



## PFAC Annual Report Form

Health Care for All (HCFA) is a Massachusetts nonprofit advocacy organization. We work to create a health care system that provides comprehensive, affordable, accessible, and culturally competent care to everyone, especially the most vulnerable among us. We achieve this as leaders in public policy, advocacy, education and service to consumers in Massachusetts.

### 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>. These reports must be made available to members of the public upon request. As we have in past years, we are requesting a copy of your report, and suggest that you use our template/web based system to assist you in collecting information.

### 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
- use all information submitted to develop the annual Massachusetts PFAC Report
- share the data so that PFACs can learn about what other groups are doing and HCFA can learn about the best ways for us to support PFACs

If you choose to use the template, we encourage you to use our web-based survey. Follow [this link](#) to complete your report. Once the survey is completed, you will be directed to a summary of your responses, which you will be able to either save as a PDF or copy and paste into another document for your own reporting.

If you wish to use this Word document or any other form, please email it to [PFAC@hcfama.org](mailto:PFAC@hcfama.org).

### Who can I contact with questions?

Please contact us at [PFAC@hcfama.org](mailto:PFAC@hcfama.org) or call us at 617-275-2919.

Reports should be completed by October 1, 2016.

## 2016 Patient and Family Advisory Council Annual Report Form

The survey questions concern PFAC activities in fiscal year 2016 only.

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 Family Advisory Council (FAC). Boston Children's Hospital has several other specialty-specific FACs, 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: Susan Shaw, Associate Chief Nurse and Director of Clinical Operations

2b. Email: Susan.Shaw@childrens.harvard.edu

2c. Phone: 617-355-7340

Not applicable

4. Patient/Family PFAC Co-Chair Contact:

3a. Name and Title: William O'Donnell

3b. Email: odonnellw@babson.edu

3c. Phone: 781-307-7134

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:

5a. Name and Title: Kristin Erikson, Project Manager, Health Literacy/Patient & Family Education

5b. Email: Kristin.Erikson@childrens.harvard.edu

5c. Phone: 617-919-3638

Not applicable

## Section 1: 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 and Twitter

Hospital banners and posters

Hospital publications

Houses of worship

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 FAC recruitment flyer specific and sent it to all 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 where it is visible to a very large and diverse population of families.

N/A – we did not recruit new members in FY 2016

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

9. Total number of patient or family member advisors on the PFAC: 15

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 Project Manager, Health Literacy/Patient & Family Education, Department of Clinical Education and Informatics.

**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 2: 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:**

Boston Children’s Hospital is the largest major pediatric tertiary care facility in the Northeast and one of the largest pediatric medical centers in the United States. It is the primary pediatric teaching affiliate of Harvard Medical School, and home to the largest, best-funded research enterprise in the country based at a pediatric hospital. Boston Children’s provides services in a number of facilities. The main hospital campus is located in the Longwood Medical Area (medical academic area of Boston) and Boston Children’s has expanded over the years to provide care at six satellite facilities in the greater Boston area.

- Martha Eliot Health Center: A community health center in Jamaica Plain, Mass., that offers primary and preventative care to children, adolescents and young adults located less than two miles from Boston Children’s Main Campus.
- Waltham: A pediatric facility with operating rooms, post-anesthesia recovery area, radiology capabilities, specialty clinics and 11 inpatient beds located 15 miles from Boston Children’s Main Campus.
- Peabody: A pediatric outpatient specialty facility located 21 miles from Boston Children’s Main Campus.
- Lexington: An outpatient facility with operating rooms, post-anesthesia recovery and specialty clinics located 22 miles from Boston Children’s Main Campus.
- Weymouth: An ambulatory care facility located 16 miles south of Boston Children’s Main Campus

- North Dartmouth: An outpatient facility with 16 pediatric specialties located approximately 60 miles from Boston Children’s Main Campus.

The main campus not only serves as a tertiary and trauma center for the greater Boston area, but it is also the #1 provider of primary and secondary care for low-income Massachusetts children and Boston’s inner-city diverse and poorer populations. Boston Children’s also serves children and families throughout Massachusetts, New England, and the United States and all over the world. Most of Boston Children’s patients come from the greater Boston area. However, more than 30 percent of patients who receive inpatient care travel great distances to come to Boston Children’s. The below table provides the patient distribution by market area for the fiscal year FY2015.

**Distribution of Patients by Market Area for FY 2015**

Geographical Area	Inpatient	Outpatient
Urban Core	14.68%	31.06%
Eastern Massachusetts	49.34%	52.27%
Other Massachusetts	7.53%	4.27%
New England	13.13%	6.44%
National	8.20%	2.89%
International	7.08%	3.06%

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 (Massachusetts demographics only from Census.gov)	0.5%	6.6%	8.4%	0.1%	82.1%	Two or more races - 2.3% White alone, not Hispanic or Latino - 73.5%	11.2%	<input type="checkbox"/> Don’t know
14b. Patients the hospital provided care to in FY 2016	Inpatient - 0.15% Outpatient - 0.16%	Inpatient - 3.68% Outpatient - 3.20%	Inpatient - 8.88% Outpatient - 11.72%	Inpatient - 0.04% Outpatient - 0.08%	Inpatient - 58.46% Outpatient - 47.76%	Declined to answer: Inpatient - 3.01% Outpatient - 6.91% Other (includes Latino) : Inpatient - 17.88% Outpatient - 21.70% Unable to answer/ask: Inpatient - 7.90% Outpatient - 8.48%		<input checked="" type="checkbox"/> Don’t know

14c. The PFAC patient and family advisors in FY 2016	We presently do not collect racial or ethnic data from families on our Family Advisory Council.	<input checked="" 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 2016		<input checked="" type="checkbox"/> Don't know
15b. PFAC patient and family advisors in FY2016	0%	<input checked="" type="checkbox"/> Don't know

**15c. What percentage of patients that the hospital provided care to in FY 2016 spoke the following as their primary language?**

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

Cape Verdean	
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Don't know

**15d. In FY 2016, what percentage of PFAC patient and family advisors spoke the following as their primary language?**

	%
Spanish	0
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 or catchment area:** Ensuring appropriate representation of our membership is an ongoing priority for our FAC. In late 2015 and early 2016, two part-time Family Partnerships Coordinators joined our Hale Family Center for Families staff and serve as staff members on our Family Advisory Council. One Family Partnership Coordinator's role has focused on supporting the FAC, including with the recruitment of new members. She recently launched a campaign to diversify membership, which includes recruiting families of varying races/ethnicities, socioeconomic status and hospital experience. She developed FAC recruitment materials and is working closely with key clinical and administrative staff to

recruit new members, including nurses, physicians, nurse practitioners, social workers and case managers. Finally, to understand the diversity of our present family partners, this Family Partnership Coordinator developed an anonymous online survey to collect demographic information.

Our second part-time Family Partnership Coordinator works with our Staff Nurse III in the Hale Family Center for Families to support our Wellness Program, which offers alternative therapies free of charge to families. In addition, she supports our Family to Family mentoring program as well as the creation of support groups. In this role, this Family Partnership Coordinator comes to understand families' challenges and needs during their time here at the hospital, and has the opportunity to learn if these families could be candidates for our FAC.

In addition, Boston Children's Primary Care at Longwood and Martha Eliot Health Center have formed their own FACs to understand and address the needs of the children and families they serve. Boston Children's offers program-specific FACs, such as ones in the Neonatal Intensive Care Unit (NICU) as well as Autism and Psychiatry practices.

Lastly, the Hale Family Center for Families has a full-time program coordinator dedicated to working with our Latino and Spanish-speaking families. We are presently looking to hire a part-time Family Partnerships Coordinator focused solely on providing support to our Latino families.

### Section 3: 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:

Each month, a Family Advisory Council Steering Committee is held and led by the parent co-chair and staff co-chair. FAC staff members also attend. The goal is to develop an agenda for the upcoming FAC meeting. In addition, FAC members are welcome at any point in time to suggest presenters and/or agenda items for upcoming meetings. Following the conclusion of the Steering Committee meeting, a FAC staff member drafts an agenda for final approval before sending it to FAC members.

#### 17b. If other process, please describe:



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**18. The PFAC goals and objectives for 2016 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 2016 – **Skip to #18**

**19. The PFAC had the following goals and objectives for 2016:**

Our 2016 FAC goals include:

1. **Creation of the FAC Seal of Approval:** The FAC set the goal to create a “Seal of Approval” that empowered them to acknowledge and support documents, projects and strategic initiatives that:
  - Improve an aspect(s) of the patient/family experience
  - Incorporate the patient/family voice

FAC members created guidelines and criteria for who could receive the Seal and worked with a graphic designer to design a Seal that represents both collaboration and diversity. They also developed a Marketing toolkit to explain to staff the importance of the Seal. Finally, the FAC compiled a list of documents, projects and strategic initiatives that could be eligible for the Seal. FAC members are presently in the voting stages to determine who should receive the Seal. Responses are due via SurveyMonkey by Monday, October 3, 2016.

2. **Growing Our Virtual Advisors Forum:** A brainchild of FAC members, this forum was launched in August 2015 and allows families to join a private social network where they can share feedback with Boston Children’s staff from the comfort of their own homes. In 2016, the FAC aimed to increase membership in this forum of local, regional, national and international parents/caregivers to this forum. To date, there are 39 members — including two who live internationally — who have high levels of engagement.
3. **Expand Our Family Engagements:** In 2016, the FAC aimed to increase the number of engagement opportunities for families. The number rose from 35 committees and workgroups to 62. These engagements span from quality and safety to research and redesign of both the hospital’s green space and new clinical tower.
4. **Strategic Planning:** The FAC is currently leading a formal strategic planning process to better define its vision and mission, and to increase its effectiveness in staying true to the mission and achieving collective goals.

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

We have created the FAC Seal subcommittee and the Strategic Planning subcommittee to lead efforts associated with two of our 2016 goals. We also created an Emergency Department Family Advisory Council on which seven FAC members serve along with Emergency Department leadership and key personnel. This will be an ongoing advisory relationship.

**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 2014, a private page 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 on this site. Prior to Yammer, the FAC utilized an e-mail DL and private Facebook page (which is no longer used) to communicate with each other.

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

## **Section 4: Orientation and Continuing Education**

**23. Number of new PFAC members this year: 4**

**24. Orientation content included (check all that apply):**

- "Buddy program" with experienced members
- Check-in or follow-up after the orientation
- Concepts of patient- and family-centered care (PFCC)
- General hospital orientation
- Health care quality and safety
- History of the PFAC
- Hospital performance information
- Immediate "assignments" to participate in PFAC work
- Information on how PFAC fits within the organization's structure
- In-person training
- Massachusetts law and PFACs
- Meeting with hospital staff
- Patient engagement in research
- PFAC policies, member roles and responsibilities

- Skills training on communication, technology, and meeting preparation
- Other (Please describe below in #24a)
- N/A – the PFAC members do not go through a formal orientation process

**24a. If other, describe:**

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**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 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.

## Section 5: FY 2016 PFAC Impact and Accomplishments

The following information only concerns PFAC activities in the fiscal year 2016.

### 26. The five greatest accomplishments of the PFAC were:

Accomplishment	Idea came from...	PFAC role can be best described as...
<p><b>26a. Accomplishment 1:</b>  <b>Incorporation of two Family Advisory Council members onto the leadership committee of Boston Children's High Reliability Organization initiative. These families helped to design an organization-wide marketing strategy as well as an error prevention toolkit for patients and families. FAC members also completed error prevention training.</b></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><b>26b. Accomplishment 2:</b>  <b>Appointing a FAC member to serve on a board-level committee</b></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><b>26c. Accomplishment 3:</b>  <b>Establishment of Emergency Department Family Advisory Council</b></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><b>26d. Accomplishment 4:</b>  <b>Implementation of Family Partnership Coordinator Roles (2 part-time roles in the Hale Family Center for Families dedicated to supporting family partnerships and initiatives)</b></p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC  <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input</p>	<p><input checked="" type="checkbox"/> Being informed about topic  <input checked="" type="checkbox"/> Providing feedback or perspective  <input checked="" type="checkbox"/> Discussing and influencing decisions/agenda  <input type="checkbox"/> Leading/co leading</p>

<p><b>26e. Accomplishment 5: Direct family impact on employees via presentations by families at New Hire Orientation and Service Excellence trainings</b></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 checked="" type="checkbox"/> Discussing and influencing decisions/agenda</p> <p><input checked="" type="checkbox"/> Leading/co leading</p>
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**27. The five greatest challenges the PFAC had in FY 2016:**

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**27a. Challenge 1:** Ensuring cultural, ethnic, educational and socio-economic diversity on the FAC.

**27b. Challenge 2:** Demand for family voices/feedback is greater than supply.

**27c. Challenge 3:** Incorporating families into more quality and safety initiatives (e.g. Root Cause Analyses) within the organization.

**27d. Challenge 4:** Partnership with department/clinic specific FACs.

**27e. Challenge 5:** Better preparation of family members (and staff) to ensure effective integration onto the new committees/workgroups they are assigned to.

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N/A – we did not encounter any challenges in FY 2016

**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 present to the group at a monthly meeting.

**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 2016

**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:**

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

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**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:**

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**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 6: 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):**

Susan Shaw, Staff Co-Chair

William O'Donnell, Parent Co-Chair

Kristin Erekson, FAC Liaison/Staff 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/family-resources/family-partnerships/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