2016 Annual PFAC Report: Boston Children's Hospital Family and Teen Council

Q130. Which best describes you ^C We are the only PFAC at a s		
We are a PFAC for a system		
^C We are one of multiple PFAC	Cs at a single hospital	
^C We are one of several PFAC	S for a system with several hospitals	
Other (please describe): We are the hospital-wide Fai	mily Advisory Co	
Q126. Will another PFAC at your	r hospital also submit a report?	
CYes		
○ No		
[⊙] Don't know		
Q127. Will another hospital withir	n your system also submit a report?	
CYes		
[⊙] No		
C Don't know		
Q2. Staff PFAC Co-Chair Contac	ct:	
Name and Title:	Susan Shaw, Associa	
Email:	Susan.Shaw@childre	
Phone:	617-355-7340	
Q2a. Is the Staff PFAC Co-Chair	r also the Staff PFAC Liaison/Coordinator?	
CYes		
[⊙] No		
CNA		

Name and Title:	William O'Donnell
Email:	odonnellw@babson.
Phone:	781-307-7134

Q4. Staff PFAC Liaison/Coordinator Contact (if applicable):

Name and Title:	Kristin Erekson, Proje
Email:	Kristin.Erekson@chile
Phone:	617-919-3638

Q23.

Section 1: PFAC Organization

Q6. This year, the PFAC recruited new members through the following approaches (check all that apply):

✓ Word of mouth / through existing members	
Promotional efforts within institution to patients or families	□Patient satisfaction surveys
Promotional efforts within institution to providers or staff	□Community-based organizations
	☐Houses of worship
□Recruitment brochures	□Community events
☐Hospital publications	 ⊘ Other
☐Hospital banners and posters	□N/A - we did not recruit new members in FY 2016

Q6a. Please describe other recruitment approach:

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.

Q7. Total number of staff members on the PFAC:

7

Q8. Total number of patient or family member advisors	s on the PFAC:
15	
Q9. The name of the hospital department supporting the	ne PFAC is:
Patient Care Services	
Q10. The hospital position of the PFAC Staff Liaison/	Coordinator is:
Project Manager, Health Literacy/Patient & Family Ed	ducation
Q11. The hospital provides the following for PFAC mer (click all that apply):	mbers to encourage their participation in meetings
Parking, mileage, or meals	Payment for attendance at other conferences or trainings
▼Translator or interpreter services	☑Annual gifts of appreciation
☑ Assistive services for those with disabilities	Conference call phone numbers or "virtual meeting options
Provision / reimbursement for child care or elder care	✓ Meetings outside 9am-5pm office hours
 ✓ Stipends	 ✓Other
Payment for attendance at annual PFAC conference	N/A - the hospital does not reimburse PFAC members
Q11a. Please describe other provision by the hospital	for PFAC members:
Annual Appreciation Dinner	
Q24. Section 2: Community Representation	
Q108. The PFAC regulations require every PFAC to hospital, which is described below.	o represent the community served by the

Q12. Our catchment area is geographically defined as (if you are unsure select "don't know"):

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. Geographical Area Urban Core- 14.68% (inpatient): 31.06% (outpatient) Eastern Massachusetts - 49.34% (inpatient); 52.27% (outpatient) Other Massachusetts - 7.53% (inpatient); 4.27% (outpatient) New England - 13.13% (inpatient); 6.44% (outpatient) National -8.20% (inpatient); 2.89% (outpatient) International - 7.08% (inpatient); 3.06% (outpatient)

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Q121.

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Tell us about racial and ethnic groups in your area (please provide percentages; <u>if you are unsure of the percentages select "don't know"</u>).

Q13aR. Our defined catchment area is made up of the following racial groups (please provide percentages; if you are unsure of percentages please select "don't know"):

This question was not displayed to the respondent.

Q91.

☑ Don't know racial groups

Q13aE. What percentage of people in the defined catchment area are of Hispanic, Latino, or Spanish origin?
This question was not displayed to the respondent.
Q92.
☑ Don't know origins
Q13bR. In FY 2016, the hospital provided care to patients from the following racial groups (please provide percentages):
This question was not displayed to the respondent.
Q93.
☑ Don't know racial groups
Q13bE. What percentage of patients that the hospital provided care to in FY 2016 are of Hispanic, Latino, or Spanish origin?
Q95.
□ Don't know origins
Q13cR. In FY 2016, the PFAC patient and family advisors came from the following racial groups (please provide percentages):
This question was not displayed to the respondent.
Q97.
☑ Don't know racial groups
13cE. What percentage of PFAC patient and family advisors in FY 2016 were of Hispanic, Latino, or Spanish origin?

Q99.
□ Don't know origins
Q122. Tell us about languages spoken in your area (please provide percentages; if you are unsure of the percentages select "don't know").
Q117. What percentage of patients that the hospital provided care to in FY 2016 have limited English proficiency (LEP)?
This question was not displayed to the respondent.
Q118.
☑ Don't know percentage that have limited English proficiency (LEP)
Q126. What percentage of patients that the hospital provided care to in FY 2016 spoke the following as their primary language?
This question was not displayed to the respondent.
Q127.
☑ Don't know primary languages
Q119. What percentage of PFAC patient and family advisors in FY 2016 have limited English proficiency (LEP)?
Q120.
□ Don't know percentage that have limited English proficiency (LEP)
Q123. In FY 2016, what percentage of PFAC patient and family advisors spoke the following as their primary language?

This question was not displayed to the respondent.

✓ Don't know primary languages

Q14.

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.

Q110. Section 3: PFAC Operations

Q15. Our process for developing and distributing agendas for the PFAC meetings (click the best choice):

- Staff develops the agenda and sends it out prior to the meeting
- PFAC members and staff develop agenda together and send it out prior to the meeting
- Staff develops the agenda and distributes it at the
- PFAC members and staff develop agenda together and distribute it at the meeting
- PFAC members develop the agenda and send it out Other prior to the meeting
- PFAC members develop the agenda and distribute it at the meeting
- CN/A the PFAC does not use agendas

Q112. 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.

Q113. If other process, please describe:

This question was not displayed to the respondent.

Q16.

The PFAC goals and objectives for 2016 were: (select the best choice):

- C Developed by staff and reviewed by PFAC members
- © Developed by PFAC members and staff
- N/A we did not have goals and objectives for FY 2016
- C Developed by staff alone

Q17. The PFAC had the following goals and objectives for 2016:

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 staving true to the mission and achieving collective goals.

Q18. 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.

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□PFAC submits annual report to Board	▼PFAC member(s) are on board-level committee(s)
□PFAC submits meeting minutes to Board	N/A – the PFAC does not interact with the Hospital Board of Directors
□PFAC member(s) attend(s) Board meetings	□Other

Action items or concerns are part of an ongoing

"Feedback Loop" to the Board

Q19. How does the PFAC interact with the hospital Board of Directors (click all that apply):

Q114. Please describe other interactions with the hospital Board of Directors.

This question was not displayed to the respondent.

☐Board member(s) attend(s) PFAC meetings

Q20. 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.

Q109.

Section 4: Orientation and Continuing Education

Q21. Number of new PFAC members this year:

4

Q22. Orientation content included (click all that apply):	
☐Meeting with hospital staff	□Other
☑ General hospital orientation	In-person training
☐Hospital performance information	
Patient engagement in research ■ ■ Patient engagement in research ■ ■ Patient engagement in research ■	Concepts of patient- and family-centered care (PFCC)
▼PFAC policies, member roles and responsibilities	Skills training on communication, technology, and meeting preparation
□Health care quality and safety	Immediate "assignments" to participate in PFAC work
	☑ Check-in or follow-up after the orientation ☐ Check-in or follow-up after the orientation
☑ "Buddy program" with experienced members	N/A – the PFAC members do not go through a formal orientation process
Information on how PFAC fits within the organization's structure	
Q115. Please describe other orientation content:	
This question was not displayed to the respondent.	
Q23. The PFAC received training on the following topic	cs (click all that apply):
Concepts of patient- and family-centered care (PFCC)	
□Patient engagement in research	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)
□Types of research conducted in the hospital	
☑ Hospital performance information	□Health literacy
□Not Applicable	
Q116. Please describe other topics:	
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.

Q83. The following information only concerns PFAC activities in the fiscal year 2016.
Q24. The five greatest accomplishments of the PFAC were:
Q24a. Accomplishment 1: 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.
© Patient/family advisors of the PFAC Department, committee, or unit that requested PFAC input
Q24b. Accomplishment 2: Appointing a FAC member to serve on a board-level committee
Q24bl. The idea for Accomplishment 2 came from: © Patient/family advisors of the PFAC © Department, committee, or unit that requested PFAC input
Q24c. Accomplishment 3: Establishment of Emergency Department Family Advisory Council
Q24cl. The idea for Accomplishment 3 came from:

© Patient/family advisors of the PFAC

O Department, committee, or unit that requested PFAC input

Ω 24d	Accomp	olishme	nt 4:
QZ IU.	, 1000111h		

Implementation of Family Partnership Coordinator Roles (2 part-time roles in the Hale Family	Center for
Families dedicated to supporting family partnerships and initiatives)	

Q24d. The idea for Accomplishment 4 came from:

Q24e. Accomplishment 5:

Direct family impact on employees via presentations by families at New Hire Orientation and Service Excellence trainings

Q24e. The idea for Accomplishment 5 came from:

Q25. The five greatest challenges the PFAC had in FY 2016:

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

Q25a. Challenge 1:

Ensuring cultural, ethnic, educational and socio-economic diversity on the FAC.

Q25b. Challenge 2:

Demand for family voices/feedback is greater than supply.

[©] Patient/family advisors of the PFAC

Operatment, committee, or unit that requested PFAC input

[©] Patient/family advisors of the PFAC

O Department, committee, or unit that requested PFAC input

Q25c. Challenge 3:	
Incorporating families into more quality and safety in organization.	itiatives (e.g. Root Cause Analyses) within the
Q25d. Challenge 4:	
Partnership with department/clinic specific FACs.	
Q25e. Challenge 5:	
Better preparation of family members (and staff) to e committees/workgroups they are assigned to.	nsure effective integration onto the new
Q26. The PFAC members serve on the following hospi groups, or Board committees (click all that apply):	tal-wide committees, projects, task forces, work
	⊽ Eliminating Preventable Harm
 ■Bereavement	Emergency Department Patient/Family Experience Improvement
	□Ethics
□Code of Conduct	□Institutional Review Board (IRB)
□Community Benefits	Patient Care Assessment
□Critical Care	Patient Education
□Other	
\square N/A – the PFAC members do not serve on these	□Pharmacy Discharge Script Program
□Board of Directors	Quality and Safety
□Discharge Delays	Quality/Performance Improvement
Lesbian, gay, bisexual, and transgender (LGBT) – sensitive care	□Surgical Home

Q117. Please describe other committees, projects, task forces, work groups, or Board committees:

□Culturally competent care

This question was not displayed to the respondent.

□ Drug Shortage

Q27.

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.

Q28. The PFAC provided advice or recommendations Massachusetts law (click all that apply):	to the hospital on the following areas mentioned in the	
Quality improvement initiatives	□Institutional Review Boards	
	N/A – the PFAC did not provide advice or □recommendations to the hospital on these areas i FY 2016	
Q29. PFAC members participated in the following active that apply):	ities mentioned in the Massachusetts law (click all	
☑ Task forces	N/A – the PFAC members did not participate in any of these activities	
□Award committees	Co-trainers for clinical and nonclinical staff, inservice programs, and health professional trainees	
✓ Advisory boards/groups or panels	□Selection of reward and recognition programs	
□Search committees and in the hiring of new staff	Standing hospital committees that address quality	
Q30. The hospital shared the following public hosp all that apply):	ital performance information with the PFAC (click	
Q30a. Complaints and serious events		
Complaints and investigations reported to Department of Public Health (DPH)	Healthcare-Associated Infections (National Healthcare Safety Network)	
Serious Reportable Events reported to Department of Public Health (DPH)	□Patient complaints to hospital	

Q30b. Quality of care	
Joint Commission Accreditation Quality Report (such as asthma care, immunization, stroke care)	Maternity care (such as C-sections, high risk deliveries)
Medicare Hospital Compare (such as complications, readmissions, medical imaging)	High-risk surgeries (such as aortic valve replacement, pancreatic resection)
Q30c. Resource use and patient satisfaction	
Patient experience/satisfaction scores (eg. HCAHPS - Hospital Consumer Assessment of Healthcare Providers and Systems) Resource use (such as length of stay,	Inpatient care management (such as electronically ordering medicine, specially trained doctors for ICU patients)
[□] readmissions)	
Q30d. Other	
N/A – the hospital did not share performance information with the PFAC	□Other
Q119. Please describe other hospital performance info	ormation:
This question was not displayed to the respondent.	
Q31. Please explain why the hospital shared only the d	lata you checked in the previous questions:
Q32. Please describe how the PFAC was engaged in cresulting quality improvement initiatives:	discussions around these data above and any
Q33. The PFAC participated in activities related to initiatives (click all that apply):	the following state or national quality of care

□Identifying patients correctly			
□Using medicines safely	□Identifying patient safety risks		
□Using alarms safely	□Preventing mistakes in surgery		
Q33b. Prevention and errors			
✓ Hand-washing initiatives	□Team training		
□ Checklists	□Electronic Health Records –related errors		
□Fall prevention	⊏Safety		
Care transitions (e.g., discharge planning, passports, care coordination, and follow up between care settings)	☐Human Factors Engineering		
Q33c. Decision-making and advanced planning			
✓Informed decision making/informed consent	□Health care proxies		
✓ Improving information for patients and families	End of life planning (e.g., hospice, palliative advanced directives)		
Q33d.			
Additional quality initiatives			
⊟Rapid response teams	□Integration of behavioral health care		
□Disclosure of harm and apology			
Q33e. Other			
N/A – the hospital did not share performance information with the PFAC	□Other		
Q120. Please describe other initiatives:			
This question was not displayed to the respondent.			

Q33a. National Patient Safety Hospital Goals

Q34. Were any members of your PFAC engaged in advising on research studies?
[⊙] Yes
° No
Q35. 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)
Q36. How are members of your PFAC approached about advising on research studies?
Researchers contact the PFAC
\square Researchers contact individual members, who report back to the PFAC
□Other
□ None of our members are involved in research studies
Q121. Please describe other ways that members of your PFAC are approached about advising on research studies:
This question was not displayed to the respondent.
Q37. About how many studies have your PFAC members advised on?
^C 1 or 2
^C 3-5
[⊙] More than 5
[©] None of our members are involved in research studies

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Section 6: PFAC Annual Report

Q107.

We strongly suggest that all PFAC members approve reports prior to submission.

Q37.5. 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

Q38. 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
- ^C Staff wrote report
- ^C Other

Q122. Please describe other process:

This question was not displayed to the respondent.

Q106.

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:

Q39. We post the report online.

[©] Yes, link:

http://www.childrenshospital.org/patient-resource

^CNo

Q40. 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

Q41. Our hospital has a link on its website to a PFAC page.

Yes, link: http://www.childrenshospital.org/patient-resourd

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