PFAC Annual Report Form

Health Care For All (HCFA) advocates for health justice in Massachusetts by working to promote health equity and ensure coverage and access for all. HCFA uses direct service, policy development, coalition building, community organizing, public education and outreach to achieve its mission. HCFA envisions a day when everyone in Massachusetts has the equitable, affordable, and comprehensive care they need to be healthy.

**Why complete an annual report for my PFAC?**

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

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

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

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

**Who can I contact with questions?**

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

Please email completed forms to PFAC@hcfama.org.

Reports should be completed by October 1, 2022.
2022 Patient and Family Advisory Council Annual Report Form

The survey questions concern PFAC activities in fiscal year 2022 only: (July 1, 2021 – June 30, 2022).

Section 1: General Information

1. Hospital Name: Dana-Farber Cancer Institute

   NOTE: Massachusetts law requires every hospital to make a report about its PFAC publicly available. HCFA strongly encourages the completion of an individual report for each hospital-wide PFAC.

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): Dana-Farber Cancer Institute has an Adult PFAC and a Pediatric PFAC; this report is for both.

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:
   - Jenny Dahlstein, Co-Chair, Adult PFAC
   - Kireina Bell Sancho, Co-Chair, Adult PFAC
   - Chloe Steimle, Co-Chair, Pedi PFAC
   - Mark Pettengill, Co-Chair, Pedi PFAC

   2b. Email:
   - jennymdahlstein@gmail.com
   - kireina.bellsancho@gmail.com
   - chloehall77@gmail.com
   - mark.pettengill@gmail.com

   2c. Phone:
   - -
   - -
   - -
   - -

4. Patient/Family PFAC Co-Chair Contact:

<table>
<thead>
<tr>
<th>3a. Name and Title</th>
<th>3b. Email</th>
<th>3c. Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jenny Dahlstein</td>
<td><a href="mailto:jennymdahlstein@gmail.com">jennymdahlstein@gmail.com</a></td>
<td>-</td>
</tr>
<tr>
<td>Kireina Bell Sancho</td>
<td><a href="mailto:kireina.bellsancho@gmail.com">kireina.bellsancho@gmail.com</a></td>
<td>-</td>
</tr>
<tr>
<td>Chloe Steimle</td>
<td><a href="mailto:chloehall77@gmail.com">chloehall77@gmail.com</a></td>
<td>-</td>
</tr>
<tr>
<td>Mark Pettengill</td>
<td><a href="mailto:mark.pettengill@gmail.com">mark.pettengill@gmail.com</a></td>
<td>-</td>
</tr>
</tbody>
</table>
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 - NA

6. Staff PFAC Liaison/Coordinator Contact:
   6a. Name and Title: Victoria Baggio
   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
   ■ Other (Please describe): DFCI website
   ☐ N/A – we did not recruit new members in FY 2022

8. Total number of staff members on the PFAC:
   Adult PFAC  9 staff members (5 have voting privileges)
   Pedi PFAC  10 staff members (5 have voting privileges)

9. Total number of patient or family member advisors on the PFAC:
   Adult PFAC  19 members
   Pedi PFAC  8 members

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

11. The hospital position of the PFAC Staff Liaison/Coordinator is:
    Program Manager, Patient and Family Advisory Councils
12. The hospital provides the following for PFAC members to encourage their participation in meetings (check all that apply):

- Annual gifts of appreciation
- Assistive services for those with disabilities
- Conference call phone numbers or “virtual meeting” options
- Meetings outside 9am-5pm office hours
- Parking, mileage, or meals
- Payment for attendance at annual PFAC conference
- Payment for attendance at other conferences or trainings
- Provision/reimbursement for child care 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 has satellites outside of the Boston area. Those include Foxborough, Chestnut Hill, Merrimack Valley, South Shore, Saint Elizabeth’s, New Londonderry, New Hampshire, and Milford.

- 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”):

<table>
<thead>
<tr>
<th>RACE</th>
<th>ETHNICITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>% American Indian or Alaska Native</td>
<td>% Hispanic, Latino, or Spanish origin</td>
</tr>
<tr>
<td>% Asian</td>
<td></td>
</tr>
<tr>
<td>% Black or African American</td>
<td></td>
</tr>
<tr>
<td>% Native Hawaiian or other Pacific Islander</td>
<td></td>
</tr>
<tr>
<td>% White</td>
<td></td>
</tr>
<tr>
<td>% Other</td>
<td></td>
</tr>
</tbody>
</table>

14a. Our defined catchment area

14b. Patients the hospital provided care to in FY 2022

14c. The PFAC patient and family advisors in FY 2022

15. The languages spoken in these areas include (please provide percentages; if you are unsure of the percentages select “don’t know”):

<table>
<thead>
<tr>
<th>Limited English Proficiency (LEP) %</th>
</tr>
</thead>
<tbody>
<tr>
<td>15a. Patients the hospital provided care to in FY 2022</td>
</tr>
<tr>
<td>6.39%</td>
</tr>
<tr>
<td>15b. PFAC patient and family advisors in FY 2022</td>
</tr>
<tr>
<td>0%</td>
</tr>
</tbody>
</table>
15c. What percentage of patients that the hospital provided care to in FY 2022 spoke the following as their primary language?

<table>
<thead>
<tr>
<th>Language</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spanish</td>
<td>2.98</td>
</tr>
<tr>
<td>Portuguese</td>
<td>0.25</td>
</tr>
<tr>
<td>Chinese</td>
<td>0.39</td>
</tr>
<tr>
<td>Haitian Creole</td>
<td>0.15</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>0.14</td>
</tr>
<tr>
<td>Russian</td>
<td>0.36</td>
</tr>
<tr>
<td>French</td>
<td>0.03</td>
</tr>
<tr>
<td>Mon-Khmer/Cambodian</td>
<td>0.03</td>
</tr>
<tr>
<td>Italian</td>
<td>0.05</td>
</tr>
<tr>
<td>Arabic</td>
<td>0.59</td>
</tr>
<tr>
<td>Albanian</td>
<td>0.06</td>
</tr>
<tr>
<td>Cape Verdean</td>
<td>0.06</td>
</tr>
</tbody>
</table>

☐ Don’t know

15d. In FY 2022, what percentage of PFAC patient and family advisors spoke the following as their primary language?

<table>
<thead>
<tr>
<th>Language</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spanish</td>
<td>7.4</td>
</tr>
<tr>
<td>Portuguese</td>
<td>0</td>
</tr>
<tr>
<td>Chinese</td>
<td>3.7</td>
</tr>
<tr>
<td>Haitian Creole</td>
<td>0</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>0</td>
</tr>
<tr>
<td>Russian</td>
<td>0</td>
</tr>
<tr>
<td>French</td>
<td>0</td>
</tr>
<tr>
<td>Mon-Khmer/Cambodian</td>
<td>0</td>
</tr>
<tr>
<td>Italian</td>
<td>0</td>
</tr>
<tr>
<td>Arabic</td>
<td>0</td>
</tr>
<tr>
<td>Albanian</td>
<td>0</td>
</tr>
<tr>
<td>Cape Verdean</td>
<td>0</td>
</tr>
</tbody>
</table>

☐ 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.
We continue to work toward improving representation on our PFAC and strive to provide education and training to help our council members advocate for all. To ensure that the PFACs are advocating for a diversity of patient/family voices, DFCI staff and PFAC members formed the PFAC Marketing & Recruitment Workgroup, which meets monthly to discuss council membership recruitment strategies, health equity, and training and development opportunities for current and future council members. Additionally, the Adult PFAC co-chairs, PFAC program manager, and Director of Volunteer Services meet monthly as an Advocacy Development Leadership Committee that focuses on PFAC program operational strategies for diversifying council membership. In FY2022, this committee completed a review of the PFAC membership application form to ensure it reflects and promotes our inclusion, diversity, and equity (IDE) goals/language. We are currently reviewing and updating our PFAC Member Handbook with this lens. The committee also led the finalization of the PFAC Advocacy Guidebook that supplements our inclusive advocacy curriculum. This “by the PFAC for the PFAC” guidebook summarizes advocacy skills building modules we offered to our pedi and adult members, and provides self-reflection activities and additional reading. The skills building modules and guidebook aim to support our PFAC members in advocating with an inclusion, diversity and equity lens when participating on Dana-Farber projects and committees.

The joint Adult and Pediatric PFAC Marketing & Recruitment Workgroup has deployed targeted recruitment messages for newsletters that reach diverse patient populations. We continue to grow our e-advisor program for adult and pediatric oncology patients and family members to participate in patient engagement activities 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.

Our IDE Workgroup, which includes both pediatric and adult PFAC members, meets monthly to discuss health equity and racism across local, national, and global spaces with a focus on cancer care. The workgroup also strategizes about how to integrate an inclusive lens to the various DFCI projects and activities PFAC members work on, and regularly invites DFCI staff working on IDE issues to participate in the workgroup’s meetings.

The orientation for new PFAC members includes learning about health equity, a video training on sharing their story while advocating for others, and an online unconscious bias training. In addition, both PFACs continue to partner closely with Dana-Farber’s Chief Inclusion Diversity and Equity Officer to provide insight on Dana-Farber’s organization-wide IDE goals and strategies. The Chief Inclusion Diversity and Equity Officer is invited to attend monthly PFAC meetings and also meets regularly with the PFAC program manager. PFAC members continue to participate on IDE action teams across the institute.

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 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:
N/A

18. The PFAC goals and objectives for 2022 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 2022:

Pedi:
- Pedi PFAC will further the council’s growth toward being an antiracist and inclusive group that fully supports the inclusion, diversity and equity goals of DFCI.
- Pedi PFAC members will share personal stories to clinical staff, including residents, oncology fellows, and nursing. Through this, we strive to keep the patient/caregiver perspective top of mind while supporting DFCI’s effort to help staff “connect to purpose.” We also hope to use this as a way to raise awareness of the council and promote referrals.
- Pedi PFAC members will participate in the necessary training and staff relationship building to become the best patient-family advocates. This includes training around advocacy skills, IDE, and patient/family communication skills. By offering proactive patient advocacy support to members, the council strives to contribute to an equitable patient experience for all patients, caregivers and families.
- Pedi PFAC members will develop and institute PFAC member and presenter evaluation surveys to measure the impact of the feedback provided by the council. By creating this feedback loop, we hope to ensure members and staff presenters, alike, feel valued and supported.

Adult:
- Adult PFAC will continue to work with DFCI staff and leadership to identify and provide a trained patient/family core group to participate in research related activities.
- APFAC will continue to work with DFCI staff and leadership to support and implement initiatives aimed at inclusive and diverse growth of patient volume locally, nationally and internationally.
● APFAC will continue to work with DFCI staff and leadership to support excellent and equitable patient and family-centered experiences across the Institute.
● APFAC will work towards having an inclusive, diverse, and anti-racist council with high levels of engagement poised to advocate for all patients/family equitably.
● APFAC, as a cancer center PFAC gold standard, will continue to work on operational efficiency, DFCI engagement, and council member productivity and to mentor other PFACs nationally.

20. Please list any subcommittees that your PFAC has established:
   ● Adult PFAC Advocacy Development Leadership Committee
   ● Adult PFAC Quality of Life Workgroup
   ● Adult & Pedi PFAC Marketing and Recruitment Workgroup
   ● Adult & Pedi PFAC Inclusion, Diversity, and Equity Workgroup
   ● Adult & Pedi Transitions to End-of-Life Care Workgroup
   ● Adult & Pedi PFAC Co-Chair Nomination Committees
   ● Pedi PFAC Weekend Initiative at Boston Children's Hospital Workgroup
   ● Pedi PFAC Best Practices in Patient Engagement

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:
    All PFAC meetings are currently held over Zoom. The majority of 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.
    □ N/A – We don’t communicate through these approaches

Section 5: Orientation and Continuing Education

23. Number of new PFAC members this year:
    Eight (8) new Adult PFAC members and one (1) new Pedi PFAC member

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 2021, DFCI continues to orient and train all new PFAC members virtually.

**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 series, Adult PFAC members received training in cross-cultural communication and Pediatric PFAC members were trained in listening and speaking with candor.
**Section 6: FY 2022 PFAC Impact and Accomplishments**

The following information concerns PFAC activities in the fiscal year 2022.

26. Please share the following information on the PFAC’s accomplishments and impacts:

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

<table>
<thead>
<tr>
<th>Accomplishment/Impact</th>
<th>Idea came from (choose one)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Accomplishment/Impact 1:</strong></td>
<td></td>
</tr>
<tr>
<td>Adult PFAC: Provided feedback to the Institute’s Welcome Center in support of their revamping of the DFCI phone intake system to improve the patient experience (including provision of an IDE statement in multiple languages, increased efficiency in caller menu options, and improvements to responsive language options).</td>
<td>☐ Patient/family advisors of the PFAC  ■ Department, committee, or unit that requested PFAC input</td>
</tr>
<tr>
<td><strong>Accomplishment/Impact 2:</strong></td>
<td></td>
</tr>
<tr>
<td>Adult PFAC: This year, the council’s membership has doubled and grown to reflect more diversity in terms of patient/family/caregiver experiences. This increased diversity reflects not only patient demographics but also a expanded breadth of experiences across more cancer types, thus expanding the council’s diverse feedback.</td>
<td>☐ Patient/family advisors of the PFAC  ■ Department, committee, or unit that requested PFAC input</td>
</tr>
<tr>
<td><strong>Accomplishment/Impact 3:</strong></td>
<td></td>
</tr>
<tr>
<td>Adult PFAC: Development of two additional, Council-led workgroups: Quality of Life workgroup and Transitions to End-of-Life Care, both of which focus on supporting DFCI’s efforts to ensure smooth transitions along the continuum of care, for patients and their family/caregivers.</td>
<td>☐ Patient/family advisors of the PFAC  ■ Department, committee, or unit that requested PFAC input</td>
</tr>
<tr>
<td><strong>Accomplishment/Impact 4:</strong></td>
<td></td>
</tr>
<tr>
<td>Adult and Pedi PFAC: Keeping council purpose and mission top of mind, PFAC members presented information about the PFAC and shared personal patient/caregiver stories and perspectives at the quarterly, all-staff DFCI Open Forum meetings.</td>
<td>☐ Patient/family advisors of the PFAC  ■ Department, committee, or unit that requested PFAC input</td>
</tr>
<tr>
<td><strong>Accomplishment/Impact 1:</strong></td>
<td></td>
</tr>
<tr>
<td>Pedi PFAC: Provided feedback and a patient/caregiver perspective on an updated pediatric Oncology Treatment Calendar.</td>
<td>☐ Patient/family advisors of the PFAC  ■ Department, committee, or unit that requested PFAC input</td>
</tr>
<tr>
<td><strong>Accomplishment/Impact 2:</strong></td>
<td></td>
</tr>
<tr>
<td>Pedi PFAC: Provided feedback to staff and composed a welcome letter for patients and families who were transitioning from Tufts Medical Center to The Jimmy Fund Clinic.</td>
<td>☐ Patient/family advisors of the PFAC  ■ Department, committee, or unit that requested PFAC input</td>
</tr>
</tbody>
</table>
26b. What were the three greatest accomplishments/impacts of the PFAC related to influencing the institution’s financial and programmatic decisions?

<table>
<thead>
<tr>
<th>Accomplishment/Impact</th>
<th>Idea came from (choose one)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accomplishment/Impact 1:</td>
<td>☐ Patient/family advisors of the PFAC</td>
</tr>
<tr>
<td><strong>Adult PFAC:</strong> Participation in the planning and walkthrough of a new satellite location; partnered with DFCI to successfully plan and prepare for the opening.</td>
<td>☐ Department, committee, or unit that requested PFAC input</td>
</tr>
<tr>
<td>Accomplishment/Impact 2:</td>
<td>☐ Patient/family advisors of the PFAC</td>
</tr>
<tr>
<td><strong>Adult PFAC:</strong> Participated in the development of a workflow and letter for DFCI clinicians to initiate conversations with affected patients regarding setting goals for end-of-life care.</td>
<td>☐ Department, committee, or unit that requested PFAC input</td>
</tr>
<tr>
<td>Accomplishment/Impact 3:</td>
<td>☐ Patient/family advisors of the PFAC</td>
</tr>
<tr>
<td><strong>Adult &amp; Pedi PFAC:</strong> Legislative advocacy: Adult and Pediatric PFAC members participated in advocacy to support legislative issues (i.e., submitting a testimony in support of H1310/S763, An Act to ensure equitable access to health coverage for children with disabilities; Testimony in support for H1110/S726 – An Act Relative to Breast Cancer Equity and Early Detection.</td>
<td>☐ Department, committee, or unit that requested PFAC input</td>
</tr>
<tr>
<td>Accomplishment/Impact 4:</td>
<td>☐ Patient/family advisors of the PFAC</td>
</tr>
<tr>
<td><strong>Pedi PFAC:</strong> Provided feedback and patient/family perspective during philanthropy presentation focused around the new clinical ambassador program, led by Senior VP and Chief of Philanthropy.</td>
<td>☐ Department, committee, or unit that requested PFAC input</td>
</tr>
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</table>

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

<table>
<thead>
<tr>
<th>Accomplishment/Impact</th>
<th>Idea came from (choose one)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accomplishment/Impact 1:</td>
<td>☐ Patient/family advisors of the PFAC</td>
</tr>
<tr>
<td><strong>Adult and Pediatric PFAC:</strong> The PFACs have worked together with DFCI’s Office of Inclusion and Diversity on numerous IDE executive and action committees (e.g., patient reported data).</td>
<td>☐ Department, committee, or unit that requested PFAC input</td>
</tr>
<tr>
<td>Accomplishment/Impact 2:</td>
<td>☐ Patient/family advisors of the PFAC</td>
</tr>
<tr>
<td><strong>Adult PFAC:</strong> Finalized a PFAC Advocacy Guidebook, which is a “by the PFAC for the PFAC” reference tool designed to be used episodically by council members for just-in-time learning or reflection around inclusive advocacy skills.</td>
<td>☐ Department, committee, or unit that requested PFAC input</td>
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</tbody>
</table>
### Accomplishment/Impact 3:

**Adult PFAC:** Conducted review of DFCI Survivorship Program’s website to offer feedback about usability/navigation, resources, and content.

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

### Accomplishment/Impact 1:

**Pedi PFAC:** Collaborated with the Psychosocial Department to support a new, online support option for teens going through cancer treatment. Assisted in the development and implementation of a comprehensive teen mentor response FAQ, the production of marketing materials, and served as mentors during live chats and web page development.

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

### Accomplishment/Impact 2

**Pedi PFAC:** Identified and engaged new pediatric leaders throughout the Institute to actively collaborate with Pedi PFAC.

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

### Accomplishment/Impact 3

**Pedi PFAC:** Conducted an extensive study of best practices in patient engagement in the pediatric hospital setting. An online survey was completed by 20 major medical centers and this was followed up with telephone interviews. Findings were supplemented with secondary research. The report was shared with leadership at all levels and used to assess opportunities for more effective engagement of patients and caregivers in the pediatric setting.

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

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**27. The five greatest challenges the PFAC had in FY 2022:**

<table>
<thead>
<tr>
<th>Challenge</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Challenge 1:</strong></td>
<td>Maintaining levels of engagement as we continue to operate in a fully virtual format for both monthly PFAC meetings as well as PFAC member volunteer work</td>
</tr>
<tr>
<td><strong>Challenge 2:</strong></td>
<td>Maintaining continuity of projects, initiatives and other Adult and Pedi PFAC work during internal DFCI program management staff changes</td>
</tr>
<tr>
<td><strong>Challenge 3:</strong></td>
<td>Figuring out sustainable “feedback loop” workflow for tracking council feedback to DFCI projects and presenters, in order to keep council members better informed about PFAC impact</td>
</tr>
<tr>
<td><strong>Challenge 4:</strong></td>
<td>Connecting with patients and caregivers to amplify concerns and opportunities</td>
</tr>
<tr>
<td><strong>Challenge 5:</strong></td>
<td>Increasing Pedi PFAC diversity and membership to better represent our catchment area</td>
</tr>
</tbody>
</table>

- ☐ N/A – we did not encounter any challenges in FY 2022
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 PFAC and Pediatric PFAC meetings, and provide email updates to the PFAC program manager.

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)

### 32c. Resource use, patient satisfaction, and other

- Inpatient care management (such as electronically ordering medicine, specially trained doctors for ICU patients)
- Patient experience/satisfaction scores (eg. HCAHPS - Hospital Consumer Assessment of Healthcare Providers and Systems)
- Resource use (such as length of stay, readmissions)

Other (Please describe):
- N/A – the hospital did not share performance information with the PFAC – Skip to #35

33. Please explain why the hospital shared only the data you checked in Q 32 above:

1 Adult and 1 Pediatric PFAC member participate in a board/leadership level committee named the "Quality Improvement and Risk Management Committee" (QIRM). This high-level and confidential committee shares information addressed in all check boxes above and engages PFAC during and after meetings. The 2 PFAC representatives are core members of this committee. Additionally, we have 1 Adult and 1 Pediatric PFAC representative 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 on project teams and committees. Members receive meeting materials prior to meetings via email 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., 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:
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, PFAC (staff)
   - Patricia Stahl, Director of Volunteer Services (staff)
   - Chloe Steimle, Co-Chair, Pediatric PFAC (patient/family advisor)
   - Mark Pettengill, Co-Chair, Pediatric PFAC (patient/family advisor)
   - Kireina Bell Sancho, Co-Chair, Adult PFAC (patient/family advisor)
   - Jenny Dahlstein, 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