The survey questions concern PFAC activities in fiscal year 2019 only: (July 1, 2018 – June 30, 2019).

**Section 1: General Information**

1. Hospital Name: Shriners Hospitals for Children — Boston

NOTE: Massachusetts law requires every hospital to make a report about its PFAC publicly available. HCFA strongly encourages you to fill out a separate template for the hospital-wide PFAC at each individual hospital.

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:
   2a. Name and Title: Sandra Barrett RN BSN CCM
   2b. Email: sbarrett@shrinenet.org
   2c. Phone: 617-371-4733
   - ☐ Not applicable

4. Patient/Family PFAC Co-Chair Contact:
   3a. Name and Title: Olga Belyakova-Parent Co-Chair
   3b. Email: bos-pfac@shrinenet.org
   3c. Phone:
   - ☐ 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): PFAC Educational Events
☐ N/A – we did not recruit new members in FY 2018

8. Total number of staff members on the PFAC: 7

9. Total number of patient or family member advisors on the PFAC: 15

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

11. The hospital position of the PFAC Staff Liaison/Coordinator is: Nurse Care 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 child care or elder care
☐ Stipends
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: Eastern United States, Puerto Rico and multiple international countries
☐ Don’t know

14. Tell us about racial and ethnic groups in these areas (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>%</td>
<td></td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>Asian</td>
</tr>
</tbody>
</table>

14a. Our defined catchment area
☐ Don’t know

14b. Patients the hospital provided care to in FY 2018
☐ Don’t know

14c. The PFAC patient and family advisors in FY 2018
☐ Don’t know

15. Tell us about languages spoken in these areas (please provide percentages; if you are unsure of the percentages select “don’t know”):
<table>
<thead>
<tr>
<th>Limited English Proficiency (LEP)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>15a. Patients the hospital provided care to in FY 2018</td>
<td>☒ Don’t know</td>
</tr>
<tr>
<td>15b. PFAC patient and family advisors in FY 2018</td>
<td>☒ Don’t know</td>
</tr>
</tbody>
</table>

**15c. What percentage of patients that the hospital provided care to in FY 2018 spoke the following as their primary language?**

<table>
<thead>
<tr>
<th>Language</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spanish</td>
<td>20</td>
</tr>
<tr>
<td>Portuguese</td>
<td>1</td>
</tr>
<tr>
<td>Chinese</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Haitian Creole</td>
<td>1</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Russian</td>
<td>&lt;1</td>
</tr>
<tr>
<td>French</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Mon-Khmer/Cambodian</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Italian</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Arabic</td>
<td>1.3</td>
</tr>
<tr>
<td>Albanian</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Cape Verdean</td>
<td>&lt;1</td>
</tr>
</tbody>
</table>

☐ Don’t know

**15d. In FY 2019, what percentage of PFAC patient and family advisors spoke the following as their primary language?**
<table>
<thead>
<tr>
<th>Spanish</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Portuguese</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>Haitian Creole</td>
<td></td>
</tr>
<tr>
<td>Vietnamese</td>
<td></td>
</tr>
<tr>
<td>Russian</td>
<td></td>
</tr>
<tr>
<td>French</td>
<td></td>
</tr>
<tr>
<td>Mon-Khmer/Cambodian</td>
<td></td>
</tr>
<tr>
<td>Italian</td>
<td></td>
</tr>
<tr>
<td>Arabic</td>
<td></td>
</tr>
<tr>
<td>Albanian</td>
<td></td>
</tr>
<tr>
<td>Cape Verdean</td>
<td></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:

We do not ask our PFAC Patients and their family members their ethnicity to be involved in PFAC. We do have members who are bilingual in both English/Russian and English/Spanish. We continue to have all meetings in both English and Spanish. Spanish is the second most common language spoken at the hospital.
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:

   Council members are asked to contribute to the agenda before the meeting and at time of the meeting.

18. The PFAC goals and objectives for 2019 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 2019– Skip to #20

19. The PFAC had the following goals and objectives for 2019:
   1. Increase membership of patient, family members and staff
   2. ABC Book 2nd edition completed
   3. Initiation of ESL Volunteer and tutor for outpatient school work
   4. Improving hospital common areas-chapel and 8th floor family waiting room

   Please list any subcommittees that your PFAC has established:
   Our council focuses on project driven versus subcommittees. We have a PFAC Core Council and PFAC Young Adult Council.

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:

Shriners Hospital for Children-Boston PFAC is listed on the hospital web site. There is an external email for users: bos-pfac@shrinenet.org All events are posted on both hospital web site and associated social media sites which the hospital utilizes.

☐ N/A – We don’t communicate through these approaches

Section 5: Orientation and Continuing Education

23. Number of new PFAC members this year: 5

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 2019 PFAC Impact and Accomplishments

The following information only concerns PFAC activities in the fiscal year 2019.

26. The five greatest accomplishments of the PFAC were:

<table>
<thead>
<tr>
<th>Accomplishment</th>
<th>Idea came from (choose one)</th>
<th>PFAC role can be best described as (choose one)</th>
</tr>
</thead>
<tbody>
<tr>
<td>26a. Accomplishment 1: Increase PFAC Awareness among staff, patients and family members</td>
<td>☒ Patient/family advisors of the PFAC</td>
<td>☒ Being informed about topic</td>
</tr>
<tr>
<td></td>
<td>☐ Department, committee, or unit that requested PFAC input</td>
<td>☒ Providing feedback or perspective</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☒ Discussing and influencing decisions/agenda</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☐ Leading/co leading</td>
</tr>
<tr>
<td>26b. Accomplishment 2: Annual Educational Event</td>
<td>☒ Patient/family advisors of the PFAC</td>
<td>☒ Being informed about topic</td>
</tr>
<tr>
<td></td>
<td>☐ Department, committee, or unit that requested PFAC input</td>
<td>☒ Providing feedback or perspective</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☒ Discussing and influencing decisions/agenda</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☐ Leading/co leading</td>
</tr>
<tr>
<td>26c. Accomplishment 3: New PFAC Volunteers for ESL and outpatient tutoring</td>
<td>☒ Patient/family advisors of the PFAC</td>
<td>☒ Being informed about topic</td>
</tr>
<tr>
<td></td>
<td>☐ Department, committee, or unit that requested PFAC input</td>
<td>☒ Providing feedback or perspective</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☒ Discussing and influencing decisions/agenda</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☐ Leading/co leading</td>
</tr>
<tr>
<td>26d. Accomplishment 4: Young Adult Council and support group</td>
<td>☒ Patient/family advisors of the PFAC</td>
<td>☒ Being informed about topic</td>
</tr>
<tr>
<td></td>
<td>☐ Department, committee, or unit that requested PFAC input</td>
<td>☒ Providing feedback or perspective</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☒ Discussing and influencing decisions/agenda</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☐ Leading/co leading</td>
</tr>
</tbody>
</table>
27. The five greatest challenges the PFAC had in FY 2019:

27a. Challenge 1: Increasing patient and family membership and awareness. The young adult council addition has been very helpful. PFAC has issues with consistency at meetings given patient population and demographics.

27b. Challenge 2: Transition of leadership of PFAC Council to patient and family members than staff led. Need to work on co-leadership more

27c. Challenge 3: Fiscal resources for program ideas, development and support

27d. Challenge 4: Having patients and family members involved in projects

27e. Challenge 5: Ongoing challenges for our hospital future among last year’s right size of patient care and affect on both patients, families and staff

☐ N/A – we did not encounter any challenges in FY 2019
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 2018

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 (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:

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

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:

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):
☐ All PFAC members were made aware of annual report and to review contents requirement. No submissions were sent to staff chairperson. Staff chairperson completed report.
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): report also reviewed by Care Management Nurse Manager prior to submission

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: www.shrinershospitalsforchildren.org/locations/boston
   ☐ 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: www.shrinershospitalsforchildren.org/locations/boston
   ☐ No, we don’t have such a section on our website