with committee members only (one of whom is a FAC member, but that information is not widely shared with the FAC).
- N/A – the hospital did not share performance information with the PFAC – **Skip to #35**

3. Please explain why the hospital shared only the data you checked in Q 32 above:

Since 2022, FAC membership have a strong interest in utilizing monthly agenda time for feedback and discussion opportunities versus informational presentations.

As such, we have eliminated several of the informational presentations that we have had in the past at monthly meetings where patient complaint information, SERS, etc., may have been shared.

FAC members serve on various safety and quality committees, including Patient Care Assessment Committee, Practice, Quality and Outcomes, Patient Identification, Discharge Optimization and select Hospital Acquired Conditions (HAC) committees. As it pertains to specific projects/workgroups/committees, those FAC members have received key information listed above as it pertains to their individual group scopes.

4. Please describe how the PFAC was engaged in discussions around these data in #32 above and any resulting quality improvement initiatives:

FAC members, as participants on various safety and quality committees, including those noted in question 33, continue to provide family perspectives and insights that impact the direction of improvement efforts. Specific to QI related initiatives, FAC members provide anecdotal education to staff to drive positive behaviors and practices by sharing 'why this is so important to families like ours.' FAC members weigh in on patient and family facing educational materials. FAC members have also partnered with the Office of Experience around a clinician coaching program and individual components contained within. Lastly, several personal videos were produced to impact staff seeking to improve safety and quality measures. Examples include a story about a patient fall, a family's experience with CLABSI, family experiences with hospital readmission.

5. The PFAC participated in activities related to the following state or national quality of care initiatives check all that apply):

35a. National Patient Safety Hospital Goals

- Identifying patient safety risks
- Identifying patients correctly
- Preventing infection
- Preventing mistakes in surgery
- Using medicines safely
- Using alarms safely

35b. Prevention and errors

- Care transitions (e.g., discharge planning, passports, care coordination, and follow up between care settings)
- Checklists
- Electronic Health Records –related errors
- Hand-washing initiatives
- Human Factors Engineering

- Team training
- Safety

35c. Decision-making and advanced planning

- End of life planning (e.g., hospice, palliative, advanced directives)
- Health care proxies
- Improving information for patients and families
- Informed decision making/informed consent

35d. Other quality initiatives

- Disclosure of harm and apology
- Integration of behavioral health care
- Rapid response teams
- Other (Please describe): Phlebotomy wait times improvement project, Hospital readmissions (family video created), 30-day inpatient room cleaning policy/patient and family facing education for long-term stays (Infection Prevention & Control)
- N/A – the PFAC did not work in quality of care initiatives

16. Were any members of your PFAC engaged in advising on research studies?

- Yes
- No – Skip to #40 (Section 6)

17. In what ways are members of your PFAC engaged in advising on research studies? Are they:

- Educated about the types of research being conducted
- Involved in study planning and design
- Involved in conducting and implementing studies
- Involved in advising on plans to disseminate study findings and to ensure that findings are communicated in understandable, usable ways
- Involved in policy decisions about how hospital researchers engage with the PFAC (e.g. they work on a policy that says researchers have to include the PFAC in planning and design for every study)

18. How are members of your PFAC approached about advising on research studies?

- Researchers contact the PFAC
- Researchers contact individual members, who report back to the PFAC
- Other (Please describe below in #38a)
- None of our members are involved in research studies

38a. If other, describe:

19. About how many studies have your PFAC members advised on?

- 1 or 2
- 3-5
- More than 5
- None of our members are involved in research studies

Section 7: PFAC Annual Report

We *strongly* suggest that all PFAC members approve reports prior to submission.

0. The following individuals approved this report prior to submission (list name and indicate whether staff or patient/family advisor):

Don Whiting (Staff, Senior Leadership Co-Chair)
Lorin Poirier (Parent Co-chair)
Lisa Rubino (Staff, FAC Liaison)
Mara Toomey (Staff, Chief Safety & Quality Officer, Chief Experience Officer)

1. Describe the process by which this PFAC report was completed and approved at your institution (choose the best option).

- Collaborative process: staff and PFAC members both wrote and/or edited the report
- Staff wrote report and PFAC members reviewed it
- Staff wrote report
- Other (Please describe):

Massachusetts law requires that each hospital's annual PFAC report be made available to the public upon request. Answer the following questions about the report:

2. We post the report online.

- Yes, link: <http://www.childrenshospital.org/patient-resources/lend-your-voice/family-advisory-council/accomplishments>
- No

3. We provide a phone number or e-mail address on our website to use for requesting the report.

- Yes, phone number/e-mail address:
- No

4. Our hospital has a link on its website to a PFAC page.

- Yes, link: <http://www.childrenshospital.org/patient-resources/lend-your-voice/family-advisory-council>
- No, we don't have such a section on our website