



PFAC Annual Report Form

Annual reports are an opportunity for Patient and Family Advisory Councils to summarize their work in the prior year, track progress toward goals, and share successes as well as challenges with the broader community.

Why complete an annual report for my PFAC?

In Massachusetts, hospital-wide PFACs are required to produce annual reports by October 1 of each year. These reports must be made available to members of the public upon request. In past years, Health Care For All (HCFA) has collected and aggregated hospital reports to share with the wider community.

This template was designed by HCFA to assist with information collection, as well as the reporting of key activities and milestones. As of 2023, the responsibility for collecting and sharing PFAC reports with the broader community has been assumed by the Betsy Lehman Center for Patient Safety. The Center is also planning to revitalize efforts to support PFAC work across the state and will have more information in the coming months on those efforts.

What will happen with my report?

PFAC reports submitted will be available online in early November at:
BetsyLehmanCenterMA.gov/PFAC

Who can I contact with questions?

Please contact Janell.Wilkinson@BetsyLehmanCenterMA.gov or call 617-701-8271.

Please email this completed form to
PFAC@BetsyLehmanCenterMA.gov by October 1, 2023.

2023 Patient and Family Advisory Council Annual Report Form

The survey questions concern PFAC activities in fiscal year 2022 only: (July 1, 2022 – June 30, 2023).

Section 1: General Information

1. Hospital Name: Boston Children's Hospital

NOTE: Massachusetts law requires every hospital to make a report about its PFAC publicly available. The Center strongly encourages the completion of an individual report for each hospital-wide PFAC.

1a. 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.

1b. Will another PFAC at your hospital also submit a report?

- Yes
- No
- Don't know

1c. Will another hospital within your system also submit a report?

- Yes
- No
- Don't know

3. Staff PFAC Co-Chair Contact:

2a. Name and Title: Jon Whiting DNP, RN, CCRN, Vice President and Associate Chief Nurse, Nursing/Patient Care & Clinical Operations

2b. Email: Jon.Whiting@childrens.harvard.edu

2c. Phone: 617-355-8564

Not applicable

4. Patient/Family PFAC Co-Chair Contact:

3a. Name and Title: Erin Poirier

3b. Email: erinmpoirier@gmail.com

3c. 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:

6a. Name and Title: Katie Litterer, Program Manager for Family Partnerships

6b. Email: Katherine.Litterer@childrens.harvard.edu

6c. Phone: 617-355-6000

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 a recruitment flyer specific to the FAC that is shared with our FAC members, key stakeholders within the hospital and community connections.
- N/A – we did not recruit new members in FY 2022

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

9. Total number of patient or family member advisors on the PFAC: 30: 23 “Active” members (attend all monthly meetings) and 7 “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
- Stipends
- Translator or interpreter services
- Other (Please describe): Annual Appreciation event, annual token of appreciation
- 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.”

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

Don’t know

INPATIENT: For FY22, more than 75.3% of patients hospitalized at Boston Children’s Hospital are from Massachusetts. In addition, 13.3% of patients hospitalized at Boston Children’s are from New England (excluding MA), 8.8% are from a national location (excluding New England), and 2.6% are from an international location (438 international inpatients (including observations)).

OUTPATIENT: For FY22, more than 87.9% of outpatient patients at Boston Children’s Hospital are from children and families who live in Massachusetts. In addition, 7.4% of patients seen at a Boston Children’s outpatient clinic are from New England (excluding MA), 4.1% are from a national location (excluding New England), and .6% are from an international location (1,916 international outpatients in FY21).

***FY23 ends 9/30/2023 so we provide FY22 data because it is complete*

14. 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 type="checkbox"/> Don’t know
14b. Patients the hospital provided care to in FY 2023	0.2%	4.9%	7.6%	0.1%	50.9%	24.2%	12.0%	<input type="checkbox"/> Don’t know
14c. The PFAC active family advisors in FY 2023	0%	8.7%	4.3%	0%	74%	0%	13%	<input type="checkbox"/> Don’t know

15. 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 2023	7.1%	<input type="checkbox"/> Don't know
15b. PFAC patient and family advisors in FY 2023	4.3%	<input type="checkbox"/> Don't know

*Based on 23 active FAC members as they attend all monthly FAC meetings and are deeply immersed in FAC activities

15c. What percentage of patients that the hospital provided care to in FY 2022 spoke the following as their primary language?

	%
Spanish	5.19
Portuguese	1.05
Chinese	0.42
Haitian Creole	0.26
Vietnamese	0.14
Russian	0.07
French	0.04
Mon-Khmer/Cambodian	0.02
Italian	0.01
Arabic	0.45
Albanian	0.02
Cape Verdean	0.23

Don't know

15d. In FY 2023, what percentage of PFAC patient and family advisors spoke the following as their primary language?

	%
Spanish	4.3%
Portuguese	4.3%
Chinese	0%
Haitian Creole	0%
Vietnamese	0%
Russian	0%
French	0%
Mon-Khmer/Cambodian	0%
Italian	0%
Arabic	0%
Albanian	0%
Cape Verdean	0%

Don't know

*Based on 23 active FAC members as they attend all monthly FAC meetings and are deeply immersed in FAC activities

16. 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 and FY23, 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 July 2022, we began making specific efforts to include all voices in the room by meeting each member where they are comfortable in order to promote authentic engagement for all. In September 2023, we kicked off a formal refresh of our FAC-specific ED&I plan which will guide us through 2026.

Section 4: PFAC Operations

17. 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

17a. If staff and PFAC members develop the agenda together, please describe the process:

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.

17b. If other process, please describe:

18. The PFAC goals and objectives for 2023 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 2022– **Skip to #20**

19. The PFAC had the following goals and objectives for 2023:

- Drive FAC strategic initiatives including: FAC-specific Equity, Diversity & Inclusion, partner with Social Work to manage the Care Bundles Program (supporting families with limited support networks), Internal FAC culture, launch new 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
- 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

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

- FAC Steering Committee: Plans all monthly agendas, addresses sensitive topics and strategic decisions.
- FAC Internal Culture (formed Q1 2020): Focuses on building and maintaining connections between our members in an effort to promote a healthy and cohesive working culture for the FAC.
- 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.

21. 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

22. Describe the PFAC's use of email, listservs, or social media for communication:

- N/A – We don't communicate through these approaches
- Email is our primary communication channel for our FAC membership.

- SmartSheet and SurveyMonkey are leveraged to reach our FAC membership with specific communications, such as completing the annual FAC Assessment, voting for annual Best in Care Award winners, voting on FAC Seal recipients, completing our annual demographic survey, etc.
- Zoom poll are used to ensure we capture as many voices as possible on decisions/preferences, etc., during virtual FAC monthly meetings.
- Social media posts are used to recruit for our E-Advisors Program – which is used as a funnel for potential future FAC members.
- We are currently pursuing a new secure forum opportunity that, we hope, will serve as a singular secure communication platform for our FAC. We utilized Yammer between 2105-2021 yet have now phased that out.

Section 5: Orientation and Continuing Education

23. Number of new PFAC members this year: 4

24. 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:

25. The PFAC received training on the following topics:

- Concepts of patient- and family-centered care (PFCC)
- 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
- 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:

Section 6: FY 2023 PFAC Impact and Accomplishments

The following information concerns PFAC activities in the fiscal year 2023.

26. 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)
<p>Accomplishment/Impact 1: Patient & Family Digital Experience</p> <p>What began with a 2020 inclusion of families in selecting a texting platform for patient and family communications has evolved into a bidirectional channel for questions and feedback that benefit ongoing improvement efforts pertaining to patient and family digital communications and the online experience. A few examples of positive outcomes include:</p> <p>Consolidation and optimized timing of electronic messages sent to patient families with a focus on what they need, when the need it. A more intuitive patient and family navigation experience on the MyChildren’s patient portal. Revamping the timing, modality, content and appearance of pre-visit communications to ensure effectiveness of those communications and minimize no-show rates. Family voices directly informing our Project Mosaic (transition to an Epic platform) and what the digital experience will look like for patients and families.</p> <p>These types of impact opportunities have all been highly effective. We have leveraged FAC meeting discussions, virtual focus groups, online surveys and informal email feedback to garner guiding insights from our patients and families.</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>
<p>Accomplishment/Impact 2: Harvard-Wide Health Services Research Fellowship Program</p> <p>For the 10th year in a row, FAC members act as advisors for research fellows conducting a wide variety of studies as part of the Harvard-wide Pediatric Health Services Research Fellowship Program.</p> <p>Since 1994, the Harvard-wide Pediatric Health Services Research (HSR) Fellowship Program has excelled at training a new generation of investigators whose work is defining and addressing critical gaps in child health services research and the provision of</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>

primary care for children. Training provided examines key issues such as access, quality, outcomes, and cost-effectiveness of care.

The principal goal of this two-year program is to develop expert investigators whose research will fundamentally improve the capacity of the U.S. healthcare system to meet the needs of children and families, including socio-economically disadvantaged and minority populations. The diverse research projects conducted by the faculty and fellows share the goal of improving pediatric care along the six dimensions of quality articulated by the Institute of Medicine — care that is safe, effective, timely, efficient, patient centered, and equitable.

In the program’s annual anonymous fellow survey, 100% felt parent faculty brought a positive experience. The successful integration of parents and teens into the fabric of our program has been highlighted in a national presentation and publication.

Accomplishment/Impact 3: External Transparency

As Boston Children’s moves to align itself with other leading standalone pediatric hospitals by sharing patient and family experience data externally, FAC members have been woven into the journey towards external transparency.

At multiple key junctures, the Patient Experience and Marketing teams have engaged our FAC membership in discussions about everything from general sentiments about star ratings and reviews, the look and feel of how the information might be presented, the access and navigation for users interested in this data.

The work continues today with insights from the FAC serving as guiding principles for providing patients and families with the most helpful information in easy to understand and easy to access ways.

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

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)

Accomplishment/Impact 1: Informing Transition to Epic: Project Mosaic

FAC members are thrilled that Boston Children’s is mid-way through the implementation process for a single electronic health record (EHR) platform from Epic. Family perspectives continue to be carefully woven into strategic decisions through committee membership, electronic surveys, focus groups, email feedback and other creative engagement opportunities such as topic-specific discussions at UX-Collaborative meetings.

At the official leadership kick off meeting in early 2023, FAC member reactions to the project brought personal connection and meaning to so many about just how important this work is. Here are some of their sentiments:

TRANSLATION

“The fact that I can select other languages to access information is SIMPLY WONDERFUL. It will make my life a lot easier.” -Maria, Portuguese-speaking mom

FREEDOM TO ROAM

“I carry around physical copies of my clinic notes from my BCH provider because EMRs in Boston, other parts of the country and world, do not talk to each other. My understanding is that Epic at least has a functionality to do one-time sharing with

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

places/providers that are beyond BCH... so if I'm in Seattle I can grant one-time access to whomever I might need to see there. This is a step in the right direction to keeping everyone on the same page.” -Erin, adult patient

SELF-SCHEDULING

“I am really looking forward to self-scheduling as a piece of this new change. The ability to look ahead for availability is really going to assist in planning when I can look at all calendars (personal/home/school and hospital) to make appointments that fit the fluidity of life.” -Suzanne, patient mom

TRANSITION OF CARE & REDUCTION OF ERRORS

“This is EPIC!! It will be wonderful to have a system in place that is compatible for the patients that transition to adult providers, even if they still have some clinicians at BCH. It will also make record sharing and position sharing and messaging much more coherent and there will be much less room for error.” -Lisa, patient mom

CARE COORDINATION ACROSS INSTITUTIONS

“My son receives care at BCH and at another major pediatric hospital. It has been very, very difficult getting all of his information to them. That hospital uses EPIC so now we know that sharing important health information about my son will be seamless and make our care much easier to manage with two hospital systems.” -Katie, patient mom

Accomplishment/Impact 2: Transforming Tomorrow: Needham, Weymouth, Waltham and a new partnership with Franciscan Children’s

Since spring of 2022, the FAC has been engaged with both the Government Relations team and the Transforming Tomorrow design and facilities team with a focus on expanding Boston Children’s patient care opportunities through satellite locations.

With a goal of making access to care easier for patient families and to promote better balance between care / school / life for its patients, our FAC has been involved from the beginning of this process, providing letters of support and testimony for the benefits of bringing care closer to home for patients and families that need Boston Children’s to advising members of the design team on concepts that create a welcoming look, feel and easy access for all, in conjunction with a robust and thorough medical care experience in satellite locations that is consistent with other Boston Children’s locations.

Most recently, FAC members provided feedback on wayfinding themes and signage for our Waltham location and also took part in listening sessions about Boston Children’s new partnership with Franciscan Children’s Hospital. Insights shared at these listening sessions will guide legislative, architectural, facilities planning, design, medical services and staffing efforts to make sure that we are moving forward with a plan that provides the most impactful and accommodating care experiences for our patients and families at Franciscan Children’s.

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

Accomplishment/Impact 3: Discharge Optimization

The enterprise-wide initiative to improve discharge readiness, execution and minimize readmissions launched in 2022 and continues today, now in phase 3 of the work, in partnership with FAC members as representative voices at the table. Discharge Optimization team members have engaged individual FAC members on multiple workgroups and have also come to monthly FAC meetings to educate members about the project, solicit insights and feedback at key strategic points in the work, and provide updates.

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

FAC members are currently engaged in providing feedback about materials that may be included in a new admissions packet as part of this work, as discharge readiness may begin upon admission.

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)
<p>Accomplishment/Impact 1: Care Bundles Program</p> <p>In January 2021, based on a significant year-over-year increase in the basic human needs of our patient and family population, specifically in the Emergency 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 procured, organized, packaged and delivered items to a dedicated storage area where BCH social workers and other staff members can access needed items for specific patients/families.</p> <p>Volunteer Family Advisors operate and administer the Care Bundles Program almost completely. From monthly inventory exercises to using provided funds to purchase new items, tracking expenses and usage of inventory 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.</p> <p>The Care Bundles initiative is now available across all inpatient units, the Emergency Department and Primary Care and is intended to show our patients and their families that they are safe and cared for here at the hospital.</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input type="checkbox"/> Department, committee, or unit that requested PFAC input</p>
<p>Accomplishment/Impact 2: FAC Strategic Planning / Sharing benefits at Beryl’s Elevate PX</p> <p>We launched our third 3-year strategic plan in early 2023 highlighting three strategic drivers based on target populations impacted by FAC efforts and activities: FAC Member Experience, Patient & Family Experience and Workforce Experience. This formal strategic plan not only helps us to maintain a family member-driven focus but also leverages formal, recurring accountability measures to ensure progress, provide opportunities to celebrate successes while also acknowledging failures and opportunities for improvement. As always, 100% collective buy in and co-ownership from all of our FAC members is imperative to the optimal execution of any strategic plan.</p> <p>We were proud to have a team of family members and FAC leadership present the merits of strategic planning at the 2023 Beryl Institute’s ELEVATE PX conference, highlighting some of our successes and lessons learned along the way.</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input type="checkbox"/> Department, committee, or unit that requested PFAC input</p>
<p>Accomplishment/Impact 3: Workforce Recognition & Gratitude</p> <p>Our FAC members inspired the creation of a 100% patient and family nomination driven award program to recognize Boston Children’s staff and volunteers for going above and beyond to positively impact the experiences of those seeking care at Boston Children’s. The Best in Care Award recognizes all nominees and highlights 5 finalists and 1-2 winners per year. In 2022 a FAC member gave the keynote address at the awards ceremony and the FAC members created a gratitude video that was shared at the celebration and then with all staff and volunteers through our intranet.</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input type="checkbox"/> Department, committee, or unit that requested PFAC input</p>

Our FAC adopted workforce experience as one of our three strategic drivers (2023-25) in recognition of how intertwined patient/family experience and workforce experience are in a pediatric healthcare setting.

27. The five greatest challenges the PFAC had in FY 2023:

Challenge 1: Driving FAC Membership Diversity While Preserving Members' Sense of Value.

In 2016 FAC membership identified diversity in membership as an area of opportunity for the FAC. The council spent most of 2017-2019 working on creating strong operational foundations to support FAC functionality in preparation for a FAC-specific ED&I commitment. In late 2019, the FAC formally committed to a ED&I strategic goal and in 2020, our volunteer members formed a taskforce and wrote/adopted our FAC-specific ED&I plan. Between 2020-2022 recruitment of new members was a driving focus of this plan. Today, our members are happy with the diversity of lived and medical experiences on the FAC yet recognize that membership is always shifting and that ensuring a membership that represents those seeking care at Boston Children's will be a forever priority. This all said, we focused so much on recruitment that our membership is now prioritizing "Belonging" in the next phase of our FAC ED&I journey. The goal is to make every member feel equally valued, comfortable and supported in bringing their authentic selves to the table. What we want to avoid is a membership that perceives that they were only invited to join the FAC for one or more elements of diversity that they may bring to the council. We invite only members who the council believes will enhance its membership yet our focus on demographics is easily confused by many, and as a result we will focus more on the PEOPLE who make up our membership than the DEMOGRAPHICS they represent.

Challenge 2: Maintaining/enhancing internal FAC culture virtually

In 2020, based on interest from our Family Advisors, we launched a strategic group focused entirely on internal FAC culture. This group works to create personal connections amongst our membership. They are involved in planning our annual celebration, sending birthday cards, recognizing personal milestones for our members, mentoring new members. The efforts of this group have yielded highly positive outcomes and feedback from our membership. This said, the shift to virtual-only operations beginning in 2020 placed an additional barrier against creating and sustaining connections between membership. Having just captured 2023 FAC member feedback in our annual FAC Assessment Survey, we will be operating as a hybrid council, again, in 2023, with virtual participation options for every meeting coupled with 2-4 in-person meeting options per year. Our internal culture strategic group will be focusing on strategies to promote healthy internal culture characterized by fostering authenticity, inclusion and belonging amongst our members. Efforts will include partnering with our FAC ED&I Committee to roll out foundational supports to promote a sense of belonging for all of our members, sending out birthday cards to members, planning and hosting our annual celebration event (virtual), taking post-meeting survey data and making recommendations to FAC leadership about improvement opportunities and more.

Challenge 3: Changes in hospital leadership and key partners (Tyonne, Aaron, etc.)

In FY23 attrition in some key hospital leadership positions caused the FAC to pause some bodies of work that were being executed in partnership with departing leaders. Additionally, the hospital welcomed some new hospital leaders in roles that traditionally liaise and partner with the FAC. As such, the FAC needed to navigate building relationships with new leaders while think about how to pivot and move existing bodies of work, such as the FAC-specific EDI education, forward in new ways.

Challenge 4: Small FAC staff

The FAC is supported by a small staff that has shrunk significantly since February 2020. As the sophistication of the FAC increases, it can be difficult to support the council at a level that drives FAC progress in a satisfactory way. Our membership is always understanding yet sometimes operational and administrative lags cause pauses in progress and everyone feels those patches of slowness. The FAC is efficient and operationally effective in sustaining a certain level of functionality yet feeling and seeing progress is what brings people back year after year. As we will continue to have a small staff we do our best to work creatively to move things forward and report impact back to our membership.

Challenge 5: How to engage a new generation of FAC members effectively

Historically, FAC members were those with time and flexibility in their calendars. Oftentimes, volunteer members would make multiple trips to the hospital to volunteer hours of their time to FAC activities, committees and workgroups per week. Post pandemic we are finding that many people simply don't have the bandwidth in their days to commit time beyond our monthly FAC meetings. Additionally, in fulfilling a priority to welcome new and representative voices to the council, other barriers for participation have added to our members not having as much time to give. We are actively working to try new avenues for feedback and engagement in an effort to meet members where they are, provide them with opportunities to add value and feel heard, yet remain conscientious and respectful about the other priorities they juggle each day. This is an ongoing venture and while we've found some effective and efficient channels/opportunities for some of our members, we are still seeking optimal solutions for others.

N/A – we did not encounter any challenges in FY 2023

28. 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
- Other (Please describe):): Innovation and technology, virtual visits, digital health, staff education, research, government relations, facilities project planning, staff and employee recognition program

N/A – the PFAC members do not serve on these – **Skip to #30**

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

FAC 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 at a meeting to share highlights of work they are involved in.

FAC members provide quotes and testimonials about specific committees or projects that may be included in an annual report.

30. 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 2022

31. 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

32. 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

- Inpatient care management (such as electronically ordering medicine, specially trained doctors for 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 Condition (HAC) committees, HCAHPS data sliced by race/ethnicity.
- N/A – the hospital did not share performance information with the PFAC – **Skip to #35**

33. 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 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.

34. 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 impacted the direction of improvement efforts. Specific to QI related initiatives, FAC members often provide anecdotal education to staff, whether through live or video-based speaking opportunities, to drive positive behaviors and practices by sharing ‘why this is so important to families like ours.’ FAC members weigh in often 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 and a family’s experience with CLABSI.

35. 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
- Fall prevention

- 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): Unplanned Extubations HAC Group; Adverse Drug Events HAC Group
- N/A – the PFAC did not work in quality of care initiatives

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

- Yes
- No – Skip to #40 (Section 6)

37. 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)

38. 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:

39. 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.

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

Jon Whiting (Staff, Senior Leadership Co-Chair)

Erin Poirier (Parent Co-chair)

Lisa Rubino (Staff, FAC Liaison)

Sara Toomey (Staff, Chief Safety & Quality Officer, Chief Experience Officer)

Emily Martins (Parent, Family Advisor, FAC Steering Committee member)

41. 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:

42. We post the report online.

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

43. 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

44. 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