



HEALTH CARE FOR ALL



PFAC Annual Report Form

Health Care For All (HCFA) promotes health justice in Massachusetts by working to reduce disparities and ensure coverage and access for all. HCFA uses direct service, policy development, coalition building, community organizing, public education and outreach to achieve its mission. HCFA's vision is that everyone in Massachusetts has the equitable, affordable, and comprehensive care they need to be healthy.

Why complete an annual report for my PFAC?

Under Massachusetts law, hospital-wide PFACs are required to write annual reports by October 1st each year. These reports must be made available to members of the public upon request. As in past years, HCFA is requesting a copy of each report and submitted reports will be posted on HCFA's website, www.hcfama.org. HCFA recommends using this template to assist with information collection, as well as the reporting of key activities and milestones.

What will happen with my report and how will HCFA use it?

We recognize the importance of sharing of information across PFACs. Each year, we

- make individual reports available online
- share the data so that PFACs can learn about what other groups are doing

Who can I contact with questions?

Please contact us at PFAC@hcfama.org or call us at 617-275-2982.

If you wish to use this Word document or any other form, please email it to
PFAC@hcfama.org.

Reports should be completed by October 1, 2019.

The survey questions concern PFAC activities in fiscal year 2019 only: (July 1, 2018 – June 30, 2019).

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): We have two PFACs at Dana-Farber Cancer Institute—an Adult PFAC and a Pediatric PFAC—and are submitting this report on behalf of both.

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:

3a. Name and Title:

3b. Email:

3c. Phone:

- Not applicable

4. Patient/Family PFAC Co-Chair Contact:

4a. Name and Title: Nicole Abair, Pediatric PFAC, Co-Chair

4b. Email: nrabair05@gmail.com

4c. Phone: 617-875-2904

- Not applicable

4d. Name and Title: Gina Paglucia, Adult PFAC, Co-Chair

4e. Email: gpaglucia@gmail.com

4f. Phone: 781-686-3492

- 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, MSW, LCSW, Program Manager

6b. Email: Renee_siegel@dfci.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): Internal and external presentations to patients and staff
- N/A – we did not recruit new members in FY 2018

8. Total number of staff members on the PFAC: 4 voting staff on Adult PFAC and 4 voting staff on Pediatric PFAC

9. Total number of patient or family member advisors on the PFAC: 16 Adult PFAC members and 11 Pediatric PFAC members

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

11. The hospital position of the PFAC Staff Liaison/Coordinator is: Program Manager, Patient and Family Advisory Councils

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 **(for Co-Chairs)**
- Provision/reimbursement for child care or elder care
- Stipends for travel and child care for the Pediatric PFAC (pilot program approved in FY19)
- Translator or interpreter services

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:

- 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 2019								<input checked="" type="checkbox"/> Don’t know
14c. The PFAC patient and family advisors in FY 2019								<input checked="" 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 2019		<input checked="" type="checkbox"/> Don't know
15b. PFAC patient and family advisors in FY 2019	0	<input type="checkbox"/> Don't know

15c. What percentage of patients that the hospital provided care to in FY 2019 spoke the following as their primary language?

	%
Spanish	2.67
Portuguese	.56
Chinese	.30
Haitian Creole	.23
Vietnamese	.23
Russian	.52
French	
Mon-Khmer/Cambodian	
Italian	
Arabic	.70
Albanian	
Cape Verdean	

Don't know

15d. In FY 2019, what percentage of PFAC patient and family advisors spoke the following as their primary language?

	%
Spanish	4
Portuguese	
Chinese	
Haitian Creole	
Vietnamese	
Russian	
French	
Mon-Khmer/Cambodian	
Italian	
Arabic	4
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 the Adult PFAC and Pediatric PFAC are representative of the entire patient voice, DFCI staff and PFAC members have created an Adult PFAC Diversity and Recruitment workgroup and Pediatric PFAC recruitment subcommittee. Members of these subcommittees meet a couple of times a year to discuss recruitment strategies, as well as training and development opportunities for current Council members – the Adult PFAC completed an unconscious bias training through the Dana-Farber Human Resources Department last winter and the Pediatric PFAC will be completing the training this year (January 2020). The PFAC marketing team, joint Adult and Pediatric PFAC 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 Adult PFAC diversity and recruitment workgroup reviewed our current application and onboarding process for Adult PFAC membership to ensure that it is straightforward and not too time consuming. We've made it clear that Adult PFAC applicants do not need a college education or specific professional expertise to apply. This year we will be launching an e-advisor program for adult and pediatric oncology patients and family members to participate in patient engagement activities remotely. The program's mission is to offer a flexible option for involvement – there will be an abbreviated screening, onboarding, and training process.

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 Adult and Pediatric PFAC meetings, 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 and meeting presentations (when appropriate) are sent to the Council the Friday before the meeting.

17b. If other process, please describe:

18. The PFAC goals and objectives for FY 2019 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 FY 2019:

The Pediatric PFAC will

- a) create and sustain a Jimmy Fund Clinic rounding program for patient and family feedback and resource awareness
- b) increase engagement and accountability of PFAC members and PFAC staff
- c) build a learning relationship with Boston Children's Hospital Family Advisory Councils

- d) create transition plans for long standing members and proactively recruit new members

The Adult PFAC will continue to work alongside DFCI staff and leadership to

- a) support and implement initiatives aimed at the growth of patients nationally and internationally
- b) deepen the patient and family centered experience at the Institute
- c) enhance patient partnering in Quality and Safety initiatives
- d) help transform the science of cancer and enhance the care provided to all patients
- e) focus on council recruitment and marketing within and outside the institute
- f) support new marketing, branding and development strategies
- g) deepen the structure, improve processes and enhance the council member experience
- h) support the investment in talent and resources
- i) APFAC co-chairs and Program Manager will continue to work collaboratively and proactively as a Leadership and PFAC team

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

Pediatric PFAC Weekend Initiative Workgroup

Pediatric PFAC Jimmy Fund Clinic Workgroup

Adult and Pediatric PFAC Marketing and Recruitment Team

APFAC Diversity and Recruitment Workgroup

APFAC 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): An Adult PFAC co-chair and a Pediatric PFAC co-chair each sits on the board level Quality and Risk Management Committee (QIRM). The co-chairs present an annual update to the board via QIRM
- 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: 3 Adult PFAC members and 1 Pediatric PFAC member

24. Orientation content for both PFACs 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:

All Adult and Pediatric PFAC members complete a Volunteer Services training, PFAC training, and an Occupational Health screening.

25. The Adult PFAC and Pediatric 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 2019 PFAC Impact and Accomplishments

The following information only concerns PFAC activities in the fiscal year 2019.

26. The five greatest accomplishments of the Adult PFAC and the Pediatric PFAC were:

Accomplishment	Idea came from (choose one)	PFAC role can be best described as (choose one)
26a. Accomplishment 1: Developed and launched the Jimmy Fund Clinic Walkaround Program; patient/family rounding program in the pediatric clinic (Pediatric PFAC)	<input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input	<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 checked="" type="checkbox"/> Leading/co leading
26b. Accomplishment 2: Improved the Adult PFAC goal-setting process; mapped PFAC goals with Institute goals (Adult PFAC)	<input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> Department, committee, or unit that requested PFAC input	<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
26c. Accomplishment 3: Supported DFCI's satellite expansion by participating on workgroups and committees (Adult PFAC)	<input type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input	<input type="checkbox"/> Being informed about topic <input checked="" type="checkbox"/> Providing feedback or perspective <input type="checkbox"/> Discussing and influencing decisions/agenda <input type="checkbox"/> Leading/co leading
26d. Accomplishment 4: Developed new promotional (brochure, banner, and flyers) material for the Pediatric PFAC (Pediatric PFAC)	<input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input	<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 checked="" type="checkbox"/> Leading/co leading
26e. Accomplishment 5: Revised/updated the Pediatric PFAC's bylaws and policies; instituted term-limits and created transition plans for longtime members (Pediatric PFAC)	<input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input	<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 checked="" type="checkbox"/> Leading/co leading
26f. Accomplishment 6: Supported and participated in the recent Magnet re-designation process and site visit.	<input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input	<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 checked="" type="checkbox"/> Leading/co leading

27. The five greatest challenges the Adult PFAC and Pediatric PFAC had in FY 2019:

27a. Challenge 1: Recruitment of diverse perspectives and experiences (Adult and Pediatric PFAC)

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 (Adult and Pediatric PFAC)

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

27e. Challenge 5: Comprehensive and ongoing record keeping of project and committee involvement (Adult and Pediatric PFAC)

N/A – we did not encounter any challenges in FY 2019

28. The Adult PFAC and Pediatric PFAC members serve on the following hospital-wide committees, projects, task forces, work groups, or Board committees:

- Behavioral Health/Substance Use
- Bereavement (Pediatric PFAC)
- Board of Directors (Adult and Pediatric PFAC via QIRM)
- Care Transitions (Presentations to Adult and Pediatric PFAC)
- Code of Conduct
- Community Benefits (Presentations to Adult and Pediatric PFAC)
- Critical Care (Adult and Pediatric PFAC)
- Culturally Competent Care (Presentations Adult and Pediatric PFAC)
- Discharge Delays
- Diversity & Inclusion (Presentations to Adult and Pediatric PFAC)
- Drug Shortage
- Eliminating Preventable Harm (Adult and Pediatric PFAC)
- Emergency Department Patient/Family Experience Improvement
- Ethics
- Institutional Review Board (IRB)
- Lesbian, Gay, Bisexual, and Transgender (LGBT) – Sensitive Care (Adult PFAC)
- Patient Care Assessment (Adult and Pediatric PFAC)
- Patient Education (Adult PFAC)
- Patient and Family Experience Improvement (Adult and Pediatric PFAC)
- Pharmacy Operations and Quality (Adult and Pediatric PFAC)
- Quality and Safety (Adult and Pediatric PFAC)
- Quality/Performance Improvement (Adult and Pediatric PFAC)
- 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 Adult PFAC and Pediatric PFAC meetings (we are working on a more efficient/effective system)

30. The Adult PFAC and Pediatric 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 2019

31. PFAC members participated in the following activities mentioned in the Massachusetts law (check all that apply):

- Advisory boards/groups or panels (Adult PFAC)
- Award committees
- Co-trainers for clinical and nonclinical staff, in-service programs, and health professional trainees (Adult PFAC)
- Search committees and in the hiring of new staff
- Selection of reward and recognition programs
- Standing hospital committees that address quality (Adult and Pediatric PFAC)
- Task forces (Adult and Pediatric PFAC)
- 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, 1 Adult and 1 Pediatric PFAC member participate in a board/leadership level committee named the "Quality Improvement and Risk Management Committee" (QIRM). 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. Additionally, we have 1 Adult and 1 Pediatric PFAC representatives on the Grievance Committee and a staff representative on the Quality Improvement 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 (Adult and Pediatric PFAC)

- Identifying patient safety risks
- Identifying patients correctly
- Preventing infection
- Preventing mistakes in surgery
- Using medicines safely
- Using alarms safely

35b. Prevention and errors (Adult and Pediatric PFAC)

- 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 (Adult and Pediatric PFAC)

- 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 (Adult and Pediatric PFAC)

- 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? (Adult PFAC)

Yes

No – Skip to #40 (Section 6)

37. In what ways are members of your PFAC engaged in advising on research studies? Are they: (Adult PFAC)

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? (Adult PFAC)

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? (Adult PFAC)

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)

Gina Paglucia, Co-Chair, Adult PFAC (advisor)

Deanna Abrams, Co-Chair, Pediatric PFAC (advisor)
Nicole Abair, Co-Chair, Pediatric PFAC (advisor)
Amanda Hollis, Attorney Fellow, Office of 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
- No

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

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