



**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 1<sup>st</sup> 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](http://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](mailto: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](mailto:PFAC@hcfama.org).

**Reports should be completed by October 1, 2018.**

## Section 1: General Information

1. Hospital Name: Dana-Farber Cancer Institute

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):

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: N/A

2b. Email:

2c. Phone:

- Not applicable

4. Patient/Family PFAC Co-Chair Contact:

3a. Name and Title: Gabby Spear, Co-Chair, Adult PFAC

3b. Email: gabriela.spear2@gmail.com

3c. Phone: (617) 283-4317

- 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: Renee Siegel, Program Manager, Patient and Family Advisory Councils

6b. Email: Renee\_siegel@atci.harvard.edu

6c. Phone: 617-632-4527

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): Clinical providers and administrative leaders
- N/A – we did not recruit new members in FY 2018

**8. Total number of staff members on the PFAC:** 9 staff on Adult PFAC; 13 staff on Pediatric PFAC

**9. Total number of patient or family member advisors on the PFAC:** 17 PFAC members on Adult PFAC; 12 PFAC members on Pediatric PFAC

**10. The name of the hospital department supporting the PFAC is:** Patient Care Services; Volunteer Services and Programs

**11. The hospital position of the PFAC Staff Liaison/Coordinator is:** Program Manager

**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):

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: Greater Boston Area

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								<input checked="" type="checkbox"/> Don’t know
14c. The PFAC patient and family advisors in FY 2018					87	10	3	<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		<input checked="" 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?

	%
Spanish	2.96
Portuguese	.67
Chinese	.32
Haitian Creole	.27
Vietnamese	.34
Russian	.56
French	
Mon-Khmer/Cambodian	
Italian	
Arabic	.76
Albanian	
Cape Verdean	

Don't know

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

	%
Spanish	6

Portuguese	
Chinese	
Haitian Creole	
Vietnamese	
Russian	
French	
Mon-Khmer/Cambodian	
Italian	
Arabic	3
Albanian	
Cape Verdean	

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:**

To ensure that PFAC is representative of the entire patient voice, DFCI staff and PFAC members have created an Adult PFAC Diversity and Recruitment workgroup and Pedi PFAC recruitment subcommittee. Members of these subcommittees meet on a biweekly basis and discuss recruitment strategies, as well as training and development opportunities for current Council members - specifically around unconscious bias. The PFAC marketing team, an additional subcommittee, has deployed targeted recruitment messages for newsletters that reach diverse patient populations. We've sent messages targeting young adult patients, patients of color, the LGBT patient and caregiver community, and former pediatric patients for the Pediatric PFAC. The PFAC diversity and recruitment workgroup has also reviewed our current application and onboarding process for PFAC membership to ensure that it is straightforward and not too time consuming. We've made it clear that PFAC applicants do not need a college education or specific professional expertise to apply. Lastly, the workgroup members and other PFAC members have presented to various stakeholders throughout Dana-Farber to inform staff and leaders of our diversity mission and need for recruitment.

These efforts have led to the recruitment of an international parent, patient of color who is also bilingual, two former pediatric patients, and two young adults.

Lastly, both PFACs are adding additional roles/levels of participation to encourage wider engagement, and capture broader spectrum of voices, experiences and perspectives.



## 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:

Two to four weeks prior to each PFAC meeting, the program manager and PFAC co-chairs have a meeting planning call. During the planning call, the program manager and co-chairs introduce potential presentations/talks and the group determines which presentations are relevant and plans the sequence of the meetings. These planning meetings also include discussions around meeting activities and workgroups. In some cases, the co-chairs and manager will meet with the interested presenter beforehand to ensure the topic is a good fit for an upcoming meeting - they will also use this time to prep the presenter. The program manager creates a draft agenda after the phone conversation and sends to the Co-Chairs for approval prior to distributing to the other members and staff. The agenda is sent to the Council one week prior to the meeting along with meeting materials to review.

#### 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:

#### Pediatric PFAC

1. Revamp the Weekend Initiative Program (parent/family feedback program)
2. Create and sustain a Jimmy Fund Clinic rounding program for patient and family feedback and resource awareness
3. Increase engagement and accountability of PFAC members and PFAC staff
4. Build a learning relationship with Boston Children's Hospital Family Advisory Councils

5. Establish staff steering committee to help guide PFAC priorities, especially during this transitional period; determine a Pediatric Oncology staff champion
6. Update PFAC documents and processes

Adult PFAC

1. Update and enhance APFAC operating structure and processes
2. Develop and support patient diversity efforts throughout the Institute and within the APFAC
3. Support the Institutes' Patient Experience Goals through APFAC led projects
4. Enhance the APFAC Council Member Experience
5. Support and further develop awareness of PFAC's mission and efforts both internally and externally
6. Build upon existing strong relationships with CEO and Leadership

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

PPFAC Weekend Initiative Sub-Committee

PPFAC Recruitment Sub-Committee

Adult and Pedi PFAC Marketing and Recruitment Team

APFAC Diversity and Recruitment Workgroup

APFAC Operations Workgroup

INFORM Workgroup

**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): Two PFAC Co-Chairs are members of the Quality Improvement and Risk Management Committee (board-level committee)
- 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:**

Majority of communication in between meetings are via email (or over the phone). PFAC works closely with DFCI's communications department to utilize social media tools for recruitment and promoting awareness.

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:

PFAC members complete a volunteer services orientation, PFAC orientation, and health screening through occupational health

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:**

## 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><b>26a. Accomplishment 1: Active member of Gastrointestinal patient education binder project team and participation on DFCI's patient education committee (e.g. reviewing/editing teaching sheets and other materials)</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 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>26b. Accomplishment 2: Developed a formal transition plan for exiting Co-Chairs</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: Developed formal project tracking and project management tools for PFAC's work</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: Developed an outpatient oncology patient-family-feedback/experience rounding program</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>26e. Accomplishment 5: Designed and led a Clinical Process Improvement Leadership Program training on patient and caregiver engagement</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 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>

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

27a. Challenge 1: **Recruitment of diverse perspectives and experiences**

**27b. Challenge 2: Limited attention and exposure to needs of international patients (Adult PFAC)**

**27c. Challenge 3: Ensuring relevancy of patient experience given that most members are years away from initial diagnosis and/or treatment**

**27d. Challenge 4: Recruitment and retention of family members of pediatric oncology patients and former patients (Pedi PFAC)**

**27e. Challenge 5: Accurate and ongoing record keeping of project and committee involvement**

---

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?**

Verbal updates at PFAC meetings (we are currently working on a more efficient/effective system)

**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:**

As mentioned above, 2 PFAC members participate in a board/leadership level committee named the "Quality Improvement and Risk Management Committee". This high-level and confidential committee shares information addressed in all check boxes above and engages PFAC during and after meetings. The 2 PFAC representatives are core members of this committee.

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

They are active participants on project teams and committees. Members receive meeting materials prior to meetings via email as well as review materials during meetings with other project team members. They play active roles and participate as any other project team member would.

**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):**

Renee Siegel, Program Manager, PFAC (staff)  
Gabby Spear, Co-Chair, Adult PFAC (advisor)  
Gina Paglucia, Co-Chair, Adult PFAC (advisor)  
Deanna Abrams, Co-Chair, Pediatric PFAC (advisor)  
Patricia Stahl, Senior Manager, Volunteer Services and Programs (staff)  
Ellen Farwell, Associate General Counsel (staff)

**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:
- 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: [pfac@dfci.harvard.edu](mailto:pfac@dfci.harvard.edu)
- No

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

- Yes, link: [www.dana-farber.org/pfac](http://www.dana-farber.org/pfac)
- No, we don't have such a section on our website