



HEALTH CARE FOR ALL



PFAC Annual Report Form

Health Care For All (HCFA) promotes health justice in Massachusetts by working to reduce disparities 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's vision is that 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 and submitted reports will be posted on HCFA's website, www.hcfama.org. 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 PFAC@hcfama.org or call us at 617-275-2982.

If you wish to use this Word document or any other form, please email it to PFAC@hcfama.org.

Reports should be completed by October 1, 2020.

2020 Patient and Family Advisory Council Annual Report Form

The survey questions concern PFAC activities in fiscal year 2020 only: (July 1, 2019 – June 30, 2020).

Section 1: General Information

1. Hospital Name:

NOTE: Massachusetts law requires every hospital to make a report about its PFAC publicly available. HCFA strongly encourages you to fill out a separate template for the hospital-wide PFAC at each individual hospital.

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: Marcie Brostoff, Associate Chief Nurse and Vice President, Nursing/Patient Care & Clinical Operations

2b. Email: Marcie.Brostoff@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, Family Partnerships Coordinator

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

6c. Phone: 617-919-1699

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 community through social media channels like Facebook and Twitter.
- N/A – we did not recruit new members in FY 2020

8. Total number of staff members on the PFAC: 7

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 childcare 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 74.6% of patients hospitalized at Boston Children’s Hospital are from Massachusetts. In addition, 14.1% of patients hospitalized at Boston Children’s are from New England (excluding MA), 8.7% are from a national location (excluding New England), and 2.5% are from an international location.

OUTPATIENT: Presently, more than 87.5%% of outpatient patients at Boston Children’s Hospital are from children and families who live in Massachusetts. In addition, 6.9% of patients seen at a Boston Children’s outpatient clinic are from New England (excluding MA), 4.8% are from a national location (excluding New England), and .8% are from an international location.

Don’t know

14. Tell us about racial and ethnic groups in these areas (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	.28	5.2	6.5	.03	78.4	4.6	5.1	<input type="checkbox"/> Don’t know
14b. Patients the hospital provided care to in FY 2020 **Unable to collect: 27.42%	.13	3.14	6.77	.04	46.36	5.34	10.80	<input type="checkbox"/> Don’t know

14c. The PFAC patient and family advisors in FY 2020	0	5	5	0	80	0	10	<input type="checkbox"/> Don't know
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15. Tell us about languages spoken in these areas (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 2020	6.9	<input type="checkbox"/> Don't know
15b. PFAC patient and family advisors in FY 2020	0	<input type="checkbox"/> Don't know

15c. What percentage of patients that the hospital provided care to in FY 2020 spoke the following as their primary language?

	%
Spanish	5.419
Portuguese	0.598
Chinese	0.579
Haitian Creole	0.218
Vietnamese	0.177
Russian	0.102
French	0.050
Mon-Khmer/Cambodian	0.030
Italian	0.016
Arabic	0.791
Albanian	0.014
Cape Verdean	0.239

Don't know

15d. In FY 2020, 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 January 2020, the FAC embarked on a journey to develop a 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. This would bring additional and more diverse voices to the table and would enhance the outcomes of the work that the FAC is committed to. Currently, we are in the final phases of review and hope to adopt this FAC ED&I plan formally in October 2020.

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 Staff Co-Chair, our Parent/Caregiver Co- Chair, our FAC Liaison staff member, the Chief Experience Officer for the hospital (who is an MD), parent co-chairs of our strategic planning groups and another supporting staff member.

17b. If other process, please describe:

18. The PFAC goals and objectives for 2020 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 2020:

- 1.) Direct impact on employees/patient families
- 2.) Administer FAC Seal of Approval Program
- 3.) Drive FAC Strategic Initiatives: “FAC Culture Club”, Engagement and Outreach/Family Voices
- 4.) Recruit diverse members
- 5.) Increase family engagement opportunities
- 6.) Support FAC members: new member training / existing member development
- 7.) Track and measure family voice impact in engagement opportunities

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

Strategic Planning Committees: Two subcommittees were formed in 2020 to drive our key strategic initiatives (began in Q4 2016): FAC Internal Culture (The “Culture Club”) and the Engagement and Outreach and Family Voices/Optimal Care Experience groups. Each FAC member joins one of these groups and efforts by both groups are ongoing over the three-year term of our current strategic plan (adopted January 2020).

FAC Equity, Diversity and Inclusion taskforce: We formed the FAC Equity, Diversity & Inclusion taskforce in Q1 2020. This group is creating a FAC specific ED&I plan. Our goal is to formally adopt this plan in 2020, complete a formal review 6-months following the adoption date, and then review annually going forward.

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): Co-Chairs of PFAC present annually at a Board meeting
- 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.

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: 3

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 socialize outside of FAC meeting time with the intent to foster connections between members, recognizing milestones with personalized cards, leveraging our FAC Yammer page to connect members each week posts to 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 2020 PFAC Impact and Accomplishments

The following information only concerns PFAC activities in the fiscal year 2020.

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: Direct Family Impact on Staff/Leadership: In FY2020 our Family Advisory Council members continued to have direct impact on staff/leadership through speaking engagements. Employees who have heard patient and family experiences directly from a patient/family member tell us that they feel more connected to the patients and families who need Boston Children's, and they understand how and why giving their best efforts day in and day out can impact families both directly and indirectly. Until mid-March 2020, Family Advisors reached staff/leadership through weekly New Employee Orientation, Resident Orientation, Department Specific Meetings, Panel Discussions, etc. We have also incorporated teen patients into these speaking engagements when possible, such as during school vacation weeks. We look forward to resuming our in-person speaking engagements in 2021.</p>	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input <ul style="list-style-type: none"> • Depending on the engagement opportunity, sometimes the idea was patient and family driven and sometimes it was by department or committee request.
<p>Accomplishment/Impact 2: Reaching families during the time of Covid-19:</p> <p>Family voices from our FAC impacted patient and family-facing communication in a variety of ways following as it pertained to Covid-19, how BCH was offering/delivering care, what would it feel like to return to BCH for in-person care, perspective pieces from family members, preparing patients and families for virtual visits, how to prepare for an in-person appointment, etc. FAC members contributed personally by writing perspective pieces for our "Discoveries" blog, playing roles in videos regarding both virtual visits</p>	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input <p>Depending on the topic of the communication, sometimes the idea was patient and family driven and sometimes patient and family perspectives/insights were solicited by our marketing, patient and family education or leadership teams.</p>

<p>and returning to the hospital, planning and facilitating a webinar for patients and families about returning to the hospital and what we were doing to keep both staff and patient families safe, etc. Families also reviewed many, many materials in draft form prior to dissemination.</p>	
<p>Accomplishment/Impact 3:</p> <p>Virtual Visits:</p> <p>While BCH was using virtual visits to provide patient care in a limited number of settings, the quick pivot to telehealth necessary to adapt to the onset of Covid-19 provided a great opportunity for FAC members to share insights, feedback and a channel for suggestions about improving multiple aspects of the virtual experience. The Virtual Visits team received feedback from the FAC during monthly meetings on two separate occasions in 2020 and a FAC VV taskforce was created to meet the needs of the virtual visits team on an ad hoc basis. Family voices have been impactful in all aspects of the virtual visit experience, from scheduling, to accessing the technology, family preparedness, provider ‘websites manner’, follow up communication and scheduling. This has blossomed into a thriving partnership with the virtual visits team and all parties have benefitted from the open lines of communication.</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input</p> <p>Family engagement around virtual visits has really been initiated by families in the form of proactive experience feedback/requests and the virtual visits team seeking specific feedback about aspects of virtual visits.</p>

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)
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<p>Accomplishment/Impact 1:</p> <p>Bidirectional texting communication between BCH and patient families:</p> <p>For several years, FAC members have been asking for texting communications from BCH regarding appointments. When BCH was ready to consider vendors, the included family members in vendor presentations and welcomed families to ask questions, etc. Families submitted reviews of vendors to the Patient and Family Access team. Ultimately, the vendor of voice aligned with family preference. Since the rollout of this new service, families have continued to provide feedback to the Access team and make requests about the look, feel and capabilities within the text communications, working together to improve the experience.</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input</p> <p>Idea started with families, but when we reached the vetting and implementation phases the Patient and Family Access team reached out for structured and ongoing family feedback.</p>
<p>Accomplishment/Impact 2:</p> <p>Equity, Diversity & Inclusion Plan:</p> <p>Over the past few years, it has become a clear priority for our FAC members to put in place a dedicated Equity, Diversity and Inclusion plan for our council. In January 2020, as part of our strategic plan refresh, the FAC ED&I taskforce took on the creation of such plan. In order to align our own plan with that of BCH's, this group met with BCH ED&I leaders and also reviewed the goals laid out by the organization. Our completed plan, in draft form, has been reviewed by key stakeholders at BCH and will be formally presented to the FAC by the taskforce in October 2020.</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input type="checkbox"/> Department, committee, or unit that requested PFAC input</p>

<p>Accomplishment/Impact 3:</p> <p>FAC member representation on the Patient Care Assessment Committee (PCAC):</p> <p>It is a priority to the FAC to have family voices represented on board level committees. Our senior leadership FAC co-chair advocated within the organization, and in 2016, we had the great honor of naming one FAC member to our board level PCAC, which oversees all of patient care with specific focus on quality and safety. PCAC members have benefitted greatly from a family perspective over the years, earning the FAC member a standing appointment to the committee. The partnership has continued through FY2020 and we look forward to continued family impact in this important venue.</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>
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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)
<p>Accomplishment/Impact 1:</p> <p>FAC Equity, Diversity & Inclusion Plan:</p> <p>In January 2020, following a strategic plan refresh, the FAC dedicated itself to making a priority into a reality. FAC member volunteers, led by our parent co-chair and advised by our senior leadership co-chair, created an Equity, Diversity and Inclusion plan to specifically guide the FAC in its purpose, goals and actions.</p> <p>We are very proud of our council for making this a priority over the years and for turning that priority into a reality. We made efforts to both gather insights from key stakeholders within our organization and to align, where</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input type="checkbox"/> Department, committee, or unit that requested PFAC input</p>

<p>appropriate, our plan with BCH's organizational plan.</p> <p>We look forward to putting the plan into action in the fall 2020.</p>	
<p>Accomplishment/Impact 2:</p> <p>Suggestion Box:</p> <p>In February 2020 the Office of Experience launched the BCH "Suggestion Box" tool. This tool is available from the main page of our external website and is a tool that gathers anonymous submissions regarding facilities, comfort/hospitality, the Patient Portal, billing, etc.</p> <p>The Suggestion Box was an idea from FAC members that came to life. Our current process includes reviewing submissions for validity, feasibility and impact. Once the initial review process is complete, key suggestions/themes are then reviewed by the FAC for priority voting.</p> <p>Due to the nature of the submissions, this tool needs to be owned by an internal department, yet it originated with the FAC and retains the FAC as partners in directing improvement suggestions received through the Suggestion Box.</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input type="checkbox"/> Department, committee, or unit that requested PFAC input</p>
<p>Accomplishment/Impact 3:</p> <p>Virtual Visits Focus Group – National Level</p> <p>BCH Participates in a national Pediatric Experience Collaborative. As members of the collaborative, we hosted two focus groups with members of our FAC regarding the Virtual Visit experience for receiving medical care.</p> <p>We have one member of our FAC who sits on the collaborative as a</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>

family voice and contributed to the designing of the questions asked by all of the participating institutions.

At BCH, we invited key leaders and team members from the virtual visits and patient and family access teams to join in the groups, making families feel valued. We enjoyed two robust conversations, with insights shared both by families with, and without, virtual visit experience. BCH results were reported back to the national collaborative and will be part of the collective data that will inform virtual visit improvement recommendations on a national level.

27. The five greatest challenges the PFAC had in FY 2020:

Challenge 1: Adapt to Virtual Engagement: 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 three brand new members in an unplanned, virtual setting. Some of our in-person engagements have not resumed and have not transitioned to virtual opportunities, 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, 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: Diversity in FAC membership: For our hospital, diversity spans beyond race and ethnicity; it represents different sexes, diagnoses, hospital experiences, parents of children of varying ages, and sexual orientation. 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). We continue to work to increase the visibility of our FAC through an external marketing campaign that includes social media posts as well as targeted recruitments through specialty/location specific Social Workers, clinicians, etc. Additionally, those 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. In January 2020 we launched a dedicated FAC Equity, Diversity and Inclusion Taskforce to create a plan for the FAC, including but not limited to recruiting, support and retention of diverse voices as well as identifying creative

opportunities to engage diverse voices and weave them into the work of the FAC so that we can be more representative of the patients and families receiving care at BCH.

Challenge 3: Identifying strategic projects for FAC to drive that will impact BCH: In 2016 the FAC completed our first formal strategic planning process. At that time, it was a very quick process to identify projects to focus our efforts on. In January 2020, after making significant headway towards those goals, we launched a strategic refresh of that plan which focused on investment in our internal FAC culture and supporting the patients and families seeking care at BCH. Within the latter category, it has taken a long time to brainstorm, identify, discuss and then vote on projects that FAC members not only would like to lead or co-lead in partnership with BCH but also projects that are not already in process within the organization or are feasible in terms of leadership support and resources. After 9 months and some frustration from members about the slow progress, we find ourselves just settling on a project of broad scope: to support those families who have limited support networks. In September 2020, we will begin the process of gathering information from key stakeholders within the organization in order to inform our decision about a specific project underneath that umbrella. We anticipate that this will continue to be a slow and cumbersome process, which will try members' patience, yet this is completely family driven and we believe the impact will be significant and fulfilling for our members.

Challenge 4: Preparing members for integration into committees: While some individuals can join any group and make themselves right at home, most tell us that they will fit in better if they have an initial introduction, some background information on the individuals in the group and the work that is being done and maybe even a mentor or veteran member they can rely on to answer one-off questions, etc. Due to time and resources constraints, we have relied heavily on our Family Advisors to figure out how to best integrate into the dozens of working groups and committees that welcome families into the mix. As part of the Operational Excellence Strategic Initiative for our FAC, we are now dedicating specific efforts to designing a standardized process that will support both family members and staff as they begin new partnerships. For FAC members, that will include introductions, a "who's who" orientation so that they understand the different voices in the room, the assigning of a veteran FAC member who can serve as a mentor OR a staff member who can be a "go-to" person for the family member as they get acquainted with a new working group or committee. In 2019 we designed a very brief (approximately 5 questions) survey for FAC members who have integrated into a group within the past year to give feedback so that we can identify areas of strength and weakness in our new process and adjust accordingly. In 2020, we will need to implement these plans in order to better support our members in their committee work.

Challenge 5: Tracking Family Advisor Engagement and Impact: After years of struggling to find a way to appropriately measure family impact on the organization's improvement efforts, in February 2020 we implemented a standardized tool, accessed through a weekly calendar invite, for our Family Advisors to log their individual engagements. Unfortunately, with the onset of Covid-19, engagement opportunities were impacted and our FAC staff person dedicated to ensuring that the tracking tool was consistently filled out by all members needed to focus on Covid-19 related projects. In the fall 2020 we intend to refocus on this effort to track family advisor impact.

N/A – we did not encounter any challenges in FY 2020

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):
- 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?

Members either utilize Yammer to report back to the group about their individual engagements and committee/workgroup/initiative updates OR they will present to the group at a monthly meeting on such topics.

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): Social Work, Child Life Services, Case Management, Office of Community Relations presented their work and themes of patient/family needs to FAC. Additionally, IDHA (Innovation and Technology), Virtual Visits, Patient & Family Access Team all came to both present work, priorities, patient and family feedback both driving improvement efforts and in response to improvement efforts.
- 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:

In 2018 Boston Children’s Hospital increased the level of transparency with respect to the Family Advisory Council. As an ongoing initiative, all FAC members sign a Non- Disclosure Agreement. Currently, patient experience data (e.g., Child HCAHPS, surveys, access) is being shared with the FAC as it pertains to experience measures that are driving bodies of work within the hospital (and for which FAC members are sought out to provide a family perspective). Currently, other information is available to members of the FAC as it is public information but is not proactively shared with the FAC currently, in large part, to avoid overload of our FAC members who are already volunteering in significant capacities.

In FY2019 and FY2020, some additional information may have been shared with specific family advisors serving on specific quality and safety committees but not with the group as a whole.

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

In FY2018 Boston Children’s welcomed Family Advisors onto six safety committees and nursing shared governance committees. Using the results of data (which may or may not have been shared directly with FAC members) from the sources listed above, the hospital is entirely vested in minimizing/preventing safety events from occurring and recognized that optimal solutions for patients and families can be achieved more efficiently with by integrating the voices and perspectives of family members. In FY2019 Family Advisors served as

partners to an additional 10 safety committees/HAC groups as a result of the success of our initial partnerships. These engagements continued through FY2020.

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):
- 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):

Marcie Brostoff (Staff, Co-Chair)
Aimee Williamson (Parent Co-Chair)
Lisa Rubino (Staff, FAC Liaison)
Kristin Barton (Staff, FAC Liaison)
Katie Litterer (Staff, FAC Liaison)

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/family-resources/familypartnerships/family-advisory-council/annual-report>
 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/family-partnerships/family-advisory-council>

No, we don't have such a section on our website