

2023 Patient and Family Advisory Council Annual Report Form

The survey questions concern PFAC activities in fiscal year 2022 only: (July 1, 2022 – June 30, 2023).

Section 1: General Information

1. Hospital Name:

Brigham and Women's Hospital

1a. 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):

At Brigham and Women's Hospital we currently have two service line PFACs:

- Emergency Department (ED), and
- Neonatal Intensive Care Unit (NICU)

and two non-service line PFACs:

- Health Messaging (formerly Health Literacy), and
- Coordinated Approach to Resilience and Empowerment (C.A.R.E.).

Our patient/family advisors also sit on other hospital-wide committees including the Care Improvement Council (CIC), Ethics Committee, Patient Experience Domain Team, and Equity Domain Team; and participate in both research and focus groups.

1b. Will another PFAC at your hospital also submit a report?

- Yes
- No
- Don't know

1c. Will another hospital within your system also submit a report?

- Yes
- No
- Don't know

3. Staff PFAC Co-Chair Contact:

2a. Name and Title: Erin Sturgeon, Patient Family Program and Case Manager

2b. Email: esturgeon@bwh.harvard.edu

2c. Phone: 617-525-3211

Not applicable

4. Patient/Family PFAC Co-Chair Contact:

3a. Name and Title: Martie Carnie, Senior Patient Experience Advisor

3b. Email: martiecarnie@hotmail.com

3c. Phone: 617-821-1144

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): Patient feedback
- N/A – we did not recruit new members in FY 2022

8. Total number of staff members on the PFAC:

PFAC	Total number of staff members
Health Messaging	1
Emergency Department (ED)	3
Neonatal Intensive Care Unit (NICU)	4
C.A.R.E.	1
TOTAL	9

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

PFAC	Total number of patient or family advisors
Health Messaging	4
Emergency Department (ED)	8
Neonatal Intensive Care Unit (NICU)	10
C.A.R.E.	6
Other	9
TOTAL	37

10. The name of the hospital department supporting the PFAC is:

Patient/Family Relations (Center for Patients and Families), Emergency Department, Neonatal Intensive Care Unit

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

Patient Family Program and Case Manager

12. The hospital provides the following for PFAC members to encourage their participation in meetings (check all that apply):

- Annual gifts of appreciation
- Assistive services for those with disabilities
- Conference call phone numbers or "virtual meeting" options
- Meetings outside 9am-5pm office hours
- Parking, mileage, or meals
- Payment for attendance at annual PFAC conference
- Payment for attendance at other conferences or trainings
- Provision/reimbursement for childcare or elder care (see other)
- Stipends
- Translator or interpreter services
- Other (Please describe): Provides space for those who do not have access to technology (ED); Phone Bill, Heat, Electric Bill (C.A.R.E.); Ensuring during the Patient Experience Domain Team meetings that those who are speaking are on video so our patient advisor who reads lips can understand them. Parking coupons are provided for any in person focus groups or meetings.
- 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: Our Hospital Service area is Boston and our Hospital Referral Region is New England.

Our priority postal codes are:

- 02121 (Dorchester, Franklin Field North/Roxbury Neighborhood),
- 02122 (Dorchester, Port Norfolk/Dorchester Neighborhood),
- 02124 (Dorchester Center, Codman Square/Dorchester Neighborhood),
- 02125 (Dorchester, Harbor Islands Neighborhood),
- 02126 (Mattapan, Southern Mattapan/Mattapan Neighborhood),
- 02130 (Jamaica Plain, Jamaica Hills/Jamaica Plain Neighborhood),
- 02120 (Roxbury Crossing, Mission Hill Projects/Jamaica Plain Neighborhood),
- 02118 (Boston, South End Neighborhood),
- 02119 (Roxbury, Washington Park Neighborhood). All priority postal codes are in Suffolk County.

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								<input checked="" type="checkbox"/> Don't know
14b. Patients the hospital provided care to in FY 2023*	0.1%	4.5%	7.3%	0%	75.3%	5.9%	9%	<input type="checkbox"/> Don't know
14c. The PFAC patient and family advisors in FY 2023								<input checked="" type="checkbox"/> Don't know

*BWH provided care to 1% of patients who designated "two or more" under race and 5.8% of patients who were cared for had "Unknown/missing" race.

14c. Sharing race and ethnicity information is not a requirement, and identities of patient/family advisors from the C.A.R.E. PFAC are kept confidential; therefore we only have data on 24.3% of our patient/family advisors. Of that 24.3%, 77.8% is White, 11.1% is Asian or Pacific Islander, and 11.1% is Black or African American.

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 2023		<input checked="" type="checkbox"/> Don't know
15b. PFAC patient and family advisors in FY 2023		<input checked="" type="checkbox"/> Don't know

15c. What percentage of patients that the hospital provided care to in FY 2022 spoke the following as their primary language? **

_____ %

Spanish	3.6%
Portuguese	0.2%
Chinese	0.3%
Haitian Creole	0.2%
Vietnamese	0.1%
Russian	0.2%
French	0%
Mon-Khmer/Cambodian	0%
Italian	0%
Arabic	0.2%
Albanian	0.1%
Cape Verdean	0.1%

Don't know

**Additional language:

Other = 0.4%

Unknown = 1.6%

15d. In FY 2023, what percentage of PFAC patient and family advisors 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: Sharing language information is not a requirement, and identities of patient/family advisors on the C.A.R.E. PFAC are survivors from interpersonal violence, therefore their identities are kept confidential (two patient/family advisors are bilingual).

16. The PFAC is undertaking the following activities to ensure appropriate representation of our membership in comparison to our patient population or catchment area:

All PFACs will continue to collaborate with our Diversity, Equity and Inclusion leaders to increase, recruit and retain patient/family advisors that fall within BWH's catchment area. In addition, the PFACs will seek guidance from patient/family advisors who do fall within the hospital's catchment on how best to recruit new patient/family advisors in the community.

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 Senior Leadership Patient and Family Advisory Board's (SLPFAB) agenda is developed by staff and patient/family advisor Co-Chairs in the PFAC Leadership Committee prior to the meeting by virtual workgroup. The NICU PFAC process is that the staff administrative team will meet to discuss goals for the next meeting agenda. After this, communication is sent to NICU patient/family advisors asking for input into the meeting agenda and follow-up on individual initiative meetings with faculty. Then, a Doodle Poll is sent to find a mutual time (after 5 pm) to have Zoom meeting (Quarterly). After a time and date is selected, patient/family advisors are asked to provide topics for discussion and briefing on individual initiative meetings attended since last the last meeting. Finally, an agenda is sent out prior to the meeting time.

17b. If other process, please describe:

C.A.R.E.: The process is to reach out to patient/family advisors requesting their input on new and developing procedures and policies.

18. The PFAC goals and objectives for 2023 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 2022– **Skip to #20**

19. The PFAC had the following goals and objectives for 2023:

- Revitalize the PFACs that are currently "on hold."
- Gather additional demographic information from patient/family advisors, if possible.

- Collaborate with Diversity, Equity and Inclusion leadership to identify strategies to recruit patient/family advisors who represent the hospital’s catchment area.
- Create toolkits for new and existing PFAC use.
- Utilize Patient Experience Survey (NRC) data for recruitment of new patient/family advisors.
- Identify new opportunities for patient/family advisors.
- Partner with the Emergency Department Unit-based Team (Quality/Safety Workgroup).
- Improve the patient experience in the Emergency Department.
- Expand the Emergency Department PFAC Communication Training for staff.
- Explore with C.A.R.E. patient/family advisors if the clinic would be best to serve patients using a primary care/medical home model.
- Engage faculty and patient/family advisors with NICU initiatives
- Review research education and teaching sheets/videos for NICU patient/family advisors prior to distribution
- Involvement of patient/family advisors to initiate meetings with faculty and staff.

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

Transition to Home Program; Outpatient research Studies and Mental Health; Parent Mental Health and Music Therapy; Retinopathy of Prematurity exams done by Advance Practitioners; Developmental projects with NICU Staff and Faculty on boarding and support.

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): The PFAC Co-Chairs present to Senior Leadership Patient and Family Advisory Board (SLPFAB) on accomplishments on a quarterly basis.
- 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

The primary method of communication between advisors is phone calls, e-mail, or Zoom (with the exception of the C.A.R.E. PFAC). The C.A.R.E. PFAC uses e-mail and text messages.

Section 5: Orientation and Continuing Education

23. Number of new PFAC members this year:

PFAC	Total number of patient or family advisors
Health Messaging	0
Emergency Department	0
Neonatal Intensive Care Unit	0
C.A.R.E.	0
Other	1
TOTAL	1

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: NICU PFAC: educational and supportive learning opportunities for all parent family advisors (Hand to Hold Training). C.A.R.E. PFAC: Trauma-Informed Care Plan through pilot testing.

Section 6: FY 2023 PFAC Impact and Accomplishments

The following information concerns PFAC activities in the fiscal year 2023.

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>1. Accomplishment/Impact 1: Patient/family advisors in the Emergency Department (ED) PFAC collaborated with ED Registration on scripting for patients and families waiting for extending periods of time in the ED. The script is actively used in the ED.</p>	<p><input type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input</p>
<p>Accomplishment/Impact 2: C.A.R.E. PFAC patient/family advisors helped inform screening for intimate partner violence during telehealth encounters.</p>	<p><input type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input</p>
<p>Accomplishment/Impact 3: In the NICU PFAC, crib cards were updated to reflect better inclusivity/diversity from parent's feedback.</p>	<p><input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input 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>1. Accomplishment/Impact 1: Leadership from the Patient Experience Team, Patient/Family Relations Team and a patient advisor presented at Thorndike Grand Rounds, a hospital-wide seminar that spread awareness about PFACs, provided experiences and insights directly from an advisor and introduced new opportunities to gain the patient perspective.</p>	<p><input type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input</p>

Accomplishment/Impact 2: The Health Messaging PFAC participated in a discussion with staff to provide feedback regarding BWH's Alzheimer's Disease and Related Dementias (ADRD) Operational Plan, which details the management and treatment of patients with dementia and delirium.

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

Accomplishment/Impact 3: The Health Messaging PFAC provided insights on BWH's 'Meds-to-Beds' service that delivers prescriptions to the patient's room before discharge. Our advisors focused on making this document easy to read and understandable for patients.

- 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: Dr. Higgins, BWH President sat down with Senior Patient Experience Advisor and the Executive Director of Patient Experience to talk about how the hospital is infusing the patient voice into our clinical, education and research work during National Patient Experience Week.	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input type="checkbox"/> Department, committee, or unit that requested PFAC input
Accomplishment/Impact 2: The ED PFAC patient/family advisors met with Magnet appraisers during as a part of the hospital's requalification for Magnet designation.	<ul style="list-style-type: none"> <input type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input
Accomplishment/Impact 3: The ED PFAC patient/family advisors held a communications skills training for newly licensed nurses via the Nora McDonough Nurse Residency seminar series.	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Patient/family advisors of the PFAC <input checked="" type="checkbox"/> Department, committee, or unit that requested PFAC input

27. The five greatest challenges the PFAC had in FY 2023:

Challenge 1: Recruitment of advisors, with DEI focus

Challenge 2: Loss of momentum

Challenge 3: Time challenges

Challenge 4: Staffing constraints

Challenge 5: Organizational changes

N/A – we did not encounter any challenges in FY 2023

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 improvement project initiatives (NICU)
- Quality/Performance Improvement
- Surgical Home
- Other (Please describe): Care Improvement Council (CIC); Patient Experience Domain Team and

Equity Domain Team

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?

Patient/family advisors on hospital-wide committees report out at their individual PFAC meetings. The Patient Family Program and Case Manager attends most meetings and minutes are usually distributed at the conclusion of each meeting.

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 2022

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: Change in leadership oversight and reorganization.

34. Please describe how the PFAC was engaged in discussions around these data in #32 above and any resulting quality improvement initiatives: The Patient Experience Domain Team includes representatives from various hospital service lines and additional patient/family advisors have joined. Data from BWH's NRC

(Patient Satisfaction Survey) is shared during these meetings. The NRC data obtained, led to the ED registration initiative to communicate with transparency and compassion to patients and families waiting in the ED waiting room for long periods of time.

35. The PFAC participated in activities related to the following state or national quality of care initiatives (check all that apply):

35a. National Patient Safety Hospital Goals

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

35b. Prevention and errors

- Care transitions (e.g., discharge planning, passports, care coordination, and follow up between care settings)
- Checklists
- Electronic Health Records –related errors
- Hand-washing initiatives
- Human Factors Engineering
- Fall prevention
- Team training
- Safety

35c. Decision-making and advanced planning

- End of life planning (e.g., hospice, palliative, advanced directives)
- Health care proxies
- Improving information for patients and families
- Informed decision making/informed consent

35d. Other quality initiatives

- Disclosure of harm and apology
- Integration of behavioral health care
- Rapid response teams
- Other (Please describe): The C.A.R.E. PFAC informed the development and testing of Trauma-Informed Care Plan
- 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)

Note: The Multi-faceted persistent Opioid use Prevention Program (MOPP) was designed for patients who have orthopedic or spine surgery. Patient/family advisors involved in this research study provided feedback on the caregiver interview, patient interview and recruitment scripts. Research projects being observed in the NICU include parent feedback on future proposed research initiatives and planning, parent information sheets, and education. Patient/family advisors were a part of a focus group for the Care Transitions Application to improve the care for patients with multiple chronic conditions following discharge from the hospital. Advisors continue to provide insight regarding the ePROs Mock Patient Design, aimed at patient's discharge progress and readmissions.

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: C.A.R.E. PFAC advisors were informed about the development of Trauma-informed Care Plan and its purpose. During the NICU PFAC quarterly meetings, (and update emails), all research studies requested in the NICU are discussed with the patient/family advisors and their recommendations on how these studies can be addressed with families already experiencing stress.

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):

Erin Sturgeon and Martie Carnie in collaboration with Co-Chairs of several PFACs.

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: *in process of being updated
- 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: *in process of being updated
- 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: *in process of being updated