



## 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 1<sup>st</sup> 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](mailto:atappan@hcfama.org) or call us at 617-275-2982.

Please email completed forms to [PFAC@hcfama.org](mailto:PFAC@hcfama.org).

**Reports should be completed by October 1, 2021.**

# 2021 Patient and Family Advisory Council Annual Report Form

The survey questions concern PFAC activities in fiscal year 2021 only: (July 1, 2020 – June 30, 2021).

## 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 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: Laura J. Wood, DNP, RN, NEA-BC, SVP, Patient Care Operations & CNO, Sporing Carpenter Chair for Nursing

2b. Email: Laura.Wood@childrens.harvard.edu

2c. Phone: 617-355-6488

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, Family Partnerships Coordinator

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 2020

**8. Total number of staff members on the PFAC: 5**

**9. Total number of patient or family member advisors on the PFAC: 20**

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

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

**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
- 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:**

**INPATIENT:** Presently, more than 75.7% of patients hospitalized at Boston Children’s Hospital are from Massachusetts. In addition, 13.7% of patients hospitalized at Boston Children’s are from New England (excluding MA), 8.4% are from a national location (excluding New England), and 2.2% are from an international location.

**OUTPATIENT:** Presently, more than 87.8% of outpatient patients at Boston Children’s Hospital are from children and families who live in Massachusetts. In addition, 7.8% of patients seen at a Boston Children’s outpatient clinic are from New England (excluding MA), 3.8% are from a national location (excluding New England), and 0.6% are from an international location.

Don’t know

**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 checked="" type="checkbox"/> Don’t know
14b. Patients the hospital provided care to in FY 2021	0.14	3.37	6.91	0.04	47.92	30.5	11.13	<input type="checkbox"/> Don’t know
14c. The PFAC patient and family advisors in FY 2021	0	5	5	0	80	0	10	<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 2021	7.1	<input type="checkbox"/> Don't know
15b. PFAC patient and family advisors in FY 2021	0	<input type="checkbox"/> Don't know

15c. What percentage of patients that the hospital provided care to in FY 2021 spoke the following as their primary language?

	%
Spanish	5.54
Portuguese	0.80
Chinese	0.47
Haitian Creole	0.24
Vietnamese	0.17
Russian	0.10
French	0.05
Mon-Khmer/Cambodian	0.02
Italian	0.01
Arabic	0.50
Albanian	0.02
Cape Verdean	0.25

Don't know

15d. In FY 2021, what percentage of PFAC patient and family advisors spoke the following as their primary language?

	%
Spanish	10
Portuguese	0
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

**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 Partnership Coordinators 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 diverse voices from various socio-economic, racial, ethnic and hospital experience populations. The FAC supplements the general call for FAC candidates each year with targeted efforts to staff who have strong working relationships with various 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 a few young adult patients. Additionally, our Hale Family Center for Families has a full-time program coordinator dedicated to working with our Latino and Spanish-speaking families and 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 are three-fold, to create an accessible, welcoming and sustainable opportunity for family members interested in lending their voices to the hospital through the FAC. Throughout 2021, we have executed on several action items associated with our plan which support an inclusive and welcoming environment for all FAC members, creative opportunities for interested family members (and sometimes patients) to lend their voices to Boston Children's in a way that works for them, as well as targeted recruiting efforts to ensure that our advisor membership accurately represents the patient and family population served by Boston Children's.

**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:

17b. If other process, please describe:

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 Liaison staff member, the Chief Experience Officer for the hospital (who is an MD), Family Advisors who represent our strategic planning groups and another supporting staff member.

**18. The PFAC goals and objectives for 2021 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 2020– **Skip to #20**

**19. The PFAC had the following goals and objectives for 2021:**

1.) Drive FAC-specific Equity, Diversity & Inclusion plan

2.) Foster and support healthy and cohesive internal FAC culture through strategic initiative

3.) Increase membership diversity

4.) Track and measure family voice impact in engagement opportunities

5.) Sustain family engagement opportunities on hospital committees, etc., in a virtual setting

6.) Effectively operate in a 100% virtual environment: FAC monthly meetings, onboard new members virtually, etc.

**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 taskforce: (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:**

In the summer of 2015, a secure online forum on the free social networking site, Yammer, was created to allow 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. Prior to Yammer, the FAC utilized an e-mail distribution list and private Facebook page (which is no longer used) to communicate with each other. Because the Covid-19 pandemic brought chaos and over-use of online applications to all, we have coupled our use of Yammer with directed emails to our FAC membership, specifically with time sensitive or response required communications.

In 2020, we have begun leveraging SurveyMonkey as a way 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.

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

**Section 5: Orientation and Continuing Education**

**23. Number of new PFAC members this year: 2**

**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:

In 2020, the FAC established a new strategic group designated improving the internal culture for the FAC. Family members who are on this team support new FAC members informally by outreach to new members, hosting social time for FAC members to connect outside of FAC meetings with the intent to foster connections between members, recognizing milestones with personalized cards, leveraging our FAC Yammer page to connect members and encourage sharing amongst FAC members (example: share your first day of school photos, etc.) and helping to plan our annual appreciation event.

**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 a group, our FAC received education/training on the above topics as it pertained to agenda items and presentations delivered to the group by senior leadership within the hospital. Several individual members of the FAC also have received relevant training as members of various committees/workgroups/project on ALL of the above topics listed.

In 2017: FAC members were invited to join HRO (High Reliability Organization) training alongside BCH staff and employees.

In 2018, we endeavored to create and deliver annual storytelling training by leveraging internal resources, colleagues at other institutions who created similar education for their advisors, etc. The intent was to hone advisor’s storytelling skills so that they can identify what pieces of their story are relevant to the conversation and would be most impactful and then deliver those pieces in a constructive and effective manner.

In 2020 FAC members received “Safe Zone” training, an opportunity available to BCH employees and staff, which covers both awareness and sensitivity surrounding gender and identity.

**Section 6: FY 2021 PFAC Impact and Accomplishments**

*The following information concerns PFAC activities in the fiscal year 2021.*

**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><b>Accomplishment/Impact 1: Transforming Tomorrow: Satellite Expansion</b></p> <p>Boston Children’s is currently pursuing expansion of its patient care opportunities through its satellite locations in an attempt to make access to care easier for patient families and to promote better balance between care / school / life for its patients.</p> <p>As part of this effort, our Family Advisory Council provided insights and feedback about how satellites are currently used for various types of care as well as comfort levels of leveraging satellite locations for more in-depth care versus being at our main Boston location. These insights shaped the application from the hospital to the Department of Public Health.</p> <p>Additionally, several families wrote letters in support of the satellite project as part of the Determination of Need process. Advocacy is an area that many of our members are passionate about and we appreciate the partnership with our Government Relations team here at Boston Children’s.</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><b>Accomplishment/Impact 2: Online experience for patients and families: Patient Portal, Online Billpay</b></p> <p>In partnership with families, Boston Children’s is committed to enhancing the online experience for users of the MyChildren’s Patient Portal and the online bill pay experience. Both of these are largely driven by family member feedback. In FY2021, the online bill pay experience has been updated several times to provide a more</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>

intuitive and simple experience for users. FAC members have provided insights on everything from content to wording to layout and resource content.

The MyChildren's Patient Portal team liaises with families several times per month to gain user insights and feedback about specific items, from how upcoming appointments appear on the screen to re-envisioning the homepage experience (a full FAC discussion at a monthly meeting) to improving the slowness of the application, mobile access to the MyChildren's patient portal, messaging from the portal and secure messaging to/from Boston Children's providers.

Over the years a true and deep partnership with this team has developed and in FY 2021 we saw frequent and numerous examples of the impact that Family Advisor voices are having on these types of user experiences.

**Accomplishment/Impact 3:  
Virtual Visits**

Following the onset of the pandemic and initial transition to virtual care experiences across the spectrum of medical specialties, FAC members have shared, on multiple occasions, their feedback and experiences surrounding the family preparation for, family experience during and follow up experience after 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

- Patient/family advisors of the PFAC
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needed during a virtual visit appointment.

Families also provided insights based on experiences as to the types of appointments that make sense/are viable in a virtual setting versus those that require an in-person examination and interaction with a clinician.

Family experiences continue to impact the virtual care experiences, as we are now preparing to harness family feedback about virtual visits which will shape Boston Children's long-term virtual care strategy.

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><b>Accomplishment/Impact 1: Effective Communication with Patients and Families: phone, email, text, patient portal</b></p> <p>In 2020 FAC members participated in selecting a vendor to support bi-directional texting capabilities between BCH and its patient families. In 2021, family partnerships with the Access, IT and Patient Portal teams have grown to further enhance digital communications between Boston Children's and patient families. Some examples of positive outcomes and change include:</p> <p>Education and training for call-center personnel, streamlining email communications through the Patient Portal (sent from a single source and clearly identified in the subject line), updates to content contained in email reminders about appointments, the appropriateness and content of text messages from Boston Children's to patient</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>

families and improvements to the user experience through our Patient Portal.

These types of impact opportunities have all been highly effective in FY2021 through virtual focus groups, online surveys and informal email feedback.

**Accomplishment/Impact 2: Bereavement Program**

After the loss of her daughter led her to experience the bereavement resources available through and outside of Boston Children's, one of our FAC members embarked on a research project to identify all of the different bereavement resources across all departments/inpatient units here at the hospital. This was done with guidance and support from our FAC senior leadership co-chair.

After months of research, the FAC member presented her findings to BCH leadership and later, to the FAC itself. The work was detailed, thorough, un-biased. What resulted was a recommitment to serving those who continue to need care and support from Boston Children's after the loss of a child and identified, targeted responses to addressing gaps in support.

While this was the work of one of our FAC members, the positive impact on many families was significant.

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**Accomplishment/Impact 3: High Reliability Organization (HRO)**

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

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

attention to detail, communicate clearly, and speaking up for safety were delivered not only to all BCH staff (Over 15,000 employees completed training) 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 will shape every aspect of the HRO efforts – the largest culture initiative at Boston Children's. All FAC members contribute to this effort at times, when a broader perspective is needed.

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><b>Accomplishment/Impact 1: FAC ED&amp;I Plan Implementation</b></p> <p>In 2020, the FAC formally adopted a FAC-specific ED&amp;I plan that was created by a taskforce of FAC members and supported by FAC/BCH hospital leadership. Throughout FY2021 the ED&amp;I task force, as well as other FAC strategic groups, have executed various components of our action plan which is driven by three overarching goals:</p> <ul style="list-style-type: none"> <li>• Goal #1: The FAC is committed to ensuring an internal FAC culture that is welcoming, inclusive, and respectful of diversity. This includes working to establish and maintain an anti-racist</li> </ul>	<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>

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.

Some highlights of our progress include: the establishment of a virtual FAC membership option to broaden the scope of our membership, the creation of new marketing materials which include a statement of our commitment to diversity and inclusion and also highlights our membership, the revamping and implementation of a demographic survey for both our FAC membership and our E-Advisor membership, targeted recruitment with the goal of enhancing our FAC membership to more accurately reflect the patients and families who seek care here at Boston Children's, maintain a focus on internal culture in an effort to create and sustain a welcoming and inclusive environment for all and promote further FAC achievements that derive from truly cohesive working groups.

We were also honored to present our journey of creating and implementing a FAC-specific ED&I plan at the 2021 Beryl Institute annual conference. Our Senior Leadership Co-Chair, Parent Co-chair, FAC member and Family Partnerships Coordinator gave that presentation.

We continue to drive our efforts and maintain accountability

through regular reviews of our plan and progress reports to our FAC membership.

**Accomplishment/Impact 2: Care Bundles Initiative:**

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 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.

The Care Bundles initiative is now expanding 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.

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

**Accomplishment/Impact 3: Measuring FAC Impact**

FAC members have long been asking to measure the impact of their efforts. In January 2021, after consulting with several other pediatric institutions on how they measure Family Advisor impact,

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



we launched an activity tracking tool for our FAC members. This tool is self-directed, so we are depended upon our family advisors to record their activities.

From 1/1/2021-9/1/2021, 22 FAC members recorded 451 activity entries (approx. 56 entries per month) for a total of 613 hours. Activities recorded range from monthly FAC meetings to providing email feedback. Engagements span the following categories: FAC driven work, patient and family experience, policy and government relations, technology and innovation, safety and quality, research and education/training.

Our next goal is to implement a qualitative impact measurement system to gauge the value of including family voices in strategic decisions here at Boston Children's.

## 27. The five greatest challenges the PFAC had in FY 2021:

### **Challenge 1: Sustain effective virtual engagement for FAC**

With the onset of Covid-19, our FAC had to cease all in-person engagements, including our monthly meetings. As a group that both values and thrives upon face-to-face conversations, this presented a significant challenge. Additionally, because we onboard new members each year in January, we were faced with trying to integrate and orient two brand new members in an unplanned, virtual setting. Some of our in-person engagements have been permanently transformed to self-directed virtual learnings and no longer offer an opportunity for engagement, including speaking to all new employees at New Hire Orientation.

This is a disappointment to our families who value the opportunity to raise awareness amongst BCH staff and employees about what it's like to walk in the shoes of patients and families. In many ways, we have been successful in our transition to virtual operation, yet there is still significant work to be done, especially surrounding virtual recruitment/onboarding and support for new members, increasing the number of family engagement opportunities in virtual settings and advocating for the reinstatement of a few engagement opportunities which hold great value for our families.

### **Challenge 2: Maintaining deep and broad partnerships with the hospital in a virtual environment**

Historically, FAC members are frequently in the hospital attending committee meetings, project workgroups or focus groups. In this way, we have developed strong working relationships with units and departments spanning inpatient experience improvement efforts to safety, to food services and facilities. With a FY2021 that has been completely virtual for our FAC members, it has been difficult to maintain the presence

necessary to sustain some of those working relationships. Some of those opportunities have been 'lost' by the FAC because there isn't the opportunity for in-person engagement: like New Hire Orientation, which was one of our top engagements since 2016 and through which family stories reaches over 10,000 employees.

In order to promote continued, and new, invitations from departments/committees, etc., we introduced creative solutions to include family voices. Our FAC members, already comfortable with Zoom from pre-pandemic virtual options for regular meetings, attended meetings 'as usual' whenever possible. For those bodies of work that needed to be accelerated or had meeting schedules that were altered due to staff managing home and work responsibilities simultaneously, we offered more casual opportunities to include families in strategic decisions or to provide feedback. Small groups of FAC members that were identified by experience/interest and availability were utilized by teams such as our Virtual Visits, Patient Access, and Patient Portal teams for ad hoc feedback. One to two family advisors were identified for specific initiatives and offered to be available for emails and phone calls in support of those efforts. We also leveraged our E-Advisors Community (all FAC members are also E-Advisors) to gather online feedback on individual initiatives across the hospital.

### **Challenge 3: Diversity in membership:**

For our hospital, diversity spans beyond race and ethnicity; it represents different sexes, diagnoses, hospital experiences, parents of children of varying ages, sexual orientation, and more. While we work with a wide variety of units and departments to recruit for the FAC, we find that the people who are most interested in joining this volunteer opportunity are those who have deep relationships with Boston Children's — often families of complex care children who see many specialties and may have frequent hospitalizations. It has been a challenge to recruit families from our satellite locations as well as those who receive episodic care (e.g. ED visits, primary care). In 2020, we created a FAC Equity, Diversity and Inclusion taskforce. This group developed a FAC specific Equity, Diversity and Inclusion plan that was put into action in Q4 2020. As part of that plan, we are working to increase the visibility of our FAC through external marketing campaigns that leverage social media posts as well as targeted recruitments through internal stakeholders, existing FAC members and external community connections.

Additionally, several diverse members that we have welcomed to the FAC seem to stay active members only for short periods of time. In 2019 we increased our retention efforts to match our recruiting efforts, as each and every patient and family voice is valuable, and we want to retain as many perspectives as possible.

Over FY21, our FAC-specific EDI plan directed targeted actions to not only recruit diverse membership but also to create and foster an accessible, welcoming and inclusive environment supported by a healthy internal FAC culture.

Our ultimate goal is to be more representative of the patients and families receiving care at BCH.

### **Challenge 4: Internal FAC Culture:**

In 2020, based on interest from our Family Advisors, we launched a strategic group called "The Culture Club." Named by our Family Advisors, this group works to create personal connections between our membership. They are involved in planning our annual celebration, sending birthday cards, recognizing personal milestones amongst our membership, mentoring new members and organizing opportunities for our members to connect outside of the monthly FAC meetings, which are very much work focused. The efforts of this group have yielded really positive outcomes and feedback from our membership. This said, the shift to virtual-only operations has placed an additional barrier against creating and sustaining connections between membership. Many of our members spend all day on Zoom for work and don't want to spend extra time on a screen after hours, even though they appreciate the opportunities being offered.

Having just captured FAC member feedback in our annual FAC Assessment Survey, the Culture Club will be focusing on some strategies to promote healthy internal culture characterized by authentic connections

between our members both in ways that have proven historically successful and also with some new strategies to try to meet the needs of all of our members.

#### **Challenge 5: 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).

Throughout this year, we have made steady progress in the initiatives that the FAC 'owns' completely (internal culture and FAC-specific ED&I). Our three new initiatives are dependent upon partnerships with BCH departments and those three have been difficult to move forward, not because of lack of support from Boston Children's but from the fact that Covid 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 hope that the upcoming months will bring new progress to our three new initiatives.

N/A – we did not encounter any challenges in FY 2021

#### **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, education of staff, research, government relations
- 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 2020

**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:**

2021 has been a 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.

FAC members of various safety and quality committees, including Patient Care Assessment Committee, High Reliability Organization Committee, Discharge timing, ED triage improvement and individual Hospital Acquired Conditions (HAC) committees have received key information listed above as it pertains to those specific committees.

As a FAC, we have found Boston Children's amenable to sharing much of the data listed above, should we request it. In FY2021, our priorities simply fell elsewhere.

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

FAC members of various safety and quality committees, including Patient Care Assessment Committee, High Reliability Organization Committee and individual Hospital Acquired Conditions (HAC) committees have received key information listed above as it pertains to those specific committees.

FAC members also provided insights that impacted the direction of experience-focused efforts such as HCAHPS data: wording of questions, interpretation of data surrounding 'staff members worked together to care for my child.' Additionally, FAC members were included in discussions about a provider coaching program currently in development and What Matters to You / About Me initiatives to humanize patients and families and bring information that matters most to patients and families into the care experiences provided at Boston Children's.

Data was used to bring context to a conversation, to create benchmarks and starting points that were integrated into improvement efforts and analyzing results of improvement efforts.

**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