



**Patient and Family Advisory Council (PFAC) Report for
the MA Coalition for the Prevention of Medical Errors
Submitted September 2009**

Patient and Family Centered-Care Liaison Contact Information:

*Wendy Martinez
Operations Supervisor, Patient Family Relations
& Patient Family Centered Care Liaison*

*Brigham and Women's Hospital
75 Francis Street
Boston, MA 02115*

*617-732-8332
617-582-6130 fax
wmartinez@partners.org*

Patient and Family Advisory Council (PFAC) Report for the MA Coalition for the Prevention of Medical Errors: Table of Contents

1. bwh Patient and family advisory council Description.....	3
2. Application Form for Patient and Family Advisors.....	6
3. Interview Questions for Potential Patient & Family Advisors.....	9
4. Patient and Family Advisor Orientation: Overview.....	10
5. Patient and Family Advisor Orientation: Hospital Tour.....	11
6. Advisor & Provider Orientation: PFCC Core Concepts.....	12
7. Advisor & Provider Orientation: PFCC BWH Background.....	13
8. Advisor & Provider Orientation: Brigham and Women's Hospital Patient-and family-centered care Philosophy.....	14
9. Advisor & Provider Orientation: bwh PFAC.....	15
10. GUIDELINES FOR Group Leaders & Facilitators on Involving Pts & Families AT MEETINGS.....	16
11. PFAC Meeting Minutes.....	18
12. Patient and Family Advisory Council structure & Membership.....	19
13. Patient and Family-Centered Care at BWH: Summary of accomplishments.....	22

1. BWH PATIENT AND FAMILY ADVISORY COUNCIL DESCRIPTION

Goal Statement:

The Patient and Family Advisory Council (PFAC) will work 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 will oversee 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 will occur in various meetings and forums.

Reporting Structure:

The Patient and Family Advisory Council will report to the BWH Care Improvement Council (CIC), the hospital's patient care assessment committee. The CIC chair is also co-chair of the PFAC and the co-chair also belongs to the CIC, thereby making the flow of information between the two groups direct.

Long Term Goals:

- Advise on the infrastructure necessary to create a patient and family-centered care culture.
 - 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
 - Understand the role and needs of patient and family advisors in order to best engage and support members of the Patient and Family Centered – Care Advisory Group

Meeting Frequency & Duration:

- Frequency: 4 times per year
- Duration: 1.5 hours

Membership:

Membership of the Council shall be comprised of patient and family advisors and select representatives of Brigham and Women's Hospital including the CMO, CNO as chairs, the Sr. VP of the Center for Clinical Excellence, the VP of Clinical Services, and the Patient and Family Advisor Liaison. The service lines join the council on an ad-hoc as the need arises and 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 completes a membership application (see table of contents item 2) and interview or who has in another form been deemed willing and able to contribute towards the larger mission of the council. The application and interview 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 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 also committed to having a council that reflects the patient population we serve here at BWH despite the effort required to accomplish this.

Recruitment is primarily reliant on clinician recommendation of potential patient and family advisors; however, members are also identified by the Department of Patient and Family Relations, and in the case of the Neonatal Intensive Care Unit, members self-identified. This summer, the Chief Medical Officer has asked that the chiefs of the various service lines identify five potential advisors which are representative of the population they serve.

Selection is based on information provided by the clinician recommending the patient/family advisor. As of June 2009, selection is also determined from the information provided on the PFAC membership application (table of contents item 2) and if invited to an interview, from the information learned in person. The term of an advisor is set for a period of one year with the option to extend term based on interest.

Roles of 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)
- ✓ Serving on local advisory councils
- ✓ 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

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

Governance:

Officers are not elected at the present time and therefore officer duties do not exist. The council was formed by the chairs, the Chief Nursing Officer and Sr. Vice President of Patient Care Services and by the Chief Medical Officer. Three patient advisors have self-selected to form part of the PFAC Steering Committee which sets forth the agendas covered at the quarterly PFAC meetings.

Minutes of Council meetings including Council accomplishments shall be transmitted to the Care Improvement Council.

Evaluation:

We believe in continuous improvement and the council intends to evaluate itself on topics which are important to the functioning of the council including but not limited to goals, membership and governance.



2. APPLICATION FORM FOR PATIENT AND FAMILY ADVISORS

Please print:

Name: _____
(Last) (First) (MI)

Address: _____

City: _____ State: _____ Zip Code: _____

Home Phone: (10 digits) _____ Cellular Phone: (10 digits) _____

Work Phone: (10 digits) _____ Fax: (10 digits) _____

E-mail Address: _____

Language(s) You Speak: _____

Will you allow your contact information to be shared with other committee/advisory council members?
(fill-in choice)

- Yes
- No

I am: (fill-in all that apply)

- A patient
- A family member of a patient
- Other, please specify: _____

Please list times when you are able to attend meetings: (fill-in all that apply)

- Daytime: _____
- Evening: _____
- Weekend: _____

My care provided at Brigham and Women's Hospital was primarily: (fill-in all that apply)

Hospitalization (inpatient): MM/YY

- Clinic visit (outpatient: MM/YY
- Emergency Department care: MM/YY
- Other programs, departments, or services: MM/YY
- Both inpatient and outpatient: MM/YY

Within the past two years, what care services have you or your family member used? (fill-in all that apply)

- AIDS & HIV
- Cardiac Surgery
- Cardiology
- Dermatology



- Endocrinology/Diabetes
- Fertility
- Gastroenterology/GI/Endoscopy
- Genetic Counseling
- Gynecology
- Infectious Diseases
- Intensive Care Unit (ICU): Where? _____
- Mental Health/Psychiatry
- Neurology
- Neurosurgery
- NICU
- Nutrition
- Obstetrics/Pregnancy/Labor & Delivery
- Oncology/Hematology/Cancer
- Orthopaedic
- Otolaryngology/ENT
- Plastic Surgery
- Pulmonary
- Pregnancy
- Primary Care
- Rehabilitation
- Renal/Kidney/Nephrology
- Rheumatology/Autoimmune/Arthritis/Skin & Connective Tissue
- Surgery: Where? _____
- Thoracic/Chest
- Transplant
- Urology
- Vascular
- Women's Health
- Other

I/We would be interested in helping to improve: (fill-in all that apply)

- Patient and family satisfaction tools
- Patient educational materials
- The hospitalization (inpatient) care experience (room, coordination of care, communication, food)
- The care systems and facilities for the surgical experience
- The clinic (outpatient or ambulatory) care experience
- The care systems and facilities for the emergency care experience
- Patient safety and the prevention of medical errors
- Education of medical students and residents, new employees, and other staff about the experience of care and effective communication and support.
- Facility design planning and way-finding
- The coordination of care and the transition to home and community care.
- Issues of special interest (please describe): _____



3. INTERVIEW QUESTIONS FOR POTENTIAL PATIENT & FAMILY ADVISORS

Please tell us about your interest in serving as an advisor.

Please tell us if you have any interest in serving in a teaching/training role such as speaking about your experience to an incoming class of medical school students or participating in a role-play with a similar group. Describe any experience you may already have in this capacity

How would you feel about expressing an opinion in front of a group?

How would you feel about hearing an opinion with which you disagree?

What are some specific things that health care professionals did or said that was most helpful to you and your family?

What are some specific things that you or your family would like health care professionals to do *differently* in order to be more helpful?

Are you interested in serving as a long term advisory council member?

Do you know other individuals and/or families who have experienced care at BWH who might be interested in serving as advisors? Please list their name(s) and phone number(s) and email address here:

4. PATIENT AND FAMILY ADVISOR ORIENTATION: OVERVIEW

The patient and family advisor orientation begins with the interview process where the potential advisor learns directly from the area leaders about the area where he/she might serve and what being an advisor would mean.

The patient and family advisor then receives a formal four-hour orientation through the volunteer office and includes training on confidentiality as well as other elements included during the regular employee orientation. At the end of this process, and after the appropriate vaccinations, as required of any new employee, advisors also receive a formal hospital badge, for a one year term.

The next step brings together the patient and family advisor with the patient and family liaison who provides the patient and family advisor a hospital tour, introduces him/her to the concepts of PFCC as set forth by the Institute for Family-Centered Care, shares the Brigham and Women's Hospital-specific philosophy statement of PFCC, and provides a brief history on the journey of Patient and Family-Centered Care at BWH.

The final step in the orientation takes place when the liaison accompanies the advisor to his/her first meeting.

The liaison is also beginning to think about how best to follow-up with the patient and family advisor during regular intervals in their time as an advisor and point to any opportunities for improving the experiencing. Something that is also being considered is the possibility of pairing seasoned advisors with novice advisors, so that they learn how to maximize their time as an advisor.



5. PATIENT AND FAMILY ADVISOR ORIENTATION: HOSPITAL TOUR

Advisor will receive a tour of the following areas of the hospital:

- Peter Bent Brigham: 15 Francis Street
- Deland Board Room
- Pike
- Connors Center for Women & Newborns
- Cafeteria
- Tower
 - Family space on 14th
 - Patient Care Unit
- Carl J. and Ruth Shapiro Cardiovascular Center
- Area where advisor will serve



6. ADVISOR & PROVIDER ORIENTATION: 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*



BRIGHAM AND
WOMEN'S HOSPITAL

7. ADVISOR & PROVIDER ORIENTATION: PFCC BWH BACKGROUND
(See PowerPoint)

8. ADVISOR & PROVIDER ORIENTATION: BRIGHAM AND WOMEN'S HOSPITAL PATIENT-AND FAMILY-CENTERED CARE PHILOSOPHY

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.

9. ADVISOR & PROVIDER ORIENTATION: BWH PFAC

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Reporting Structure:

The Patient and Family Advisory Council will report to the BWH Care Improvement Council (CIC), the hospital's patient care assessment committee. The CIC chair is also co-chair of the PFAC and the co-chair also belongs to the CIC, thereby making the flow of information between the two groups direct.

Long Term Goals:

- Advise on the infrastructure necessary to create a patient and family-centered care culture.
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Meeting Frequency & Duration:

- Frequency: 4 times per year
- Duration: 1.5 hours



10. GUIDELINES FOR GROUP LEADERS & FACILITATORS ON INVOLVING PTS & FAMILIES AT MEETINGS ¹

Preparation for Meetings

- *Consider the convenience and schedules of patients and families as well as staff in planning the times and locations for meetings.*
- *Send agenda and minutes ahead of time to all committee members, remembering to allow time for material to reach patients and families (they may not have faxes, email, etc.)*
- *Provide a list of committee members with a brief description of who each person is.*
- *Offer a mentor, an experience patient or family advisor or another committee member, to serve as support for a new advisor.*
- *Offer to have someone come to the first meeting with the new member and debrief afterwards.*
- *Remember that this type of collaboration is new for many people so preparation and orientation is important for staff as well as patients and family members.*
- *Plan for compensation of time, expertise, and expenses for patients and families.*

During Meetings

- *Spend extra time on introductions at the beginning of a meeting, especially for a new committee or when there are new members.*
- *Consider beginning some meetings with a brief story that captures patients' and families' experiences and perceptions of care.*
- *As the leader or chair, discuss the concept of collaborating with patients and families explicitly, recognizing that it is a process with everyone learning together how to work in new ways. Convey that it will be important for the group to discuss how the process is working from time to time.*
- *Acknowledge that there will be tensions and differing opinions and perceptions.*
- *Provide clear information about the purpose of the committee or task force and the roles of individual members.*
- *Avoid using jargon. Explain technical terms when used.*
- *Ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as committee members.*
- *To avoid becoming stuck in the power of a negative situation, acknowledge the negative experience and ask if there was anything supportive, helpful, or positive for the group to learn from the situation. Ask for ideas and suggestions to prevent or improve the situation.*
- *If a personal story becomes very prolonged, acknowledge the power and the importance of the story, suggest that some policy implications can be learned from the story and there may be other more appropriate forums where this story should be shared.*
- *When there are extreme differences in opinions or perceptions, consider:*
 - *Appointing a task force to further study of the issue*
 - *Asking the opinion of the other groups (e.g., another hospital committee or patient/family advisory group)*
 - *Delaying a decision and considering at a future meeting.*

¹ Institute for Family-Centered Care 1/2009
7900 Wisconsin Avenue, Suite 405, Bethesda, MD 20814



Anticipate Illness Demands

- *Patients and their family members may not be able to attend every meeting. There are other demands on their time and stamina.*
- *Acknowledge to patients and families themselves and to the committee as a whole that their presence was missed and their participation is valued when they are able to participate. Mailing the minutes and future agendas helps reinforce that their participation is valued.*
- *Having shared memberships on the committee may help.*
- *Consider having a “patient and family leave policy” so that consumers can choose an inactive role but maintain their membership should there be circumstances that require some time off.*
- *Creating a variety of ways for patients and families to participate in the consideration of issues may be useful (e.g., conference calls, written review of materials).*

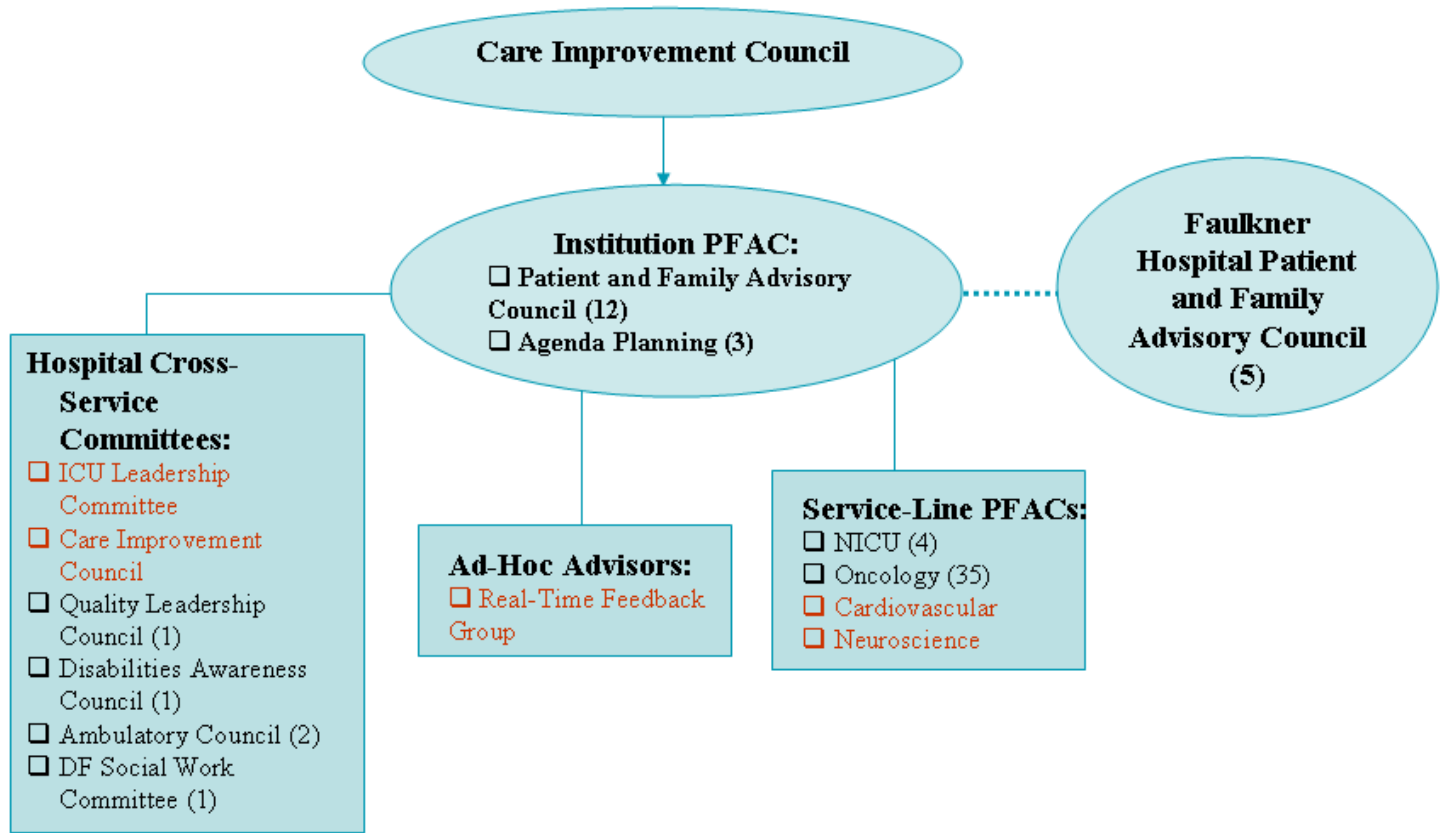


11. PFAC MEETING MINUTES

- ✓ Minutes 3-25-08
- ✓ Minutes 6-24-08
- ✓ Minutes 9-23-08
- ✓ Minutes 12-4-08
- ✓ Minutes 3-24-09
- ✓ Minutes 6-30-09

12. PATIENT AND FAMILY ADVISORY COUNCIL STRUCTURE & MEMBERSHIP

Patient & Family Advisory Council Structure*



Quality, Safety and Service Excellence

Committees in black have PFCC advisors on them, and the number in parentheses indicates how many.



A. Institution 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: Elayne Anderson, Martie Carnie, Mrs. Linda Gelb, Estrellita Karsh, John and Natty McArthur, Patricia P. Petraglia, Gayle Shumacher, Marla Wolke

2. Patient and Family Advisory Council Agenda Planning Committee

- Purpose: Plans the agendas for upcoming PFAC meetings.
- Meeting Frequency: Meets twice before and once after each PFAC meeting for about one hour.
- Current Advisors: Martie Carnie, John and Natty McArthur

B. Hospital Cross-Service Committees

3. Care Improvement Council (CIC)

- Purpose: This hospital board level committee oversees all departments in terms of quality & safety; regulatory requirements and new hospital policies. It also reviews faculty appointment and privileges.
- Meeting Frequency: Meets one time per month for two hours.
- Current Advisors: TBD

4. Intensive Care Unit (ICU) Leadership Committee

- Purpose: Intensive Care Unit clinical leaders share and address practice and quality of care issues such as hand washing and Joint Commission requirements.
- Meeting Frequency: Meets one time per month for one hour.
- Current Advisors: TBD

5. Quality Leadership Council

- Purpose: Develop multiyear strategic quality and patient safety plan and to review current quality and safety initiatives to ensure integration within hospital operations.
- Meeting Frequency: Monthly. 2nd Tuesday of each month
- Current Advisors: Jim Stam

6. Council on Disabilities Awareness (contact: Janet Razulis)

- Purpose: TBD
- Meeting Frequency: TBD
- Current Advisors: Melissa Hoyt

7. Ambulatory Council



- Purpose: BW/F initiative established to create and oversee the development of a comprehensive strategic plan for the BW/F ambulatory enterprise
- Meeting Frequency: Monthly (started meeting in April 2008)
- Current Advisors: Altshuler, David, Petraglia, Patricia
- Additional Members: Council membership includes BWH and BWPO leadership and consumers from across the institution, representing many disciplines within ambulatory services. Adler, Dale S.,M.D.; Bailey, Jack; Beard, Clair,M.D.; Carusi, Daniela Anne,M.D.,M.S.C.; Chiodo, Christopher,M.D.; Coblyn, Jonathan Scott,M.D.; Daphnis, Margo E.; Delvecchio, Michael; Dinkin, Marc J.,M.D.; Ferrazza, Dawn; Gandhi, Tejal K.,M.D.,M.P.H.; Goplerud, E. Jan; Greene, Alyson F.; Hoyt, McCallum Robinson,M.D.,M.B.A.; Hu, Jim C.,M.D.,M.P.H.; Patel, Nipa; Sampson, Christian Edward,M.D.; Schneider, Louise Isabel,M.D.; Stevens, Lori J.; Whittemore, Elizabeth; Vitti, Sharon; Walls, Judy

8. Dana Farber Social Work Committee (contact: Martha Burke)

- Purpose: TBD
- Meeting Frequency: TBD
- Current Advisors: Linda Gelb

C. Service-Line Patient and Family Advisory Councils:

With the exception of the NICU PFAC, all committees are in the process of recruiting members and solidifying purpose.

9. Oncology PFAC

10. NICU PFAC

11. Neuroscience PFAC

12. Cardiovascular PFAC

D. Ad-Hoc Advisors:

13. PFCC Real-Time Feedback Group

- Purpose: We envision this as a virtual network of Advisors who can provide quick feedback on issues that the hospital may be facing at any particular moment in time.
- Meeting Frequency: Meets via email, by conference call, or in small, focus-group-like settings on a need by need basis.
- Advisors who have served: Gayle Shumacher, Martie Carnie, Jim Stam



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

1998-2001

- *Our journey began in 1998 with efforts dedicated to laying the foundation for understanding the voice of our patients and families:*
 - 1st Public Reporting of Patient Satisfaction data to Massachusetts Health Quality Partners and renewed commitment to improving the patient experience
 - Established several multidisciplinary inpatient care improvement teams
 - Established a Patient and Family Relations Department
 - Bretholz Center and Kessler Library for patients and families opens - created with patient/family input

2002-2005

- *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.*
 - Family areas created in Obstetrics
 - Multidisciplinary rounds instituted
 - Web nursery created
 - Enhanced nurse call system implemented
 - Improvement design teams included patient advisors
 - Senior leaders attended Institute for Family Centered Care conference to explore ways to include patient and family advisors

2005-2008

- *The third period on the road to PFCC was defined by efforts to assess the culture and values at BWH while continuing to make improvements:*
 - Formation of 1st local patient advisory council in the NICU
 - Roll out of meals room service house-wide
 - Development of PFCC philosophy with input from patients and families and over 300 staff from across both service and discipline spectra
 - Inclusion of expert nurses in “Describing what excellent nursing care looks like at BWH” as part of unit-based focus groups
 - Patient & family inclusion in design of Shapiro Cardiovascular Center and seeking input for family zone design

2008-2009

- *The journey does not end, it continues to be reinvigorated by ideas from the outside and by fortifying linkages between patients/families and those who deliver the care, all with the goal of providing the very highest level of quality care in all of its dimensions.*
 - Press-Ganey Satisfaction Surveys Administered in Ambulatory Practices
 - BWH PFAC Meets for first time and provides input on hospital PFCC Philosophy and Family and Visitor Policy
 - Cardiovascular Staff (RNs, PCAs, etc.) receive 4-hr interactive “Connecting with Care” training to learn communication strategies to create, manage and sustain a PFCC environment



- PFAC hears the Dana Farber PFAC story and receive tour of the Carl J. and Ruth Shapiro Cardiovascular Center Prior to Opening
- Carl J. and Ruth Shapiro Cardiovascular Center Opens
- PFAC hears the how family involvement in the NICU lead to creation of a PFAC and to changes in the experience
- PFAC invites Public Affairs director to discuss Boston Globe articles describing care at the BWH
- Institute for Family Centered Care Conference: BWH sends 20 delegates from CV, NICU, Ambulatory, Neuroscience, and administration to create action plans to start local councils or further develop existing councils
- Patient and Family Advisor Liaison is hired
- PFAC hears updates from IFCC Conference
- Patient and Family Advisor Liaison develops member recruitment, interview, and orientation process with input from PFAC advisors
- PFAC hears additional reports from IFCC Conference and recommends learning about the safety agenda
- Membership efforts are bolstered by CMO and CNO reaching out to chiefs to help identify potential advisors from the various service lines they serve