

Health Care For All

FY 2015 Patient and Family Advisory Council Annual Report Template

Under Massachusetts law, all PFACs are required to write annual reports each year and to make them available to members of the public upon request. To assist you in collecting information, Health Care For All (HCFA) has developed this revised report template with 6 sections, with the hope that you will use it to complete your report for the fiscal year 2015 (October 1, 2014 – September 30, 2015).

We encourage you to submit your hospital's PFAC report through an on-line survey to ease reporting burden. Follow this link to complete the FY 2015 PFAC Report. Once the survey is completed, you will be directed to a summary of your responses, which you will be able to save as a PDF or copy and paste into another document for your own reporting.

HCFA recognizes the importance of supporting the work of the PFACs and facilitating cross-PFAC learning and sharing. Your PFAC report should be made publically available and sent back to us (using the attached word document or preferably the on-line survey) no later than October 1, 2015.

If you have questions or concerns, please contact Margo Michaels at mmichaels@hcfama.org.

2014 Patient and Family Advisory Council Annual Report

Please list

- 1. Hospital Name: Boston Children's Hospital
- 2. Year PFAC Established: 1982
- 3. Staff PFAC Contact (name and title): Kristin Erekson, MA, CHES, Health Education Project Manager & Editor
- 4. Staff PFAC Contact E-mail and Phone: kristin.erekson@childrens.harvard.edu and 617-919-3638

Note: The following questions only concern PFAC activities in fiscal year 2015.

Section 1: PFAC Organization

5. Our F	PFAC has (check the best choice)
	🗷 By-laws
	☐ Agreed-upon policies and procedures
	☐ Neither

6. (If neither) Our PFAC manages itself through (describe in 1500 characters or fewer):
7. Our PFAC recruits new members using the following approaches (check all that apply):
▼ Word of mouth
☐ Promotional efforts within institution to patients
☐ Promotional efforts within hospital to providers or staff
Through existing members
🗷 Facebook and Twitter
Recruitment brochure
☐ Hospital publications
☐ Hospital banners and posters
☐ Through care coordinators
☐ Through patient satisfaction surveys
☐ Through community based organizations
☐ Through houses of worship
☐ At community events
✗ Other
None
8. If other, describe (in 1500 characters or fewer):
The Family Advisory Council (FAC) began working closely this year with the hospital's Marketing Department to raise more awareness about our family partnership programs, including the FAC. Marketing utilizes the hospital's website, social media channels and blog to increase the FAC's visibility. For example, Marketing recently wrote a blog post profiling a FAC mother and her family, and shared the story on the hospital's <i>Thriving</i> blog and Facebook page. Following the posting of this story, FAC support staff received an influx of inquiries from families interested in becoming involved in the FAC and/or other patient- and family-centered care hospital activities. This Marketing strategy has truly allowed for a broader recruitment of family partners and potential FAC members.
In addition, when recruiting new members for the FAC each year, FAC support staff reach out to a multidisciplinary team throughout the hospital for referrals. Staff consulted include nurses, physicians, child life specialists, social workers, chaplains, and case managers. FAC support staff also reach out to various departments for recruitment for the FAC, including Patient Relations, Interpreter Services and the Hale Family Center for Families.
9. Our PFAC chair or co-chair is a patient or family member.
X Yes
\square No
10. Our PFAC chair or co-chair is a hospital staff member.
▼ Yes
□No

11. This person's position title: Associate Chief Nurse and Director of Clinical Operations

2. This person is the official PFAC staff liaison
☐ Yes
X No
3. Our PFAC has seven staff members.
4. Our PFAC has 15 current or former patients or family members.
5. The name of the hospital department supporting the PFAC is: Patient Care Services
16. If not mentioned above, the hospital position of the PFAC staff liaison is: Presently, we do not have one dedicated PFAC staff liaison role. Rather, it is a shared responsibility among staff in Patient Care Services and our Hale Family Center for Families.
77. The hospital reimburses PFAC members for the following costs associated with attending or participating in meetings (check all that apply)
X Provide free parking
X Provide meals
Provide translator or interpreter services
Provide assistive services for those with disabilities
Provide meeting conference call or webinar options
☐ Provide mileage or travel stipends
Provide financial support for child care or elder care
Provide stipends for participation
Provide on-site child or elder care
Provide reimbursement for attendance at annual PFAC conference
Provide reimbursement for attendance at other conferences or trainings
☐ Provide gifts of appreciation to PFAC members annually
X Cover travel expenses to attend conferences
Provide other supports
None

18. If other, describe (in 1500 characters or fewer):

Section 2: Community Representation

The PFAC regulations require every PFAC to represent the community served by the hospital.

19. Our catchment area is geographically defined as:

INPATIENT: Presently, more than 75% of patients hospitalized at Boston Children's Hospital are from Massachusetts (the largest population - at 52.9% - is from Eastern Massachusetts). In addition, 13% of patients hospitalized at Boston Children's are from New England, 6.3% are from a national location, and 2.9% are from an international location.

OUTPATIENT: Presently, more than 90% of outpatient visits at Boston Children's Hospital are from children and families who live in Massachusetts (the largest population - at 51.7% - is from Eastern Massachusetts). In addition, 6.2% of patients hospitalized at Boston Children's are from New England, 2.2% are from a national location, and 1.2% are from an international location.

20-25. Our catchment area is made up of the following demographic percentages:

	RACE			ETHNICITY			
	%	%	%	%	%	%	%
	American Indian or Alaska Native	Asian	Black or African American	Native Hawaiian or other Pacific Islander	White	Latino	Not Latino
Our catchment area is made up of the following ethnic and racial groups (Massachusetts demographics only from Census.gov)	0.5	6.3	8.3	0.1	74.3	10.8	
In FY 2015, the our institution provided care to patients from the following ethnic and racial groups	0.2	3.3	10.1	0.1	50.6	5.8	Other - 10.5 Unknown - 19.5
In FY 2015, our PFAC <u>patients</u> and family members came from the following ethnic and racial groups -	We presently do not collect racial or ethnic data from families on our Family Advisory Council.						

26. Our PFAC is undertaking the following activities to ensure appropriate representation of our membership in comparison to our patient or catchment area (describe): Recruitment for the FAC is targeted to ensure diverse membership, including families seen throughout many different specialty services; patients with many inpatient hospital stays and those seen primarily as outpatients; patients followed for primary care and those seen in satellites. While we continue to strengthen the diversity of our council, current or former Family Advisory Council members have included parents of color, bilingual parents as well as three fathers. In regards to community outreach, Boston Children's Primary Care at Longwood and Martha Eliot Health Center have formed their own FACs to better understand and address the needs of the children and families they serve. In addition, 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 Spanish-speaking families. Utilizing feedback she received from focus groups with Spanish-speaking families, this program coordinator created several videos for Spanish-speaking families that help them to prepare for their visit and navigate the hospital. She is also exploring the idea of creating a Latino Family Advisory Council.

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	⊒ n/a			
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Section 3: PFAC Operations

	The staff develops the agenda and sends it out prior	☐ PFAC members develop the agenda and distribute in
	to the meeting	at the meeting
□′	The staff develops the agenda and distributes it at the meeting	The PFAC has a collaborative process between staff and patients/family members to develop and
		distribute the agenda
Ш.	PFAC members develop the agenda and send it out prior to the meeting	None
	prior to the ineeding	☐ Other process
pare mee	ent co-chair and staff co-chair. FAC staff members also at eting. In addition, FAC members are welcome at any poin	ily Advisory Council Steering Committee is held and led by the stend. The goal is to develop an agenda for the upcoming FAC t in time to suggest presenters and/or agenda items for upcoming the meeting, a FAC staff member drafts an agenda for final approval
29.	If other process, describe:	
0. The	PFAC goals set for FY 2015 were:	
	 Establishment of the Virtual Advisors Program Increasing the presence of — and presentations by - 	— FAC members at local and national conferences
		ch invites Boston Children's patients/families to recognize staff
		•
 31. The	PFAC goals for FY 2015 were (check the best choice)):
1. The	PFAC goals for FY 2015 were (check the best choice) ☐ Developed by staff and reviewed by PFAC members	
 1. The		
	Developed by staff and reviewed by PFAC members	
	☐ Developed by staff and reviewed by PFAC members ☑ Developed by PFAC members and staff	
	Developed by staff and reviewed by PFAC members Developed by PFAC members and staff PFAC has the following subcommittees (check all the	nat apply):
	☐ Developed by staff and reviewed by PFAC members ☑ Developed by PFAC members and staff PFAC has the following subcommittees (check all the Government relations	nat apply): \[\sum \text{Nominations} \\ \sum \text{Marketing} \\ \text{Marketing} \\ \text{Marketing} \\ \sum \text{Marketing} \\ Marketi
	☐ Developed by staff and reviewed by PFAC members ☑ Developed by PFAC members and staff PFAC has the following subcommittees (check all the Government relations ☐ Recruitment	nat apply): \[\sum \text{Nominations} \] \[\sum \text{Marketing} \] \[\sum \text{Behavioral Health} \]
	☐ Developed by staff and reviewed by PFAC members ☑ Developed by PFAC members and staff PFAC has the following subcommittees (check all the Government relations) ☐ Recruitment ☐ Emergency Department	nat apply): Nominations Marketing Behavioral Health Medication Safety
	☐ Developed by staff and reviewed by PFAC members ☑ Developed by PFAC members and staff PFAC has the following subcommittees (check all the Government relations) ☐ Recruitment ☐ Emergency Department ☐ Education and Communication	nat apply): Nominations Marketing Behavioral Health Medication Safety Hospital Safety
	☐ Developed by staff and reviewed by PFAC members ☑ Developed by PFAC members and staff PFAC has the following subcommittees (check all the Government relations ☐ Recruitment ☐ Emergency Department ☐ Education and Communication ☐ Family Support	Nominations Marketing Behavioral Health Medication Safety Hospital Safety None
	□ Developed by staff and reviewed by PFAC members ☑ Developed by PFAC members and staff PFAC has the following subcommittees (check all the Government relations □ Recruitment □ Emergency Department □ Education and Communication □ Family Support □ Policies and Procedures	nat apply): Nominations Marketing Behavioral Health Medication Safety Hospital Safety

33. If other, describe (in 1500 characters or fewer): The FAC develops priorities to lead each year. In FY15, the FAC formed three subcommittees to tackle its priorities: 1.) Virtual Advisors Committee - Charged with establishing an online "virtual advisory council" for family partners to join, 2.) Staff Appreciation Committee - Charged with creating an awards program that recognizes staff for outstanding patient- and family-centered care and 3.) Family Advisory Council Marketing Strategy - Charged with developing a roadshow about the FAC as well as completing the FAC's external webpage. In addition to these

subcommittees, FAC members serve on a wide range of hospital committees. There are 40+ committees throughout the organization with family representation.

34. Our PFAC interacts with the Hospital Board of Directors in the	following ways (check all that apply):
☐ PFAC submits annual report to Board	☐ PFAC member(s) are on board-level committee(s)
☐ PFAC submits meeting minutes to Board	☐ None of the above
☐ PFAC member(s) attends Board meetings	▼ Other
☐ Board member(s) attends PFAC meetings	△ Other
35. If other, describe (in 1500 characters or fewer): Family members so families do not serve on our FAC. Rather, FAC accomplishments and leaders who serve as staff on the FAC. This includes our chief nursin	d news are reported up to the Board of Directors via hospital
36. This is the url/link to the PFAC section on our hospital's website	e:
www.childrenshospital.org/patient-resources/family-resources	/family-partnerships/family-advisory-council
☐ We don't have such a section on our website	
37. Describe the PFAC's use of email, listservs, or social media:	
In the summer of 2014, a private page on the free social networking site Y with one another between meetings, read meeting minutes, take surveys at Yammer, the FAC utilized an e-mail DL and private Facebook page (which	nd more. All of our FAC members are on this site. Prior to
☐ We don't communicate through these approaches	
Section 4: Orientation and Continuing Education	
38. The PFAC had <u>five</u> new members this year	
39. Our PFAC orientation program this year was provided by one st	aff and one PFAC member.
40. The content included (check all that apply):	
☐ Meeting with hospital staff	
🗷 A general hospital orientation	
☒ Information on concepts of patient- and family-centered care	e (PFCC)
☐ Information on patient engagement in research	
▼ PFAC policies, member roles and responsibilities	
☐ Information on health care quality and safety	
☒ History of the PFAC	
X A "buddy program" with old members	
M How PFAC fits within the organization's structure	
Other 41. If other, describe (in 3000 characters or fewer):	

42. PFAC members are considered hospital volunteers and therefore (check all that apply):
X Attend hospital volunteer trainings
🗷 Require immunizations or TB checks
🗷 Require CORI checks
☐ Not applicable
Other
43. If other, describe:
44. Our PFAC provides education to our members on the topic patient-centered outcomes research
X Yes
\square No

Section 5: FY 2015 PFAC Impact and Accomplishments

45-50. The three greatest accomplishments of our PFAC were:

Accomplishment (describe each in 3000 characters or fewer)	Idea originated from PFAC	Idea originated from Department/ Committee/ Unit that requested PFAC input
Accomplishment 1: With the increasing amount of requests from hospital staff for patient and family participation, FAC members identified the need to create a "virtual advisory council" to give more families the opportunity to contribute to hospital initiatives (from the comfort of their own homes!). In the beginning of 2015, a subcommittee of FAC members came together to conduct an environmental scan of similar organizations that offer virtual participation for patients and families. A FAC member and staff member interviewed the Director of Service Excellence at Nemours/Alfred l. duPont Hospital for Children to understand how he established a virtual advisory council, the challenges he faced and his successes to date. Following the research phase, the subcommittee explored technology platforms to use, determining that Yammer would be the best fit. The subcommittee created a privacy statement, social media guidelines and invitation email to send to current family partners. The virtual advisory council, which we call the Virtual Advisors Program, launched in August 2015 and has more than 20 members to date (as of September 2015). Topics where we ask for Virtual Advisors' input include patient and family education materials; hospital experience, such as with hospital navigation or scheduling appointments; patient safety and quality initiatives; parking and transportation; food and dining; and more. Said a member of the Virtual Advisors Program, "I think this is a wonderful forum. Thank you for including me."	X	
 Accomplishment 2: This fiscal year, FAC members and staff identified the need to increase their presence at local and national patient- and family-centered conferences. The FAC felt it was important to share its work and to learn about initiatives led by other organizations. Below are some of the presentations given and conferences attended by FAC members and staff to date: October 9, 2014 Beryl Institute Regional Roundtable at Boston Children's: FAC families and staff helped to plan this roundtable and attended the one-day event. November 3-6, 2014 Institute for Patient- and Family-Centered Care's (IPFCC) Partnerships for Quality & Safety - An Intensive Training Seminar: Two FAC families attended this event. April 8-10, 2015 Beryl Institute's Patient Experience Conference: A FAC family and two FAC staff members attended this conference. May 17-20, 2015 Cleveland Clinic' Empathy + Innovation Summit: A FAC family and two FAC staff members attended this conference. May 20, 2015 Massachusetts PFAC Conference: A FAC family and staff member presented on the topic of engaging families in education and health literacy initiatives. Two FAC members displayed a poster on the hospital's high reliability initiative, which focuses on reducing preventable harm events to patients, families and staff. Several FAC members also attended the conference. October 12 and 13, 2015 Planetree Conference: Two FAC families will present on their involvement in a research fellowship program. In addition, a FAC family and staff member will present on the topic of engaging families in education and health literacy initiatives. October 16, 2015 Health Care Education Association Conference: A FAC family and staff member (who will participate virtually) will present on the topic of engaging families in education and health literacy initiatives. 	X	

Accomplishment 3: Currently, there are more than 40 committees in the hospital with family	. Iv	[V]
participation. However, the FAC and hospital leadership felt it was important to also embed	X	X
families on senior-level committees. To date, Boston Children's has families on its Senior		
Experience Leadership Committee as well as senior-level committees focused on digital		
engagement (e.g. telehealth) and patient safety initiatives. In addition, several families will be		
attending an upcoming hospital leadership forum that aims to outline goals and high-level		
strategies for the enterprise.		

51-56. (If not already listed above) Our PFAC's three greatest accomplishments in relation to quality of care initiatives in FY 2015 include

Quality of Care Accomplishment (describe each in 3000 characters or fewer)	Idea originated from PFAC	Idea originated from Department/ Committee/ Unit that requested PFAC input
Accomplishment 1: In March 2015, a team within Patient Care Services and three FAC families were awarded a grant to help improve complex clinical care teaching for patients and families before being discharged home. The idea for the grant arose after FAC families actively involved in health education expressed facing unforeseen challenges when they got home. While these families learned how to care for their child in the hospital, they found the care they must provide at home is often slightly different. For example, families may have different equipment in the home than the equipment they used in the hospital. The project team is now seeking a patient population to collaborate with (e.g. G-tubes, tracheostomies) in order to launch this discharge teaching improvement project.		X
Accomplishment 2: FAC members have made great strides in helping to launch and improve the technology of Boston Children's patient portal, called MyChildren's. On MyChildren's, families and caregivers can view portions of their child/dependent's health records; send secure messages to a clinician; request an appointment; pay a bill; and more. A FAC member serves as the parent chair of the Patient Portal Committee, which is comprised of hospital staff and leadership who meet regularly to discuss the patient portal's functionality as well as upgrades needed. The latest achievement is giving families and caregivers the ability to have access within the patient portal to medical notes. A medical note is a health care provider's report of an office visit or hospital stay. Boston Children's is one of the first children's hospitals to provide online access to medical notes.		X
 Accomplishment 3: Boston Children's is on a journey to become a High Reliability Organization (HRO). An HRO is a complex and high-risk environment that delivers exceptionally safe and consistently high quality care and service experience over time. Building and sustaining a HRO is a long process that requires consistent effort. The goal is to have zero preventable harm for patients and employees. The family voice in pediatric settings is essential in building and sustaining culture change towards high reliability. Using this principle, the hospital has involved FAC families in its journey to become a HRO. Two FAC members now serve on the HRO Safety Leadership Core Team and help to drive forward the following projects: Leadership methods Daily Operations Brief: A 15-minute huddle led by a senior leader every weekday morning to maintain situational awareness of operations and to give direction about priority and responsibility for problem resolution. Members of the FAC are invited to join and participate. Rounding to Influence: A brief interaction between leaders and frontline staff that address staff behaviors related to safety, quality or satisfaction. Patient Experience rounding will involve senior and local leaders asking patients and families experience questions. Leadership training The High Reliability Leadership Series is a lecture series of eight topics related to high reliability leadership. Error prevention toolkit This toolkit is a set of standard tools and techniques taught by senior leaders to frontline staff to help provide safe, quality care. Our families are also developing an error prevention toolkit specifically for patients/families to empower them to advocate for safe and high quality care. 		X

57-59. The greatest three challenges our PFAC had (describe each in 3000 characters or fewer):

- **57. Challenge 1:** Like many other PFACs, Boston Children's experiences challenges around the diversity of its Family Advisory Council. 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 us 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 see us for 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 the launch of our new website and blog posts about and by FAC members.
- **58. Challenge 2:** With a heightened focus on the patient experience over the past few years, the demand for family participation on committees as well as in initiatives has been on the rise. A challenge for Boston Children's is determining whether our FAC families are having meaningful experiences and influence on these committees/initiatives. FAC staff conducted a survey in early 2015 among its families and committee/initiative leads to understand how impactful these experiences were for both parties. While feedback was mostly positive (both parties, for the most part, felt their partnerships were meaningful), we learned that there was work we could do to help improve these family-staff committee/initiative relationships. For example, some families expressed the need for an orientation before joining a committee (i.e. what is the committee about, what are the committee's expectations of them?). We also learned that families were sometimes not communicated to when a committee/initiative was regrouping or disbanded. There were similar requests from our staff. They, too, felt some families needed better orientation to the purpose of the group. FAC staff now utilize a form that asks staff to fill out the expectations of the parent partner, helping us to better orient the families we partner with these committees/initiatives. We've also developed a "tips and tricks" document for staff leading committees/initiatives with parent partners. We are also checking in regularly with committee/initiative leads and parent partners to track progress and satisfaction.
- **59. Challenge 3:** Boston Children's is fortunate to have a dedicated group of former and current FAC members who are committed to helping us lead our mission of patient- and family-centered care. We now recognize that we need a formal process to both recognize former FAC members and keep them engaged in the hospital (if they still choose to stay engaged). Current FAC members have discussed the idea of creating an alumni program. This past summer, we launched our Virtual Advisors Program, which gives the opportunity for family partners to participate virtually in hospital initiatives, surveys and more.

60. Our PFAC provided advice or recommendations to the hospital on the following areas mentioned in the law (check all that apply):

Quality improve	rement initiatives
🗷 Patient educati	on on safety and quality matters
🗷 Patient and pro	ovider relationships
☐ Institutional Re	eview Boards
Other	
☐ None	
61. If other, describe	(in 1500 characters or fewer):
62-63. PFAC members pa	articipated in the following activities mentioned in the law (check all that apply):
☐ Serve as memb	pers of task forces; number of people serving
☐ Serve as memb	pers of awards committees; number serving
☐ Serve as memb	pers of advisory boards/groups or panels
☐ List names of	each group and number serving on each
Serve on searc	h committees and in the hiring of new staff; number serving

serving Serve on selection of reward and recognition programs; Number serving Serve as members of standing hospital committees that address quality	
X Serve as members of standing hospital committees that address quality	
(List) names of each group and number serving on each • Program for Patient Safety and Quality (PPSQ) Implement • PPSQ: Alarm Management (1 family) • PPSQ: Consent Process (2 families) • PPSQ: Pain Management (2 families) • High Reliability (2 families)	ntation Committee (1 family)
☑ Other areas of service not listed above;	
 (List) names of each group and number serving on each Access-related projects (4 FAC families) Construction projects (5 FAC families) Digital strategy projects (2 FAC families) Experience projects (1 FAC family) Family-centered care projects (1 FAC families) Family Education projects (3 FAC families) IPASS projects (2 FAC families) Patient Portal Committee (1 FAC family) Process improvement projects (3 FAC families) Research-related projects (7 FAC families) 	
None	
64. The hospital shared the following public hospital performance information with the Serious Reportable Events Healthcare-Associated Infections Department of Public Health (DPH) information on complaints and investigation Staff influenza immunization rate	`
 ☒ Patient experience/satisfaction scores ☒ Patient complaints ☐ Patient Care Link ☐ Joint Commission surveys, ☐ Hospital Compare ☒ Family satisfaction surveys ☐ Quality of life data ☒ Rapid response data ☐ None 	

65. If other, describe (in 1500 characters or fewer): discussed at meetings

66. The process by which this public hospital performance information was shared (describe in 1500 characters or fewer):

Each year, Boston Children's president and CEO, or a designated senior leader, presents the hospital's performance and goals to the FAC. In addition, our chief nursing officer and chief administrative officer are active members of FAC. They regularly attend meetings to provide updates on hospital performance and initiatives.

☐ Healthcare-associated infections	▼ Health care proxies/substituted decision
Rapid response teams	making
☐ Hand-washing initiatives	☑ End of life planning (e.g., hospice, palliative, advanced directives)
Checklists	☐ Care transitions (e.g., discharge planning,
☐ Disclosure of harm and apology ☐ Fall prevention	passports, care coordination & follow up between care settings)
☑ Informed decision making/informed consent	Observation status for Medicare patients
▼ Improving information for patients and families	✓ Mental health care☐ None

Section 6: PFAC Annual Report 69. The hospital shares the PFAC annual reports with PFAC a

69. The hospital shares the PFAC annual reports with PFAC members:
🗷 Yes
\square No
70. Massachusetts law requires that the PFAC report be available to the public. Our hospital:
X Posts the report online
Provides a phone number or e-mail to use for accessing the report
▼ Other

71. If other, describe (in 1500 characters or fewer): In addition to accessing it online, the PFAC report can be obtained by sending an email to FamilyPartnerships@childrens.harvard.edu or by requesting a copy in our Hale Family Center for Families.