



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, 2018.

2018 Patient and Family Advisory Council Annual Report Form

The survey questions concern PFAC activities in fiscal year 2018 only: (July 1, 2017 – June 30, 2018).

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 you to fill out a separate template for the hospital-wide PFAC at each individual hospital.

2a. Which best describes your PFAC?

- We are the only PFAC at a single hospital – **skip to #3 below**
- We are a PFAC for a system with several hospitals – **skip to #2C below**
- We are one of multiple PFACs at a single hospital
- We are one of several PFACs for a system with several hospitals – **skip to #2C below**
- Other (Please describe): We are the Hospital-Wide FAC. Boston Children's Hospital has several other specialty-specific FAC's but we serve the entire population.

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

- Yes
- No
- Don't know

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

- Yes
- No
- Don't know

3. Staff PFAC Co-Chair Contact:

2a. Name and Title: Marcie Brostoff, Associate Chief Nursing Officer and Vice President, Patient Care Services

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: Valerie Fleishman

3b. Email: vfleishman@nehi.net

3c. Phone: 617-794-8126

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 created a recruitment flyer specific the FAC and sent it to Social Workers for posting in their respective clinics or distributing directly to prospective FAC candidates. We also posted this flyer in our Hale Family Center for Families. Lastly, we created a version of this flyer that could be utilized through social media channels like Facebook and Twitter.

N/A – we did not recruit new members in FY 2018

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

9. Total number of patient or family member advisors on the PFAC: 19

10. The name of the hospital department supporting the PFAC is: Patient Care Services

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 Dinner
- 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 69.0% of patients hospitalized at Boston Children’s Hospital are from Massachusetts. In addition, 15.1% of patients hospitalized at Boston Children’s are from New England (excluding MA), 10.5% are from a national location (excluding New England), and 5.4% 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, 7.9% of patients seen at a Boston Children’s outpatient clinic are from New England (excluding MA), 3.4% are from a national location (excluding New England), and 1.2% 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								<input checked="" type="checkbox"/> Don't know
14b. Patients the hospital provided care to in FY 2018	0.21	3.27	7.41	0.06	52.40	5.29	8.39 *14.15% answered "unknown or unable to answer"	<input type="checkbox"/> Don't know
14c. The PFAC patient and family advisors in FY 2018			5.26		89.5		5.26	<input type="checkbox"/> Don't know

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 2018	13.9%	<input type="checkbox"/> Don't know
15b. PFAC patient and family advisors in FY 2018	0%	<input type="checkbox"/> Don't know

15c. What percentage of patients that the hospital provided care to in FY 2018 spoke the following as their primary language?

	%
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Spanish	5.62
Portuguese	0.62
Chinese	0.58
Haitian Creole	0.22
Vietnamese	0.19
Russian	0.11
French	0.05
Mon-Khmer/Cambodian	0.03
Italian	0.02
Arabic	0.79
Albanian	0.01
Cape Verdean	0.24

Don't know

15d. In FY 2018, what percentage of PFAC patient and family advisors spoke the following as their primary language?

	%
Spanish	5.26
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
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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 experience. 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 Virtual Advisors Forum on specific bodies of work where a more broad perspective is beneficial. Our Virtual Advisors Forum is made up of local, regional, national and international family members of 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.

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 Steering Committee — comprised of six families and hospital staff — meets monthly in person 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 three strategic planning groups and another supporting staff member.

17b. If other process, please describe:

18. The PFAC goals and objectives for 2018 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 2018 – Skip to #20

19. The PFAC had the following goals and objectives for 2018:

- 1.) Direct impact on employees/patient families
- 2.) Administer FAC Seal
- 3.) Drive FAC Strategic Initiatives: Operational Excellence, Optimizing Partnerships, Define Optimal Patient and Family Experience
- 4.) Recruit diverse members
- 5.) Increase family engagements
- 6.) Support FAC members: new member training / existing member development

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

Strategic Planning Committees: Three separate subcommittees were formed in 2017 to drive our three key strategic initiatives: Operational Excellence, Optimizing Partnerships and Defining the Optimal Care Experience. Each new FAC member joins one of these groups and efforts by all three groups are ongoing.

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

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

Section 5: Orientation and Continuing Education

23. Number of new PFAC members this year: 5

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 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 2018, we also endeavored to create and deliver storytelling training by leveraging internal resources, colleagues at other institutions who created similar education for their advisors, etc. The intent is 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.

Section 6: FY 2018 PFAC Impact and Accomplishments

The following information only concerns PFAC activities in the fiscal year 2018.

26. The five greatest accomplishments of the PFAC were:

Accomplishment	Idea came from (choose one)	PFAC role can be best described as (choose one)
<p>26a. Accomplishment 1: Direct Family Impact on Staff/Leadership: In FY2018 our Family Advisory Council members have continued to have direct impact on staff/leadership through speaking engagements. Employees who have heard</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><input type="checkbox"/> Being informed about topic</p> <p><input type="checkbox"/> Providing feedback or perspective</p> <p><input type="checkbox"/> Discussing and influencing decisions/agenda</p> <p><input checked="" type="checkbox"/> Leading/co leading</p>

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. Family Advisors reach staff/leadership through weekly New Employee Orientation, Resident Orientation, Department Specific Meetings, Panel Discussions, etc. In FY 2018 our Family Advisors reached over 2,000 staff/leadership directly through speaking engagements. We have also incorporated teen patients into these speaking engagements when possible, such as during summer vacation.

26b. Accomplishment 2: Training/Development and Integration of new FAC members

In 2018 we implemented a new orientation and training program for new FAC members. All new FAC members join the council in January. We created a very structured and deliberate program which began in December to orient new members to their roles as FAC members. Components of the training range from "Who's who" on the council, to how to use our secure online forum, to expectations about etiquette and representing the FAC in and around the organization. Monthly meetings/calls were held during the first four

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

- Being informed about topic
- Providing feedback or perspective
- Discussing and influencing decisions/agenda
- Leading/co leading

<p>months of a new member's time on the FAC. Those training sessions were followed by an opt-in style mentorship program with veteran FAC members which runs through the end of the calendar year. An assessment tool has been created and will be implemented in late October to measure the impact of this program and adjustments will be made accordingly for the class of 2019.</p>		
<p>26c. Accomplishment 3: Staff appreciation program: FAC Seal of Approval: The Seal of Approval is a staff appreciation program created and managed by the FAC. The purpose of the Seal is to acknowledge materials, groups and initiatives that integrate family voices into the body of the work and that demonstrate improved outcomes as a result of partnering with families. Initially an annual program when it was implemented in January 2017, the FAC Seal program now awards groups and initiatives for their family-centered work on a semi-annual basis while materials are considered on an ongoing basis.</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> Department, committee, or unit that requested PFAC input</p>	<p><input type="checkbox"/> Being informed about topic <input type="checkbox"/> Providing feedback or perspective <input type="checkbox"/> Discussing and influencing decisions/agenda <input checked="" type="checkbox"/> Leading/co leading</p>
<p>26d. Accomplishment 4: FAC Parent Co-Chair presented to Board of Directors: In January 2018 our parent co-chair presented key successes of the FAC to the Board of Directors. The presentation was very well received and the FAC has been invited to present to the Board of Directors going forward on</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> Department, committee, or unit that requested PFAC input</p>	<p><input type="checkbox"/> Being informed about topic <input type="checkbox"/> Providing feedback or perspective <input type="checkbox"/> Discussing and influencing decisions/agenda <input checked="" type="checkbox"/> Leading/co leading</p>

<p>an annual basis.</p>		
<p>26e. Accomplishment 5: Annual Experience Week: “Moments that Made You Smile” Wall: In 2018 the FAC helped to staff and manage a week-long patient and family engagement exercise during our annual Experience Week. In our main lobby, patients and families were invited to write and/or draw a moment that made them smile while at the hospital. With over 160 submissions from patients, families and staff that covered a large portion of the display wall, the "Moments that Made You Smile" wall was an incredible success. It was left up throughout the remainder of the month and enjoyed by both families and staff. This event was a great success and will be repeated again in 2019. Due to its success, FAC members will be joined next year in staffing this engagement opportunity by members of hospital leadership.</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><input type="checkbox"/> Being informed about topic</p> <p><input type="checkbox"/> Providing feedback or perspective</p> <p><input type="checkbox"/> Discussing and influencing decisions/agenda</p> <p><input checked="" type="checkbox"/> Leading/co leading</p>

27. The five greatest challenges the PFAC had in FY 2018:

27a. Challenge 1: FAC Membership Diversity: Recruitment and Retention of Diverse FAC Members: 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 will be increasing 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.

27b. Challenge 2: Preparing FAC 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. We will also work to design a very brief (possibly 2-3 questions) survey for FAC members who have integrated into a group within the past year so that we can identify areas of strength and weakness in our new process and adjust accordingly.

27c. Challenge 3: Preparing staff to integrate family members into committees: Please see 27b. The same challenge that exists for family members integrating into new committees exists for staff/leadership preparing to welcome a family member into a committee or workgroup. Often times there is not a shared expectation about how to solicit family input so families are not asked for their feedback but expected to speak up, while a family member may be waiting to be asked and/or not know when it is appropriate to speak up. By preparing staff/leadership coordinators of a committee or workgroup to welcome a family voice we can set some shared expectations and practices to optimize family partnership in each group.

27d. Challenge 4: Volunteer Family Advisors have less time for in-person engagements: Over the past three years our demographic has changed from parents/caregivers with great flexibility and time to be at the hospital in-person for committee work to almost all of our advisors working full-time, without flexibility for in-person engagements. This has forced us to leverage virtual participation and to lean on a few members heavily for commitments that need in-person attendance. We hope to recruit some new family members who will have the flexibility to volunteer in-person at times as well as to better prepare both our FAC members and staff/leadership for family integration into committee work so that virtual attendance can be optimized.

27e. Challenge 5:

N/A – we did not encounter any challenges in FY 2018

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 2018

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):

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.

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 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.

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)
Kristin Barton (Staff, FAC Liaison)
Valerie Fleishman (Parent Co-Chair)
Katie Litterer (Staff, FAC Liaison)
Lisa Rubino (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: FamilyPartnerships@childrens.harvard.edu
- No

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

Yes, link: <http://www.childrenshospital.org/patient-resources/family-resources/family-partnerships/family-advisory-council>

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