Beth Israel Deaconess Medical Center

2018 Patient and Family Engagement

2018 Patient and Family Engagement Annual Report



Annual Report

Hospital Name: Beth Israel Deaconess Medical Center (BIDMC)
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Report is available by request and posted online at https://www.bidmc.org/centers-and-departments/social-work/patient-and-family-engagement

Summary

This annual report provides an overview of contributions made by Beth Israel Deaconess' patient and family advisors from October 1, 2017 through September 30, 2018, BIDMC's fiscal year. It includes information about five advisory councils, which include the Hospital-Wide (HW) PFAC, the Health Care Associates Advisory Council (HCA PFAC), the Adult Intensive Care Unit (ICU) PFAC, Universal Access Advisory Council (UAAC), and the Neonatal Intensive Care Unit Family Advisory Council (NFAC). It also briefly highlights several other ways in which advisors have partnered with staff and providers on improvement efforts, including on committees, in research, on focus groups, in presentations, as educators, and in many other ways.

The breadth of advisor contributions demonstrates the versatility of patient and family engagement as a valuable quality improvement resource at BIDMC. Advisors at BIDMC are increasingly joining committees and task-forces, taking part in staff and provider trainings, presenting at conferences, and assisting with pilot projects and research studies. The Patient and Family Engagement team makes every effort to select the most appropriate format in order to get the most relevant, representative, and substantive feedback from advisors.

The figure on the following page demonstrates the wide range in types of engagement in which advisors participated in FY 2018 and the number of hours that advisors contributed to each type of engagement.

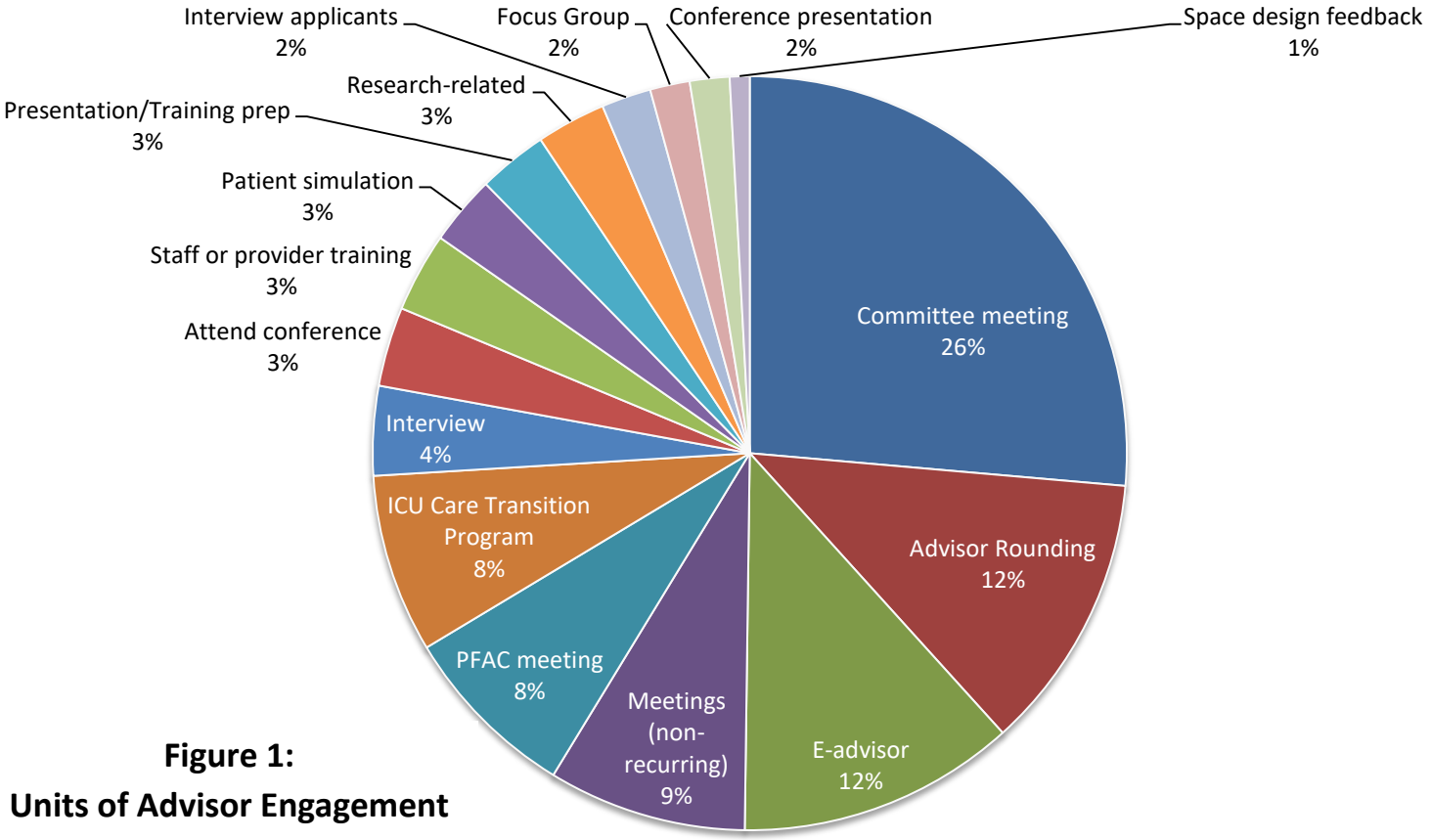


Figure 1:
Units of Advisor Engagement in FY18, by Type

Type of Advisor Engagement	Number and percent of units of each type of engagement in FY18 (N=235 units)	
Committee meeting (recurring)	62	26%
Advisor Rounding	28	12%
E-advisor	28	12%
Meetings (non-recurring)	20	9%
PFAC meeting	18	8%
ICU Care Transition Program	18	8%
Interview	9	4%
Attend conference	8	3%
Staff or provider training	8	3%
Patient simulation	7	3%
Presentation/Training prep	7	3%
Research-related	7	3%
Interview applicants	5	2%
Focus Group	4	2%
Conference presentation	4	2%
Space design feedback	2	1%

Figure 1 shows the frequency of individual instances, or units, of different modalities of patient/family engagement. For the purpose of measurement, a unit of engagement would be one PFAC meeting; one request for email feedback; one shift of advisor rounding; one conference. The charts show that, in terms of the number of times in which one or more advisors were partnering with BIDMC employees or providers throughout the year, committee meetings represented the majority of this partnership, 26% of all advisor engagement, while PFACs made up 8%. 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 three 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 breadth of advisor activities, Figure 1 does not take into account the number of advisors participating in a given activity. Figure 2 reflects the number of total hours that were spent on each type of engagement by advisors over the course of the year; figures are impacted by the numbers of advisors involved in each activity, as well as the duration of activities. This figure shows that, while fewer PFAC meetings took place than many other types of engagement, PFAC meetings did represent the highest contribution of "advisor hours". PFAC meetings had an average of 8 advisors per meeting, e-advisor activities and focus groups had an average of 6, patient simulation/role play activities had an average of 5 advisors, and other activities tended to have 1 or 2 advisors participating each time; the mean was 1.4 and the range was 1 – 32 advisors. The average number of hours spent by each advisor on a given activity was 1.5 hours.

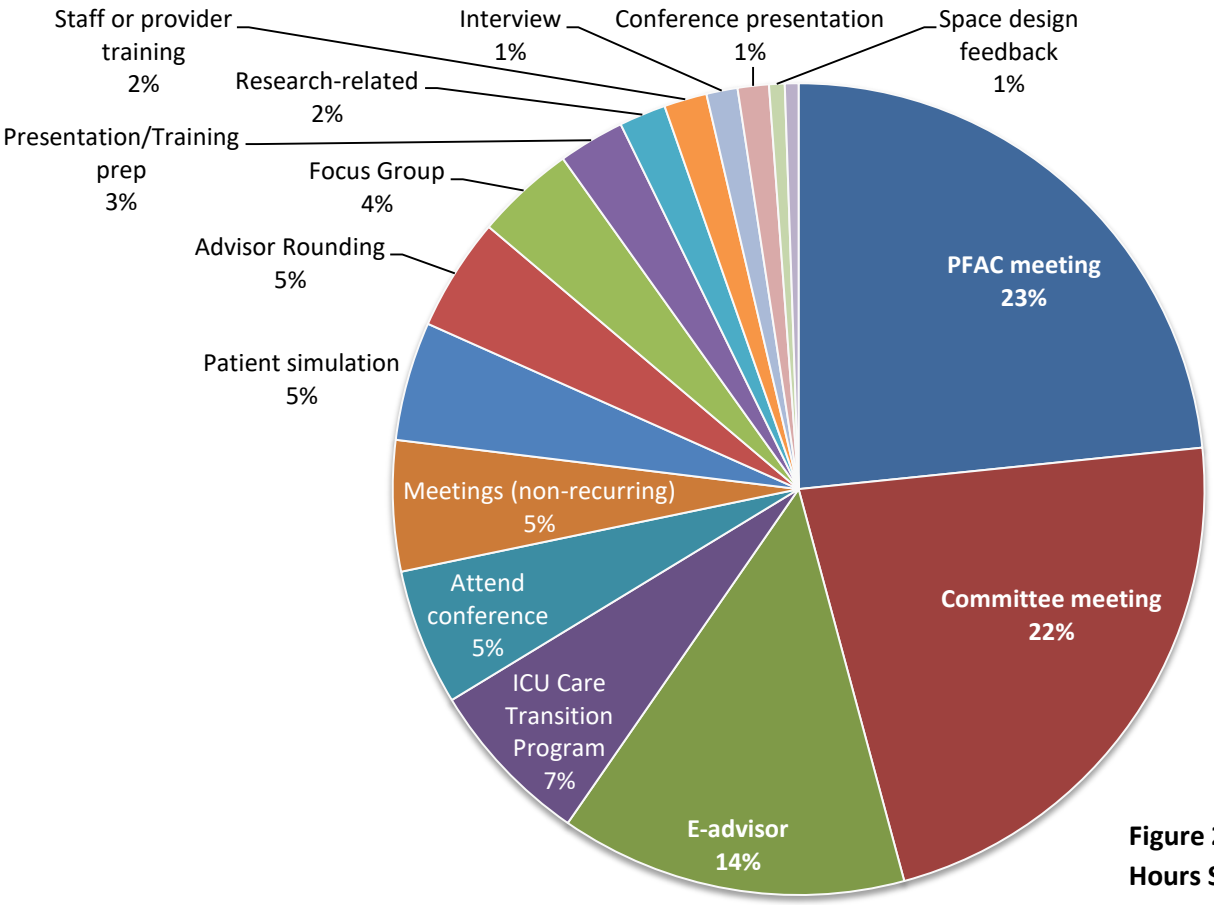


Figure 2: Number of Total Advisor Hours Spent on Each Type of Engagement in FY18 (N=1288 hours)

Type of Engagement	Number and percent of total advisor hours contributed to each type of activity in FY 2017 (N=1288 hours)	
PFAC meeting	301	23%
Committee meeting	289	22%
E-advisor	178	14%
ICU Care Transition Program	86	7%
Attend conference	70	5%
Meetings (non-recurring)	67	5%
Patient simulation	61	5%
Advisor Rounding	58	5%
Focus Group	51	4%
Presentation/Training prep	34	3%
Research-related	24	2%
Staff or provider training	22	2%
Interview	16	1%
Conference presentation	16	1%
Space design feedback	8	1%
Interview applicants	7	1%

Overall this past year, 85 active advisors contributed a combined total of 1288 volunteer hours. The value of FY 2018's volunteer advisor hours was valued at approximately $40,147. Since the Patient and Family Engagement program was launched in 2010, advisors at BIDMC have contributed a total of 8,204 hours, valued at $208,646.

Factors which have influenced the strength and endurance of BIDMC's Patient and Family Engagement program include: BIDMC's continued investment in the program through the funding of a program leader position; an increase in requests for advisor feedback from parties both inside and outside of our institution; growing awareness of the Patient and Family Engagement program within and beyond the institution; and continued advisor participation in presentations, at conferences, and rounding on patients to gather real-time feedback.

By far the most important asset of BIDMC's program is the dedication of its advisors. This year, advisors offered the following reflections:

- *I am very pleased and honored to be part of the BIDMC PFAC's. Being my husband's health care advocate for the many years that he was a patient here, in particular the last year of his life, taught me the importance of speaking up, listening carefully and asking questions. I am very thankful to have the opportunity to be able to give back and to hopefully speak on a subject that will help a patient or a family member. I believe very strongly that BIDMC is Human First which can clearly make a difference in a loved one's care.*
  - **Sue Maxcy, HW PFAC and ICU PFAC**

- *BIDMC is in the planning stages of building a new building, and the Universal Access Advisory Council in which I participate has been one of the partners with the design firm as we want accessibility features to be the best possible for the new place. I have to say that I feel the new building is "mine", something I get to help create. How often does one get to feel they have had input into the design of part of a hospital?! It is a responsibility, but yet I am enjoying brainstorming what could be possible, and I know that what I help to decide could have ramifications for people with disabilities and others for decades to come.*
  - **Sandy Novack, Universal Access Advisory Council**

- *First, I would like to thank PFAC/HCA Access Task Force for accepting me. What a great team. Being a member, offered me the opportunity to advocate for other patients, as well as myself. I also, witnessed first-hand the difficulties the staff endure. Regardless, they continue to provide quality care. Thanks for the opportunity.*
  - **Georgia Grace Patient, HCA PFAC, Access Task Force**

- *The most meaningful work I've done with the ICU PFAC involved participating in a role-play exercise with interns who were being trained to do intakes. Dressed in a johnny and lying in hospital bed, I was asked to present with the same symptoms I had when I was admitted to the ICU several years ago. During the role play, one of the interns asked questions about end of life planning at the start of our conversation. I explained that beginning the conversation this way could cause significant stress and anxiety. I described a way she might frame the questions by explaining to the patient that this is standard operating procedure—not unique to that patient because of the severity of his or her condition. Adding this context would normalize what could be a very frightening experience. The intern thanked me for helping her understand the patient perspective and then repeated the exercise, following my suggestions the second time around.*
    - **Nancy Michaels, ICU PFAC**

- *The breadth and depth of the projects I am offered continue to please me. As a recent ambulatory surgery patient, I was happy to see that the opioid information sheet I was given was familiar: other advisors and I had edited it several months earlier! Credit was given at the bottom of the page to Patient and Family Advisors. The results of our volunteer work absolutely get incorporated into BIDMC policies, procedures, and paperwork!*
    - Peggy Hooper, "Ad Hoc" Advisor, numerous long and short term projects

- *The Committee for Codifying Respect is a wonderful example of one of the many empowering experiences I've had. I met BIDMC staff and realized once again that my thoughts and contributions are appreciated, valued, and implemented.*
    - **Joyce Black, Committee for Codifying Respect**

- *Being a patient advisor is an honor and a privilege to contribute, to the shape, and the future of BIDMC, to not just be the best in New England, but to be the best in the world.*
    - **Theresa Lee, BIDMC New Inpatient Building Community Advisory Committee**

Patient/Family Advisor Recruitment

Advisor recruitment involves paper and electronic applications, social media postings, word of mouth, presentations at staff meetings, and referrals from providers. This year, the Program Leader presented at the Interpreter Services staff meeting and the Department of Social Work staff meeting with the goal of recruiting for diversity. 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 screening process 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 as needed for the assignment; and an orientation and training session as needed for 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 public transportation. Food and beverages are served during PFAC meeting and at other meetings and functions that occur during mealtimes. Accommodations available to advisors if needed include interpreter services, assistive devices, reimbursement for childcare or eldercare, and the ability to participate in meetings by conference call. The hospital holds an annual appreciation celebration for advisors, where they receive a small gift. Advisors do not receive stipends from BIDMC. In rare instances, advisors have received a gift card or small stipend when they have assisted with grant-funded research projects where the project budget included such compensation.

Since 2010, 312 patient and family advisor applications have been submitted to BIDMC, and after careful screening, approximately 172 of these applicants have gone on to participate in councils, committees, short-term projects, or e-advising projects. This year, 17 individuals submitted applications. Of these, 4 applicants joined the Hospital-Wide PFAC; 3 joined the HCA PFAC; 1 joined the Opioid Task Force, 4 became e-advisors/ad hoc advisors, and 2 are still in the application and screening process; 3 did not complete the application or screening process. Reasons for applicants not participating as advisors after submitting applications include: loss to follow-up; lack of an opening on a particular council in which an advisor was interested; 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 most fitting candidate at this time for the desired role. The team seeks advisors who have been patients or family members of patients within the recent two years; occasionally new applicants do not have recent experience at the medical center. The team also continually strives to increase diversity on BIDMC's PFACS and committees.

The next sections provide summaries of the accomplishments of BIDMC's five PFACs from October, 2017 through September, 2018.

BIDMC's 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.

At the start and close of FY 2018 HW PFAC was comprised of 13 patient and family advisors (52%) and 12 BIDMC staff members (48%). Four advisors departed and four new advisors joined. Staff members include the Senior Director of Social Work and Patient and Family Engagement, the Senior Vice President for Patient Care Services and Chief Nursing Officer; the Vice President of Health Care Quality, a Director from the Office of Improvement and Innovation; a Hospitalist with an appointment as Associate Director for Inpatient Quality; two Ambulatory Directors; the Senior Director and the Program Director of the Office of BIDMC Experience; the Clinical Director of Operations in the Emergency Department and a Clinical Nurse Specialist in the Emergency Department (who resigned mid-year due to a new job), and a representative from BIDCO (Beth Israel Deaconess Care Organization).

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 additional one or two years, for a maximum of four years. After the terms are completed, as emeritus members, they will no longer attend meetings, but will have opportunities be active participants in other patient and family engagement opportunities.

The HW PFAC is co-chaired by a patient/family advisor and the Senior Director of Social Work and Patient and Family Engagement. The advisor chairperson is elected by patient/family advisors and serves for two years. If an advisor is elected at the end of his/her third or fourth year, that person may extend his/her membership for one or two years in order to fulfill the two year co-chair term. In FY

2018, advisors elected a new chairperson, an advisor who was in his fourth year on PFAC who will serve until September, 2020. The outgoing chair of the HW PFAC will continue to be a member of BIDMC's 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 Program Leader for Patient and Family Engagement and the advisor co-chair. Orientation topics include BIDMC's mission and goals, the HW PFAC's mission and bylaws, member responsibilities, what to expect at meetings, themes of PFAC work, and projects past and present.

HW PFAC Agendas and Meetings

The council meets every other month, 6 times per year for 2 hours in the evening. Agendas are typically shaped by requests by hospital staff members, providers, researchers, as well as health care professionals from outside organizations. Areas of focus include new hospital initiatives, marketing materials, policies, research projects, patient and family support protocols, communication strategies, and other initiatives.

When requests are made to the Program Leader and Senior Director of Patient and Family Engagement, they 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 most meetings, advisors have an opportunity to share health care experiences that they have had 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).

A typical meeting involves at least two topics for discussion. Topics discussed at HW PFAC meetings over the past year include:

- November, 2017
    - New Inpatient Building
    - Beth Israel Deaconess Care Organization (BIDCO) and PFAC
    - BIDMC Experience Roadshow

- January, 2018

- An initiative to improve teamwork in inpatient care: FIRM (Fully Integrated Regionalized Micro-teams) Initiative
- Members voted in favor of having a representative of BIDCO as a regular member of PFAC.

- April, 2018
  - Radiology Service Excellence Action Planning
  - ID Badge Redesign
  - Nurse Ballot initiative

- May, 2018
  - MASCO Placemaking Project
  - Changes to the Beth Israel System (network and affiliations)

- July, 2018
  - Patient Self-Scheduling
  - eCommunications & Development
  - New Inpatient Building

- September, 2018
  - Embedding Respect Behaviors in BIDMC Culture
  - Patient surveys and signage about feedback
  - MHQP (Massachusetts Health Quality Partners) – development of a patient engagement tool

HW-PFAC Partnerships:

Society of Hospital Medicine (SHM)

BIDMC's HW PFAC is part of the national PFAC of the Society of Hospital Medicine (SHM). SMH is a professional medical society representing more than 15,000 of the 48,000 practicing hospitalists in the U.S. dedicated to providing exceptional care to the hospitalized patient. PFACS from the following institutions will collaborate on their national PFAC and provide patient/family input: BIDMC, University of Wisconsin, Denver Health, St. Louis Children's Hospital, St Louis Children's Hospital, HealthPartners Regions Hospital, St Paul, UT Health Science Center, and Ohio State University Medical Center.

NE QIN-QIO Patient & Family Advisory Council

The New England QIN-QIO (New England Quality Improvement Network/Quality Improvement Organizations) Patient and Family Advisory Council (PFAC) is made up of advisors from across the region who share their experiences, give their opinion about patient materials and provide guidance to the staff of QIN/QIO. QIN/QIO sought partnership with BIDMC's HW PFAC last summer. A member of our HW PFAC has been an active member since last fall.

Beth Israel Deaconess Care Organization (BIDCO)

This year, the HW-PFAC voted to add a representative from BIDCO to the PFAC membership. BIDCO is a value-based Accountable Care Organization (ACO) with a network of physicians and hospitals that work together to coordinate care delivery and improve care quality for individuals and populations of patients. BIDCO has more than 2,500 participating physicians (primary care and specialist physicians) and is affiliated with numerous community hospitals, including Anna Jaques Hospital, Beth Israel Deaconess Hospital-Milton, Beth Israel Deaconess Hospital-Needham, Beth Israel Deaconess Hospital-Plymouth, the Cambridge Health Alliance, and Lawrence General Hospital. BIDCO has a tertiary affiliation with Beth Israel Deaconess Medical Center. Network-wide contracts with public and private payers promote our ability to work as an integrated delivery system.

BIDCO sought partnership with BIDMC's Hospital-Wide PFAC in late 2017, in order to get input on issues such as access to care and cultural competency, and other issues that impact patient and family experience. The PFAC voted in favor of adding a representative from BIDCO to the membership of PFAC; the bylaws were modified accordingly. A representative from BIDCO joined PFAC in January of 2018.

HW PFAC Goals:

The HW PFAC has not had a formal goal-setting process; the work of the PFAC aligns with BIDMC's annual operating goals. The mission of BIDMC is "to provide extraordinary care, where the patient comes first, supported by world-class education and research", and the operating goals of the institution are grounded in this mission. Having advisors partner with providers and employees on our PFACs, committees, and other projects, helps keep the needs and preferences of patients at the center of improvement initiatives.

The BIDMC Experience

An important strategic goal for this fiscal year has been to "create infrastructure and key foundational components to support overarching BIDMC Experience strategy." Over the last several years, BIDMC's leaders have recognized that living the BIDMC mission requires a more holistic approach to understanding and improving patient, family, employee and physician experiences. In fall of 2017, the Office of BIDMC Experience was launched to unify and address foundational priorities in order to enhance these individual and collective experiences. The BIDMC Experience team's efforts have focused on high yield opportunities to overcome the most pressing challenges identified by patients, families, employees and physicians. Since the start, PFAC advisors have been key members of the BIDMC Experience Task Force, and serve on subcommittees that are focused on the foundational priorities of the BIDMC Experience initiative:

- Enhancing team collaboration,
- Improving tools and resources,

- Codifying the practice of respect,
- And promoting diversity and inclusion.

Each group has been working to identify priority areas and create implementation plans and timelines. The BIDMC Experience work has been a major focus at PFAC meetings this year. The Senior Director and Program Manager of the BIDMC Experience are members of the Hospital-Wide PFAC. Advisors have been invited to tell their stories at meetings of senior leaders, serve on a focus group about teamwork, and provide written input on multiple inquiries from the BIDMC Experience team. This dynamic partnership has greatly improved awareness of the Patient and Family Engagement program across the institution.

Health Care Associates Advisory Council (HCA PFAC)

Health Care Associates (HCA) is a primary care group practice at BIDMC. HCA PFAC was launched in 2013. It is co-chaired by an advisor and a physician leader. With the recruitment of 3 new advisors to this diverse group, and changes in the leadership of the Health Care Associates Primary Care division this year, HCA PFAC members' contributions soared. As regular participants on multiple new committees, task forces, and projects, six HCA advisors make up just 7% of BIDMC's advisor pool, but their contributions to HCA represent about 25% of all BIDMC advisor hours in FY 2017, 300 hours out of 1200 total advisor hours. Advisors participated on/in:

- **No-show task force (weekly) - NEW**
- **Access task force (weekly) - NEW**
- **AR^{2}C (Arrive, Register, Room, Care) task force (biweekly) and patient simulations - NEW**
- Interdisciplinary operations committee (weekly)
- HCA team meetings
- Call center redesign committee
- Center for Primary Care projects
- Primary Care Initiative Network meetings
- Opioid control project
- Quarterly HCA PFAC meetings

The goal of the No-Show Task Force is to minimize missed appointments which impair HCA's ability to give other patients prompt appointments. The task force has developed several strategies including improved patient-centered signage about the no-show policy, and additional reminders by phone, text, email, and mail.

The Access Task Force focuses on improving the availability of timely appointments for patients, and improving the system by which appointments are scheduled. HCA seeks to replace a system that books

patients with the "next available" provider, with a system that will foster continuity of care; patients will be scheduled to see their own providers, or a member of that provider's team, in as timely a manner as possible. The new system aims to be more patient/family centered, and benefits not only patients and their family members, but providers as well. Improved access will ideally reduce the use of the Emergency Department for health issues that can be managed in a primary care setting.

The AR^2C (Arrive, Register, Room, Care) Task Force focuses on improving the patient, provider, and staff experiences from the moment the patient arrives at the clinic to when the physician arrives in the examining room. Using the PDSA model and simulations involving real patients, providers, and staff members, the Task Force has worked to make the clinic run more smoothly, with improved teamwork, reduced waiting time, and better communication between patients, family members, and members of the health care team.

In addition to participating in the above groups, advisors will be joining the Diabetes Task Force and the Population Health Task Force this coming fall. Through their regular involvement at multiple weekly leadership meetings, advisors have had an enormous impact on strategically improving the patients', providers' and staff members' experiences in Health Care Associates this year.

ICU Patient and Family Advisory Council

The ICU PFAC was initiated in 2008. Currently, the council membership includes six advisor members, four staff members, and two physicians. It meets quarterly. This year, advisors partnered with providers and staff members on the following projects:

- A study about the use of intravenous vitamin B1 in cardiac arrest: Our advisors provided valuable insight into how patients or family members may feel about this unique trial which involves enrolling patients under the exception from informed consent ("EFIC") process. Due to the critical time-sensitive nature of the intervention, patients must be enrolled often before families can arrive to the hospital, and the surrogate consent process then happens once they arrive. This is the first EFIC trial to be done at BIDMC and the input from the ICU PFAC advisors was very helpful for the investigators and the BIDMC Committee on Clinical Investigations.

- ICU Visitor Guide: Our advisors provided the ICU Nurse Directors with feedback on the content and design of the new ICU Visitor Guide. The new ICU Visitor Guide now includes unit specific information about each ICU and additional general information about the healthcare proxy, entering the ICU, parking, and dining options.

- ICU Transition Guide Program: Advisors have been instrumental in the development of a volunteer-based patient/family support program for patients/family members who are transferring

from the ICU to medical or surgical units. Specially trained volunteers provide information about what to expect in the transition process, utilizing a checklist that was based on feedback from PFAC advisors. A case/control study is taking place to evaluate the efficacy of this intervention.

An advisor on the ICU PFAC whose spouse has spent numerous months in BIDMC ICUs has played a critical role in the creation, evaluation, and ongoing management of this program. She has led volunteer trainings and conducted regular shadowing and supervision of volunteers. As a result of this advisor's leadership role in this project, the ICU Transition Guide program was selected for an honorable mention 2018 IPFCC Partnership Award, an award that recognizes innovative partnerships among patients, families, and health care professionals. The program was featured in a poster presentation at the International Conference on Patient- and Family-Centered Care in June 2018.

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 work of the UAAC is focused on the built environment, equipment, services for those with disabilities, informing and educating staff members about disabilities and accessibility, and identifying opportunities for improvement based on patient and family feedback.

The UAAC currently includes 6 patient/family advisor members who have experienced a range of accessibility challenges, and approximately 20 regular staff attendees from a wide variety of disciplines and departments including facilities, ambulatory care, nursing, radiology, interpreter services, food services, physical therapy, and several others.

This year, representatives from the Alzheimer's Association conducted an in-service about dementia, and about providing optimal care to persons with dementia in acute care settings. They shared recommendations on how to improve the quality of care for the patient and the caregiver/provider experience, and information about the CARE act. The council also discussed emergency preparedness as well as accessibility in some of the older BIDMC buildings.

Over the course of the year, the council concentrated on providing feedback on the new inpatient building that will be built over the next several years. Architects met with the council three times to elicit feedback on technology as well as on number of areas of the new building including ICU rooms, the lobby, waiting rooms, the café, the roof garden, and corridors between adjacent buildings. Advisors were invited to visit a scale model of two patient rooms and provide feedback on layout, fixtures, furnishings, and bathrooms. Feedback has resulted in several changes that will improve accessibility for patients and families.

One of UAAC's advisors has partnered with a staff member of the council to put out a quarterly newsletter, BIDMC Universal Access News Clips, which highlights current events and publications related to accessibility.

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.

NICU Family Advisory Council

The NICU Family Advisory Council (NFAC) was created in 2006. Currently, the council includes 17 family members and 15 staff members. Between 2017-2018 (September), the council met six times, advising on the following initiatives:

- The NICU expansion and renovation including a brand new unit on Stoneman 9 slated to open in Fall of 2018.

- The creation and launch of the online portal MyNICU. MyNICU is a quality improvement initiative using online technology to connect NICU families to their baby. This tool gives NICU parents information about their baby and the NICU directly.

- Launch of a Music Therapy program in partnership with Berklee College of music.

- Through the support 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 continues to host alumni craft nights in support of current NICU families. The Halloween Costume creation in 2017 and the partnership with Project Sweet Peas in Winter 2017 to bring Santa to the NICU garnered significant media attention.

- 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 2018.

- An ongoing NICU Peer mentorship program in support of current NICU families connecting with NICU Graduate parents for support.

- The eventual creation of a sibling program to better support NICU siblings and their parents during infant hospital stays on the NICU.

Beyond the PFACs:

Patient/family engagement permeates a wide variety of projects and outcomes at BIDMC; its value is inestimable. The following tables list the contributions that advisors made in FY 2018 outside of PFAC meetings.

Committees and Task Forces

Below is a list of BIDMC committees on which advisors have participated in FY 2018.

Ongoing Committees	**# of Advisors**
Patient Care Assessment Committee of the Board of Directors (quality & safety)	2
Ethics Advisory Committee	1
Medication Safety Subcommittee	1
Care After Death taskforce	2
PatientSite Governance Committee	2
Inpatient QI Retreat and work group	2
Quality Innovation Network / New England Quality Improvement Organization PFAC	1
BIDMC Experience Taskforce	2
New Committees in FY 2018	
BIDMC Experience: Codifying Our Practice of Respect work group	2
BIDMC Experience: Enhancing Team-Based Care workgroup	2
Diversity and Inclusion Workgroup	1
Opioid Task Force	2
BIDMC New Inpatient Building Community Advisory Committee	1
Health Care Associates Task Forces (No Show, Access, AR^2C)	5

Focus Groups

Advisors have participated in four focus groups this year.

Focus Group Topic:	# of Advisors
Advance Care Planning, facilitated by Richard Averbuch, Executive Director of	8

Mass Coalition for Serious Illness Care	
Teaching cultural competency in medical school training, facilitated by Dr. Daniele Olveczky	4
Teamwork in inpatient setting, facilitated by Dr. Julius Yang	8
Diagnostic uncertainty, facilitated by Dr. Gordon Schiff	8

Education of Medical Students, Staff Members, Volunteers, and Physicians

Type of training/event:	# of Advisors
Ambulatory Service Excellence Trainings	4
Opioid Use Disorder classes and videos	2
"You Know Me" video about privacy to be used at employee orientation	5
Ethics Case Conference, Sexual Harassment Panel	1
ICU Transitions Guide Volunteer Trainings	1

Presentations

Advisors participated in presentations about the following topics in FY 2018:

Presentation:	# of Advisors
Patient/Family Engagement, at Israeli Inbal meeting	1
Patient/Family Engagement at The New England QIN-QIO (Quality Improvement Network/Quality Innovation Organization)	1
Advisor Rounding at Massachusetts Coalition for the Prevention of Medical Errors Annual Meeting	1
Open Notes in Mental Health Care at IPFCC Conference	1
ICU Transition Guide program at IPFCC conference	1
Personal testimonial at BIDMC Experience Taskforce meeting	1
AR^2C Initiative at PCIN	1

E-Advisor Projects

Advisors provided feedback by email on the following projects or documents in FY 2018.

Project/Document	# of Advisors
Numerous Health Care Associates documents, grant proposals and papers	5
MA CARE Act factsheet	32
Open Notes Pt Reporting Tool – OB/Gyn	7
Ournotes patient letter and info sheet	10

Universal Access News Clips	1
New England Quality Innovation Network- Quality Improvement Organization (NE QIN QIO) materials	1
Society of Hospital Medicine, various requests	4
Antibiotic factsheet	14
MRI intake form	8
Guidelines For Children Accompanying Patients In Patient Care Areas	5
Medical Chaperone policy	12
Terminology in MACRMI literature	20
Technological solutions for improving experience in radiology waiting rooms	35
BIDMC Experience Vision Statement	4
"When is it ok for a provider to hug their patient?"	4
Online Cancer Community Flyer feedback	22

Other Ad Hoc/ Short Term Initiatives

Project	# of Advisors
Patient visit simulations in Health Care Associations clinic	5
Patient shadowing in radiology	1
Cancer Center waiting room renovations	2

Research

Advisors provided feedback or participated on the following research initiatives in FY 2018:

Grant proposal to test a decision aid for breast cancer patients	1
Grant proposal to develop a breast cancer prediction model for postmenopausal women	1
Grant proposal about relationships of trust and respect between pts and docs	1
Research study about communicating diagnostic uncertainty	8
Research study about implementing intravenous vitamin B1 (thiamine) in the setting of cardiac arrest	5
Research study on the involvement of specialists during inpatient hospitalizations	1
Grant proposal about opioid control	1
Survey development for OBGYN OpenNotes medical education initiative	7

Publications:

BIDMC Advisors were featured or acknowledged in the following publications in FY 2018:

- *Acute Respiratory Distress Syndrome*, in Journal of the American Medical Association, February 20, 2018. Co-authored by Jackie Giannakoulis, ICU PFAC Advisor.

- *In Their Own Words,* in 2017 BIDMC Dept. of Medicine Annual Report. Interview of Jackie Giannakoulis, ICU PFAC Advisor.

- *Tackling Ambulatory Safety Risks Through Patient Engagement: What 10,000 Patients and Families Say About Safety-Related Knowledge, Behaviors, and Attitudes after Reading Visit Notes*, in Journal of Patient Safety, published online, ahead of print, April 2018. Several advisors assisted with survey development.

- *Patient and Family Advisors Perform Rounds at BIDMC* , in EngagingPatients.org Patient Experience blog, May 10, 2018. Article about Advisor Rounding program.

- *Case in Microethics: Is It OK to Hug Your Patient?*, in Vital Signs, a publication of the Massachusetts Medical Society, Volume 23, Issue, May 2018. Discussion of panel presentation that included Betsy Lowe, Emeritus PFAC Advisor, Patient Site Governance Committee; Betsy Lowe is quoted.

- *OpenNotes: Sharing Visit Notes with Patients and Families*, in Pediatric Nursing, May/June 2018 Co-authored by Betsy Lowe, Emeritus PFAC Advisor, Patient Site Governance Committee.

- From ICU to I See You, in Asian Hospital & Healthcare Management, Jan 29, 2018. Authored by Nancy Michaels, ICU PFAC Advisor.

- *A Multi-Stakeholder Consensus-Driven Research Agenda for Better Understanding and Supporting the Emotional Impact of Harmful Events on Patients and Families*, in The Joint Commission Journal on Quality and Patient Safety, Volume 44, Issue 7, July 2018, Pages 424-435. Co-authored by Betsy Lowe, Emeritus PFAC Advisor, Patient Site Governance Committee.

- *Disability Issues Newsletter*

  Sandy Novack, Universal Access Advisory Council Advisor on Editorial Board.

- *BIDMC Universal Access News Clips*

  Created and co-edited by Sandy Novack, Universal Access Advisory Council Advisor.

Advisors Help Replenish the Emergency Clothing Closets

Leaving the hospital wearing clean, comfortable, and warm clothing, rather than a hospital gown, helps to restore our patients' dignity and sense of well-being, particularly when they are heading to another facility, such as a rehabilitation center, a nursing home, or a homeless shelter. Patients may arrive at the hospital in inadequate, damaged, or soiled clothing or have no shoes; clothing may need to be cut off for treatment; or patients may not have family members or friends who can bring them a change of clothes. The Social Work Department maintains emergency clothing closets to provide shoes, socks, jackets, shirts, sweatpants, and underwear to those patients who need them.

When the clothing closets were depleted of certain items in fall of 2017, a request for gently- used clothing was posted on the Patient and Family Advisor Facebook page. The response was overwhelming. Over the course of the last year, Patient and Family Advisors - and their children - have delivered bag after bag of clothes, many items brand new. As a result of their generosity, grateful social workers have been able to assist numerous patients, who may have otherwise been inadequately dressed.



Taking Stock and Looking Ahead

Patient and Family Engagement has become an instrumental resource for fulfilling BIDMC's mission to "provide extraordinary care, where the patient comes first, supported by world-class education and research." The program will continue to find ways to expand its impact, by increasing advisor diversity, promoting awareness, and fostering efficient integration of advisors into committees, education, research, short term projects, and other ventures.

Appendix:
Hospital-Wide Patient and Family Advisory Council Bylaws



Beth Israel Deaconess
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

Amendment:

(f) BIDCO (Beth Israel Deaconess Care Organization) representative - see Appendix I
- *Attend each Council meeting.*
- *Respectfully listen to diverse opinions*
- *Agree to work within meeting infrastructure determined by Council*
- *Adhere to Confidentiality Agreement*
- *Provide updates on work in progress*

(g) 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.

(h) 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.

Section 3.02 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 3.03 Council Makeup

The Council will be made up of a broad base of 12 to 16 patients and/or family members and up to 12 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 12, recruitment efforts will be immediately triggered.

Section 3.04 Participation

Members are expected to participate in bi-monthly meetings consisting of 2 -3 hours.

Section 3.05 Membership Term

A term of active membership consists of two years. 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 3.06 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 3.07 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 IV. 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 for Co-Chair 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 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 V. Meetings

Section 5.01 Regular Meetings
Regular meetings of the Patient and Family Advisory Council will be held on the fourth Wednesday of every other 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 in advance of 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 VI. Committees

Section 6.01 Special Committees or Projects

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 VII. 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, a TB skin test, and a CORI background check.

Article VIII. 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 IX. 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.

Appendix I.

Referenced in Article III, (f), BIDCO (Beth Israel Deaconess Care Organization) is a physician and hospital network that provides "value-based" care. Value-based care refers to healthcare services that are "bundled" and reimbursed based on the **quality** of the care. This differs from a "fee-for-service" model, in which services are reimbursed individually, with the focus on quantity rather than quality. BIDCO's network includes 2,500 physicians, including 600 primary care physicians (PCPs), 1,900 specialists, and eight hospitals. BIDCO's 8 hospitals include:

- Beth Israel Deaconess Medical Center,
- Beth Israel Deaconess Hospital Needham,
- Beth Israel Hospital Milton,
- Beth Israel Hospital Plymouth,
- Ana Jacques Hospital,
- New England Baptist Hospital,
- Lawrence General Hospital and
- Cambridge Health Alliance.

The mission of BIDCO is to move health care forward by providing the highest quality of care that is coordinated, safe, and cost-effective. In order to promote this goal we will be participating in BIDMC's Hospital-Wide PFAC. BIDCO believes the PFAC will help the organization address barriers related to issues such as access to care and cultural competency, in order to improve patient and family experience and health outcomes.