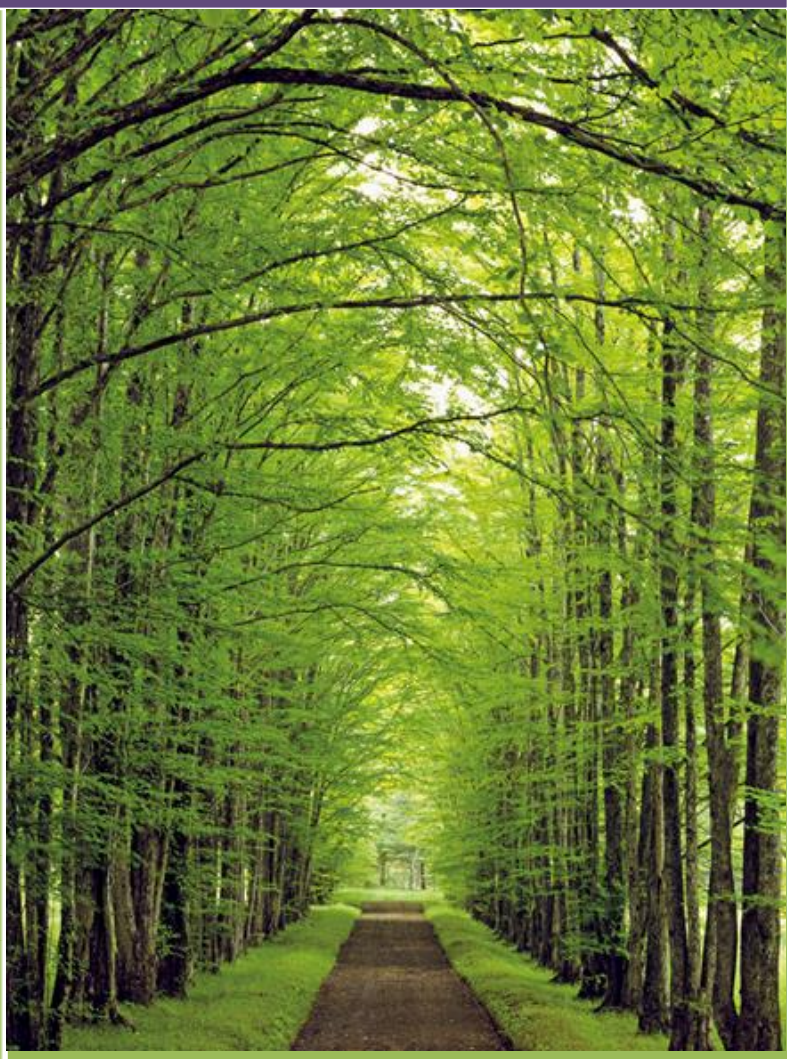
Beth Israel Deaconess Medical Center

2017

Patient and Family Engagement Annual Report



The image of the arbor represents the coming together of BIDMC's work in patient and family engagement and healthcare quality and safety.

2017 Patient and Family Engagement Annual Report

Hospital Name: Beth Israel Deaconess Medical Center (BIDMC)
Date of Report: September 30, 2017
Year Covered by Report: October 1, 2016-September 30, 2017, or FY (Fiscal Year) 2017
Year Patient and Family Engagement Program and Hospital-Wide PFAC Established: 2010
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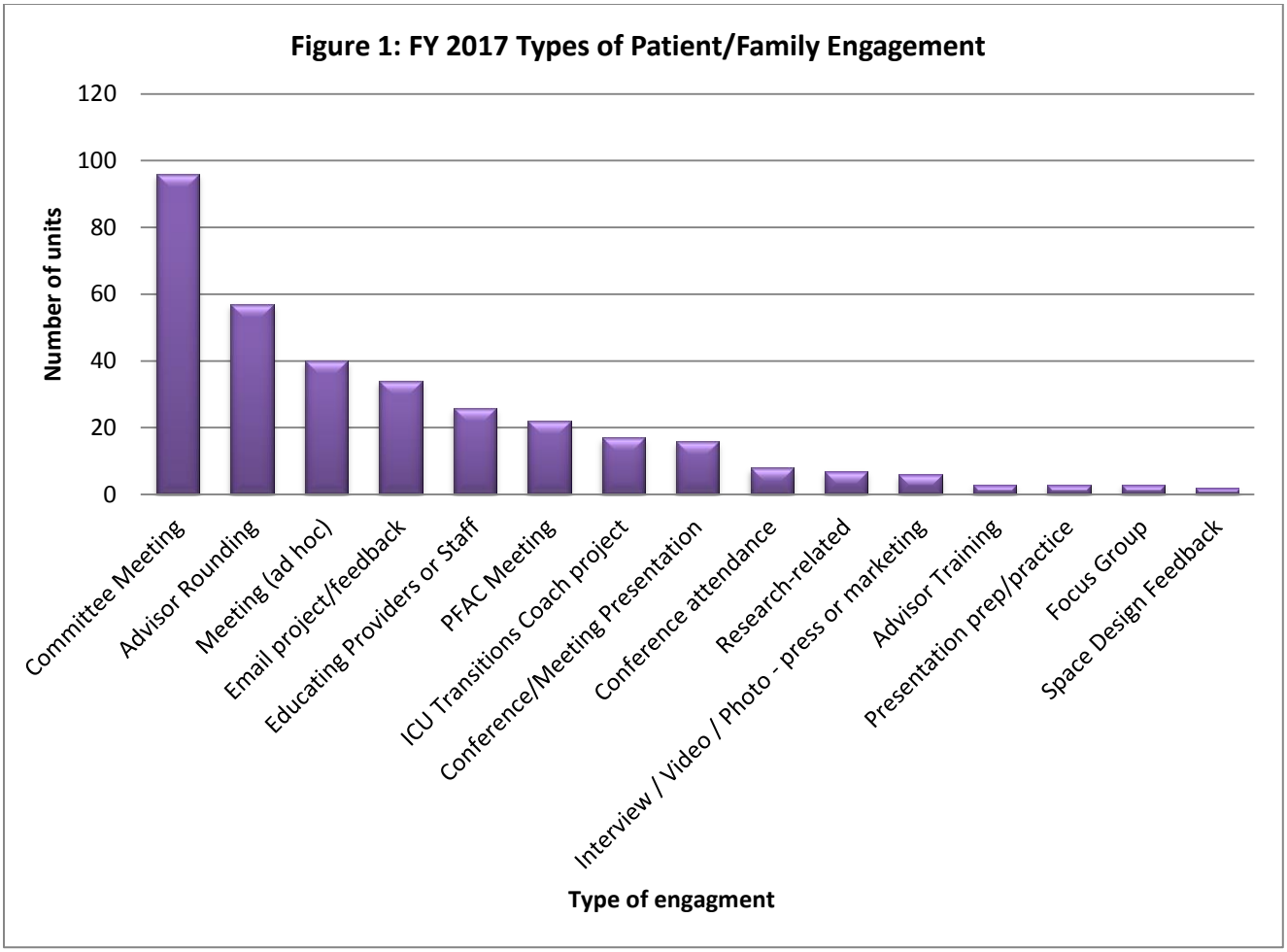
Report is available by request and posted online at http://www.BIDMC.org/quality-and-safety/patient-family-advisory-council.aspx

Summary

Under Massachusetts Law, hospitals are required to submit an annual report for their Hospital-Wide Patient and Family Advisory Councils (PFACs) publicly available by October 1 of each year. The Patient and Family Engagement program at BIDMC uses this requirement as an opportunity to provide an overview of not only its HW (Hospital-Wide) PFAC, but of overall contributions made by our patient and family advisors. The FY 2017 report includes information about four advisory councils, which include the HW PFAC, the Adult Intensive Care Unit (ICU) PFAC, Neonatal Intensive Care Unit Family Advisory Council (NFAC), and the Universal Access Advisory Council (UAAC). It also highlights several other ways in which advisors have partnered with staff and providers over the past year.

The spectrum of advisor contributions in FY 2017 underscores the adaptability of patient and family engagement to any kind of improvement initiative, simple or complex, short-term or long-term, hospital-wide or highly specific. The Patient and Family Engagement team makes every effort to select the right format in order to get the most well-timed, relevant and substantive feedback from advisors. PFAC meetings are an invaluable resource; for some projects, however, they may not be the optimal means by which to effectively partner with patients and family members. Certain improvement initiatives, research projects, written material review, or other projects, call for a targeted or tailored strategy involving advisors who can best speak to specific issues or experiences, in a format that is fitting to the goals of the project. Advisors at BIDMC are increasingly joining standing committees and task-forces, taking part in staff and provider education and retreats, presenting at national conferences, and assisting with pilot projects that allow us to collect real-time feedback from current patients and family members.

The two figures and charts on the following pages demonstrate the wide range in types of engagement in which advisors participated in FY 2017 and the number of hours that advisors contributed to each type of engagement.



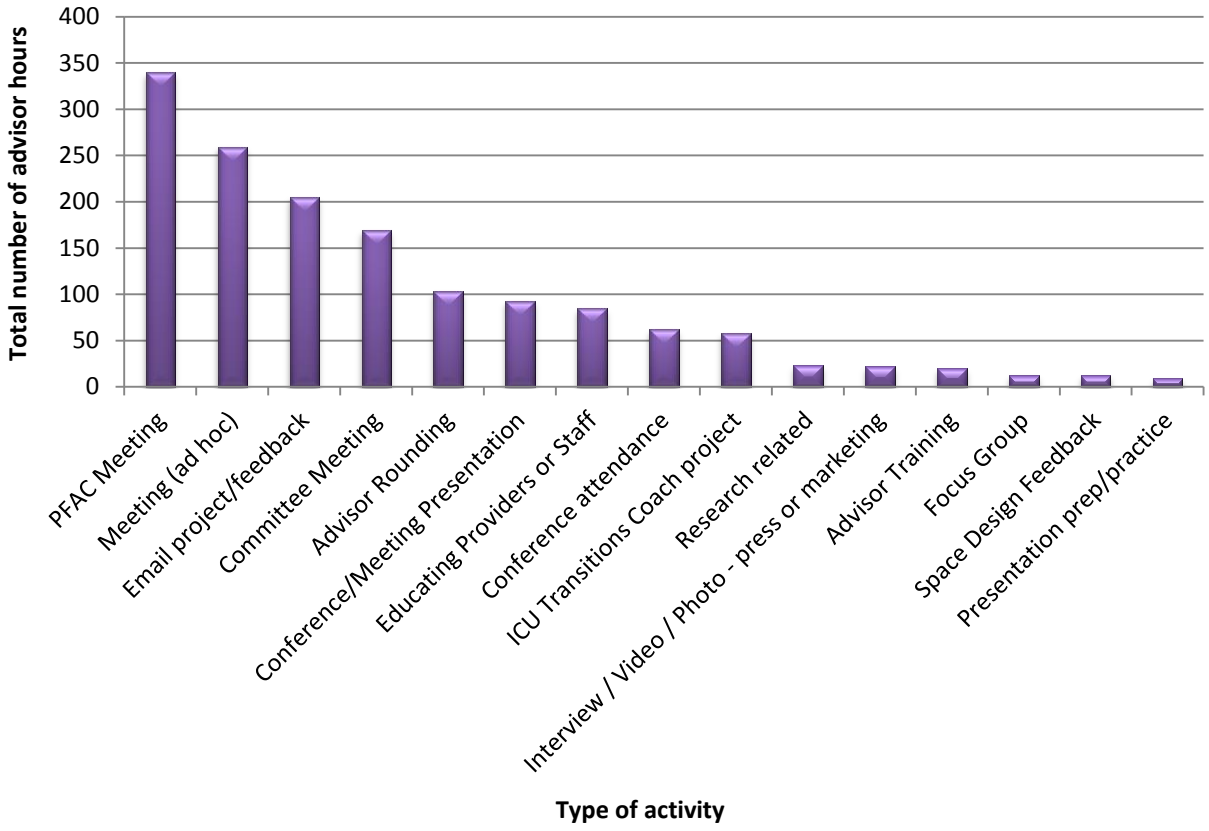
Type of Engagement	Number and percent of units of each type of engagement in FY2017 (N=340 units)	
Committee Meeting	96	*28%*
Advisor Rounding	57	*17%*
Meeting (ad hoc)	40	*12%*
Email project/feedback	34	*10%*
Educating Providers or Staff	26	*8%*
PFAC Meeting	22	*6%*
ICU Transitions Coach project	17	*5%*
Conference/Meeting Presentation	16	*5%*
Conference attendance	8	*2%*
Research related	7	*2%*
Interview / Video / Photo - press or marketing	6	*2%*
Advisor Training	3	*1%*
Presentation prep/practice	3	*1%*
Focus Group	3	*1%*
Space Design Feedback	2	*1%*

In Figure 1, a “unit” of engagement indicates a unique instance of a meeting/event/email request in which one or more advisors participated. For example, a unit would be one PFAC meeting; one request for email feedback; one shift of inpatient rounding; one conference. The charts show that, in terms of the number of instances in which one or more advisors were partnering with BIDMC employees or providers throughout the year, committees represented the majority of this partnership, 28% of all advisor engagement, while PFACs made up only 6%. Committees in which advisors participated are listed later in the report. Advisor rounding, launched in 2015, has continued to thrive, allowing us to collect and utilize real-time patient and family feedback on inpatient units, using peer-to-peer engagement. Email projects/feedback and educating staff and providers have also figured prominently this year.

While indicative of the spread and range of engagement, Figure 1 does not take into account the number of advisors participating in a given activity. Examples of activities that typically involved fewer advisors each time are committee meetings, advisor rounding, educating providers or staff, giving a presentation. E-advisor activities (advisors providing feedback via email) and PFAC meetings had the highest number of advisors per instance of engagement, an average of 7 advisors per e-advisor request and an average of 11 advisors at each Hospital-Wide PFAC meeting. The average number of advisors participating in each engagement activity was 2.4.

Figure 2 reflects “advisor hours” given to each type of engagement; that is, the numbers of advisors involved and the duration of engagement activities. This figure shows that, while far fewer PFAC meetings took place than other types of engagement, PFAC meetings did represent the highest contribution of advisor hours.

Figure 2: Number of Total Advisor Hours Spent on Each Type of Engagement in FY 2017 (N=1472 hours)



Type of Engagement	Number and percent of total advisor hours contributed to each type of activity in FY 2017 (N=1472 hours)	
PFAC Meeting	340	23%
Meeting (ad hoc)	259	18%
Email project/feedback	205	14%
Committee Meeting	169	11%
Advisor Rounding	103	7%
Conference/Meeting Presentation	93	6%
Educating Providers or Staff	85	6%
Conference attendance	62	4%
ICU Transitions Coach project	58	4%
Research related	23	2%
Interview / Video / Photo - press or marketing	22	1%
Advisor Training	20	1%
Focus Group	12	1%
Space Design Feedback	12	1%
Presentation prep/practice	9	1%

As shown in the figures, overall this past year, 98 advisors contributed a combined total of 1,472 volunteer hours, **142 more hours than in the previous year**, continuing a steady upward trend. The value of FY 2017's volunteer advisor hours was valued at approximately $44,000. In the seven years since the Patient and Family Engagement program was launched, advisors at BIDMC have contributed a total of 6,917 hours, valued at $168,466.

Factors which have influenced continuous growth in the range of advisor activities as well as greater contributions of advisor time have included: BIDMC's continued investment in a Patient and Family Engagement program; an increase in requests for BIDMC advisors from parties both inside and outside of our institution; an increase in awareness of the patient and family engagement program within the institution; and increases in advisor participation in presentations, at conferences, and in pilot projects such as the advisor rounding project and the ICU transitions guide project.

By far the most important factor in the strength and endurance of BIDMC's program is the dedication of its advisors. This year, advisors offered the following statements as reflections of appreciation of the Patient and Family Engagement program at BIDMC:

- *As a full-time caregiver, I've lost a lot of professional purpose I once had with a corporate career. Being part of the BIDMC volunteer community/PFAC, I have been given a way to feel useful and have a sense of purpose. Seeing patients being helped by our work has become a very rewarding part of my life.*

  Ingrid Cohen, Hospital-Wide PFAC

- *I participated in staff training this year which proved to be very interesting. Previously, I thought of issues patients and families have, but now I know some of the difficulties the staff can have and how they still do their work with caring and compassion. Hearing other people's points of view is a learning experience for all involved and increases understanding.*

  Joyce Black, Service Excellence Steering Committee

- *Being a Patient Advisor is an honor and a delight. My suggestions and insight are appreciated, which makes me feel respected and smart. More importantly, the ever-growing interest on the part of myriad hospital departments to solicit Patient and Family Advisors' counsel sends an important message to both employees and patients: BIDMC is Human First, always striving to provide the best care and support to the entire BIDMC community.*

  Peggy Hooper, Service Excellence Steering Committee

- *Being a PFAC member has helped me advocate for my husband throughout his own illness. During this time, he has become a PFAC member. Now, we advocate side by side as a team. Not only for us, but for others who may need a voice.*

  Jackie Giannakoulis, ICU PFAC; Advisor Rounder

- *Patient Rounding has been an amazing experience! Having the opportunity to meet people at such a vulnerable time in their lives is inspirational, and giving them the opportunity to share their feelings, voice their concerns, and to express appreciation for the people who give them care is a gift. I learned a lot and was touched by the courage they demonstrated – a lesson to be learned and remembered. Thank you for that opportunity!*

  Deedee O'Brien, Advisor Rounder; Advisor for Health Care Associates

- *Volunteering has opened so many doors for me, provided me with a sense of purpose again, and rekindled my sense feeling smart and feeling intellectually challenged. Helping others energized me and fills me with good feelings which only provides me with positive energy and motivation; a reason for getting out of bed every morning and fighting my MS head on!*

  Stacey Whiteman, UAAC PFAC

- *We have a responsibility as citizens to give back for what we receive. I appreciate being a part of the Universal Access Advisory Council because it gives me an opportunity to "pay it forward".*

  Richard Hackel, UAAC PFAC

Patient/Family Advisor Recruitment

Advisor recruitment involves paper and electronic applications, social media postings, word of mouth, and referrals from providers. Application brochures are located in waiting areas and inpatient solariums. The Patient and Family Engagement program maintains a presence on the BIDMC website (www.BIDMC.org/pfac), where potential advisors can find an online version of the application. In-person interviews are conducted by current members of the PFAC along with the Project Leader for Patient and Family Engagement. Members are selected with the following qualifications in mind:

- Ability to listen and hear other points of view
- Ability to share personal experiences in ways that others can learn from them and to then think beyond those experiences
- Culturally sensitive and competent with respect to the diverse patient base that BIDMC serves
- Ability to see the big picture
- Enthusiastic about supporting BIDMC's mission/vision
- Willingness to learn to be an effective council member (know how to ask the tough questions and what to do when not in agreement)
- Seen at BIDMC within the last two years; and
- A sense of humor

The complete screening process of a new candidate includes: completion of a paper or web-based application; a phone interview with the Program Leader for Patient and Family Engagement; an in-person interview with the Program Leader and an advisor and/or a staff chair of a PFAC; standard volunteer onboarding including CORI (criminal background) screening, HIPAA and compliance training; medical screening if appropriate to the assignment; and, for certain roles, in-person, an orientation and training session specific to the assignment.

Advisors who travel to the medical center or to off-site meetings and events receive free parking or reimbursement for The Ride or the MBTA. Food and beverages are served during PFAC meeting and at other meetings and functions that occur during mealtimes. If requested, advisors receive reimbursement for childcare or eldercare. Advisors do not receive stipends. The hospital holds an annual appreciation celebration for advisors, where they receive a small gift.

Since 2010, 305 patient and family advisor applications have been submitted to BIDMC, and after careful screening, 185 of these applicants have gone on to participate in councils, committees, short-term projects, or e-advising projects. Reasons for applicants not participating as advisors after submitting applications include: lack of an opening on a particular council in which an advisor was interested; loss to follow-up; change in an applicant's availability to serve as an advisor; or determination by the Patient and Family Engagement team (including advisors who assist with interviewing candidates) that an applicant is not the best candidate for the role that the applicant desires.

Between October 1, 2016 and the end of September, 2017, the period covered by this report, BIDMC received 12 new advisor applications. Of these new applicants:

- 4 joined the HW PFAC;
- 3 joined the ICU PFAC;
- 3 became ad hoc advisors;
- 2 did not become an advisor.

New advisors are invited to join a private Patient and Family Engagement Facebook group, and are added to the mailing list to receive invitations to participate in new projects.

The next sections provide summaries of BIDMC's four PFACs.

Hospital-Wide PFAC

Overview and infrastructure

The HW PFAC was formed in 2010, the same year that BIDMC established a Patient and Family Engagement program. The program is managed by a Program Leader for Patient and Family Engagement, a full-time position in the Department of Social Work. The Senior Director of Social Work and Patient and Family Engagement oversees the program, which encompasses the hospital's PFACs, as well as other patient and family engagement work throughout the institution. The Program Leader is responsible for coordinating the HW PFAC, recruiting, onboarding, and assigning patient and family advisors, managing the Advisor Rounding project and co-managing the ICU transitions guide program, giving internal and external presentations about patient and family engagement, and working with providers, researchers, and employees to develop and support partnerships with advisors.

The HW PFAC is co-chaired by a patient/family advisor and the Senior Director of Social Work and Patient and Family Engagement. In FY 2017 HW PFAC was comprised of 13 patient and family advisors (57%) and 10 BIDMC staff members (43%). Staff members include the Senior Director of Social Work and Patient and Family Engagement, Senior Vice President for Patient Care Services and Chief Nursing Officer; Director of the Office of Improvement and Innovation; Director of Patient Safety; a Hospitalist with an appointment as Associate Director for Inpatient Quality; 2 Ambulatory Directors; a Quality Improvement Senior Project Manager; Clinical Director of Operations in the Emergency Department, and a Clinical Nurse Specialist in the Emergency Department.

As dictated in the Hospital-Wide Patient and Family Advisory Council Bylaws (attached, see appendix) the HW PFAC utilizes term limits. A term is two years; advisors are able to extend their terms for an additional year after the second and third years, for a maximum of four years. In FY 2017, four advisors on the PFAC stepped off the council; 3 of these advisors completed the maximum term of 4 years, while 1 completed 3 years. As emeritus members, they will no longer attend meetings, but will have opportunities be active participants in other patient and family engagement opportunities. Five new advisors joined the council in September, 2017.

Two patient/family advisors are members of BIDMC's board-level quality and safety committee, the Patient Care Assessment Committee.

HW PFAC Orientation

New HW PFAC members are oriented at the beginning of their terms by the Project Leader for Patient and Family Engagement and a current advisor. Orientation topics include BIDMC's mission, the HW PFAC's bylaws, member responsibilities, what to expect at meetings, themes of PFAC work, and projects past and present.

HW PFAC Agendas and Meetings

The council typically meets every other month, 6 times per year for 2 hours in the evening. In FY 2017, one meeting was cancelled due to scheduling conflicts. Agendas are largely shaped by requests by staff members, providers, researchers, as well as health care professionals from outside organizations. Areas of focus include new hospital initiatives, research projects, marketing materials, policies, patient and family support protocols, communication strategies, and other initiatives. When requests are made, the Program Leader and Senior Director consult with the advisor co-chair before deciding whether a topic is appropriate for the agenda and how a presentation should be framed to ensure a productive discussion, such as whether to send "homework" or questions to members in advance of the meeting, or how much time to allot to a topic. After review by the co-chairs of the PFAC and the Program Leader of Patient and Family Engagement, the agenda is finalized and emailed to members at least one week prior to the meeting.

At the start of each meeting, advisors share health care experiences that they have encountered since the last meeting. Hospital leaders who are members of the council make note of these experiences to share at monthly leadership meetings. After the meeting, with the permission of the advisor, the staff co-chair or Program Leader ensures that the experiences and associated feedback are shared with the appropriate department leader(s). In FY 2017, after it was noted that experiences were frequently related to the Emergency Department (ED), two ED staff leaders were invited to become members of the PFAC.

Following the exchange of advisor experiences and announcements, a typical meeting involves at least two presentations, with the majority of time dedicated to advisors providing feedback.

HW PFAC Impact

Topics discussed at HW PFAC meetings over the past year include:

- BIDMC's new senior leadership structure and roadmap (presented by BIDMC's new president, Peter Healey);
- Support for family members of patients who die in the hospital;
- Development of InfoSage, a web-based care coordination platform for family caregivers;
- Increasing usership of OpenNotes and PatientSite and understanding the barriers;
- Shared decision making in the setting of serious illness ;
- Improving the phone experience ;
- Improving inpatient food service;
- Improving communication of radiology recommendations; and
- Self-scheduling appointments.

Presenters in 2017 have adopted several suggestions of advisors. Advisor feedback guided the contents of a comfort cart that has been created to provide support to families whose loved one is actively dying

in the hospital. Feedback provided by PFAC members about the phone experience has led to improvements in phone coverage and more consistent service standards in the Department of Surgery. Advisors strongly urged the food services team to improve access to a healthy meal after 7:00 PM, when many patients are admitted; advisors also stressed the benefits of online ordering. Both suggestions are now being piloted.

Presenters have cultivated relationships with the PFAC and its individual members (including emeritus members) by working with advisors outside of PFAC meetings to advance improvement projects. One example of such a project is OpenNotes. Following a presentation at HW PFAC, the OpenNotes team enlisted PFAC members as ambassadors to assist with outreach to other hospitals. Advisors were also active in the development of the OpenNotes website and review of a mental health toolkit.

The following table shows HW PFAC representation on committees and task forces in FY 2017.

Committee Name	**Advisor Representation**
Patient Care Assessment Committee of the Board of Directors (quality & safety)	1 HW PFAC member; 1 Emeritus HW PFAC member
Ethics Advisory Committee	1 HW PFAC member; 1 other advisor
Medication Safety Subcommittee	1 HW PFAC member
Drug Shortage Task Force	1 HW PFAC member
OpenNotes Workgroup	4 HW PFAC members; 4 other advisors
Inpatient Psychiatry Advisory Committee	1 HW PFAC member; 3 other advisors
Health Care Associates work groups	1 HW PFAC member; 3 other advisors
PatientSite Governance Committee	1 Emeritus HW PFAC member; 1 other advisor
Inpatient QI Retreat and work group	1 HW PFAC member and 1 other advisor
Society of Hospital Medicine National PFAC	All HW PFAC members
Quality Innovation Network / New England Quality Improvement Organization PFAC	1 HW PFAC member

HW PFAC Goals and Challenges:

The HW PFAC has not had a formal goal-setting process; the work of the PFAC aligns with BIDMC's strategic goals. An ongoing PFAC-specific priority has been to increase membership diversity. It is a constant challenge to recruit advisors who are representative of the diverse patient population served by BIDMC. The most effective means of increasing diversity has been outreach to employees in order to get targeted referrals. The patient/family advisor membership of FY 2017 was made up of 4 men and 9 women. Ages of members span nearly 50 years. It is difficult to delineate the degree to which our HW PFAC members represent the population in terms of race, ethnicity, income, or education level, as applicants are not asked to identify these characteristics in the screening process. The Patient and Family Engagement program remains committed to seeking members who reflect the diversity of the populations that we serve.

NICU Family Advisory Council

The NICU Family Advisory Council (NFAC) was created in 2006. Currently, the council includes 20 family members and 8 staff members. In FY 2016, the council met three times, advising on the following initiatives:

- The NICU continues to work on its major care initiative for patients and families this year to have skin-to-skin with their infant.

- The NICU rolled out a new Crib News program that gives parents a review of the past 24 hours of their infants care on the NICU.

- The NICU will launch MyNICU in fall of 2017. Adapted from the BIDMC ICU application, MyNICU is an online tool that helps parents and families stay connected to their baby's care. They can learn what it is like to be in the NICU and how to be a part of their baby's care team.

- The NICU launched the LTL (Language through Listening) Learners Program. It is a program that encourages parents and other caregivers to talk to and read to their babies more often

- The NICU provided feedback about how newly expanded facilities can best serve families and provide care. Renovation and expansion construction expected to begin before the end of 2017.

- Through the generosity of the NFAC, families of patients continue to receive Sweet Peas care packages to help with their comfort and daily concerns in the NICU.

- The NICU held its 25th anniversary celebration and reunion, a tradition that occurs every five years. This year 1,300 NICU graduates, parents, siblings, and staff gathered together to celebrate the NICU. The event was covered by the Boston Globe.

Council members have also informed the following NICU programs:

- Meet and Greet parent lunches and dinners, where NICU families connect with each other in a casual setting to share their experience and socialize with NICU peers.

- Eve of Thanks: The NICU also hosts an evening for alumni families to come and share pie and good cheer with current NICU families. This event will take place again this year in November 2017.

ICU Patient and Family Advisory Council

The ICU PFAC was initiated in 2008. The council gained 3 new patient/family advisors this year, for a total of 9 advisors. Four staff members and a physician also participate in the council. The ICU PFAC has a unique structure: every three months, the ICU PFAC and the Critical Care Experience Taskforce (made up of staff members and providers) have a combined one-hour meeting; following this meeting, the ICU PFAC meets on its own for one hour. Though it typically meets quarterly, the ICU PFAC only met in January and April this year. Below are the highlights/accomplishments for FY 2017:

- Improving ICU transitions to inpatient floors—the creation of the ICU Transition Guide program at BIDMC:
    - Advisors helped ICU quality leaders realize that transitions from the ICU are one of the most difficult experiences patients and families face as they are leaving an environment where trust and relationships have formed, and they are entering a new environment where they do not know staff or routines.
    - Advisors have been instrumental in helping us develop the information that patients and families want to know about regarding the transfer process, and also suggested that it would be ideal if volunteers could help provide comfort during the transition process.
    - Through continued collaboration between ICU advisors, Critical Care Quality, Social Work, Volunteer Services, Medicine Residents, and Nursing, a new program has been developed where specially-trained hospital volunteers accompany the patient/family in a non-medical capacity through the ICU to floor transition process. The program is designed to have volunteers meet the patient/family in the ICU to help set expectations and then check in with the patient/family after the patient transitions to the floor to help orient them to their new room.
    - A member of the ICU PFAC has partnered on the development of the volunteer training curriculum, and conducts trainings.
    - The ICU Transition Guide program was first piloted in four ICU's earlier this year and recently expanded to all the ICUs on the West campus.
- Advisors shared their invaluable stories and insights to a packed room of BIDMC's Physical Therapists (about 30 people) regarding mobility, weakness, and delirium in the ICU.
- Advisors are helping Dr. Somnath Bose develop patient/family preferred outcome measures by answering a questionnaire and rating which outcomes are most important following critical illness.

Universal Access Advisory Council

The Universal Access Advisory Council (UAAC) was created in 2010. The goal of the council is to provide accessible and respectful care to those with disabilities, and to ensure that people with disabilities are getting the same excellent quality of care that other patients are getting at the medical center. The first five years, the focus was on physical improvements, such as accessible scales, door openers, low counters, and ramps. As this work progressed and with the help of advisors, it became apparent that staff education needed to coincide with the physical plant changes. As a result, the focus of the past two years has shifted away from facilities issues, and more toward awareness, training and operations.

The shift in focus prompted an alteration in the structure of the UAAC. The co-chairs of the UAAC recognized that the meeting agendas were often identical to those of the Universal Access Staff Council, an interdisciplinary council launched in 2016 that included one advisor from the UAAC. With that in mind, the two councils merged in 2017. Benefits of the merger included increased awareness of patient and family engagement among employee members of the committee; increased leadership presence when advisors were providing feedback; ability for a larger, more interdisciplinary group of employees to hear and respond to advisors' recent experiences (shared at the start of each meeting); and improved, more efficient partnership on accessibility initiatives.

The new UAAC currently includes 8 patient/family advisors who have experienced a range of disabilities, and approximately 20 staff members. This year, the council and/or individual members:

- established a new organizational structure to continue building off the work accomplished around the Dept. of Justice settlement;
- created a quarterly newsletter, *BIDMC Universal Access News Clips;*
- worked on a shared drive for the team for easy access to committee information, and other resources and presentations;
- provided feedback on patient information regarding our service animal policy;
- partnered on efforts to provide better care for patients with cognitive impairment;
- consulted with the food services department about braille and large print menus;
- Provided valuable input to the OpenNotes team on a variety of initiatives;

The UAAC looks forward to continuing this important work, integrating critical improvements in facility accessibility with expanded awareness and training for all staff, and identifying operational improvements to that support equitable and improved access to care universally.

Health Care Associates Advisors

Advisors are active partners of the Health Care Associates (HCA) primary care practice. Embedding advisors in standing committees and projects is the engagement model that is most fitting this setting. Four HCA advisors make up just 4% of BIDMC's advisor pool, but their contributions to HCA represent 10% of all BIDMC advisor hours in FY 2017, 147 hours out of 1472 total advisor hours. Advisors participated on/in:

- Weekly interdisciplinary operations committee
- Monthly provider team meetings
- Call center redesign committee
- Staff orientations and trainings
- Center for Primary Care/Primary Care Initiatives Network event
- Community outreach project – patient follow-up on medications, appointments, and screenings
- Primary Care Initiative Network meetings
- Advance care planning improvement in the primary care setting
- A presentation about patient and family engagement to BIDCO (Beth Israel Deaconess Care Organization

Other Committees and Task Forces

In addition to the committees mentioned in the HW PFAC summary and in the Health Care Associates summary, advisors were active members in the following committees:

- Service Excellence Steering Committee (2 advisors)
- BIDMC Experience Committee (2 advisors)

Retreats

Advisors participated in interdisciplinary retreats:

- Week-long inpatient quality retreat aimed at improving care delivery to enable more proactive care planning among ALL members of care team (2 advisors)
- Day-long BIDMC Experience Summit (3 advisors)

E-Advisor Initiatives

- Development of a parking information sheet for patients and visitors
- Review of "Healing After Harm" documents

- Review of an Open Notes mental health toolkit
- Review of the Open Notes website
- Review of Cancer Center welcome brochure
- Review of Respect and Dignity manuscript
- Review of an advance care planning survey
- Employee gift policy feedback
- Feedback about gender identification
- Feedback about radiology experience
- Testing of a cardiac webinar
- Society for Hospital medicine survey about being cared for by residents
- Review of a packet of materials for family members of a patient who dies in the hospital
- Review of a provider guide to death pronouncement
- Review of an Opioid factsheet
- Survey about phone encounters

Video Trainings for Providers and Employees

Advisors were filmed for employee training on the following topics:

- Code conversations / advance care planning
- BIDMC's gift policy
- Patient confidentiality
- Radiology service excellence

Presentations

Advisors participated in the following presentations in FY 2017:

- Tufts Healthcare Innovation Conference, panel presentation, December 2016
- Institute for Healthcare Improvement webinar on Respect and Dignity, February 2017
- Institute for Healthcare Improvement Conversation Ready Learning Collaborative, March 2017
- The Patient, The Practitioner and The Computer: Holding on the Core of Our Healing Professions in A Time of Technological Change (PPC) Conference: Where We Want To Go: Future Directions, March 2017

- American College of Medical Quality Annual Conference: Respect and Engagement: Opening a Path to Safer Care, April 2017
- Mass Coalition for the Prevention of Medical Errors: Open Notes: a Patient & Parent Perspective, May 2017
- Massachusetts Coalition for the Prevention of Medical Errors: Patient and Family Engagement at BIDMC: Capturing the Patient Voice, May 2017
- Silverman Symposium poster: What Are We Learning from Advisor Rounding? , May 2017
- Silverman Symposium poster: Improving Transfers from the ICU to the Floor with a "Transition Coach", May 2017
- Human Resources staff meeting: Patient and Family Engagement at BIDMC,
- World Congress 4th Annual Patient Engagement and Experience Summit: Incorporate the Patient Voice into Care Planning and Program Design, September 2017

Research

Advisors were involved in the following research projects in FY 2017:

- PCORI-supported K08 grant from the Agency for Healthcare Research and Quality on inpatient consultations (an advisor is the co-investigator and several advisors were interviewed for the study)
- CRICO-supported research on Open Notes and patient safety (advisors assisted in the development of the survey and spoke at the research team's kickoff meeting)
- Pilot project on Improving Transfers from the ICU to the Floor with a "Transition Coach", May 2017 (advisors partnered in the development of the project and one advisor helped to create a volunteer training curriculum and conducted trainings
- Project about advance care planning aimed at determining whether patients have preferences about which provider they would be comfortable speaking with when having conversations about advance care planning (advisors reviewed the research survey)
- Research to better understand outcomes following Acute Respiratory Distress Syndrome (ARDS) (Advisors reviewed the survey instrument and provided input about their own experience with ARDS)
- Research on improving the quality and outcomes of older women's decision-making around breast cancer screening and treatment (advisors assisted in review of the grant proposal and will provide ongoing assistance)

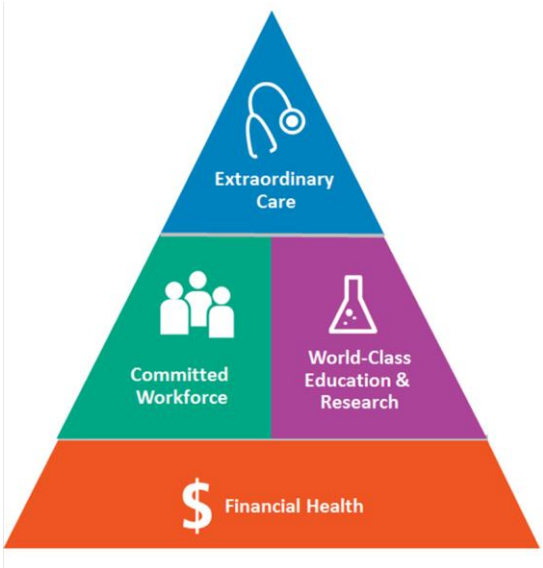
Publications:

BIDMC Advisors were featured or acknowledged in the following publications in FY 2017:

- The FY 2017 Department of Medicine Annual Report
- Macda Gerard, Alan Fossa, Patricia H Folcarelli, Jan Walker, Sigall K Bell. What Patients Value About Reading Visit Notes: A Qualitative Inquiry of Patient Experiences With Their Health Information. *Journal of Medical Internet Research*, 2017; 19 (7)
- Sigall K. Bell, Samuel M. Brown, Ariel Mueller , Erica Dente , Tae-Eun Kim , Barbara Sarnoff Lee , Kristin O'Reilly , Ken Sands , Daniel S. Talmor. Speaking Up About Care Concerns in the ICU: Patient and Family Attitudes. *American Journal of Respiratory and Critical Care Medicine* 2015;191:A3779

Mission Driven

The mission of BIDMC is "to provide extraordinary care, **where the patient comes first**, supported by world-class education and research." The strategic operating goals of the institution are grounded in this mission. Having advisors partner with providers and employees on our PFACs, committees, and other projects, ensures that the patient comes first in the fulfillment of improvement initiatives. The following charts demonstrate how the contributions of advisors align with BIDMC's mission and goals:



Extraordinary Care

Advisors have partnered with BIDMC on the following projects, initiatives, and goals:

Achieving Quality Targets Through the Practice of Respect	•Providing support for family members of patients who die in the hospital. •Mystery shopping program •Working with and supporting gender-diverse people
Population Management	<u>Disease management</u> •A proposal involving radiologists communicating results to patients •Development of an OpenNotes website and mental health toolkit •Improving the cancer welcome brochure •Testing of cardiac webinar for patient education before surgery •MyNICU - online tool that helps parents and families stay connected to their baby's care <u>Demand management</u> •Call center improvements for scheduling in Department of Surgery and in primary care •Improvements in inpatient food service ordering •Patient self-scheduling •Improvement of parking information for patients •Feedback about "MyChat" pilot to enable two-way "paging" <u>Disability management</u> •Development of a toolkit for the employee portal •Creation of a "BIDMC Universal Access News Clips" newsletter •Improving accessibility for patients of size <u>Lifestyle management</u> •Development of a web-based program for family caregivers to communicate with one another, get information, and document appointments, medications , and health history •Shared decision making in the setting of serious illness, and improving advance care planning.

	Extraordinary Care
	Advisors have partnered with BIDMC on the following projects, initiatives, and goals:
Safe, Efficient Inpatient Progression and Reducing Avoidable Readmissions	• Reorganization of the way that patients are assigned to providers in inpatient units, with a goal to provide better, more efficient coordination and teamwork between our physician and nursing staff, enabling them to be a more cohesive team. • Development and implementations of the ICU Transitions Guide program, to improve safe and efficient transfer from ICU to floor. • Participation on Society for Hospital Medicine National PFAC
Implement Leading Opioid Management Strategy	• Development of an opioid oversite committee (2 advisors are members) • Development of a patient information sheet about opioids
Organization-Wide Approach to Patient Experience	• Launch of a BID Experience Committee (2 advisors are members) • Advisors involved in trainings of providers and employees • Advisor rounding – advisors collect real-time patient experience data ; metrics are shared with leadership

World Class Education & Research

	Advisors have partnered with BIDMC on the following projects, initiatives, and goals:
Education	• Simulating inpatient scenarios to teach new physicians how to have a "code conversation" with patients and family members • Orientation of ambulatory staff members • Conference presentations about: respect and dignity; health technologies for disease management; OpenNotes; patient/family engagement; conversation ready • Poster presentations at Silverman Symposium
Research	• Research to identify the principle elements that shape patient, family member, and physician perceptions about the quality of an inpatient consultation • Research to evaluate an ICU transition intervention • Research about inter-hospital transfers • CRICO grant–OpenNotes safety survey

Committed Workforce

	Advisors have partnered with BIDMC on the following projects, initiatives, and goals:
Integrate Employee Experience & Patient Experience	• BID Experience summit • Development of service standards in radiology • Use of MyApplause so that advisors could recognize employees who provided extraordinary care. • Advisors nominated a Unit Coordinator for an annual award based on her positive impact on patient experience • Teaching service excellence standards to front line ambulatory staff members • Assessment of impact of MyChat pilot on patient experience • Employee education films involving advisors – gift policy, confidentiality

Financial Health

	Advisors have partnered with BIDMC on the following projects, initiatives, and goals:
Financial Health	Cost-efficient renovation of ICU family waiting rooms

BIDMC Leaders Recognize the Contributions of Advisors in 2017

Perhaps the best indication of the valued and widespread impact of our Patient and Family Engagement program is feedback from hospital leaders and providers who have partnered with advisors. The following statements were shared with advisors at our annual appreciation event, in May 2017:

- *Advisors are vital members of our community who share our commitment to improving the BIDMC experience for our patients, families, physicians and staff. You help us maintain the high expectations we set for ourselves to deliver compassionate, high quality care. Thank you for your dedicated service.*

  Pete Healy, President, BIDMC

- *Thank you for your many contributions over the years, from attending monthly Ambulatory Service Excellence meetings to participating in our staff trainings - we appreciate all that you do, and your input is invaluable!*

  Sherry Calderon, Director, Ambulatory Operations Chair, Service Excellence Steering Committee

- *We are so grateful for our volunteer ICU Transition Guides who help our vulnerable patients cope with the stress and confusion of a care transition. The Advisors have been essential to the successful launch of this program!*

  Stephanie Harriston-Diggs, Director, Volunteer Services
  Shannon Lawson, Program Coordinator, Volunteer Services

- *Your work as advisors is an essential part of crafting a shared vision for the Practice of Respect at BIDMC. Thank you!*

  Lauge Sokol-Hessner, Attending Physician, Internal Medicine; Associate Director of Inpatient Quality; Staff Advisor; Hospital-Wide PFAC

- *The advisors on the Ethics Advisory Committee are not afraid to speak up, help us think about the patient and family experience, and encourage us to always be patient-centered. It is a pleasure to work with them.*

  Katie Rimer, Director, Department of Spiritual Care and Education

- *It was such a pleasure to have Advisors participate in our QI retreat alongside a group of physicians and nurses. Their insights were integral to providing the voice of the patient as we worked through how to design a more collaborative care team.*

  Ali Wang, Management Engineer III, Office of Improvement & Innovation (i^2)

- *We love having patient advisors attend the trainings with the frontline employees. The advisors provide wonderful insights that help the staff have more empathy for patients, and engagement in the learning. The presence of patients results in staff feeling acknowledged for their hard work.*

  Ann Rogers, Organizational Development Professional Coach, Ambulatory Service Excellence Trainings

- *Advisors have provided valuable insight and feedback to us on several communications projects over the years. Their input always helps us communicate more clearly, concisely and compassionately with patients and family members. Thank you for all that you do!*

  Jennie Greene, Communications Director, Department of Medicine

- *The commitment of the PFAC to our patients and the advisors' thoughtful insights have improved the care that we provide and humbly remind us all of the great privilege and honor that we share in caring for patients.*

  Amber Moore, MD, Hospitalist, Instructor in Medicine, Harvard Medical School

- *Thank you for all the energy and enthusiasm you bring to PFAC. Your effort and commitment are greatly valued and appreciated.*

  Monique Willett, Social Worker; Chair, Inpatient Psychiatry Advisory Committee

- *Our Advisors have been instrumental not only in improving accessibility at BIDMC, but also in helping us to teach staff members about how to best care for and communicate effectively with our patients. Thank you!*

  Sarah O'Neil, Director, Care Connection; Co-Chair of Universal Access Advisory Council

- *Thank you for helping us to engage in more fulfilling, equitable, and compassionate care.*

  Leonor Fernandez, MD, Assistant Professor of Medicine, Harvard Medical School; Co-Chair of the Health Care Associates advisory council

- *We are often exhorted that the trick in caring for the patient, is .... caring... for the patient. No one does this more powerfully than our patients and the Patient and Family Advisory Committee. The PFAC plays a critical role in recentering the focus for hospitals and providers in this mission critical task. Thank you for the time, attention and care you give to help keep these organizations focused on caring for the patient. I wish that every provider had the chance to present to the PFAC. You strengthen and energize the best in us.*

  Narath Carlile MD MPH, Associate Physician, Brigham and Women's Hospital
  Lecturer, Informatics and Innovation Fellowship, Harvard Medical School

- *Our managers love to go to the floors and hear directly from patients on their experience with our service. Unfortunately, we don't get to see everyone and really appreciate the feedback that Advisors share with us. Nothing means more in the "patient/human first" model than having patients as partners. Thank you for all that you do!*

  Shana Sporman, Director, Food Services

- *The information that comes from the advisors about the little things that the staff members do that make a positive impact on our patients' experience is invaluable to me. The employees really appreciate the acknowledgement!*

  Sandra Sanchez, Nurse Director, Farr 7

- *Thank you for your contribution and great feedback towards improving our BIDMC community.*

  Mary Chan, Project Manager, Capital Facilities and Engineering

- *I am honored to have the opportunity to work alongside our ICU patient and family advisors on many projects, as I have seen firsthand how their stories and insights inspire staff and promote change. I am forever grateful for all the time our advisors have dedicated to different projects and the profound impact they have had in improving the patient and family experience at BIDMC.*

  Kate Zieja, Senior Project Manager, Critical Care Quality

- *Advisors have been extremely helpful to the OpenNotes initiative, sharing their stories and expertise. Their feedback was tremendously helpful as we developed our new website earlier this year.*

  Deborah Wachenheim, Manger, Stakeholder Engagement, OpenNotes

Taking Stock and Looking Ahead

In 2017, we saw an increase across all measures of patient and family engagement, introduced advisors to many novel roles both inside and outside of the medical center, and broke new ground with the launch of the ICU Transitions Guide volunteer role. Going forward, we will continue to foster awareness and partnerships between patient and family advisors and leaders across the organization; strive to recruit a more diverse team of patient, family, and staff advisors; and explore new methods for improving the patient experience through innovative approaches to patient and family engagement.

Appendix: Hospital-Wide Patient and Family Advisory Council Bylaws

Beth Israel Deaconess Medical Center

Hospital-Wide Patient and Family Advisory Council Bylaws

Article I. Name

The name of the organization is Patient and Family Advisory Council of Beth Israel Deaconess Medical Center (BIDMC). It is sometimes also referred to as the PFAC. It is also called the Council.

Article II. Mission

The mission of the BIDMC Patient/Family Advisory Council is to ensure that patients and their families come first and are consistently treated with respect, compassion, and the highest quality of care in all aspects of the BIDMC experience. It will accomplish this by actively collaborating with BIDMC leadership to ensure that the diverse voices of patients/families are included in all aspects of care, generating advice that leads to tangible changes in the organization.

Article III. Membership

Section 3.01 Roles and Responsibilities

(a) Patient and Family Advisors

- Attend each council meeting
- Engage thoughtfully with the issues presented for council review
- Provide constructive feedback from a patient and family perspective
- Respectfully listen to diverse opinions
- Agree to work within meeting infrastructure determined by Council
- Adhere to Confidentiality Agreement
- Inform Project Leader of changes or conflicts that would affect their ability to attend council meetings

(b) Staff Advisors

- Attend each council meeting
- Engage thoughtfully with the issues presented for council review
- Provide constructive feedback from a staff perspective
- Respectfully listen to diverse opinions
- Agree to work within meeting infrastructure determined by Council
- Adhere to Confidentiality Agreement

- Advocate for and report on progress towards incorporating Council feedback within the organization
- Inform Project Leader of changes or conflicts that would affect their ability to attend council meetings

(c) Co-chairs
- Attend each council meeting
- Work in collaboration with Project Leader
- Define process for future agenda setting and plan agendas
- Adhere to Confidentiality Agreement
- Facilitate meetings
- Present follow-up from previous meetings and provide updates on work in progress

(d) PFAC Project Leader
- Attend each council meeting
- Prepare and follow-up with staff who come to the Council seeking feedback
- Send reminders and communicate meeting logistics to members
- Recruit and orient new members and sustain current Council membership
- Report organizational outcomes as a result of PFAC feedback annually
- Define a clear process for following up on Advisory Council recommendations
- Adhere to Confidentiality Agreement
- Ensure that minutes are taken at each meeting
- Distribute minutes within 2 weeks of the date the meeting is held

(e) Board Liaison – selected by the Council co-chairs and the Patient Care Committee of the Board.
- Attend each Council meeting
- Report to the Patient Care Committee when appropriate

(f) Alumni/ae – If they request, Council members who have served their term may become Alumni/ae Members. In this role, they may be involved in subcommittee projects and working groups, but will not have Council voting privileges.

(g) Alternate – chosen from a short list of screened applicants to serve as either a staff or patient/family advisor in the event that a sitting member of the PFAC must step down for any reason. They must meet with the Project Leader for orientation prior to joining the PFAC.

Article IV.

Eligibility

Patients, family members and staff from Beth Israel Deaconess Medical Center (BIDMC) are eligible to be members of the Council. New patient and family members will have been seen at the medical

center within the past two years. Members should be committed to building a partnership of advisors and staff working to understand the needs of the constituents they represent and to implement programs and policies to address health care challenges within the medical center.

Section 4.01 Council Makeup

The Council will be made up of a broad base of fifteen to twenty patients and/or family members and up to seven staff members from the institution. The Council base shall consist of at least half patient and family representatives. If the number of patient/family Council members falls below 15, recruitment efforts will be immediately triggered.

Section 4.02 Participation

Members are expected to participate in bi-monthly meetings consisting of 2 hours.

Section 4.03 Membership Term

A term of active membership consists of two years. Following the initial creation of the Council, up to two thirds of the members may elect to serve one additional year. Each year thereafter approximately one third will rotate and new members will be added.

Amendment: After two years, members in good standing will be invited to renew their membership for an additional year. Members may serve for two additional years, for a maximum of four years. All active members must be in compliance with the responsibilities listed in Section 3.01.

Section 4.04 Vacancies/Leaves of Absence

Council members may resign or request a Leave of Absence from the council at any time during their term. A member may request a leave of absence when unusual or unavoidable circumstances require that the member be absent from meetings and activities from 3 to 6 months. The member will submit his/her request in writing to the Co-Chairs, stating the reason for the request and the length of time requested. The Co-Chairs will determine if the request will be accepted.

If a member cannot return at the end of the requested leave, he/she will resign from the Council. At any resignation, the Council may choose to add a replacement at that time or to leave the position open until the next rotation of members.

Section 4.05 Recruitment & Selection

Council members and BIDMC staff and resources will be utilized to recruit and recommend future members. Potential members will fill out an Advisor Application Form. The PFAC Project Leader will review the application, conduct a brief phone interview, and then interview the candidate with another member of the PFAC interview subcommittee. After successful completion of the interview the candidate will be invited to a Council meeting. The PFAC Project Leader and Council

Co-Chairs will determine the candidate's eligibility for membership. The PFAC Project Leader will notify the potential member of the decision.

Article V. Officers

Section 4.01 Co-Chairs and Duties

There shall be two chairpersons, known as Co-Chairs. One BIDMC staff Co-Chair will be chosen by the institution. The second patient/family member Co-Chair will be elected by the Council. The Co-Chairs will be responsible for setting Council meeting agendas, chairing and conducting meetings, providing leadership for the Council members and representing the Council within the Institution.

Section 4.02: Nomination Procedure

To be eligible as a nominee, Advisors will have had at least one year of experience on the council by the start of the next Co-Chair term (See Section 4.04: Term). Council members may communicate nominations for the office of Advisor Co-Chair to the Program Leader by email, phone, or in person. A Council member may not nominate him or herself.

Section 4.03: Election Procedure

The Advisor Co-Chair will be elected by an online, emailed, or mailed ballot. Members will have a minimum of two weeks to return their ballots. Once the established deadline has been reached, the Program Leader will tally the votes. The nominee with the highest number of votes will be elected as co-chair. In the case of a tie, the standing Advisor Co-Chair will determine how to break the tie.

Section 4.04: Term

The standard term of office will begin and end at an annual meeting held in September, unless otherwise specified. The standard term will be two years, even if this means the Co-Chair will exceed member term limits by one or two years.

Section 4.05 Vacancies

A Co-Chair may resign from office at any time. The Council may choose to either elect a replacement who will serve the remainder of the resigned officer's term, or leave the position open until the start of the next annual meeting, whereupon a newly elected Co-Chair will begin a standard two-year term of office.

Article VI: Meetings

Section 5.01 Regular Meetings

Regular meetings of the Patient and Family Advisory Council will be held on the fourth Wednesday of each month from 6:00 PM to 8:00 PM, with dinner served at 5:30, unless otherwise ordered, presuming the presence of a quorum.

Section 5.02 Special Meetings

Special meetings may be called by the Council Co-Chairs as they deem necessary. Council members will be given at least 48 hours' notice of the meeting schedule and agenda.

Section 5.03 Quorum

An official meeting will require the presence of a minimum of one-half of the members to be called to order.

Section 5.04 Attendance Requirements

Advisors will be dismissed from Patient and Family Advisory Council membership when they have missed three scheduled meetings during any calendar year. Advisors may call-in to one meeting per year and still be considered present. When absences are expected, Advisors must notify the PFAC Project Leader prior to the scheduled meeting. Up to two exceptions may be made by the Project Leader or Co-Chairs for emergencies, inclement weather, unexpected personal or family illness, etc. Additional absences will be monitored.

Section 5.05 Voting

Votes may be conducted to address the business and structure of the Council, including review of mission and bylaws. Amendments to Council Bylaws, including the mission statement will require the affirmative vote of two-thirds of the members present and voting.

Votes may also be conducted when appropriate, if the organization requests a definitive recommendation from the Council. The majority will rule in such cases.

Section 5.06 Agenda

Meeting agendas will be set by the Co-Chairs and PFAC Project Leader and distributed to the membership a week prior to each meeting. Anyone, PFAC member or otherwise, may request time on the Council agenda by submitting an Agenda Request to the PFAC Project Leader.

The Co-Chairs and Project Leader will evaluate and prioritize each request by discussing with prospective presenters their item's appropriateness and/or clarifying the subject matter. Co-Chairs and the Project Leader may also suggest alternative means of involving the PFAC, including email, focus groups and subcommittees.

All recipients of PFAC assistance must submit to the Council or Project Leader a follow-up report summarizing the help requested, the recommendations made by the PFAC, and the current status of the initiative.

Section 5.07 Minutes

The PFAC Project Leader will distribute the minutes in a timely manner to all PFAC members and the BIDMC Board. The Project Leader will keep the minutes and all other pertinent council records.

Section 5.08 Inclement Weather

Council meetings will be cancelled in weather emergencies. If a member resides in a different county that declares a weather emergency, that member must notify the PFAC Project Leader to have their absence excused. Should a meeting be cancelled due to inclement weather, all Patient and Family Advisory Council members will be notified in a timely manner by the PFAC Project Leader or Council Co-Chairs.

Article VII. Committees

From time to time, the Chairs may deem it necessary to create a special committee or task force in order to further the work of the Council. The initiation of such a committee may be requested by any Council member.

Article VIII. Volunteer Requirements

Patient and Family Advisors are considered BIDMC volunteers and must adhere to volunteer requirements specific to our advisors. Prior to membership, incoming council members will participate in an orientation to BIDMC, including HIPAA (Health Insurance Portability and Accountability Act of 1996) training, and a CORI background check.

Article IX. Confidentiality

Council members must not discuss any BIDMC business, personal or confidential information revealed during a council meeting outside their role as a patient or family advisor. What happens in a meeting should stay in the meeting.

Council members must adhere to all applicable HIPPA standards and guidelines. Confidential information includes, but is not limited to a patient's name, contact information, date of birth, diagnosis, treatment and current medical status, as well as information about the patient and his/her family's social history and overall experience here at BIDMC.

If an advisor violates these guidelines, membership status may be revoked.

Article X. Amendment Procedure

These bylaws may be amended at any regular meeting of the Council by the affirmative vote of two-thirds of the members present and voting, provided that the amendment has been submitted in writing at the previous regular meeting.