

2024 Patient and Family Advisory Council Annual Report Form

The survey questions concern PFAC activities in fiscal year 2024 only: (July 1, 2023 – June 30, 2024).

Section 1: General Information

NOTE: Massachusetts law requires every hospital to make a report about its PFAC activities publicly available by October 1 each year. Submitting the report to Betsy Lehman Center for inclusion on its website will fulfill that requirement.

1. Hospital Name: Dana- Farber Cancer Institute

2. PFAC Name:

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):

Dana-Farber Cancer Institute has an Adult PFAC and a Pediatric PFAC: This report is for 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:

3a. Name and Title:	Austin Sarat Co-chair, Adult PFAC	May Hara Co-chair, Adult PFAC	Katherine Page Co-chair, Pediatric PFAC	Meghan Shea Co-chair, Pediatric PFAC
3b. Email:	adsarat@amherst.edu	maythara@gmail.com	katherinehelenpage@gmail.com	meghan.shea@persistentproductions.com
3c. Phone:	-	-	-	-

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: Victoria Baggio, MSW, Program Manager, Patient and Family Advisory Councils

6b. Email: Victoria_baggio@dfci.harvard.edu

6c. Phone: 857-215-1417

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: We also utilized the DFCI website and partnered with the communications team for digital screens in waiting rooms.

Other (Please describe):

N/A – we did not recruit new members in FY 2024

8. Total number of staff members on the PFAC:

Adult PFAC: 10

Pediatric PFAC: 13

9. Total number of patient or family member advisors on the PFAC:

Adult PFAC: 20

Pediatric PFAC: 11

E-Advisors: 36

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
- Provision/reimbursement for childcare 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:

Dana-Farber defines the catchment area for DFCI’s main campus as Boston’s priority neighborhoods which include Roxbury, Mission Hill, Dorchester, Mattapan, and Jamaica Plain. Dana-Farber’s prioritization of these five neighborhoods within its local service area reflects a commitment to reducing the health disparities in cancer care and improving the overall health and well-being of neighborhood residents. Dana-Farber also serves patients and caregivers at our Chestnut Hill and regional campuses throughout Massachusetts (Milford, Merrimack Valley, South Shore, Foxborough, Brighton) and in Londonderry, New Hampshire.

14. The racial and ethnic groups in these areas include (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 2024	0.2%	3.5%	4.9%	~0.0%	82.3%	N/A	~2.5%	<input type="checkbox"/> Don't know
14c. The PFAC patient and family advisors in FY 2024	Our PFACs include members of Asian, Black, African American, Latinx, and white backgrounds. Members provide this self-identifying information voluntarily.							<input type="checkbox"/> Don't know

15. The languages spoken in these areas include (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 2024	~6.0%	<input type="checkbox"/> Don't know
15b. PFAC patient and family advisors in FY 2024	0%	<input type="checkbox"/> Don't know

15c. What percentage of patients that the hospital provided care to in FY 2024 spoke the following as their primary language?

	%
Spanish	3.6
Portuguese	0.3
Chinese	0.4
Haitian Creole	0.2
Vietnamese	0.2
Russian	0.3
French	~0.0
Mon-Khmer/Cambodian	N/A
Italian	~0.0
Arabic	0.5
Albanian	0.1
Cape Verdean	0.1

Don't know

15d. In FY 2024, what percentage of PFAC patient and family advisors spoke the following as their primary language?

	%
Spanish	3.2
Portuguese	3.2
Chinese	3.2
Haitian Creole	0
Vietnamese	0
Russian	0
French	0
Mon-Khmer/Cambodian	0
Italian	3.2
Arabic	0
Albanian	0
Cape Verdean	0

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:

Both PFACs are committed to an antiracist and social justice approach to addressing the patient and family experience, specifically amplifying the voices of patient communities with historical cancer care inequities. We aim to ensure that PFAC nurtures an inclusive culture and advocates for equity in health care throughout our interactions with DFCI.

One way we seek to increase access to patient engagement activities as a whole is by continuing to grow our e-advisor program for adult and pediatric oncology patients and family members to participate remotely. The e-advisor program's mission is to offer a flexible option for patient and family/caregiver involvement and input via short-term or one-off advisory input (vs. the longer-term and more time-intensive work of PFAC members). There is an abbreviated screening, onboarding, and training process for e-advisors.

We have had success with better aligning our membership with DFCI's catchment area. The PFAC Program Manager has conducted extensive outreach and relationship building with DFCI's regional campus locations in 2024, which will continue in 2025, in order to identify and recruit Adult PFAC members from those locations. In 2024, we recruited and onboarded 2 new members to our Adult PFAC who had experience at one of our network locations detailed within the catchment area response in question 13 above. However, we have work to do in order to ensure that our membership aligns with DFCI's patient population. The joint Adult and Pediatric PFAC Marketing & Recruitment Workgroup has deployed targeted recruitment messages for newsletters that reach diverse patient populations, and efforts are ongoing.

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:

The PFACs meet monthly for two hours each; meeting participants include all council members, the PFAC program manager, DFCI staff and leadership members, and guest presenters. Two to four weeks prior to each Adult and Pediatric PFAC meeting, the program manager and PFAC co-chairs have a planning meeting. During the planning meeting, the program manager and co-chairs discuss potential co-chair presentations, meeting topics, leadership and/or staff presenters, and working sessions. The group determines which presentations are relevant and plans the sequence and content of the meeting. The co-chairs and program manager meet with an interested presenter(s) beforehand to ensure the topic is a good fit for a PFAC meeting and discuss ways that the presenter(s) can most productively engage the council members through specific questions and or direct feedback. The program manager and co-chairs develop the agenda. All presenters are asked to submit their presentations a week prior to the monthly PFAC meeting. To give council members the opportunity to review materials in advance, 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 2024 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 2024 – Skip to #20

19. The PFAC had the following goals and objectives for 2024:

Pedi PFAC:

1. Leverage the data collected from our weekend initiative to create an information tool from PPFAC to caregivers.
2. Revisit the walk-around program at the Jimmy Fund Clinic and make recommendations for ways to get feedback from outpatient families.
3. Support of patient and family communications related to care transitions and Project Mosaic.
4. Recruit & Connect: Continue to rebuild the Council and add four new members this year, including 2 from diverse backgrounds. Connect with existing members at a social event.

Adult PFAC:

1. Provide significant involvement of PFAC in conversations about the new inpatient hospital.
2. Re-engage the Transitions to End of Life PFAC working group.
3. Engage in conversation with disease centers about coordination of care at DFCI. "Coordination of care beyond Dana-Farber"
4. Learn more from the Institute about how it imagines the use of AI in cancer diagnosis and treatment.

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

- PFAC Marketing and Recruitment Workgroup
- Pedi PFAC Marketing and Recruitment Workgroup
- PFAC Speakers Bureau
- PFAC Transitions to End of Life Care 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):
- 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:

- N/A – We don't communicate through these approaches

Adult PFAC meetings are currently held over Zoom and every other month meetings of the Pedi PFAC are held via Zoom or hybrid. Most of the communication in between meetings is via email, Zoom, or over the phone. PFAC also works closely with Dana-Farber's Communications Department to use social media tools for awareness building and member recruitment.

Section 5: Orientation and Continuing Education

23. Number of new PFAC members this year:

APFAC: 2 New Members

Pedi PFAC: 2 New Members

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:

As in 2022, DFCI continues to orient and train new PFAC members virtually. Volunteers schedule a time to get a volunteer-focused tour and their DFCI badge after completing onboarding and orientation.

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:

As part of our inclusive advocacy training, Adult PFAC members received training and a guidebook that covers cross-cultural communication. We also have quarterly trainings available for all of our volunteers on topics such as Emotional Intelligence, Resource Integration and Diversity, Equity and Inclusion.

Section 6: FY 2024 PFAC Impact and Accomplishments

The following information concerns PFAC activities in the fiscal year 2024.

26. Please share the following information on the PFACs accomplishments and impacts:

26a. What were the three greatest accomplishments/impacts of the PFAC related to providing feedback or perspective?

Accomplishment/Impact	Idea came from (choose one)
<p>Accomplishment/Impact 1:</p> <p>Pedi and Adult PFAC members provided feedback and perspective on a new lounge space that will support AYA patients. The space opened in spring 2024.</p>	<p><input type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input</p>
<p>Accomplishment/Impact 2:</p> <p>Pedi PFAC members worked with inpatient nursing leadership to review, advise and continually develop a tip sheet for parents/families on the unit using feedback from a PFAC-led program on the floor.</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input type="checkbox"/> Department, committee, or unit that requested PFAC input</p>
<p>Accomplishment/Impact 3:</p> <p>PFAC members provided insight into 10+ projects and committees in partnership with Quality and Patient Safety to move forward process improvement projects that will benefit a more equitable patient and family experience.</p>	<p><input type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input</p>

26b. What were the three greatest accomplishments/impacts of the PFAC related to influencing the institution's financial and programmatic decisions?

Accomplishment/Impact	Idea came from (choose one)
<p>Accomplishment/Impact 1:</p> <p>PFAC members met with Magnet Appraisers and supported the Institute in its 5th Magnet Re-designation process.</p>	<p><input type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input</p>
<p>Accomplishment/Impact 2:</p> <p>PFAC members participated in many meetings on 15+ topics regarding the ongoing development and planning for the new DFCI inpatient hospital. This work remains ongoing.</p>	<p><input type="checkbox"/> Patient/family advisors of the PFAC</p> <p><input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input</p>

Accomplishment/Impact 3:

PFAC members led a series of conversions with Institute leaders related to the care provided as patients are transitioned to end of life care. They are embarking on a data gathering of best practices in this area. The group has reconvened and met monthly since March 2024.

- Patient/family advisors of the PFAC
- Department, committee, or unit that requested PFAC input

26c. What were the three greatest accomplishments/impacts of the PFAC related leading/co-leading programs and initiatives?

Accomplishment/Impact	Idea came from (choose one)
Accomplishment/Impact 1: PFAC members were engaged in developing a new program to support patients with intellectual and developmental disabilities launched in 2024.	<input type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input
Accomplishment/Impact 2: PFAC members were instrumental in planning for DFCI's Patient Experience Week (Pt Ex) recognition in partnership with Quality and Patient Safety. Hundreds of gratitude cards were shared, in multiple languages, at all DFCI locations during Pt Ex Week 2024.	<input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> Department, committee, or unit that requested PFAC input
Accomplishment/Impact 3: Adult and Pedi PFAC members helped to facilitate and participated in a panel discussion in partnership with New Hire Orientation. PFAC members' experiences helped to support new DFCI staff as they become acclimated in their roles.	<input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> Department, committee, or unit that requested PFAC input

27. The five greatest challenges the PFAC had in FY 2024:

Challenge 1: Recruitment of new advisors, particularly to advance diversity on our Councils.

Challenge 2: Finding the right balance of volunteer work between our co-chairs and the rest of the Council members

Challenge 3: Building community and facilitating member engagement during monthly meetings, considering time constraints and life circumstances of our PFAC members.

Challenge 4: As the number of asks of PFAC continues to grow, it has been a challenge to strike the appropriate balance ensuring of involvement opportunities to make the most impact while being mindful of time constraints our PFAC members.

Challenge 5:

N/A – we did not encounter any challenges in FY 2024

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?

PFAC Members share verbal updates at the monthly Adult and Pediatric PFAC meetings as well as provide email updates to the Program Manager. PFAC members also check in with the co-chairs individually on a bi-annual basis.

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 2024

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 (e.g. 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:

1 Adult and 1 Pediatric member participate in a board/leadership level committee called the Quality Improvement and Risk Management Committee (QIRM). This high-level and confidential committee shares information addressed in all check boxes and engages PFAC during and after meetings. The 2 PFAC members are core members of the committee. Additionally, we have 1 Adult and 1 Pediatric PFAC member 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:

The above PFAC members are active participants in project teams and committees. Members receive meeting materials prior to meetings and 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
- Human Factors Engineering
- Fall prevention ., discharge planning, passports, care coordination, and follow up between care settings)
- Checklists
- Electronic Health Records –related errors
- Hand-washing initiatives

- 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:

Researchers contact the PFAC Program Manager

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):

Victoria Baggio, Program Manager, Patient and Family Advisory Council (staff)
 Patricia Stahl, Director of Volunteer Services and Patient Programs (staff)
 Maritza Nassif, Director of Centers for Patients and Families and Volunteer Services
 Meghan Shea, Co-Chair Pediatric PFAC (patient/family advisor)
 Katherine Page, Co-Chair Pediatric PFAC (patient/family advisor)
 May Hara, Co-Chair Adult PFAC (patient/ family advisor)
 Austin Sarat, Co-Chair Adult PFAC (patient/ family advisor)

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