

# 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: Massachusetts General for Children, Pediatric Oncology

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):

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: Elyse Levin-Russman, LICSW, OSW-C Clinical Social Worker

3b. Email: [elevinrussman@mgb.org](mailto:elevinrussman@mgb.org)

3c. Phone: 617-724-0757

Not applicable

4. Patient/Family PFAC Co-Chair Contact:

4a. Name and Title: Dawn Regan, Parent

4b. Email: [dcregan519@gmail.com](mailto:dcregan519@gmail.com)

4c. Phone: 508-717-7348

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:

6b. Email:

6c. Phone:

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

**8. Total number of staff members on the PFAC: 3**

**9. Total number of patient or family member advisors on the PFAC: 8/4 alumni members as advisors**

**10. The name of the hospital department supporting the PFAC is: Pediatric Hematology-Oncology**

**11. The hospital position of the PFAC Staff Liaison/Coordinator is: Clinical Social Worker**

**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): Virtual meetings/hybrid model
- 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:** Boston and greater Boston, New Hampshire, Maine and extended areas for specialty care

Don’t know

**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	.1%	4.3%	6.8%	0	71.2%	.8%	15.6%	<input type="checkbox"/> Don’t know
14b. Patients the hospital provided care to in FY 2024								<input checked="" type="checkbox"/> Don’t know
14c. The PFAC patient and family advisors in FY 2024	0	.08%	0	0	84%	0	.08%	<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		<input checked="" type="checkbox"/> Don’t know
15b. PFAC patient and family advisors in FY 2024	English	<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	
Portuguese	
Chinese	
Haitian Creole	
Vietnamese	
Russian	
French	
Mon-Khmer/Cambodian	
Italian	
Arabic	
Albanian	
Cape Verdean	

Don't know

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

	%
Spanish	0
Portuguese	0
Chinese	0
Haitian Creole	0
Vietnamese	0
Russian	0
French	0
Mon-Khmer/Cambodian	0
Italian	0
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:** Ongoing efforts to recruit diverse

members by ethnicity. Diversity has varied over the years with continued efforts by staff to engage interest from diverse groups of patient families. When not available, have used surveys and personal meetings with diverse members to gain input for Advisory Committee activities.

### 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:

17b. If other process, please describe: Co-chairs develop agenda together (staff and parent) and solicit input from members prior to the meeting to add to the agenda.

**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:**

1. Provide guidance to clinical staff for program initiatives to support parents during their child’s cancer treatment.
2. Identify ways to engage parents for mutual support through groups, networking, and events.
3. Parents of the Family Advisory Committee to develop staff appreciation program to recognize the work of the clinical staff
4. Investigate resources for additional integrative therapies to support patient care in the outpatient clinic.
5. Continue to address diversity in the committee through outreach and engagement with parents

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

None this year

**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

**Section 5: Orientation and Continuing Education**

**23. Number of new PFAC members this year: 3**

**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:

**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 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)
<b>Accomplishment/Impact 1:</b> Provided guidance around communication with families in clinic for information sharing	<input type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input
<b>Accomplishment/Impact 2:</b> Provided guidance, and then support during programs for parents including group for parents when a child completes treatment, parents of children newly diagnosed and Celebrating Amazing Moms.	<input type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input
<b>Accomplishment/Impact 3:</b> (Ongoing) Identifying resources for adding more time for integrative therapies into the clinic to enhance patient care	<input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> Department, committee, or unit that requested PFAC input

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)
<b>Accomplishment/Impact 1:</b> Duplicate of initial goals	<input type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> Department, committee, or unit that requested PFAC input

<b>Accomplishment/Impact 2:</b>	<input type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> Department, committee, or unit that requested PFAC input
<b>Accomplishment/Impact 3:</b>	<input type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> 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?

<b>Accomplishment/Impact</b>	<b>Idea came from (choose one)</b>
<b>Accomplishment/Impact 1:</b> <b>Duplicate of initial goals</b>	<input type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> Department, committee, or unit that requested PFAC input
<b>Accomplishment/Impact 2:</b>	<input type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> Department, committee, or unit that requested PFAC input
<b>Accomplishment/Impact 3:</b>	<input 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:** Attracting new members, particularly those who represent diverse populations

**Challenge 2:** Engaging clinical staff's interest in the work of the Committee

**Challenge 3:** Limited ability to influence change within the institution

**Challenge 4:** Time constraints of members due to many competing demands, often as parents of sick children

**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?**

**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
- Advice is provided to the Pediatric Oncology practice leadership, not the larger hospital

**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:**

The scope of our program is limited. We meet 5X/year and offer guidance and advice to the Pediatric Oncology program only. We are not a hospital-wide Advisory Group, although there are those programs already established at MGH

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

Relevant reports are shared with our PFAC related to Pediatric Oncology specific data, which represents the scope of their interest

**35. The PFAC participated in activities related to the following state or national quality of care initiatives (check all that apply):** Please see data from other PFACs at MGH, which is more relevant to the adult programs.

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):** Elyse Levin-Russman, LICSW, OSW-c

**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. Will defer to those that direct the PFAC program**

- 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:
- No

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

- Yes, link:
- No, we don't have such a section on our website