



BRIGHAM AND  
WOMEN'S HOSPITAL

**Brigham and Women's Hospital  
Patient and Family Advisory Council (PFAC) Report  
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## **Patient and Family Advisory Council (PFAC) Report**

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## **1. BWH PATIENT AND FAMILY ADVISORY COUNCIL DESCRIPTION**

### **Goal Statement:**

The Patient and Family Advisory Council (PFAC) works in partnership with the leadership and clinical staff of Brigham and Women's Hospital to create an environment of patient and family-centered care across the entire institution, and provide feedback regarding patient and family centered care activities at Brigham and Women's Hospital (BWH). The Patient and Family Advisory Council guides the BWH Patient and Family Centered Care Philosophy and the way it is interpreted and implemented throughout the institution. Through this partnership, discussions and decisions about patient and family-centered care occurs in various meetings and forums.

### **Reporting Structure:**

The Brigham & Women's Hospital Patient Family Advisory Steering Committee is co-chaired by the Chief Medical Officer, Chief Nursing Officer, and the Senior Patient Advisor and nine patient advisors. This council is the overarching Council for each of the service line patient and family advisory councils. There are currently twelve service line councils that are either in the existing, launching or preparing to start a council phase along with six research studies that have patient advisors collaborating with research investigators (See Attachment 2). One to two advisors from each of the service line sits on the Steering Committee. During the Steering Committee meeting, specific topics are discussed by the Chief Medical Officer and Chief Nursing Officer in an effort to provide information on hospital initiatives and to obtain feedback from the advisors on ongoing projects. Advisors from each service line advisory council reports to the Steering Committee and reports back to their service line on what they learned thereby making a direct flow of information between the two groups.

### **Long Term Goals:**

- Advise on the infrastructure necessary to create and maintain a patient and family-centered care culture.
- Continue to identify opportunities for improving the patient and family experience
- Advise on policies and practices to support patient and family-centered care
- Recommend how to better measure/quantify/evaluate patient and family centered-care evolution at BWH



## **Membership:**

Membership of the Council is comprised of patient and family advisors and select representatives of Brigham and Women's Hospital including the Chief Medical Officer (CMO), the Chief Nursing Officer (CNO) and the Senior Patient Advisor as chairs, the Executive Director of The Center for Patients and Families, and The Patient and the Family Advisor Liaison. The BWH service line leadership joins the council on an ad-hoc basis as the need arises they are not considered official members. Qualifications for membership as an advisor include, being a current or former BWH patient or family member in addition to having a willingness to contribute towards the overall mission of the council while not seeking to pursue a personal agenda. A qualified member shall be someone who successfully satisfies the previous two requirements and an interview or who has, in another form, been deemed willing and able to contribute towards the larger mission of the council. The interview process seek to identify individuals who are:

- interested in serving as advisors
- comfortable in speaking in a group with candor
- able to use their personal experience constructively
- able to see beyond their own experience
- concerned about more than one issue or agenda
- able to listen and hear differing opinions
- representative of patients and families served by the hospital or a hospital program

However, it does not seek to exclude anyone who would need more support than others to serve in the role of advisor. We recognize that individuals can grow and develop in this role. We are committed to having a council that reflects the diverse patient population we serve here at BWH.

Recruitment is primarily reliant on clinician recommendation of potential patient and family advisors; however, members are also identified by the Center for Patients and Families, and in some of the councils, members self-identified.

Selection is based on information provided by the clinician recommending the patient/family advisor. The nominated advisor will have either a phone or in person interview with the,



Executive Director, Center for Patients and Families, Patient Family Advisor Liaison and Senior Patient Advisor. Advisors will be invited to join the Patient Family Advisory council based on the information learned on the interview.

### **Members Roles & Responsibilities:**

The duties of the members include but are not limited to:

- ✓ Serving as a sounding board for initiatives which the institution deems important in order to establish balance with priorities of patients and families
- ✓ Generating new ideas to drive initiatives at all levels of the hospital
- ✓ Sharing best practices across the institution (service-specific & cross-service)
- ✓ Providing feedback as requested by the local advisory councils and subgroups
- ✓ Program planning and evaluation
- ✓ Providing input on institutional policies, programs, and practices, particularly those which affect the care and services that individuals and families receive
- ✓ Providing input on institutional research projects and programs, particularly those that involve Patient Family Centered Outcomes Research Institute and research that engages patient family perspectives

Responsibilities of members include but are not limited to:

- ✓ Adhering to the confidentiality requirements and other responsibilities set forth by the hospital during the formal hospital orientation program for volunteers

Council members can participate in various hospitals setting and on various hospital committees, tasks forces and/or service line patient family advisory councils. Some of the committees that members can participate in are Patient Centered Outcomes Research Institute (PCORI) research projects, Ethics Committee, and Health Literacy Committee. Some of our departments request that advisors participate as co-trainers for clinical and nonclinical staff, in-service programs, grand rounds, inter-professional rounding and health professional trainees.

### **Structure:**

Currently the BWH Steering Committee council has eight patient/family advisors and four staff advisors. The patient/family advisors and staff advisors represent their respective service line advisory councils on the Steering Committee.

### **Governance:**



Officers are not elected at the present time, therefore, officer duties do not exist. The Patient and Family Advisory Steering committee structure consists of our senior patient advisor co-chairing the council with the CNO and CMO. The Center for Patients and Families is responsible for organizing the Council meetings. The staff liaison for the Council is the project manager for The Center for Patients and Families.

The term of an advisor is set for a three year period with the option to extend the term or become an advisor emeritus based on their area of interest.

The council meets quarterly with each meeting being an hour and a half in duration. It is expected that advisors attend at least 75% of these meetings. Meeting minutes are taken for each meeting and are maintained for five years by the staff liaison. The Executive Director for the Center for Patients and Families presents once a year to the Care Improvement Council to provide an update on all of the patient family advisory council activities.

## **PFAC MEETING MINUTES**

- ✓ Minutes 3-8-12
- ✓ Minutes 6-12-12
- ✓ Minutes 9-13-12
- ✓ Minutes 11-28-12
- ✓ Minutes 3-20-13
- ✓ Minutes 6-5-13
- ✓ Minutes 9-25-13
- ✓ Minutes 11-10-13
- ✓ Minutes 3-19-14
- ✓ Minutes 6-11-14
- ✓ Minutes 9-10-14
- ✓ Minutes 11-20-14
- ✓ Minutes 3-25-15
- ✓ Minutes 6-18-15
- ✓ Minutes 9-24-15
- ✓ Minutes 12-9-15
- ✓ Minutes 3-24-16
- ✓ Minutes 9-29-16
- ✓ Minutes 11-16-16
- ✓ Minutes 3-17-17
- ✓ Minutes 10-11-17
- ✓ Minutes 4-30-18



## **2. PATIENT AND FAMILY ADVISOR PHILOSOPHY & ORIENTATION**

Brigham and Women's Hospital (BWH) commits to working with patients and their families and considers them to be partners at the center of the health care team. At the core of this partnership are the patient's wishes and priorities to help guide their care. Each patient will determine who to define as "family" and choose if and how to involve "family" in care and decision-making. We commit to working with patients and their families to be active participants rather than passive recipients of care.

We seek to understand and meet the needs of our patients and their families, and with the patient's consent, strive to deliver information, which is open, timely, complete, and understandable to them. We extend this commitment with attention to the dignity of and respect for the preferences of both patient and family with respect to culture, capacity, and abilities in determining care. To maintain the vitality of our commitments to patients and families, BWH recognizes the need to incorporate patient and family input on care delivery, policies, and in designing and improving operations and facilities.

After the candidates agree to become a patient and family advisor, they must participate in a formal three-hour orientation through the volunteer office including training on patient confidentiality. The orientation through the Volunteer Office is provided once a month and as needed individually. After completing the orientation and obtaining the appropriate vaccinations, as required of any new employee, advisors will receive a hospital badge, for their term as an advisor.

The next step brings together the patient and family advisor with the patient and family liaison and senior patient family advisor who will introduce him/her to the concepts of PFCC as set forth by the Institute for Family-Centered Care (See Attachment 1), share the Brigham and Women's Hospital-specific philosophy statement of PFCC, and provide a brief history on the journey of Patient and Family-Centered Care at BWH. A hospital tour of specific areas is available to the advisors for their respective council. The final step in the orientation takes place when the liaison accompanies the advisor to his/her first meeting.



### 3. PATIENT AND FAMILY ADVISORY COUNCIL STRUCTURE & MEMBERSHIP

#### A. Brigham & Women's Hospital Enterprise Patient and Family Advisory Council (PFAC)

##### 1. Patient and Family Advisory Council (PFAC) est. 12/6/07

- Purpose: Forum for sharing best practices across the institution (service-specific & cross-service); Sounding board for initiatives which the institution deems important in order to establish balance with priorities of patients and families; Place where new ideas are generated by patients and families to drive initiatives at all levels of the hospital
- Meeting Frequency: Quarterly
- Current Advisors: Cassandra Campbell, Martie Carnie, Estrellita Karsh, Barry Nelson, Joe Nies, Mary Reynolds, Dena Salzberg, Joyce Gillespie

#### B. BWH Hospital Cross-Service Committee

##### 2. Ethics Committee

- Multidisciplinary advisory group comprised of physicians, nurses, social workers, administrators, clergy and representatives of the community.
- Purpose: Provide consultation through the Ethics Service and a peer review forum for recent ethics consultations, to educate Committee members and the hospital community about the principles and clinical applications of bioethics, to develop new or revise existing hospital policies and procedures that relate to ethics and patient care
- Meeting Frequency: bimonthly

#### C. BWH Service-Line Patient and Family Advisory Councils (See Attachment 3):

3. **NICU PFAC**— This Council was the first PFAC at BWH and was the first to have paid advisors on staff. The council is continuing to develop NICU family support programs, reviewing and discussing current programs while looking into providing better educational/social programs to keep NICU parents from feeling isolated in their private rooms. This council meets once a month and has 10 patient/family advisors.
4. **Obstetric (OB) PFAC**—This council was established in 2012. They have been involved in many of the changes and operation issues that occur in the Connors for Women's and Newborns (CWN). They were actively engaged in the transition to Baby Friendly and provided feedback on process improvement specifically in the visitor policy. Currently there are nine patient/family advisors on this council. This council meets quarterly. In between meetings advisors have been called upon to help think about operational changes.
5. **Emergency Department(ED) PFAC**—this council is in its seventh year. Advisors have been working closely with the Nursing Director on the expansion of the





- Emergency Department. They have also advised on the digital signage in the Emergency Department waiting area and the patient photo initiative. Advisors have also participated in a panel discussion with medical residents on how to communicate effectively with patients. There are currently eight patient/family advisors. This council meets monthly.
6. **South Huntington Medical Home PFAC**—this council was established in 2013. The advisors worked with the Medical Director on improving the flow process in the clinic by examining the patient “no-show” policy, reviewing different types of visits offered to patients (virtual vs in person vs group visit) and increasing patient use of Patient Gateway. Advisors continue working on the quality improvement project of improving communications and patient experience between staff, providers and patients. There are currently eight advisors. This council meets monthly.
  7. **Women’s Council on Health**— This Council is comprised of eleven members who are all survivors of interpersonal violence. The advisors informed on the development of a website for the Coordinated Approach to Recovery and Empowerment (C.A.R.E.) clinic, are participating in discussions related to implementation of Trauma-Informed Care and will be joining the Partners-Informed Care Steering Committee. A number of our advisors are actively participating in activities for Domestic Violence Awareness month. Lastly, as we develop policies and procedures to care for patients affected by interpersonal violence, members of the advisory council are provided direct feedback on these policy and procedures.
  8. **Patient & Family Health Literacy Council**—This council was previously the Patient and Family Nursing Education. Advisors work on patient facing material through multiple media outlets to ensure patients understand materials that are provided to them. There are three advisors.
  9. **Jen Center PFAC**—This council was established in July 2014. The Jen Center is an internal medicine clinic located within the Brigham. The council provided feedback on the clinic website, patient gateway handbook, and the clinic call center. They were actively engaged with leadership regarding how to engage with patients on social determinates health screenings and with annual wellness visits. This council has eight advisors and meets once a month.
  10. **Fish Center PFAC**—This council was established in May 2015. The Fish Center is a multidisciplinary clinic. This council was placed on hold this past year due to leadership transition. This council will re-launch Fall 2018. This council has eight advisors.
  11. **General Medical Services**—This council is comprised of hospitalists, staff and 4 patient family advisors for inpatient general medical care. The council assisted with discharge rounds, 5pm huddle, scheduling follow up appointments after discharge and with hand hygiene. Council meets bimonthly.



12. **At Large Patient and Family Advisors**—these patient and family advisors provide a broad perspective on the hospital environment, issues of disability, medical records and application of computer systems. The advisors are requested ad hoc based on project scope.

#### **D. BWH Patient and Family Advisory Councils in Research**

13. **Strategies to Reduce Injuries and Develop confidence in Elders (STRIDE)**—is the acronym for the PCORI/NIA (National Institute for Aging) grant. This grant is a ten site falls reduction effort focused on patients 70 and older. BWH is the lead site and we have four patient advisors on various committees as well as the National Patient and Stakeholders' Committee. This is a five year grant. BWH is one of the sites and has a local STRIDE council consisting of 4 advisors.
14. **Research Ethics in Patient Centered Outcomes Research**—This grant will focus on understanding the regulatory oversight challenges posed by PCOR and CER and to develop guidelines, policy and recommendations to address those challenges. There are two patient advisors currently on this study.
15. **Integrating Online Weight Management**—this grant will focus on an online weight management program integrated with support from BWH primary care practices to help patients lose weight in a more convenient and accessible way. There is one advisor on this study.
16. **Patient Safety Learning Lab**—This grant focuses on developing tools to engage patients, family and professional care members in identifying, assessing and reducing patient safety concerns in real time. This grant has several components and includes fall prevention, safety checklist and my safe care, which is an app to improve safety reporting and response in the hospital. This grant is funded by the Agency for Healthcare Research and Quality. There are three advisors on this study.
17. **Patient Empowered Strategy to Reduce Asthma Morbidity in Highly Impacted Populations (PESRAMHIP)**—This grant will test the effectiveness of using a daily preventative inhaler with symptom based use for reducing asthma exacerbations in African-American and Hispanic Adults. This is a PCORI funded five year grant and will be multisite study. There are four advisors from BWH on this study.
18. **Navigating High Risk Surgery: Empowering Older Adults to Ask Questions that Inform Decisions about Surgical Treatment**—This grant is funded by PCORI and will focus on creating a questionnaire that will assist patients and families with the decision on whether to proceed with high risk surgical procedures or not. This is a three year grant and will have five sites participating in this study. There are three patient advisors on this study.



**Supporting :**

The Center for Patients and Families project manager organizes the Steering PFAC meetings, the Obstetrics PFAC, Jen Center PFAC meetings, Fish Center meetings and South Huntington PFAC meetings. The other PFAC meetings are managed by either a program manager or nurse manager within their own service lines. The amount of administrative time to support the councils is about twenty hours a month. The council members are provided with parking vouchers when they attend the PFAC meetings. Parking is allotted through the Center for Patients and Families budget. We do not provide stipends to our patient/family advisors.

**Maintaining Success with Council:**

The Councils have made significant strides in bringing awareness of Patient Family Centered Care to care providers and staff. This past year our advisors provided feedback to leadership regarding technology platforms to enhance the patient experience. Several of our Patient Family Advisory Council members participated in the Magnet process to attain Magnet status. Advisors were engaged on the digital visitor guide for the hospital and provided feedback on the redesign of the hospital's website. Our advisors continue to offer their support to the chair of the Brigham Comprehensive Opioid Response and Education regarding the opioid policy.

This past year, we continue to emphasize the patient family-centered care principles and the effect it has on the patient experience throughout our council projects. Our advisors worked diligently on improving the patient facing educational materials that are used by multiple departments and service lines. They provided tremendous feedback in ensuring all materials were easily understandable and followed the health literacy guidelines. The Executive Director for the Center for Patients and Families and her staff redesigned the Obstetrics Curriculum for Obstetric residents with the input of our Obstetrics PFAC. The revised curriculum focuses on patient/provider communication and the importance of effective communication based on the Institute for Patient Family Centered Care, patient family centered care core principles. Our South Huntington patient advisors continued their quality improvement project by shadowing the medical residents to evaluate patient family centered care behaviors specifically focusing on patient/provider communication.



Please see the section on BWH accomplishments on page 18 for additional accomplishments. Staff members in each PFAC service line will track the specific council's accomplishments. The staff liaison will ensure that the accomplishments are recorded.

**Patient and Family Advisory Council 2018-2019 Agenda:**

The Patient and Family Advisory Steering Committee's overarching goal is to continue to enhance communication and patient and family centered care throughout the institution for the upcoming year. To achieve this, we will continue to expand our service line patient family advisory councils to ensure that we capture the patient's voice of experience within the organization. We will also reinvigorate a couple of our councils that have been placed on a pause due to leadership transition. Leadership has requested patient family advisors to assist with the Emergency Department expansion to ensure that the new design space will meet the needs of the Emergency Department patients, families and staff through the use of the patient/family advisor perspectives. They will also provide feedback and guidance regarding signage for patients and families who utilize the ED during renovations to ensure that message is clear and compassionate.



#### 4. PATIENT AND FAMILY-CENTERED CARE AT BWH: SUMMARY OF ACCOMPLISHMENTS

The BWH journey of patient family centered care began in 1998 with efforts dedicated to laying the foundation for understanding the voice of our patients and families. Once the foundation was set, the next stage was marked by a period of searching for innovative improvement ideas that could be readily tested and applied. BWH adopted the core patient family centered care principles from the Institute for Patient Family-Centered Care. While continuing the patient family centered care journey, the first patient family advisory council was established in 2008. This council included hospital leadership and patient family advisors. In 2010, under the leadership of the Executive Director for the Center for Patients and Families, patient family advisory councils expanded from a hospital wide patient advisory council to department and service line patient family advisory councils and including patient family advisors on existing hospital committees.

##### 2010 – 2011

- *The journey continues as more departmental committees and service lines become interested in developing Patient and Family Advisory Councils or having a patient on their existing committee.*
- Maureen Fagan, WHNP – BC / MHA appointed the Executive Director, Center for Patients and Families
- Identification of service line patient and family service line committee development begins
- Training clinical leadership and staff in the principles of patient and family centered care
- BWH welcomed Jacqueline Somerville, RN, PhD, the new Chief Nursing Officer (CNO) and Senior Vice President of Patient Care Services
- BWH welcomed Stanley Ashley, MD, the new Chief Medical Officer (CMO)
- The new CMO and CNO will continue the commitment of having a patient family centered care environment in the organization.
- A large OB delegation goes to IPFCC conference in St. Louis Missouri
- Cardiovascular PFAC held their first monthly meeting in May 2011
- A patient/family advisor was invited on to the Orthopedic Care Improvement Council.
- Readyng the environment for patient family centered care in the BWH OR and ED.
- ED delegation will be attending the IPFCC conference this fall in Madison, Wisconsin
- Adding diverse advisors to the Steering Committee

##### 2011- 2012

- *Our patient family centered care journey continues as we focus on spotlighting our council's achievements and how our councils can assist each service line in providing patient family centered care.*
- In April our Shapiro Patient and Family Advisory Council hosted Nursing Grand Rounds. The topic of the grand rounds was Patients and Families Reflect on Their Hospital Stay.



- The ED started their patient and family advisory council. They have three advisors on their councils. Advisors are working on changing the environment and redefining visitors to support person.
- The South Huntington Medical Home is in the beginning phases of starting a patient and family advisory council.
- The Biomedical Research Institute is exploring the idea of creating a patient and family advisory council.
- Some of our patient and family advisors participated in selecting our hospitals next electronic medical record vendor.
- Our NICU council is the first department in our hospital to have a paid patient/family advisor
- Our councils and council members are being featured in the hospitals bulletin for nurses and physicians.
- Currently our Shapiro Patient and Family Advisory Council are working on having the hospital become a fragrance free environment.
- The Director of Volunteer Services attended the IPFCC conference in fall 2011.
- The ED sent two delegates to the IPFCC conference earlier this spring.

### 2012-2013

- *Our patient family centered care journey continues as we focus on bringing the patient and family members perspective to staff and clinicians.*
- In October our Shapiro Patient and Family Advisory Council hosted their second Nursing Grand rounds. The topic of the Grand Rounds was reflecting on the Healing Process.
- BWH Center for Patients and Families hosted its first Patient and Family Advisory Council Symposium for Partner's Hospitals in November featuring Julie Moritz as the key note speaker.
- Architects designing a new building for BWH requested patient and family advisors feedback on the blueprints
- In January, two of our advisors were requested to be part of a Psychiatric Nursing panel discussion to talk about delirium and the family's experience with caring for someone with delirium.
- Empowering Women PFAC held their first Patient and Family Advisory Council meeting in March.
- The South Huntington Medical Home held their first Patient and Family Advisory Council meeting in April.
- The patient and family advisors on the ED council were requested to be part of the interview process for nursing candidates.
- BWH Center for Patient and Families presented with their patient and family advisors at the 13 established medical grand rounds this past academic year. Grand rounds were a one hour panel discussion with 2-3 advisors sharing their narrative.
- The Jen Center/Internal Medicine is in the initial phase of developing a patient and family advisory council.
- The Executive Director for the Center for Patients and Families brought a large delegation to the fall 2012 and spring 2013 Institute of Patient Family Centered Care Conference. Delegates included a patient advisor, ED physician and nursing



- leadership, Social Worker leadership, Human Resources Leadership and several Executive Directors.
- BWH Ethics Committee and Patient Engagement Committee have each recruited patient advisors to their committees.
  - Three advisors are a part of the Inter-professional Rounding research study. Advisors are shadowing clinicians during bedside rounding.
  - Two of our patient advisors were asked to participate in a video for the National Association of Healthcare Transport Management. The topic of the video was on how to transport patients when they have delirium.
  - The BRI/PCERC received a grant called the Relative Patient Benefits of a Hospital—PCHM (Patient Care Home Model) collaboration within an ACO to Improve Care Transitions. There are six advisors in this study advising the researchers.

### 2013-2014

- *The patient and family centered care journey continues as we focus on bringing the patient and family perspectives to a wider audience including research.*
- PCORI/BRI is requesting the patient voice and advisors for their research grants
- Patient and Family advisors are becoming more aware about HCAHPS through presentation and discussion
- Patient Family Advisory Steering Committee has been providing feedback on the EPIC system specifically the patient portal.
- Three of our advisors participated with the hospitalist on in-patient bedside rounding
- Three advisors participated in Schwartz Rounds and Medical Residents Grand Rounds in February 2014. Topic of discussion for both sessions were on delirium
- Patient Family Education Committee on boarded three patient advisors in March 2014
- Executive Director for Center for Patients and Families presented on HCAHPS tactics in May 2014 in Cleveland for the Empathy and Innovation Conference.
- Shapiro PFAC participated in interviewing Nursing Directors at the request of the Associate Chief Nurse. They provided feedback on the top three candidates.
- We featured one of our advisors on the TV monitors throughout the hospital asking visitors and staff to be fragrance free.
- Phyllis Jen Center held their first Patient and Family Advisory Council meeting in July.
- Executive Director for Center for Patients and Families, Senior Patient Advisor and Patient Family Staff Liaison attended the International Patient and Family Centered Care Conference in Vancouver, August 2014. They presented on Patient and Family Centered Care in Medical Grand Rounds: The Impact of Patients' Perceptions of Care on Physicians.
- ED Nursing educator and staff nurse created a video featuring the ED advisors on how patient advisors have influenced ED culture change in patient centered care. This video was presented as part an interactive media poster presentation at the International Patient Family Centered Care Conference in Vancouver, August 2014. The video will also be used in the future to introduce staff to patient advisors.
- Associate Chief Nurse presented on research for women affected by violence at the International Patient Family Centered Care Conference in Vancouver, August 2014.



- Four of our patient and family advisors participated in a video for the annual Nursing Celebration dinner. They spoke about their overall experience and the nursing care they received.
- Our patient and family advisors were featured in the semi-annual BWH magazine. The article focused on patient family advisory councils and the role they have at BWH.
- Our advisors have been continually sought after for PCORI studies. Currently about 10 advisors have partnered with researchers PCORI research grants.

#### 2014-2015

- *The patient and family centered care journey continues as we branch out to ambulatory practices and continue to respond to requests for patient family advisory councils within the institution and patient family advisors for research studies*
- BWH sponsored the Institute for Patient Family Centered Care Conference in Fall 2014
- Fish Center held their first Patient Family Advisory Council meeting in May 2015
- General Medical Services held their first Patient Family Advisory Council meeting in November 2014
- Patient family advisors were invited to participate on improving the BWH website for patients and families
- Patient family advisors were involved in providing feedback for the new electronic medical records system which was implemented June 2015
- ED PFAC promoted a patient family centered care orientation for new ED nurses
- Jen Center Patient Advisor was featured in a vidscript for colonoscopy screening
- Jen Center Patient advisor was invited to participate on task force for creating the prerequisites for terminating a patient from clinical care
- Sleep Apnea PFAC applied for a PCORI sleep apnea peer to peer grant
- BWH patient family advisors participated in validating a direct observational tool for a primary care setting
- LGBTQIA PFAC is preparing to launch in October 2015
- BWH Researchers continues to reach out to the Executive Director of the Center for Patients and Families for patient family advisors for PCORI grants and other institution.

#### 2015-2016

- *The patient and family centered care journey continues to be advanced by our patient family advisors and patient family advisory councils as their expertise and experience matures.*
- Advisors from our multiple PFACs participated on a focus group on how to engage patient advisors in research. Focus group was conducted by Planetree who received a PCORI grant to develop a toolkit on engaging patient family advisors onto research grants and projects
- Project Manager for the Center for Patients and Families along with senior patient advisor and with a patient family advisor attended the International Institute for Patient Family Centered care in New York City, July 2016. They presented at two sessions. First session was Partnering with Patient and Family Advisors to Validate a





- Patient-Centered Care Tool. The second session was Implementing a Pragmatic framework for Authentic patient-Researcher Partnership in Clinical Research
- Obstetric Patient Family Advisors participated in the Patient Family Centered Care Curriculum launched in January 2016. Target audience for this curriculum was for the Obstetric medical residents.
  - South Huntington Patient Family Advisors participated on a quality improvement project on improving communications between patient, provider and staff. Project required advisors to be trained to be a direct observer for patient encounters with staff and provider from check in to check out. Project was piloted May 2016 and is ongoing.
  - ED patient family advisors are working with researchers on how to capture gender identify orientation information from patients in the ED
  - Jen Center Patient Family Advisors worked on improving the hospital signage for way-finding
  - Fish Center Patient Family Advisors worked with leadership on crafting letter to patients notifying that their physician is retiring and will need to select a new primary care
  - Shapiro Patient Family Advisors worked with the Patient Safety Learning Lab and provided feedback on their fall prevention toolkit and assisted with validating their My Safe Care survey
  - LGBT PFAC launched October 2015 and hosted in May 2016, an education panel discussion on Creating a Caring Environment for Transgender Patients: A Panel Discussion for Care Providers and Staff
  - BWH Center for Patients and Families published two articles in May 2016. The first article, Patients, Persistence, and Partnership: Creating and sustaining Patient and Family Advisory Councils in a Hospital Setting was published in the Journal of Clinical Outcomes Management. The second article, Implementing a pragmatic framework for authentic patient-researcher partnerships in clinical research was published in the Journal of Comparative Effectiveness Research
  - Executive Director for Center for Patients and Families continues to receive requests for patient family advisors for PCORI grants

#### 2016-2017

- *The patient and family centered care journey continues as our patient family advisors and patient family advisory councils become more recognized for their expertise and experience.*
- Executive Director for the Center for Patients and Families along with Senior Patient Advisor presented on “Designing, Implementing and Sustaining a Patient Family Advisory Council in your Healthcare Organization” at the Next Generation Patient Experience Conference, November 2016
- LGBT PFAC co-sponsored “Tackling Disparities in Health Care for Transgender Patients” and featured a LGBT advisor, April 2017
- Several patient family advisors participated in a research project involving Difficult End of Life conversation with the Attending Physicians in the Emergency Department



- Advisors from our multiple PFACs participated on the following focus groups: Building capacity for patient, family member and researcher engagement in comparative effectiveness research and patient centered outcomes research in hospital medicine, focus group on how to engage patient advisors in research, Cultural Sensitivity in Medical Education and All of Us Research Program
- Advisors provided extensive feedback on patient facing education materials for various departments and service line
- Executive Director for the Center for Patients and Families and two patient family advisors presented at the Partners Patient Experience Summit
- Executive Director for the Center for Patients and Families and two patient family advisors presented at the Patient Experience Symposium. Presentation was on “Opportunities for Expanding the Engagement of Patient Advisors in an Academic Medical Center”
- South Huntington Patient Family advisors completed the pilot phase of shadowing attending physicians and medical staff in the South Huntington Medical Home
- Executive Director for Center for Patients and Families and Senior Patient Advisor co presented with the Institute for Patient Family Centered Care, July 2017. Webinar presentation was on “Evaluating Patient Family Advisory Programs”
- Obstetric Patient Family Advisors provided feedback on redesigning the Patient Family Centered Care curriculum for Obstetric Residents—Center for Patients and Families launched revised curriculum June 2017
- Three patient family advisors attended the American College of Surgeon Conference and participated on a patient panel focusing on Informed Decision and Consent Forms for High Risk Elders, September 2017
- Project Manager for the Center for Patients and Families along with Senior Patient Advisor attended the National Association for Healthcare Quality in Cincinnati, Ohio, September 2017. They presented on “Improving Quality by Providing Timely Feedback Among Patients, Families and Providers/Staff.”
- Neurosciences is working on launching a Neuroscience PFAC in Winter 2018

#### 2017-2018

- *The patient and family centered care journey continues as our patient family advisors and patient family advisory councils are being utilized more within the institution as they are recognized as subject matter experts.*
- Project Manager for the Center for Patients and Families and Senior Patient Experience Advisor organized a patient family advisory workshop for the Patient Experience Symposium in Boston, featuring the chairs of the South Huntington Patient Family Advisory Council, General Medical Specialty Council and the Emergency Department Patient Family Advisory Council
- Patient Family Advisors participated in the “All of Us Research” focus groups
- Project Manager for the Center for Patients and Families provided guidance to the Health Ministry of Israel on creating Patient Family Advisory Councils
- Senior Patient Experience Advisor assisted with redesigning the Patient and Family Nursing Education Council to become the Health Literacy Patient Education Council



- Project Manager for the Center for Patients and Families and Senior Patient Experience Advisor is providing assistance to Radiology leadership to launch a Radiology Patient Family Advisory Council
- Project Manager for the Center for Patients and Families and Senior Patient Experience Advisor provided assistance to Rheumatology leadership to launch Rheumatology Patient Family Advisory Council this Fall
- Project Manager for the Center for Patients and Families and Senior Patient Experience Advisor recruited additional patient family advisors for South Huntington PFAC and Fish Center PFAC
- South Huntington Patient Family Advisors shadowed medical residents to ensure residents communicated effectively with their patients
- Senior Patient Experience Advisor participated in Patient Centered Outcomes Research Study session at Harvard Law focusing on IRB and ethics for patients in research
- Senior Patient Experience Advisor participated in the 2018 International Institute for Patient Family Centered Care conference and facilitated a research breakout session
- Patient Family Advisors participated in a focus group on Safe discharge with medication from the hospital
- Emergency Department Patient Family Advisors held a luncheon panel discussion for medical residents and students on how to effectively communicate with patients and families in the Emergency Department



## ATTACHMENT 1: PFCC CORE CONCEPTS

### Patient and Family Centered Care

- The priorities and choices of patients and their families are identified in **collaboration with** the provider to drive the delivery of health care.
- Interventions are done **with** patients and families rather than to and for them

### Definition of Family

- The patient and family define the “family”
- The patient and family determine if and how the family will be involved in care and decision-making

### PFCC Core Concepts

- Dignity and respect
  - Providers include individual's preferences, culture, capacity and abilities in determining care
- Information sharing
  - Communication is open, timely, complete, understandable
- Participation in care and decision making
  - Presence allows involvement, practice and learning
- Collaboration in policy, program development and design
  - Patient and family advisement at all levels of operations and care delivery



**Attachment 2: PATIENT AND FAMILY ADVISORY COUNCIL STRUCTURE & MEMBERSHIP**



