



PFAC Annual Report Form

Health Care For All (HCFA) advocates for health justice in Massachusetts by working to promote health equity and ensure coverage and access for all. HCFA uses direct service, policy development, coalition building, community organizing, public education and outreach to achieve its mission. HCFA envisions a day when everyone in Massachusetts has the equitable, affordable, and comprehensive care they need to be healthy.

Why complete an annual report for my PFAC?

Under Massachusetts law, hospital-wide PFACs are required to write annual reports by October 1st each year. These reports must be made available to members of the public upon request. As in past years, HCFA is requesting a copy of each report which will be posted on HCFA's website, <https://hcfama.org/pfac/>. HCFA recommends using this template to assist with information collection, as well as the reporting of key activities and milestones.

What will happen with my report and how will HCFA use it?

We recognize the importance of sharing of information across PFACs. Each year, we:

- make individual reports available online
- share the data so that PFACs can learn about what other groups are doing

Who can I contact with questions?

Please contact us at atappan@hcfama.org or call us at 617-275-2982.

Please email completed forms to PFAC@hcfama.org.

Reports should be completed by October 1, 2022.

2022 Patient and Family Advisory Council Annual Report Form

The survey questions concern PFAC activities in fiscal year 2022 only: (July 1, 2021 – June 30, 2022).

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. HCFA strongly encourages the completion of an individual report for each hospitals-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: Aimee Williamson

3b. Email: awilliamson@suffolk.edu

3c. Phone: 303-748-9663

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: 5

9. Total number of patient or family member advisors on the PFAC: 29 (22 active members, 7 emeritus members)

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 child care 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 FY21, more than 74.9% of patients hospitalized at Boston Children’s Hospital are from Massachusetts. In addition, 14.5% of patients hospitalized at Boston Children’s are from New England (excluding MA), 8.7% are from a national location (excluding New England), and 1.9% are from an international location (413 international inpatients (including observations)).

OUTPATIENT: For FY21, more than 88.6% 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), 3.5% are from a national location (excluding New England), and .5% are from an international location (1,674 international outpatients in FY21).

***FY22 ends 9/30/2022 so we provide FY21 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 2022 <i>**FY22 ends 9/30/2022 so we provide FY21 data because it is complete</i>	.14%	3.8%	6.9%	0.1%	47.8%	30.4% <i>*Largely 'unknown'</i>	10.9%	<input type="checkbox"/> Don’t know
14c. The PFAC patient and family advisors in FY 2022	0%	6.9%	6.9%	0%	75.9%	0%	10.3%	<input type="checkbox"/> Don’t know

*****Other includes unable to collect, declined to answer, and unknown**

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 2022 <i>**FY22 ends 9/30/2022 so we provide FY21 data because it is complete</i>	6.6%	<input type="checkbox"/> Don't know
15b. PFAC patient and family advisors in FY 2022	3.4%	<input type="checkbox"/> Don't know

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

	%
Spanish	5.1
Portuguese	0.85
Chinese	0.39
Haitian Creole	0.23
Vietnamese	0.15
Russian	0.09
French	0.05
Mon-Khmer/Cambodian	0.02
Italian	0.01
Arabic	0.40
Albanian	0.02
Cape Verdean	0.22

Don't know

***FY22 ends 9/30/2022 so we provide FY21 data because it is complete*

15d. In FY 2022, 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

***In addition to the above, in FY22 we have Family Advisors who speak the following languages at home in addition to English: Kannada, Italian, Korean, Haitian Creole, Spanish, Armenian.*

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 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 and FY22, we have completed several action items break down barriers for application and entrance to the FAC and to support an inclusive and welcoming environment for FAC members. As of July 2022, we are focused on including all voices in the room and are currently seeking creative opportunities to meet each member where they are comfortable in order to promote authentic engagement for all.

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 multiple family members 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, our FAC staff members, the Chief Experience Officer (who is an MD), and Family Advisors who represent each strategic planning groups

17b. If other process, please describe:

18. The PFAC goals and objectives for 2022 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 2022:

- 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), Online support for patients and families, Internal culture, Experience Education
- 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

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

FAC Steering Committee: Plans all monthly agendas, addresses sensitive topics and strategic decisions.

Strategic Planning Committees: The following subcommittees were formed to drive our key strategic initiatives (begun in Q4 2016):

- FAC Internal Culture (The “Culture Club”) (formed Q1 2020)
- 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.
- Experience Education (formed Q1 2021): This group seeks to infuse education and training across Boston Children’s, and ultimately to patients and families, about what it’s like to walk in a patient/family member’s shoes with the ultimate goal of enhancing partnership between staff and families and improving aspects of the patient and family experience.
- Online Support for Patients and Families (form Q1 2021): This group seeks to bring helpful information to patients and families through simple and intuitive navigation and presentation of information online (BCH specific). Ultimately, this group seeks to provide active support online through a mentorship program (long-term goal).
- FAC Equity, Diversity and Inclusion Committee: (formed in Q1 2020). This group created our FAC specific ED&I plan and oversees the execution of it.

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

Yammer has been utilized since 2015 as a secure online forum. It continues to be used to enable our FAC members to connect with one another between meetings, read meeting minutes, take surveys and more. All of our FAC members are registered on this site.

In 2020, we shifted to a dual model of direct email requests and Yammer to share meeting materials and connect with our 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 also currently leverage SmartSheet and SurveyMonkey 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. Social media posts are used to recruit for our E-Advisors Program – which is used as a funnel for potential future FAC members.

Section 5: Orientation and Continuing Education

23. Number of new PFAC members this year: 6

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:

As part of our ongoing FAC-specific EDI efforts, we partnered with two of the Boston Children’s EDI leaders to bring an tailored, interactive educational experience focused on inclusion to the FAC. It was a wonderful experience for all and we have committed, as a FAC, to annual (possibly more often) opportunities for our council.

Section 6: FY 2022 PFAC Impact and Accomplishments

The following information concerns PFAC activities in the fiscal year 2022.

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: Transforming Tomorrow: Hale Building, Weymouth and Needham locations</p> <p>In 2020-2021, our Family Advisory Council provided insights and feedback about spaces, amenities, décor and details for the new Hale clinical building that opened at our main campus in June 2022.</p> <p>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</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>

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 this beginning of the 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 aim to 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.

Accomplishment/Impact 2: ED Triage Improvement Process

Amidst a significant increase in both the volume of patients and families seeking care in the Boston Children's Emergency Department and the acuity of the needs of ED patients causing a strain on resources: personnel, space and time, members of the ED team partnered with our Enterprise Project Management Office (EPMO) and the FAC to identify ways to improve the triage experience and wait time communications for newly arrived patients and families.

This highly structured project included representatives of each of the roles played by members of the ED team, BCH teams that focus on efficiency and improvement, hospital leadership and family voices. From observations to visioning sessions to really hashing out the viability and sustainability of possible solutions, this project engaged all team members and is a wonderful example of collaboration.

Having recently completed this project, the ED has seen an increase in the positivity ratings for ED visitors and patient experience survey comments praising their efforts and the changes that have been implemented so far. We appreciate the opportunity to partner in ways like this, and to be able

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

to produce change that is visible to more than just our family advisors.

**Accomplishment/Impact 3:
Digital communications with families (pre-visit communications, communication preferences, patient portal)**

(*Both boxes are checked because this partnership is driven by both the Virtual Visits team and the FAC)
2022 was a year characterized by a deep partnership driven by multiple departments AND family advisors. What began with a 2020 inclusion of families in selecting a texting platform for patient and family communication has evolved into a bidirectional channel for questions and feedback that benefit improvement efforts pertaining to patient and family digital communications and the online experience. One significant example of positive outcomes and change include:

Consolidation of multiple messages to focus on sending patient families what they need, when the need it, a more intuitive navigation experience on the MyChildren’s patient portal, a revisiting of the timing, modality, content and appearance of pre-visit communications to ensure effectiveness of those communications.

These types of impact opportunities have all been highly effective in 2022 and we have leveraged virtual focus groups, online surveys and informal email feedback to garner guiding insights from our patients and families.

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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:

High Reliability Organization 2.0 Core Team (HRO 2.0)

In 2015, Boston Children’s officially launched a cultural initiative to

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become a High Reliability Organization (HRO). FAC members were included in the original core team and worked very closely to ensure that the principles of HRO: attention to detail, communicate clearly, and speaking up for safety were delivered not only to all BCH staff (Over 15,000 employees completed training as part of HRO 1.0 efforts) but also to families. The FAC members who served on that core team led an effort to engage the FAC in designing a brochure that invited families to be partners in this effort as partners in their child's care.

In early 2021, Boston Children's launched HRO 2.0, a redesign and refresh of these core principles to continue to drive this culture initiative. Again, FAC members were invited to join the core team that shapes and drives every aspect of the HRO 2.0 efforts – the largest culture initiative at Boston Children's. Throughout 2022, two members of our FAC have continued to serve on the core team, leveraging the entire FAC membership at times, when a broader perspective is needed.

Accomplishment/Impact 2:

**Culture of Partnership for Safety:
HAC Committee Engagements**
(*Both boxes are checked because this partnership is driven by both the safety and quality team and the FAC)

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) with the exception of the Acute Kidney Injury (AKI) group. 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.

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This is an ongoing partnership that has become a cultural norm within our safety organization. It was initiated by the Family Advisory Council and we're happy to say that our safety and quality team welcomed the opportunity to partner with families.

Accomplishment/Impact 3:

Virtual Visits: Navigating long-term integration and supporting legislation (*Both boxes are checked because this partnership is driven by both the Virtual Visits team and the FAC)

Since the onset of the pandemic and initial transition to virtual care experiences across the spectrum of medical specialties, FAC members have continued share their feedback and experiences surrounding family preparation for, family experience during and follow up experience for virtual visits.

Throughout FY2021, Family feedback impacted the content incorporated into patient and family directed emails, texts and portal messaging to ensure that families were in optimal position to receive the care their children needed during a virtual visit appointment.

In 2022, families worked with the Virtual Visits and Digital Health teams to identify chronic conditions that should be included in legislation that frames the eligibility of pediatric patients for ongoing virtual care. Family partners spoke at legislative hearings in support of sustaining virtual care for the pediatric population. Family experiences continue to impact and help shape Boston Children's long-term virtual care strategy as we continue our ongoing partnership with the Virtual Care team.

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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)

Accomplishment/Impact 1: 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, 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 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.

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Accomplishment/Impact 2:

Equity, Diversity & Inclusion: membership, LEP integration, education, engagement:

In 2020, the FAC formally adopted a FAC-specific ED&I plan that was created by a taskforce of FAC members and supported by FAC/BCH hospital leadership. In 2021: That taskforce transitioned to a standing FAC ED&I Committee. Throughout FY2022 the ED&I committee, as well as other FAC strategic groups, have executed various components of our action plan which is driven by three overarching goals:

- Goal #1: The FAC is committed to ensuring an internal FAC culture that is welcoming, inclusive, and respectful of diversity. This

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includes working to establish and maintain an anti-racist environment, free of any discrimination or bias.

- Goal #2: The FAC is committed to elevating diverse family voices beyond the FAC and E- Advisors forum, particularly those of historically marginalized groups.
- Goal #3: The FAC is committed to recruiting, developing, and retaining diverse membership in the FAC and E-Advisors Program.

In 2022, we worked to eliminate barriers for application to and joining the FAC: including leveraging virtual membership capacity and incorporating interpretation and translation support for LEP member(s). All of this has been done in an effort to welcome and sustain a membership that is representative of those we care for.

Our EDI Committee worked closely with hospital EDI leaders to bring a tailored workshop to the FAC in July 2022 that focused on authentic engagement and inclusion as key elements of building mutual respect and a cohesive working group. We also reviewed and restructured our FAC candidate process, including revising the list of application requirements, reviewing onboarding requirements for FAC members with Volunteer Services, HR Compliance, Legal and Occupational Health. We have a new list of talking points and questions that will be leveraged in conversations with interested FAC candidates. This fall the EDI committee will be looking to develop a statement of commitment to inclusivity and support of all members engaging as their authentic selves at FAC meetings. This will be read at the top of each meeting to remind people of our expectations for engagement and appreciation of individual perspectives.

Accomplishment/Impact 3: Online Support 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

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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 compromised by worry or fear over 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.

Our next steps include reviewing all of the existing content for clarity, implementing organization and design changes in the upcoming weeks and months and gathering family insights and testimonials that will be included in the web design with the purpose of tying the information on the page to the user.

27. The five greatest challenges the PFAC had in FY 2022:

Challenge 1: Integration of Membership with Limited English Proficiency (LEP)

We are incredibly excited to report that we welcomed our first FAC member with Limited English Proficiency to the council in January 2022! Integrating this member's voice has allowed us to gain more unique input on key hospital topics, but has also pushed us to learn how to better prepare and support LEP members. Weaving in an LEP voice has forced us to prepare more in advance of each meeting. It has led us to seek out leadership approval and budget to spend on interpretation and translation services. We, as a council, are learning how best to engage members who don't speak English and how best to show respect for those voices, especially when an interpreter is involved.

It's difficult to call a great stride in our membership journey a challenge yet, as something completely new to us, we have stumbled along the way, are learning from our mistakes, and regularly ask our members for feedback as we continuing to work to make our meetings the best they can be for all of our members.

Challenge 2: Driving FAC Strategic Initiatives

In 2021, the FAC continued to drive our internal culture and our FAC-specific ED&I strategic initiatives (both launched in 2020). Additionally, we added strategic initiative groups dedicated to driving Experience Education, Online Support for Patients and Families and our Care Bundles initiative (in partnership with Social Work).

In 2022, we have transitioned three of these initiatives into cultural or practice “norms” for the FAC: Internal culture, FAC-specific ED&I and the Care Bundles Program (in partnership with Social Work). Online Support for Patients and Families and Education Experience are both large scope initiatives that are highly dependent upon partnerships with BCH stakeholders/groups/departments. These two have been much slower to move forward, not because of lack of support from Boston Children’s but from the fact that Covid-19 impacted every department across the organization deeply and has led to attrition of staff, redirection of resources for Covid-related bodies of work, increased needs of our patient and family population leaving little time for progress on ‘optional’ projects. We have made exciting progress on the Online Support for Patients and Families initiative since June 2022 yet have had to put the pause button on most of the projects within the scope of the Education Experience initiative. We are about to embark on a FAC strategic plan refresh and hope that the exercise will help to revamp, reprioritize and refocus FAC efforts in that area.

Challenge 3: Maintaining/enhancing internal FAC culture virtually

In 2020, based on interest from our Family Advisors, we launched a strategic group called “The Culture Club.” 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 for 2020-2022 placed an additional barrier against creating and sustaining connections between membership.

Having just captured 2022 FAC member feedback in our annual FAC Assessment Survey, we will be operating as a hybrid council in 2023, with virtual participation options for every meeting coupled with quarterly in-person options. The Culture Club will be focusing on strategies to promote healthy internal culture characterized by fostering authenticity, inclusion and belonging amongst our members. They will be gauging communication preferences during meetings for individual members, working with FAC leadership to identify creative avenues for engagement to meet the needs of each of our members, hosting brief small-group social opportunities at the top of each FAC meeting and implementing a post-meeting survey so that we can capture real-time feedback and make quick adjustments for optimal effectiveness.

Challenge 4: Leadership transitions / FAC staffing capacity

We have experienced a number of shifts and transitions within FAC leadership and the FAC staff that provides administrative and operational support to the FAC. We are proud of our ability to be flexible and understanding during times of transition and limited capacity associated with those transitions yet it continues to be a consistent challenge for us in supporting the progress that our FAC membership craves.

Since 2020, we have reduce FAC staff members supporting the FAC by 50% due to attrition. In 2021, we had three different senior leadership co-chairs in the role. Now, in 2022, we are in a great place with a new leadership co-chair who is celebrating his first full year in the role yet we are still operating with limited FAC staff support.

Challenge 5: Reengaging hospital partners to revive historically in-person engagements ‘post pandemic’

Between 2016 and February 2020, FAC members addressed over 10,000 Boston Children’s employees to bring personal stories and tie staff and employees to the mission of Boston Children’s in live meetings. When the pandemic forced us into virtual engagement, many of these opportunities evaporated because of logistical challenges and Zoom fatigue. FAC member have missed these opportunities for direct impact deeply. In the late summer 2022, having embraced a new ‘hybrid/virtual’ cultural norm, key stakeholders

and partners to the FAC are now ready to reengage family voices for impact. This is a very real yet still emerging opportunity, yet it is one that FAC members have mourned and focused on as a significant casualty of the pandemic. In some ways, members who have deep personal connections to these direct impact opportunities have suffered personal losses without these opportunities and their engagement as FAC valued voices has been impacted. We are very excited to begin a new era of direct impact for our FAC members!

N/A – we did not encounter any challenges in FY 2022

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?

One member is selected each month to share with the FAC what they are currently working on. Additionally, members are invited to utilize Yammer to report back to the group about their individual engagements and committee/workgroup/initiative updates.

Strategic groups report formally to the FAC twice per year to promote strategic planning and accountability.

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 (eg. 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:

2022 has been another year characterized by FAC membership priorities aligned with driving FAC strategic initiatives and a strong member 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. At the request of the FAC,

the Chief Experience Officer and Director of Patient Experience did share HCAHPS data sliced by race/ethnicity as well as care setting (in-patient vs. ambulatory vs. ancillary services).

FAC members serves on various safety and quality committees, including Patient Care Assessment Committee, High Reliability Organization Core Team, Discharge Timing Improvement, ED Triage Improvement and most 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 Patient Care Assessment Committee, High Reliability Organization Committee and individual Hospital Acquired Conditions (HAC) Have continued to provide family perspectives and insights that impacted the direction of improvement efforts. Specific to QI related initiatives, FAC members often provide anecdotal education and awareness to staff, whether through live or video-based speaking opportunities, to drive positive behaviors and practices by sharing the ‘why this is so important to families like ours.’ FAC members weigh in often on patient and family facing educational materials – specific 2022 examples include: preparing for a sedation procedure, Resources available while you are waiting in the Emergency Department, Diabetes education for newly diagnosed families, educational comic book about ARFID (Avoidance Restrictive Feeding Disorders), and more. 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, sepsis prevention, adverse drug events, CLABSI / CAUTI prevention
- 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)
Aimee Williamson (Parent Co-chair)
Lisa Rubino (Staff, FAC Liaison)
Sara Toomey (Staff, Physician Liaison)

Katie Litterer (Staff, FAC Liaison)
Emily Martins (Parent, Family Advisor, Steering Committee Member)
Steve Favulli (Parent, Family Advisor, Steering Committee Member)
Katie Baker ((Parent, Family Advisor, 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