

Patient and Family Advisory Council (PFAC) Annual Report Form



Patient and Family Advisory Councils (PFACs) are an integral part of health care organizations. All licensed hospitals, as well as accountable care organizations devoted to MassHealth members, are required to convene a PFAC on a regular basis and tap its members' expertise and lived experience to help the health care organization better meet the needs of its patients.

The Betsy Lehman Center for Patient Safety oversees PFAC work in Massachusetts. Read more [on the Center's website](#).

Use this form to capture the essential activities of your PFAC during the past fiscal year (July 1 – June 30) and submit to the Betsy Lehman Center by October 1. If your hospital has multiple PFACs, please fill it out for the work of your hospital-wide PFAC, and use the last section to describe the work of any additional PFAC groups. The Center will generate a report from the information submitted and return it to you to distribute throughout the organization and post to your organization's website. The Center will also aggregate information and share an annual report of all PFAC activities in the state.

SECTION I: GENERAL INFORMATION

1. Hospital name: **Dana-Farber Cancer Institute**
2. How many PFACs does your hospital have in total? **2 to 4**
3. The information on this form reflects the work of a PFAC that serves as:
 The sole PFAC at our hospital, ACO, or organization
 A hospital-wide PFAC, but there are additional department, unit, population-specific or specialty PFACs as well
 A hospital department, unit, or specialty PFAC
 A hospital-based PFAC that also serves an ACO
 A system-wide PFAC
4. Patient/family co-chair:
 - a. Name: **May Hara/Judy Fine Edelstein (Adult) and Katherine Page/Meredith Lepper (Pedi)**
 - b. Email address: **pfac@dfci.harvard.edu** (personal emails at the end of the document)
5. Hospital co-chair:
 - a. Name: **Maritza Boudrow (Currently Covering the PFAC Manager Position at DFCI)**
 - b. Title: **Director, Centers for Patients and Families and Volunteer Services**
 - c. Email address: **Maritza_Boudrow@DFCI.Harvard.edu**
 - d. Phone number: **857-215-5609**
6. PFAC membership [as of June 30]:
 - a. Total number of members: **>30**
 - b. Total number of patient/family advisers: **>30**
 - c. Total number of staff advisers: **6 to 10**

7. Preferred PFAC membership:

- a. Total number of members: >30
- b. Total number of patient/family advisers: >30
- c. Total number of staff advisers: 6 to 10

8. If patient/family members of the PFAC are subject to term limits, please select the length of terms: > 5 years

9. Which recruiting efforts does your hospital use to identify and attract new PFAC members from the community? (select all that apply)

<input type="checkbox"/> After visit summary or survey messages	<input type="checkbox"/> Patient/family feedback
<input checked="" type="checkbox"/> Clinicians' recommendations	<input checked="" type="checkbox"/> Social media
<input checked="" type="checkbox"/> Discussions with people in the clinic	<input checked="" type="checkbox"/> Tables at hospital entrances
<input checked="" type="checkbox"/> Hospital website	<input type="checkbox"/> Visits to the units
<input type="checkbox"/> Grievances	<input checked="" type="checkbox"/> Word of mouth
<input type="checkbox"/> Pamphlets	Other: Tables at Events like Summer Fest-at the zoo

10. How often does your PFAC meet? Monthly

If other, please specify: We have two councils that each meet monthly

11. How do you typically convene your PFAC? A mix of both in-person and virtually

If a mix, please describe: Quarterly opportunities to be in person.

12. How often do PFAC members engage in these ways with initiatives presented to them? (Please respond to each.)

- a. Approval: The department asks for approval from the PFAC on a completed initiative Sometimes
- b. Feedback: The department asks the PFAC for input on a project in progress Often
- c. Codesign: The PFAC is involved at the inception of the project Often
- d. Other, please specify:

Our PFAC's are very engaged in Institute wide projects and initiatives. The VS Manager of PFAC at DFCI is responsible for triaging requests for patient and family involvement. That involvement varies based on the need. Our preference is for patients and families to be involved from the start which means the co-design process. The best example of that is the Future Cancer Hospital as they have been involved in all the design meetings and have been integral in that process. Many times though there is an issue that staff have that they bring to PFAC as a question/concern. They may ask for support regarding language, communication or other areas. PFAC members also have select priority topics they would like to work on and the VS Manager of PFAC works with staff around the Institute to identify opportunities for the PFAC members to engage on those priority topics.

SECTION II: ABOUT THE COMMUNITY

13. State regulations call for hospital PFAC membership to be reflective of the community it serves. Two sets of data can help better understand the racial/ethnic makeup of the community and primary languages spoken.

a. Race/Ethnicity: Use the links in the table below to find data about the race and ethnicity of the community served by your hospital. If your hospital gathers this information differently, please enter it here.

	Percentage of population	
	<u>Catchment area</u>	<u>Patients served</u>
White	47%	78.7%
Black	14%	5.78%
Hispanic	22%	7.03%
Asian	11.35%	4.06%
Native Hawaiian and Pacific Islander (NHPI)	.034%	.0000
American Indian or Alaska Native (AIAN)	.12928%	.7819%
Other	5.6%	3.909%
Multi	17.13%	8.053%

b. Languages spoken: The best source will be within your hospital. You may need to ask colleagues in community relations, patient experience, informatics or other record-keepers for this information.

	Percentage of patient population
Spanish	3.34%
Portuguese	.44%
Chinese	.44%
Haitian Creole	.22%
Vietnamese	.16%
Russian	.27%
French	.02%
Mon-Khmer/Cambodian	.000
Italian	.02%
Arabic	.38%
Albanian	.07%
Cape Verdean	.17%
Limited English proficiency (LEP)	5.96%

c. How well do the demographics of your PFAC match the demographics of your hospital's patient population? Well

14. There are many ways to describe the array of perspectives in a community, including age, income, gender, sexual orientation, gender identity, disability, veteran status, career, chronic or rare disease status, religion, etc. How would you describe your PFAC membership's representation of the community it serves more broadly?

Our PFAC members bring an array of perspectives and cancer experiences that aligns well with our population served. We aim to balance the patient and caregiver perspectives and currently have X patients and X caregivers (including siblings, parents, and partners) as we know that ones relationship to their experience may change their perspective. When it comes to facets of diversity such as gender, sexual orientation, racial/ethnic background, etc., we regularly analyze the diversity factors of our councils before planning marketing and recruitment efforts. This allows us to focus our efforts on inviting patients/families from backgrounds that are not yet fully represented on the councils. Sometimes, this means working with individual clinics to identify candidates with an unrepresented disease type or treatment experience or working with satellite locations to identify PFAC members who can represent the portion of our patients treated in their community.

15. Describe any strategies and activities during the last year to align PFAC membership with the diversity of the community served by your organization.

Our team has worked hard to recruit patients and families who have different experiences(racial and ethnic backgrounds, languages spoken, locations they were treated at and even cancer types and treatment plans) to broaden the councils representation. That has included intentional recruitment pushes to include patients and families treated at our satellite locations as we know those experiences are very different than that of those patients treated at our main campus location.

SECTION III: KEY ACCOMPLISHMENTS AND IMPACT

16. How often do you measure the impact of the PFAC on initiatives? Often

17. How often do you track outcome metrics related to PFAC advice? (e.g., improvement in patient experience scores, reduction in falls, etc.) Sometimes

18. How often do you track process metrics? (e.g., number of meetings, number of initiatives, etc.) Always

19. Describe key work accomplished by the PFAC last year. For example, in what ways did the PFAC provide feedback/perspective, lead or co-lead programs and initiatives, or influence the institution's financial and programmatic decisions? Include at least three accomplishments.

1. PFAC members have been instrumental in planning for Dana-Farber's Future Cancer Hospital. They have sat on the user groups and design committees and have been able to give feedback on the design of the patient rooms, imaging suites and more.
2. PFAC helped to advocate for the formalizing of the Survivorship liaisons role. The Director of Survivorship worked with leadership, based on PFAC feedback, to get compensation for the liaisons. The role will continue to evolve and PFAC feedback will continue to be needed to best advocate for the resources needed to support the expansion of the survivorship program
3. Our pediatric PFAC provided feedback to the Patient Education materials that our pedi patients and families were receiving. Staff shared that the pedi member insights helped us shift from a more provider-centered perspective to one that prioritized patient experience. Based on their recommendations, we revised the materials to increase plain language, add visual aids, and to generally be more inclusive of different patient/caregiver experiences.

20. How do you promote the accomplishments of your PFAC? (Select all that apply)

- Newsletter
- Presentation
- Report
- Word of mouth
- We currently do not promote

Other:

21. Did the hospital/organization leadership share its goals for the year with the PFAC membership? Yes

22. Did the work accomplished by your PFAC help advance the organization's goals? Yes

Please describe:

These are the four operating goals the institute had in Fy2025:

Lead in the Field in Discovery and Innovation - Our PFAC's have worked with researchers to ensure that the patient and family lens is at the table in the beginning stages of grant applications and then again once funding is secured. Provide the Best Outcomes for More Patients - Our PFAC's have been involved in the design and development of our new satellite, our Future Cancer Hospital that will have 300 inpatient beds and the renovations of our Jimmy Fund Clinic. All of these initiatives ensure that we will have the space needed to treat more patients and provide them with the best outcomes possible. Invest in Talent and Resources - Our PFAC's have been heavily involved in the New Employee Orientation Process as it was re-designed. They have also shared their stories during those orientation sessions. Inclusion, Diversity, & Equity - By representing a wide variety of backgrounds and treatment experiences, PFAC members bring diverse patient and family perspectives to every project they are involved with. They have identified potential barriers to accessing treatment with FCH, they have been involved in quality improvement projects related to language access, etc.

23. What were the greatest challenges your PFAC faced?

1. Balance of Pro-active and Re-active Work
2. Bandwidth of the staff supporting the councils and the PFAC members themselves
3. Attendance Issues - PFAC members being able to attend all meetings that they are invited to. It is difficult to prioritize asks and to ensure that the members involved in each project have the information (and calendar invites) they need to be able to join the meetings.

SECTION IV: SAFETY

Patient safety is the prevention of harm to patients while receiving health care. It's a fundamental principle of health care, and it's considered the foundation of high-quality care. Patient and family input and insight about safety considerations and risks is an essential component of safety improvement work.

24. For each of the following items, indicate your PFAC's level of involvement.

- a. Patient/family advisers were represented at board meetings: Occasionally
- b. Patient/family advisers were consulted on safety goal-setting and metrics: Occasionally
- c. Patient/family advisers participated in safety improvement initiatives: Occasionally

25. Summarize your PFAC's contributions to patient safety work at your organization.

Our PFAC's support many of the patient safety initiatives at Dana-Farber. They sit on many committees including:

- Wayfinding Committee - Project based work. New elevator covers and labels in Yawkey garage, new wayfinding accents, development of new parking ticket and patient itinerary
- Pharmacy Phone Line Redesign - Launch of phoneline redesign in top 6 DFCI languages this June
- HQEIP Disability Competent Care Working Group
- Clinical Access and Equity Committee
- Cares Advisory Committee

SECTION V: ADDITIONAL INFORMATION

26. Indicate the committees within your organization on which a PFAC member serves:

<input type="checkbox"/> Behavioral Health/ Substance Use	<input checked="" type="checkbox"/> Diversity and Inclusion	<input checked="" type="checkbox"/> Patient Education
<input type="checkbox"/> Bereavement	<input type="checkbox"/> Drug Shortage	<input type="checkbox"/> Patient and Family Experience Improvement
<input type="checkbox"/> Board of Directors	<input type="checkbox"/> Eliminating Preventable Harm	<input type="checkbox"/> Pharmacy Discharge Script Program
<input type="checkbox"/> Care Transitions	<input type="checkbox"/> Emergency Department Patient/ Family Experience Improvement	<input checked="" type="checkbox"/> Quality and Safety
<input type="checkbox"/> Code of Conduct	<input checked="" type="checkbox"/> Ethics	<input type="checkbox"/> Quality/Performance Improvement
<input type="checkbox"/> Community Benefits	<input type="checkbox"/> Institutional Review Board (IRB)	<input type="checkbox"/> Surgical Home
<input type="checkbox"/> Critical Care	<input type="checkbox"/> Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ+)	Other: <input type="text"/>
<input checked="" type="checkbox"/> Culturally Competent Care	<input type="checkbox"/> Patient Care Assessment	
<input type="checkbox"/> Discharge Delays		

27. Are there any PFAC-led workgroups or projects you would like to highlight?

1. TELOC - Transitions to End of Life - Working with our supportive oncology team to ensure that Transitions in Care are thought of and planned for.
2. Marketing and Recruitment - work to recruit patients and families to join the councils but also to increase awareness of the Patient and Family Advisory Councils throughout Dana-Farber. The goal is to ensure that staff engage the councils and bring them into the process early so that new initiatives can be co-designed.
3. Pedi Marketing and Recruitment - A marketing and recruitment work-group specific to the pediatric council.

SECTION VI: LOOKING AHEAD

28. Does your PFAC have goals for the current year? Yes

a. If yes, what are your PFAC's goals for the year?

Adult PFAC Goals:

Meetings and member input to have significant impact on projects and initiatives that enhance these three areas related to patient care and the development of the future DFCI inpatient cancer hospital:

1. Survivorship
2. Mental Health
3. Continuity of Care

Pedi PFAC Goals:

1. Build and Strengthen Connections within our Community
2. Advocate for Improvements to Equitable Pediatric Cancer Care

29. Do these goals support the organization's goals and priorities for the year? Yes, the goals directly relate

a. If yes, in what ways do these goals support the organization's goals and priorities?

The adult council is focused on the improvement of services offered to patients and families. The Institute is in a time of transition and as we work to scale operations we will be focused on improvements to processes. This is the time to highlight these three important areas. The pedi council is working to strengthen relationships and expand the resources offered to our pediatric patient populations. As we scale the adult side of treatment this will be of utmost importance.

30. Is there anything else your hospital would like to highlight that has not been captured above?

We have a new Manager of PFAC starting on October 6, 2025 this report was prepared in a time of transition so it is possible we missed a few things. Hopefully this encompasses enough of what was requested!

31. This report was prepared and reviewed by:

- a. Name: Maritza Boudrow
- b. Title: Director, Centers for Patients and Families and Volunteer Services
- c. List additional people's names and titles as needed below:

May Hara (Adult PFAC Co Chair) maythara@gmail.com
Judy Fine Edelstein (Adult PFAC Co Chair) judyfineedelstein@gmail.com
Katherine Page (Pedi PFAC Co Chair) katherinehelenpage@gmail.com
Meredith Lepper (Pedi PFAC Co Chair) leeleaf@verizon.net

32. This report is for the state's fiscal year ending June 30, 2025.