



PFAC 2015

**A Review of 2014 Massachusetts
Patient and Family Advisory
Council Reports**

Health Care For All
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Executive Summary

2015 marks five years of Patient and Family Advisory Councils (PFACs) in all Massachusetts hospitals. At this point in their development, all PFACs must be at a place where they are valued members of the hospital community and partners in improving care. Patient and family advisors must feel empowered to speak up, take action and determine where and how they can make the most difference. Councils must be able to initiate their own projects and become deeply involved in existing hospital initiatives. Much of this is dependent on open and significant support from hospital leadership.

This report, the fourth PFAC summary report produced by Health Care For All, focuses on impactful and unique projects. Many, but not all, Councils have moved beyond just serving as monthly or bi-monthly sounding boards and are part of the fabric of the institutions in which they sit. These PFACs take the lead on projects, are present throughout the hospital on committees, staff trainings, and elsewhere, and bring in diverse voices to inform their work. Patients and families bring valuable perspectives to the work of a hospital and often contribute in ways that hospital employees do not or cannot. Successful PFAC initiatives lead to increased patient satisfaction, expanded and improved community outreach, more meaningful and effective patient and family education efforts and materials, and improved patient outcomes.

All PFACs can learn from the examples highlighted throughout this report. All patient, family and staff Council members should read this report and discuss which of these projects they would like to learn more about.

Together, Massachusetts Patient and Family Advisory Councils can form a statewide movement to make significant patient and family partnership and engagement a vital and high-priority goal and a reality for every hospital and health care institution. With 30 Councils represented on the Massachusetts PFAC Advisory Board, Health Care For All and the Board can be the driving force for change.

Patient and Family Advisory Councils A Review of 2014 PFAC Reports

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Section I: Massachusetts PFACs' Impact on Quality of Care

Introduction

“Nothing about us without us.” Patient and family advocates across the country are driven by the deeply held belief that they must be fully informed about and involved in their own health care as well as systemic efforts to improve health care. They are the ones most directly impacted and have the experiences and perspectives of care recipients. Therefore, they must be partners with care providers in improving the quality of health care and the patient and family experience.

Patient and Family Advisory Councils (PFACs) are groups of patients, family members and staff who partner with a hospital or other health care organization in improving the quality of health care and the care experience. Councils exist at hospitals across the United States, and there are powerful examples of how they have contributed to important and lasting changes.

Massachusetts, recognizing the value of the patient and family voice, is the only state that requires hospitals to establish PFACs. This law is a bold statement about the importance of patient and family involvement in care. As a result of the law, there are 93 Patient and Family Advisory Councils in Massachusetts acute care and rehabilitation hospitals, and all Massachusetts hospitals have patient and family advisors working with them to improve care. These individuals serve as representatives for health care consumers across the Commonwealth. The efforts of these volunteers positively impact the quality of care for everyone.

The Massachusetts PFAC Advisory Board, established in June 2014 by Health Care For All (HCFA), brings together 42 PFAC members from 30 Councils across Massachusetts. The Advisory Board works with HCFA to develop resources, technical assistance, and networking opportunities for all Councils in the state. The Board has four committees: the PFAC Peer Support Program Committee, the Best Practices Committee, the Conference Planning Committee, and the Report Review Committee. The Board members share challenges and best practices in order to better inform their work and HCFA's work. The Board serves as a statewide voice for all PFACs and seeks to influence hospital policies to fully engage patients and families in all institutions.

The statewide PFAC Advisory Board has endorsed three goals for 2015/2016 for all Massachusetts PFACs and their partner hospitals to aspire to meet:

- PFAC takes the lead on a project improving care.
- Patients and families are involved in all aspects of the hospital's work.
- Council is representative of the community served by the hospital.

There are many examples of how Massachusetts PFACs have made a difference in care, including giving feedback on patient education materials, taking leadership of the development of new materials, partnering with the hospital in setting research priorities and direction, and educating community members about end-of-life care options. Hospital leadership that truly values patient and family input will seek their involvement in as many aspects of the institution's work as possible, in order to create a culture where their voice is considered vital for any decision-making at the hospital. This report highlights the impact of Massachusetts PFACs during 2013-2014 along with lessons learned and promising practices for Councils to replicate.

PFACs Directly Impacting Care

All PFACs should take the initiative on a project directly improving care within their institutions or communities. This can mean starting a project and partnering with the hospital to develop and implement it. Or it can be on-going, meaningful involvement in some aspect of an existing initiative. These are projects that go beyond just giving feedback on an existing hospital initiative. This is the heart of the PFAC mandate in Massachusetts: patients and families should have a meaningful and lasting impact on improving care. Below are examples of Councils that took the lead on projects they determined were important to improving patient care and the patient and family experience.

Improving Information for Parents in the PICU: Baystate Children's Hospital

The Patient and Family Advisory Council at Baystate Children's Hospital formed a subcommittee to work on developing information "for parents by parents" for the Pediatric Intensive Care Unit (PICU). The group initiated this project because of experiences that members of the PFAC had when their children were in the PICU. They did not have any kind of information written by other parents to guide and support them during this time. They knew that their experiences and what they learned as a result of having a child in the PICU could assist other parents. The focus of the project was the creation of a brochure giving advice on how to deal with being in the PICU, including information on care conferences, taking care of yourself as a parent, and having a notebook with you at all times. The PFAC members know that having this kind of information can be very useful and provide some much-needed comfort and support.

Wendy Franz, who joined the Baystate Children's Council in 2010 and worked on the brochure, talked about why this particular project is important to her:

"I joined the PFAC because my daughter spent 11 days in a medically induced coma in the PICU. For the most part the experience went well. Waiting for an hour and half in the PICU waiting room with no contact was hell. I never wanted another family to sit there waiting, wondering what was going on with their loved one and feeling helpless. Creating information for parents by parents was important to those of us who had

children in the PICU. Now parents do not have to feel so alone and scared because they have advice from others who have been in their shoes. I believe this project will have a positive impact on PICU families.”

Other PFACs should take on projects like this to provide information and support to family members of patients, whether they are in a PICU, an ICU, or receiving any inpatient care. The Baystate Children’s Hospital brochure serves as an example of what other PFACs can accomplish.

Improving Care and Communication in the Emergency Room: Mount Auburn Hospital and Cooley Dickinson Hospital

The Emergency Room can be a confusing and overwhelming place -- no matter the hospital or the situation that brings someone there. PFACs should be involved in improving care in the Emergency Department (ED) and in trying to make the patient/family experience less overwhelming. The Mount Auburn and Cooley Dickinson Councils’ efforts provide insight into how advisors can become deeply engaged in improving the ED experience.

Mount Auburn: The PFAC at Mount Auburn Hospital redesigned the “Welcome to the Mount Auburn Emergency Department” brochure, adding in a lot of information essential to patients and families. This educational tool focuses on expectations while in the Emergency Department, provides specific examples of diagnostic testing that may happen while in the ED, and explains why some patients may be seen sooner than others. The brochure addresses safety issues and helps to identify areas of patient and family concern, such as explaining why information is asked several times by several providers throughout their visit. It also explains care coordination among providers, and it encourages patients to call the Emergency Department and/or their Primary Care Physician or referring physician if they have questions once they have been discharged.

The PFAC initiated this project and partnered with the leadership of the Emergency Department to implement it. The advisors’ input, observations, and recommendations were instrumental in helping to create an educational tool that answers frequently-asked questions and gives guidance to patients and families on expectations for care and follow-up care. Committee members worked on the content, layout and wording, making sure it was easy to read and understand.

Hospital leadership and staff were very appreciative of the Council’s work creating a new brochure. This project not only created vital information for patients and families in the ED, but it also raised the PFAC’s profile and the importance of patient and family involvement in improving care.

Cooley Dickinson: The Cooley Dickinson PFAC is divided into a variety of committees and teams covering different aspects of the hospital’s work, including an Emergency Department Committee and a Palliative Care Committee. The Emergency Department Committee works

closely with ED management and staff to improve the patient and family experience. The committee's accomplishments include: designing and implementing a survey of recent patients to provide immediate service feedback; creating an ED brochure to help patients and families know what to expect; creating an information sheet titled "What Does Triage Mean to You?"; and, in teams of PFAC members and staff, visiting other hospitals with excellent Emergency Departments to learn more about their operations. Members of the committee brought their own experiences to this work and recognized the need to inform ED patients and families about the ED experience *and* to gather feedback from those who have used the ED, in order to improve that experience for others.

Barbara Williams joined the Cooley Dickinson Advisory Council as a founding member in 2009, and she is an active member of the ED Committee. Barbara talks about the impact of the ED Committee's efforts:

"As a member of the PFAC's ED Subcommittee, I have been deeply involved in efforts to improve care in the ED. The ED experience can be very confusing and stressful. Those seeking care are often scared and feel very vulnerable. I believe our efforts are making a real difference by informing patients and families about ED care and making their experiences a bit smoother and less stressful."

Medication and Health Information Cards: Nantucket Cottage Hospital

Nantucket Cottage Hospital's PFAC launched a major education campaign for "medication reconciliation." One goal of the campaign is to improve the safe and effective use of medications by individuals who are at higher risk for non-compliance. A second goal is to create a way for patients to present complete and accurate medication lists at every encounter with health care professionals. Initially, the project was co-led by the hospital pharmacist and a PFAC member.

The project team created a medication card that allows people to keep track of their prescription and over-the-counter medications, chronic medical conditions, and emergency information -- all in one place. This makes it easier for health care providers to be aware of patients' medical status, special needs and medications. It also helps prevent people from taking the wrong dose of medication or the wrong combination of medications. The card is also an educational brochure, with health tips and information about preparing for a doctor's visit, health proxy information, and pharmacy and emergency contacts.

To promote knowledge of and access to the medication cards, the PFAC collaborated with a number of community groups and organizations including local pharmacies, the Nantucket Visiting Nurses Association, and the Nantucket Sheriff's Department. The card is distributed within the hospital, at hospital-sponsored events, and at meetings of community organizations. It is included in every inpatient information kit and can be downloaded from the hospital website in

English or Spanish. An island-wide campaign included presentations in public places, posters, flyers and mailings. As a result of this outreach, island residents now take a more active role in their medical care and safety. The hospital's inpatient medication reconciliation process is more effective because patients are more aware of the importance of clearly communicating information about their medications. Hospital-based clinicians are more consistent in their efforts to document complete and accurate medication histories.

The Nantucket PFAC recognized the importance of ensuring the accuracy of every individual's medication history and health information, and it initiated action to make this a priority within the hospital and across the island. Other PFACs should consider initiating a similar project. Both inpatient and outpatient care are greatly impacted if medication information is incorrect or incomplete. Community collaboration and outreach are a large part of the success of Nantucket's initiative, and other Advisory Councils can learn a lot from Nantucket about how to carry out such a campaign.

Education on Organ Donation: Mercy Medical Center

Mercy Medical Center's Patient and Family Advisory Council joined efforts with Life Choice Donor Services to educate the public about organ and tissue donation and to encourage people to become donors. Four times over the course of a year, PFAC members set up a table in the Mercy Medical Center lobby with educational materials and information about how to sign up to become an organ and tissue donor. Handmade quilts were displayed with pictures and names honoring donors. Life Choice and the PFAC hosted a Life Choice Flag Raising to honor two particular donors, a staff nurse's sister and a hospital physician. As a result of these efforts, Mercy Medical Center received a Silver Level of Recognition for education and outreach about donation and registration.

Mercy Medical Center's Council learned about the work of Life Choice Donor Services and decided to partner with them on a public education campaign. PFACs often decide to take on a specific initiative as a result of personal experiences and/or learning about the need for education or outreach. Mercy's PFAC took the lead on a piece of a larger program, bringing a patient/family perspective to the effort to increase the number of registered organ donors. When PFACs learn about a hospital or community program, they should consider what role they, as patients and family members, can have in advancing work that they deem important.

Supporting Parents as Treatment Ends: Dana-Farber Pediatric PFAC

The Pediatric Patient and Family Advisory Council (PPFAC) at the Dana-Farber/Children's Hospital Cancer and Blood Disorder Center identified a need to support, educate and prepare parents for the changes they may experience as their children transition from active treatment to survivorship mode.

Ending treatment is often a very stressful time for parents. Coming to the clinic regularly, knowing that their child is being well cared for and supported, is comforting to many parents. New fears arise when that “safety net” is removed when treatment ends. Parents are often concerned about their ability to recognize relapse, about who they will call when their child gets sick, about how they transition to their regular routines, school, and about handling discipline issues now that their child may no longer be the center of attention.

Members of the PPFAC discussed these issues and recognized commonalities across their experiences. Several members wrote stories to help address these issues for some of Dana-Farber’s publications, including “How to manage life when your child has cancer,” “Questions to ask when your child finishes cancer treatment,” and “What to do if your child relapses.”

The Council wanted to do more to assist parents during transitions, and it initiated the development of a new program to provide them with additional and improved education and support. They collaborated with the Psycho-Social department to create a quarterly information session, “Transitioning Off Treatment,” co-led by a Psycho-Social Clinician and two parent PPFAC members. The purpose of the session is to provide an opportunity for parents to learn about resources that will be available to them as they transition off treatment, discuss their fears and concerns, and hear from other parents who have experienced this. Participants also meet other families who are at a similar point in the transition journey, and they can have their concerns addressed by a trained psycho-social clinician in a supportive environment. The collaboration between parents and clinicians strengthens the program, because each brings a unique perspective to the session. This new program began in November 2014.

Advisors in other PFACs who have had experiences transitioning off treatment for themselves, for children, or other loved ones should use this program as a model to partner with their hospitals to initiate a similar program. The Dana-Farber Pediatric Council recognized a need based on common experiences. Other PFACs can similarly determine areas of focus based on common themes across their experiences with care.

Summary: Massachusetts PFACs can learn from one another to develop and implement projects that directly impact care. The projects highlighted above all have one thing in common: the project involves patient and family education. Council members must have a role in all patient/family education initiatives because they are the most qualified to determine what will be most effective. All PFACs must be supported and encouraged to determine areas of care that need education and/or support for patients and families -- and then take the lead, in partnership with the hospital, in developing new programs or enhancing existing ones.

PFACs Engaged Throughout Hospital

PFACs must be partners in all aspects of a hospital's work. In the first section of this report, there are examples of PFACs taking the lead in projects that directly impact care. This section looks at ways in which hospitals can engage Councils in work that impacts care more indirectly. The Massachusetts PFAC law lists some examples of how Councils can be involved in hospital operations, including placing advisors on hospital committees and task forces (with a specific mention of patient safety committees), participating on search and hiring committees, and serving as co-trainers for clinical and non-clinical staff. Below are examples of how PFACs are actively engaged in these and other areas.

Patient Experience Rounds: UMass Memorial Medical Center

At UMass Memorial Medical Center, the Council is involved in Patient Experience Rounding. Teams of one staff member and one PFAC volunteer meet with inpatients and their visitors to talk to them about their experiences, what has gone well and what could be improved. The program started as a pilot on one unit and has now expanded to three units. PFAC volunteers share their own experiences with the inpatients and their families and also discuss aspects of inpatients' and their families' experiences that could be replicated elsewhere, or that point to where the hospital needs to make improvements.

Dan Wolpert, who joined the PFAC as a founding member in 2010, is very excited to be involved in the Patient Experience Rounding program:

"I received spectacular care at UMass Memorial when I had my heart attack. I was treated with respect and felt as though I was in an environment that truly promoted healing and recovery. In addition, I received cutting edge clinical care. I heard the hospital was starting a PFAC. I had already witnessed that not everyone's experiences were as positive as mine, and I thought this would be an opportunity for me to try to share my positive experiences to try to promote more consistently excellent care throughout the system. I've been involved in many projects at UMass since then, and I find that the staff are always very grateful to have a patient's perspective included in the process. I am particularly excited about the Patient Experience Rounding program. Hearing directly from inpatients and their families about their experiences and then working in partnership with others to implement changes based on those discussions will lead to improvements in care that will positively impact patients and families for many years to come."

In addition to participating in the rounds, Dan is also involved in a workgroup that is examining the best way to implement ideas generated by the Patient Experience Rounding process. He is hopeful that the rounding will have an impact on improving patient and family centered care at

the hospital, as well as increasing awareness of the PFAC among patients, families, and staff. Changes have already taken place as a result of feedback from the Patient Experience Rounds. Complaints about noise at night led to the creation of “sleep bags” for patients with items to help them sleep better. Concerns about not being able to read and understand information on the patients’ whiteboards led to the redesign and reorganization of the boards.

A number of hospitals involve PFAC members in rounding or are interested in learning how to do so. UMass has not only taken the important step of bringing advisors on rounds so they can share their experiences and hear from others, but they also have formed a team, which includes PFAC members, to discuss ideas brought forth from the rounds and how best to implement changes. Other Councils can learn from the UMass experience of involving advisors both in rounds and in discussions about how to use rounds to make a real difference in care.

Patients and Families as Teachers: Beth Israel Deaconess Medical Center

BIDMC and its PFAC are sending the message that the best experts in the field of patient experience are the patients and family members themselves, and that utilizing the voices of advisors in the teaching setting can send a more impactful message than using satisfaction data or having staff members teach about patient experience from their own perspective. Patient and family advisors share their stories and personal experiences through video and live presentations in a variety of settings, including annual nurse competency trainings, Critical Care Grand Rounds and Schwartz Center Rounds.

At the mandatory nurse competency trainings, nurses learn how to go “from good to great” in responsiveness. They watch and discuss a series of vignettes modeling both good and bad care and then view videotaped reactions from advisors, including one man who states:

“I like it better if a nurse slows down a little bit, if she comes in the room and doesn’t just say her name, but says ‘How are you feeling? How are you doing?’ and explains what she is going to do instead of just doing it. One can easily feel like a cog in the machinery if there isn’t some effort to personalize the experience.”

Preliminary data from these trainings shows that 90% of nurses are finding the sessions useful to their practice.

At Critical Care Grand Rounds, a PFAC advisor talked about a critical life event she experienced while in the ICU in a medically induced coma, awaiting a liver transplant. In telling her story, she highlighted the effect of delirium on her perceptions of the providers, procedures, and clinical environment in the weeks that followed, as well as the impact of small things on her sense of dignity and trust. Many commented on her remarkable courage in sharing her experience before a standing-room-only audience of doctors, nurses, social workers and other

staff members. The PFAC advisor commented:

“For a long time, I was scared to talk about my experience, to hear what people thought, to see their reactions. Now I see that none of that matters, and if I can help someone, just one person, with my message, that is enough for me.”

The same advisor participated in a Schwartz Center Rounds titled “Listening to Patient and Family Advisors,” which raised awareness among attendees of the PFAC’s accomplishments and ways to engage with the PFAC.

Engaging PFAC members as teachers for clinical and non-clinical care staff raises the profile of the PFAC and elevates the importance of bringing the voices of patients and family members to all of the hospital’s work. While a few Massachusetts PFACs are involved in teaching staff, most are not, and BIDMC can serve as one model for how to move ahead in this area. Hearing patient and family stories can have a lasting impact on patient and provider relations and communication.

Advising on Research: Baystate Medical Center

Baystate Medical Center received funding from PCORI (the Patient-Centered Outcomes Research Institute) for a project called “Shared Decision Making and Renal Supportive Care.” Patient and family advisors partner with the project staff to help them design and carry out the study in a way that best supports patients. Advisors include people who are receiving dialysis for kidney failure and/or their family members. The project looks at the choices patients make about their medical care, including end-of-life care choices such as the decision to receive hospice services. The project will inform doctors and dialysis staff about the best ways to have meaningful conversations with patients and their families. Advisors bring open and honest feedback based on their own experiences.

Advisors believe this work has given greater purpose and meaning to the struggles they have had dealing with kidney failure, and they hope that sharing their experiences will ease the challenges of others. One member, Sue Lawson, joined the Baystate Medical Center PFAC as a founding member in 2010. Sue shares her thoughts about the importance of patient and family involvement in this research project:

“Personally, I chose to accept the invitation to join the project as a direct result of my experience walking the dialysis journey with my mother. That was a huge challenge, and my father and sisters and I began it with Mom while really in the dark...What does renal failure mean?....What does dialysis involve?.... Is it the only choice? Communication with doctors was always clinical, never human or compassionate. The opportunity to work with this PCORI team gave me voice, a voice that hopefully will help improve communications, making health care and renal support truly a shared decision.”

It is vital to involve patients and family members in research taking place at a hospital because, inevitably, the research will impact their care. PCORI requires their involvement in order to obtain a grant. As more Massachusetts hospitals seek to attain PCORI funding, they can learn from Baystate Medical Center and others (including Brigham and Women’s Hospital, Franciscan Hospital for Children, and Boston Children’s Hospital) about how to engage their PFACs most effectively. Ideally, patients and families are engaged from beginning to end, from idea-conception through to the dissemination and implementation of research findings.

Summary: PFACs must partner with hospitals beyond working on a discrete project that directly impacts care. Including advisors on rounds, engaging them in teaching and mentoring staff, and involving them in research are all ways to move Council members outside of the PFAC silo and into the day-to-day operations of the hospital. This raises the profile of the PFAC across the institution and contributes greatly to the development of a culture that values meaningful patient and family engagement.

PFACs Engaging Diverse Communities

In order to ensure that a variety of experiences and perspectives inform the work of the council and of the hospital, PFACs must listen to voices from all communities that receive care at the hospital. As is clear in the below example, different communities can often have very different experiences of care as well as needs and concerns. The Massachusetts PFAC regulations state that Councils should be representative of the communities served by the hospital. Berkshire Medical Center is one unique example of how a hospital is bringing the voices of its communities to its work.

Spanish-Speaking PFAC: Berkshire Medical Center

Berkshire Medical Center’s Spanish Patient and Family Advisory Council (SP –PFAC) was created in order to diversify the existing PFAC. Berkshire County’s population is 93% white. It was difficult to find Spanish-speaking candidates to join the Council. The Spanish-speaking community often had concerns, needs and experiences that were different and/or were perceived differently from those of members on the original PFAC. In 2012, a Council for the Latino community began formally meeting as a group. The sessions are held solely in Spanish, with interpreters present to facilitate communication with non-Spanish-speaking staff and presenters. This allows the members to express themselves more clearly, because they are heard in their own language. They also find it easier to ask questions.

Meeting and talking directly with staff, including senior staff, has had an impact on both the Spanish-speaking (“SP”)-PFAC members and the staff. “We are thankful to have the opportunity to express and bring to the room what my neighbors experience in the hospital and how they value the ability to access their information in their own language,” said Raul, one of the

advisors. Another advisor, Miryam, added, “The fact that I can access medical care in Spanish, through an interpreter, makes me feel that I am in control and can make informed decisions.”

Changes implemented as a result of the SP-PFAC’s efforts include placement and relocation of signs so that it is easier for patients in waiting areas to see them; changes to the phone system so patients receive information about appointments and test results over the phone in their own language; and educating the Spanish-speaking community about interpreting services and how to access care at Berkshire Medical Center. SP-PFAC members carry informational cards to distribute to their family and friends so they can voice suggestions or concerns using them.

The leadership at Berkshire Medical Center is eager to find ways to engage other communities, and the hospital plans to start a Russian-speaking PFAC.

Summary: Many PFACs struggle with how to involve diverse communities. Berkshire Medical Center’s experience provides one example of how this can be done. They have been successful in engaging Spanish speakers and making changes as a result of their input. Other Councils should consider a similar model. As a start, PFACs can reach out to departments within the hospital that work directly with diverse communities.

Conclusion

Many Patient and Family Advisory Councils across Massachusetts are working hard to improve care for patients and families. This report gives examples of impactful projects, advisor involvement in the hospital beyond the PFAC, and how to engage diverse voices. However, not all Massachusetts hospitals and Councils have working partnerships, and some Councils are unable to make a significant difference in care, because they are not fully valued by the institution.

Hospital leadership must fully support their PFACs and insist on meaningful patient and family involvement across the institution. Individuals volunteer to join a Council because they are deeply invested in improving care and ensuring that all patients and families receive optimal care. Hospitals must recognize the value of these volunteers and empower them to be leaders and true partners in improving the quality of health care.

PFACs must move beyond serving only as sounding boards to taking the lead on vital projects and becoming directly involved in hospital decision-making and hospital operations. This is challenging and groundbreaking work. Massachusetts PFACs are making a real difference in care, and all Councils must aspire to reach higher levels of impact. Patient and Family Advisory Councils can and must implement changes that will have a powerful positive impact on all Massachusetts health care consumers.

Section II: Detailed Analysis of 2014 PFAC Reports

Massachusetts PFAC Data

By-laws or Policies and Procedures

By-laws or policies and procedures are required by the Massachusetts PFAC regulations and are also important to the effective functioning of any organization.

- 73% of PFACs have by-laws and/or policies and procedures
- 4% of PFACs do not have either
- 23% unable to determine from PFAC report

This is the first year we (HCFA report reviewers) are tracking this item. One-fourth of PFACs either do not have by-laws or did not report on this. We would like to see many more PFACs with by-laws in place. The Massachusetts PFAC Advisory Board's Best Practices Committee will assist PFACs in developing or improving by-laws.

Patient or Family Chair or Co-Chair

The Massachusetts PFAC regulations recommend that every Council have a patient or family member as chair or co-chair.

- 72% of PFACs have a patient or family member as chair or co-chair
- 14% do not have a patient or family chair or co-chair
- 13% unable to determine from PFAC report

In the 2014 HCFA report (reviewing PFACs' 2013 reports), we found that 61% of PFACs had a patient or family member as chair or co-chair. The increase this year is laudable, but not enough. Empowering patients/family members to lead the Council is a signal of how much the hospital values their partnership.

PFAC Composition and Community Representation

The Massachusetts PFAC regulations require all PFACs to have at least 50% patient/family membership. The regulations also state that Councils should represent the communities served by the hospital.

- 91% of PFACs are at least 50% patient and family members
- 3% of PFACs are not at least 50% patient and family members
- 6% unable to determine from PFAC report

Further:

- 81% of PFACs reported on community representation, either that they represent the community or that they are actively striving to represent the community served
- 19% did not report on community representation

Last year's report found that 72% of PFACs stated that at least 50% of the Council was made up of patients and family members. This year that figure is 91%, which is a significant increase and a very positive sign. We hope to see 100% next year.

The 2014 HCFA report pointed out that 51% of PFACs provided information about community representation. The increase to 81% this year makes clear that this has become a higher priority for many PFACs. We applaud their focus on this and look forward to learning more about their efforts in the coming year.

Support for PFAC Members

Patient and family Council members are volunteers and often have many other responsibilities. Providing some support to them is vital to ensuring their full and active participation. The percentage offering important supports such as translator/interpreter services, child or elder care assistance, and travel stipends has not changed from last year. In order to have a diverse group of voices at the table, these types of supports must be offered.

- 53% provide free parking
- 51% provide other supports
- 47% provide meals
- 15% offer translator or interpreter services
- 10% provide meeting conference call or webinar options
- 8% provide mileage or travel stipends
- 3% offer financial support for child care or elder care
- 2% provide stipends for participation
- 1% provide on-site child or elder care
- 25% unable to determine from PFAC report

Examples of other supports include:

- Reimbursement for attendance at annual PFAC conference
- Reimbursement for attendance at other conferences or trainings
- Gifts of appreciation given to PFAC members annually
- Cover travel expenses to attend conferences

Setting PFAC Meeting Agendas

PFAC members should be included in determining meeting agendas. This is the first year we tracked data for this area. We hope to see increases in coming years in the percentage of PFACs that encourage input from all Council members.

- 45% of PFACs report that chair or co-chairs set the agendas
- 43% of PFACs encourage agenda input from all PFAC members
- 29% of PFACs report that the hospital liaison sets the agendas
- 23% unable to determine from PFAC report

PFAC Committees and Workgroups

PFACs that are empowered to develop their own initiatives or become deeply involved in on-going hospital initiatives often develop committees or workgroups.

Last year's HCFA report stated that 42% of PFACs did not have their own committees or workgroups. This year, we saw a small increase in those reporting workgroups, but also a small increase in those reporting that they did not have committees or workgroups. As PFACs take on more responsibility and become more empowered to initiate projects, we hope to see more subcommittees develop over time.

- 46% of PFACs do not have their own committees or workgroups
- 23% of PFACs have committees or workgroups
- 31% unable to determine from PFAC report

Examples of PFAC committees/workgroups include:

- Government relations
- Recruitment
- Emergency Department
- Education and Communication
- Family Support
- Policies and Procedures
- Palliative Care
- Annual Report
- Publications
- Nominations
- Marketing
- Behavioral Health
- Medication Safety
- Hospital Safety

PFAC Interaction with Board

The hospital's governing body should be fully aware of the PFAC's activities and its areas of focus and should encourage PFAC involvement in board committees and throughout the hospital.

- 50% of PFACs share the PFAC annual report with the board or governing body
- 28% share minutes with Board
- 17% of PFACs have members on board-level committees
- 12% report board members attend PFAC meetings
- 12% report other forms of interaction
- 11% report PFAC members attend board meetings
- 28% unable to determine from PFAC report

Last year, we found that 33% of PFACs shared their annual reports with the hospital board, 16% shared meeting minutes, 4% reported that board members attend PFACs meetings, and 1% reported that PFAC members attend board meetings. The increases in these percentages this year are moves in the right direction but are not enough. The Massachusetts regulations require that PFAC meeting minutes be shared with the board, but that is still only done by approximately one-quarter of PFACs. PFAC-board interaction is another sign of how much the leadership values the PFAC and takes its work and its concerns into account as it sets hospital-wide goals and priorities.

PFAC Section of Hospital Website

Members of the hospital community, both patients/families and staff, as well as members of the general public, should be able to easily access information about the PFAC and its efforts. This is the first year we are tracking this. By next year, we would like to see PFAC pages on 100% of hospital websites. This is a simple way to highlight the hard work of the hospital's PFAC.

- 57% of PFACs have a page or pages on the hospital website
- 15% do not have a PFAC section of the hospital website
- 28% unable to determine from PFAC report

PFAC Goal Setting

Goal-setting is an important exercise for any organization. PFAC members must be included in full discussions on a regular basis about past and future goals.

- 71% of PFACs set goals for coming year
- 4% do not set goals
- 25% unable to determine from report

In the 2014 HCFA report, we found that 62% of PFACs reported on goals for the coming year. The increase to 71% this year is a positive sign, but this figure should be 100%.

Common themes among goals:

- Recruit and retain members
- Recruit members to better represent community served
- Increase awareness of PFAC among patient and family population and among staff
- Start or increase PFAC participation on hospital committees
- Share more information about quality of care
- Improve PFAC orientations

PFAC Role in Advising Hospital

All of these areas for PFAC advisory roles are listed in the Massachusetts PFAC law.

- 71% of PFACs advised the hospital on quality improvement initiatives
- 64% of PFACs advised about patient education on safety and quality matters
- 57% advised about patient and provider relationships
- 14% advised about Institutional Review Boards
- 19% unable to determine from PFAC report

This is the first year we are tracking these broad areas listed in the law. We are pleased to see that almost 75% are working on quality improvement initiatives, and we hope to see that number climb in coming years. The percentages working on patient education and on patient and provider relations should be much higher, since patient and family advisors bring such needed perspectives to efforts in these areas.

Advisor Involvement in Hospital Beyond PFAC

All of these activities that involve PFAC members in hospital activities beyond the PFAC are listed in the Massachusetts PFAC law.

- 48% of PFACs have members on standing hospital committees that address quality
- 40% of PFACs have members on hospital task forces
- 47% have members on hospital advisory boards
- 20% of PFACs have members as co-trainers for clinical or non-clinical staff or health professional trainees
- 13% of PFACs have members on hospital search committees
- 12% have members participating in hospital reward and recognition programs
- 6% of PFACs have members on hospital awards committees
- 32% unable to determine from PFAC report

There were significant increases from last year in some of these figures. In particular, there was a large increase in the percentage of hospitals that have PFAC members on committees (33% in 2014), task forces (27% in 2014), and advisory boards (14% in 2014). There were also increases in the areas of serving on search committees (4% in 2014) and acting as co-trainers (13% in 2014). However, the percentage of hospitals reporting on this area did not change by much, so there are still almost one-third of PFACs for which we do not know whether and how their members are involved in the hospital, beyond PFAC meetings. Strong hospital leadership support for the PFAC will lead to engagement throughout the hospital, and we hope to see these numbers increase next year.

Sharing Public Quality Information with PFAC

PFACs must be informed about the hospital's quality measures in order to help them determine areas of focus.

- 24% of PFACs were given information on healthcare-associated infection rates
- 21% of PFACs were given information on staff influenza vaccination rates
- 20% were given information on Serious Reportable Events (SREs)
- 49% were given other public information (examples include: patient experience/satisfaction scores, patient complaints, Patient Care Link, Joint Commission surveys, Hospital Compare, family satisfaction surveys, quality of life data, rapid response data)
- 38% unable to determine from PFAC report

We are pleased to see a large decrease in the percentage of hospitals that did not report on this item this year. In the 2014 HCFA report, 66% of PFAC reports did not mention sharing public quality information, while the unreported figure this year is 38% (an improvement, but still too high). As a result, there were many more hospitals reporting that they shared information about infections (up from 8% last year), SREs (up from 10% last year) and staff influenza vaccination (up from 9% last year).

PFAC Involvement in Specific National/State Priority Areas

This list is updated each year by the PFAC report review committee and includes many of the areas of state and national focus in improving health care quality. More PFACs reported on their work in these areas this year. Both last year and this year, the area with the highest percentage of PFAC involvement was in improving information for patients and families, with care transitions as the second most common area.

- 68% of PFACs were involved in improving information for patients and families
- 32% were involved in improving care transitions
- 27% were involved in improving end-of-life planning/information
- 26% were involved in fall prevention
- 20% were involved in hand-washing initiatives
- 19% were involved in improving information about health care proxies
- 17% were involved in improving mental health care
- 12% were involved in rapid response team information
- 11% were involved in shared decision-making or informed consent
- 10% were involved in apology or disclosure of harm
- 7% were involved in observation status information for those on Medicare
- 6% were involved in checklists for procedures
- 19% unable to determine from report

Recruitment Strategies

Some of the unique or effective recruitment strategies highlighted in reports, including strategies aimed at better representing the community served, are:

Potential PFAC candidates have the opportunity to meet with other PFAC members and/or attend a Council meeting prior to accepting membership. (Emerson Hospital)

PFAC uses Facebook and Twitter. (UMass Memorial Medical Center)

Recruitment brochures, introductory letters, and applications are mailed to 7000 patients randomly selected from a list of recently discharged patients. (Massachusetts General Hospital)

PFAC members set up tables to speak with patients and families and inform them about the Council. (Spaulding Rehabilitation Hospital Cape Cod)

Brochures are distributed to targeted community groups through speaking engagements in the community. (Southcoast Hospitals)

Information about PFACs is placed in hospital publications like NSMC Now, Healthy Living, and NSMC Giving. (North Shore Medical Center)

A large PFAC banner is placed in the hospital lobby. PFAC brochures are displayed in brochure holders with drop box with applications. A rolling TV screen highlighting the PFAC is viewable in the lobby and cafeteria. Framed PFAC posters are in elevators. Current PFAC members recruit new members via community groups and forums. (Morton Hospital)

Each patient/family is made aware of the PFAC in writing and/or verbally by their care coordinator. Employees are provided with a token of appreciation when they recruit new members. The hospital placed classified ads in local publications. The hospital placed public service announcements on the local public access channel. PFAC information is provided during the hospital's annual patient reunion. (HealthSouth Rehabilitation Hospital of Western MA)

Patient satisfaction surveys include a question regarding interest in becoming a PFAC member. (South Shore Hospital)

The PFAC formed a membership subcommittee. They did outreach through the Greater Lowell Health Alliance and the Greater Lowell Chamber of Commerce. They also posted on the hospital's Facebook site and on the hospital TV, and presented at the hospital's annual volunteer dinner. Pamphlets were distributed at area physician offices, and an article ran in the Lowell Sun. (Lowell General Hospital)

Notices were placed on community blogs. (Dana-Farber Cancer Institute)

PFAC members are encouraged to bring a friend to a meeting. (Baystate Mary Lane Hospital)

Outreach was done through local houses of worship and local public health agencies. (Newton-Wellesley Hospital)

Information is given out during Grotonfest and Hunger Run. Information is placed on the patient portal. The first meeting of the PFAC year involved setting up an action plan for recruitment and how to be more accommodating to members with difficulty getting to meetings. (Nashoba Valley Medical Center)

The PFAC formed a diversity planning committee to explore how to recruit for more diversity. (Beth Israel Deaconess Medical Center)

Membership was expanded to include representatives from community organizations who can convey the experiences of themselves and their family members and also represent their organizations' constituents. (HealthAlliance Hospital)

Read a hospital's individual PFAC report on the [HCFA website](#) for more information or contact Deb Wachenheim at HCFA (dwachenheim@hcfama.org) to connect with a specific PFAC.

Orientation Processes

While many new member orientations mirror those for new hospital volunteers, some PFACs have additional specific content and processes for new PFAC members:

Current PFAC members play an active role in orienting new members. There is a buddy system and peer mentoring. New members are also encouraged to attend new staff orientation. (Massachusetts General Hospital Cancer Center)

After the required hospital orientation, a new member meets with the patient and family liaison, who introduces him/her to the concepts of patient- and family-centered care (PFCC), shares the hospital's philosophy statement about PFCC, and provides a brief history of the journey of PFCC at the hospital. The liaison also accompanies the new advisor to his or her first meeting. (Brigham and Women's Hospital)

A PFAC orientation packet includes the Department of Public Health (DPH) PFAC regulations, the Steward Health Care System PFAC policy, member roles and responsibilities, an overview of health care quality and safety, and patient- and family-centered care core concepts. (Morton Hospital)

There is an initial PFAC orientation and then an annual training thereafter. Orientation includes the DPH PFAC regulations and HCFA's PFAC resources. It also includes a history of the MetroWest PFAC and related documents. (MetroWest Medical Center)

Orientation involves the role of a PFAC member, the DPH PFAC regulations, recent meeting minutes and annual reports. Current PFAC members "buddy up" with new members. (Shriners' Hospital for Children-Boston)

Members are given an orientation to the facility, vision and goals of the Council, how the PFAC fits within the organization's structure, and how the Council can assist the institution in achieving its vision and goals. (Kindred Hospital Northeast)

Orientation includes a review of the PFAC's mission, by-laws, and policies and an overview of the hospital's culture including the core concepts of patient- and family-centered care. Each member is oriented to their roles and responsibilities. When a Council member joins another hospital committee or team, an orientation relative to that group's focus and goals is provided. Materials are available in English and Spanish. (Baystate Medical Center and Baystate Children's Hospital)

New members receive the *Newton-Wellesley Hospital Patient and Family Advisory Council Resource and Members Guide*. (Newton-Wellesley Hospital)

Read a hospital's individual PFAC report on the [HCFA website](#) for more information or contact Deb Wachenheim at HCFA (dwachenheim@hcfama.org) to connect with a specific PFAC.

Quality Improvement Activities

In addition to the PFAC initiatives highlighted in the main section of this report, there are many Council projects across Massachusetts that can serve as examples and resources for other PFACs:

A “Flip the Discharge” Council subcommittee partners with the hospital to design new materials to prepare patients/families for discharge. (Beth Israel Deaconess Medical Center)

The Council worked with the hospital’s government relations staff to research and advocate for two mental health bills. The Council also initiated a project to better understand the barriers teens and young adults face when transitioning to adult care. They developed criteria they would like included in an “ideal web based transition tool.” (Children’s Hospital Teen Advisory Council)

The PFAC’s Palliative Care committee partners with a number of hospital units to conduct community outreach sessions on end-of-life care, including information about the use of shared decision-making in setting personal end-of-life goals. More recently, they have expanded their efforts to include outreach to younger individuals who may be caring for elders. (Cooley Dickinson Hospital)

The PFACs of two hospitals in the same system partnered to develop information for patients and families about Medicare observation status, including clarification of the differences between observation status and inpatient admission status. (Cape Cod Hospital and Falmouth Hospital)

The PFAC initiated and contributed to the development of a “Guide to Transitioning from Inpatient Care-Hospital Information for Families and Friends of Patients.” (McLean Hospital)

The PFAC created a new subcommittee on hospital safety, looking at how to improve safety within and around the hospital. There is also a new subcommittee on home medication looking at how to educate the community about the need to bring updated medication lists to appointments. (Milford Regional Medical Center)

The third annual PFAC Educational Event, “When Bandages Come Off: Managing Your Child’s Skin Changes,” took place in the spring of 2014. Events are held in English and Spanish. (Shriners’ Hospital Boston)

The PFAC has a human resources subcommittee. Council members interviewed candidates for several hospital leadership positions. Questions included knowledge of patient- and family-centered care concepts. The hospital offers a behavioral interviewing educational program to interested Council members. The PFAC also participated in the hospital’s strategic planning process. (South Shore Hospital)

The three Councils at the hospital (Hospital PFAC, Cancer Center PFAC, Home Care PFAC) worked together on the first Patient and Family Centered Care week. The goal was to promote the principals of patient- and family-centered care to hospital colleagues. (South Shore Hospital)

A PFAC member attends every monthly meeting of the UMass leadership team, at which 100 leaders discuss strategic goals. Council members participate in interviews of potential medical school students during which they are presented with different scenarios. They also participate in Graduate Medical Education patient experience modules, during which PFAC members act-out scenarios as patients and participate in debriefs about patient-provider communication. The PFAC partnered with the medical school to develop live simulated trainings on communication styles and techniques for attending physicians. The Council reviews many new or revised patient education materials, and every reviewed item gets an approval stamp stating that the PFAC contributed. (UMass Memorial Medical Center)

Council members worked to improve patient/provider relations through participation in physician simulation trainings, emergency department simulation trainings, end-of-life discussion simulation trainings, and informed consent trainings. They also participate in resident orientation sessions. (Baystate Medical Center)

PFAC members do community outreach to improve understanding and completion of health care proxies. They formed a new End of Life Committee. (Holyoke Medical Center)

The Council implemented a comprehensive orientation program for patients and families. From this, they developed a Peer Guide Program which trains volunteers to serve as peer support for patients and families undergoing outpatient cancer treatments. (Massachusetts General Hospital Cancer Center)

The PFAC is seeking to develop relationships with populations that are unlikely to be able to participate regularly in the Council. They held a focus group at a local retirement community, with the goal of gathering input and feedback from attendees about experiences in the emergency room. This led to further discussions about how to enhance continuity of care for residents who go to the ER. (North Shore Medical Center)

Read a hospital's individual PFAC report on the [HCFA website](#) for more information or contact Deb Wachenheim at HCFA (dwachenheim@hcfama.org) to connect with a specific PFAC.

Evaluating Individual PFAC Accomplishment

(Note: Hospitals that met all four criteria are indicated with an asterisk.)

Hospital	PFAC Reported Implementing Change In The Hospital	PFAC Reported Its Goals For The Coming Year	PFAC Reported That It Placed Members On Hospital Committees	PFAC Reported That It Is, Or Strives To Be, Representative Of The Hospital Service Area
AdCare Hospital				
Anna Jaques Hospital				
Athol Hospital	✓	✓		✓
*Baystate Children’s Hospital	✓	✓	✓	✓
Baystate Franklin Medical Center		✓		✓
Baystate Mary Lane Hospital	✓			✓
*Baystate Medical Center	✓	✓	✓	✓
*Baystate Wing Hospital	✓	✓	✓	✓
*Berkshire Medical Center	✓	✓	✓	✓
*Beth Israel Deaconess Medical Center	✓	✓	✓	✓
Beth Israel Deaconess—Milton				
*Beth Israel Deaconess—Needham	✓	✓	✓	✓
*Beth Israel Deaconess-Plymouth	✓	✓	✓	✓
*Beverly and Addison Gilbert Hospitals	✓	✓	✓	✓
*Boston Children’s Hospital—Family Advisory Council	✓	✓	✓	✓
Boston Children’s Hospital—Teen Advisory Council	✓		✓	✓
*Boston Medical Center	✓	✓	✓	✓
*Braintree Rehabilitation Hospital	✓	✓	✓	✓
Brigham and Women’s Hospital—Boston	✓	✓	✓	
Brigham and Women’s Faulkner Hospital	✓	✓	✓	
Cambridge Health Alliance		✓	✓	✓
*Cape Cod Hospital	✓	✓	✓	✓
Carney Hospital	✓	✓		✓
Clinton Hospital	✓	✓		✓
*Cooley Dickinson Hospital	✓	✓	✓	✓

Hospital	PFAC Reported Implementing Change In The Hospital	PFAC Reported Its Goals For The Coming Year	PFAC Reported That It Placed Members On Hospital Committees	PFAC Reported That It Is, Or Strives To Be, Representative Of The Hospital Service Area
*Dana-Farber Cancer Institute	✓	✓	✓	✓
*Emerson Hospital	✓	✓	✓	✓
*Fairlawn Rehabilitation Hospital	✓	✓	✓	✓
*Fairview Hospital	✓	✓	✓	✓
Falmouth Hospital	✓		✓	✓
Franciscan Hospital for Children	✓	✓		✓
*Good Samaritan Medical Center	✓	✓	✓	✓
Hallmark Health System	✓		✓	✓
Harrington Hospital		✓	✓	✓
*HealthAlliance Hospital	✓	✓	✓	✓
*HealthSouth Rehabilitation Hospital of Western MA	✓	✓	✓	✓
*Hebrew Rehabilitation Center	✓	✓	✓	✓
*Heywood Hospital	✓	✓	✓	✓
Holy Family Hospital (no report sent)				
Holyoke Medical Center	✓	✓	✓	
Kindred Hospital-Boston	✓			
Kindred Hospital—Boston North Shore (no report sent)				
*Kindred Hospital—Northeast	✓	✓	✓	✓
*Lahey Hospital & Medical Center	✓	✓	✓	✓
Lawrence General Hospital	✓	✓	✓	
Lowell General Hospital	✓		✓	✓
Marlborough Hospital	✓			✓
Martha’s Vineyard Hospital	✓		✓	✓
Massachusetts Eye and Ear Infirmary	✓			
*Massachusetts General Hospital	✓	✓	✓	✓
McLean Hospital	✓		✓	
Mercy Medical Center	✓	✓		✓
MetroWest Medical Center			✓	✓

Hospital	PFAC Reported Implementing Change In The Hospital	PFAC Reported Its Goals For The Coming Year	PFAC Reported That It Placed Members On Hospital Committees	PFAC Reported That It Is, Or Strives To Be, Representative Of The Hospital Service Area
*Milford Regional Medical Center	✓	✓	✓	✓
Morton Hospital		✓	✓	✓
*Mount Auburn Hospital	✓	✓	✓	✓
*Nantucket Cottage Hospital	✓	✓	✓	✓
Nashoba Valley Medical Center	✓	✓		✓
New Bedford Rehabilitation Hospital (no report sent)				
New England Baptist Hospital	✓	✓	✓	✓
New England Rehabilitation Hospital	✓	✓		
*New England Sinai Hospital	✓	✓	✓	✓
*Newton-Wellesley Hospital	✓	✓	✓	✓
Noble Hospital	✓	✓		✓
North Shore Medical Center	✓	✓		✓
Norwood Hospital	✓			✓
*Saint Anne's Hospital	✓	✓	✓	✓
Saint Vincent Hospital	✓	✓		✓
Shriners Hospital for Children—Boston	✓	✓		✓
Shriners Hospital for Children—Springfield		✓		✓
Signature Health Care Brockton Hospital	✓	✓	✓	
*Southcoast Health System	✓	✓	✓	✓
South Shore Hospital	✓		✓	✓
Spaulding Hospital—Cambridge	✓			
Spaulding Rehabilitation Hospital—Boston	✓	✓		✓
*Spaulding Rehabilitation Hospital—Cape Cod	✓	✓	✓	✓
Spaulding Hospital North Shore	✓			
St. Elizabeth's Medical Center	✓			✓
Sturdy Memorial Hospital	✓			
Tufts Medical Center and Floating Hospital for Children	✓		✓	

Hospital	PFAC Reported Implementing Change In The Hospital	PFAC Reported Its Goals For The Coming Year	PFAC Reported That It Placed Members On Hospital Committees	PFAC Reported That It Is, Or Strives To Be, Representative Of The Hospital Service Area
UMass Memorial Medical Center	✓		✓	✓
Whittier Rehabilitation Hospital Bradford	✓	✓		✓
Whittier Rehabilitation Hospital Westborough	✓	✓		✓
*Winchester Hospital	✓	✓	✓	✓

Section III: Appendices

Appendix A: Massachusetts PFAC Law and Regulations

2008 PFAC Law:

<http://www.malegislature.gov/Laws/GeneralLaws/PartI/TitleXVI/Chapter111/Section53E>

“The department (of public health) shall promulgate regulations for the establishment of a patient and family advisory council at each hospital in the commonwealth. The council shall advise the hospital on matters including, but not limited to, patient and provider relationships, institutional review boards, quality improvement initiatives and patient education on safety and quality matters. Members of a council may act as reviewers of publicly reported quality information, members of task forces, members of awards committees for patient safety activities, members of advisory boards, participants on search committees and in the hiring of new staff, and may act as co-trainers for clinical and nonclinical staff, in-service programs, and health professional trainees or as participants in reward and recognition programs.”

Department of Public Health PFAC Regulations:

<http://www.mass.gov/eohhs/docs/dph/regs/105cmr130.pdf>

(Sections 130.1800 and 130.1801)

- PFACs must be established by October 2010.
- PFACs must meet at least quarterly.
- At least 50% of PFAC members must be current or former patients and/or family representatives.
- PFAC membership should reflect the community served by the hospital.
- Each hospital must write an annual report on the work of the PFAC. Annual reports, to be completed by October 1st each year, must be publicly available.
- It is recommended that each PFAC have a patient or family member as a chair or co-chair.
- Minutes of PFAC meetings, including accomplishments, must be sent to the hospital's governing body.
- A hospital shall develop and implement written policies and procedures for the PFAC that include, at a minimum, the PFAC's purposes and goals, membership eligibility, officers, orientation and continuing education, and roles and responsibilities of members.

Appendix B: Massachusetts PFAC Advisory Board: Agenda for 2015/2016

Massachusetts is the first and only state in the country to mandate the development of Patient and Family Advisory Councils (PFACs) in all hospitals. Health Care For All (HCFA) recognizes the importance of supporting their work and helping them develop and grow as valuable partners to their affiliate hospitals. HCFA established a statewide PFAC Advisory Board whose members, representing a broad cross section of Massachusetts hospitals, communicate the interests and concerns of the Councils on which they serve. The Advisory Board recommends PFAC priorities for the state and helps to coordinate Council activity across Massachusetts.

The Advisory Board recently adopted its goals for the coming year. These are based on the annual reports from the 93 PFACs in Massachusetts, HCFA's meetings with Councils, a survey sent out to PFAC members in the fall of 2014, and recent discussions among the members of the Advisory Board. We believe that working toward and attaining these goals should be the next steps in the development of Massachusetts PFACs. A great deal has been accomplished in the last five years. But a great deal more can be accomplished with a deeper level of partnership between Councils and hospitals. The goals are:

- **PFACs to take the lead on projects impacting patient care.** The intent of the PFAC law is for Councils to function as an independent voice of patients and families to further the collaborative relationship between the hospital and the community it serves. They should initiate and implement ways in which to improve the patient experience by partnering with hospitals to improve care. An important element of this partnership is for PFACs to not only assist the hospital by providing feedback when solicited, but also to take the initiative on projects which they deem to be priorities. Hospital support and encouragement is vital in promoting this goal.
- **PFACs are vital partners in collaborating with hospitals in all aspects of their work.** This includes actively serving on committees and task forces that focus on improving care and the patient and family experience, participating on search committees, interviewing and hiring staff, and acting as co-trainers for both clinical and nonclinical staff. Members of a PFAC bring a unique and important perspective to the work of any hospital. Hospitals that collaborate with their Councils have implemented many changes as a result of input from them.
- **PFACs represent the diversity of the communities served by their hospitals.** Councils have been challenged to more accurately reflect their larger patient community, which is vital to better meeting the needs of all patients and families served by the hospital. PFACs should partner with the hospital and with community organizations to ensure all voices are heard.

As an Advisory Board, we have adopted these goals for the next year. We call on all members of PFACs across the state to promote these goals within their own Council and hospital. We urge hospital leadership to collaborate with patients and families in helping to make these goals a successful reality. Hospitals and PFACs that have already begun to move in this direction have found the partnership to be rewarding and productive.

We invite all PFACs to evaluate, reflect and institute measures necessary to become a vital part of their hospitals. The voice of the patient and family is a natural and essential part of excellent health care. We have been given a way to ensure that. **Let's move forward.**

Appendix C: Method of Review

Report Review Committee: HCFA staff, volunteers and PFAC members formed a PFAC report review committee to gather and analyze annual reports. Members are listed in Appendix G.

Report Gathering: The committee searched Massachusetts hospital websites for 2014 PFAC reports. For those reports not posted online, committee members contacted the hospital to request a copy of the report. These reports are posted to the [PFAC webpage](#) for use by the public and fellow PFACs. Though the committee made a concerted effort to collect all reports, three hospitals did not provide HCFA with their 2014 reports. The three hospitals with missing reports are Holy Family Hospital, Kindred Hospital: Boston North Shore, and New Bedford Rehabilitation Hospital. (A full list of reporting and non-reporting hospitals can be found in Appendix H).

Creation of Measurement Tool: HCFA created a review instrument based on the PFAC report template distributed to PFACs in June and again in early September of 2014. The review tool utilizes both quantitative and qualitative data to inform the results highlighted in this report, and it addresses topics such as PFAC membership and leadership, PFAC integration into the hospital organization, current and planned quality improvement initiatives, and the extent to which PFAC quality improvement initiatives relate to national or state health care system reform priorities.

Each year, both the report template and the review instrument are updated to reflect the maturity of PFACs across the state. Future review questions will continue to focus less on process and more on how PFACs impact the overall hospital culture and care experience.

The recommended template and the review instrument are included in this report and can be found in Appendices E and F, respectively.

Review of Reports: All committee members served as report reviewers and entered data according to the review tool into an online survey. Peer consultation was available throughout the review period to maximize consensus on best response coding. Upon the review of all reports, HCFA organized and analyzed the data. As with previous years, the workgroup will critique the measurement tool and overall review process and make suggestions for improving the review methodology in the future.

Appendix D: 2014 Annual PFAC Reports Reviewed and not Reviewed

Hospital 2014 Annual PFAC Reports Reviewed

AdCare Hospital
Anna Jaques Hospital
Athol Hospital
Baystate Children's Hospital
Baystate Franklin Medical Center
Baystate Mary Lane Hospital
Baystate Medical Center
Baystate Wing Hospital
Berkshire Medical Center
Beth Israel Deaconess Medical Center
Beth Israel Deaconess Hospital Milton
Beth Israel Deaconess Hospital Needham
Beth Israel Deaconess Hospital Plymouth
Beverly and Addison Gilbert Hospitals
Boston Children's Hospital: Family Advisory Council
Boston Children's Hospital: Teen Advisory Council
Boston Medical Center
Braintree Rehabilitation Hospital
Brigham and Women's Hospital
Brigham and Women's Faulkner Hospital
Cambridge Health Alliance
Cape Cod Hospital
Carney Hospital
Clinton Hospital
Cooley Dickinson Hospital
Dana-Farber Cancer Institute
Emerson Hospital
Fairlawn Rehabilitation Hospital
Fairview Hospital
Falmouth Hospital
Franciscan Hospital for Children
Good Samaritan Medical Center
Hallmark Health System
Harrington Hospital
HealthAlliance Hospital
HealthSouth Rehabilitation Hospital of Western MA
Hebrew Rehabilitation Center-Boston and Dedham
Heywood Hospital
Holyoke Medical Center
Kindred Hospital: Boston
Kindred Hospital: Northeast
Lahey Hospital & Medical Center
Lawrence General Hospital

Lowell General Hospital
Marlborough Hospital
Martha's Vineyard Hospital
Massachusetts Eye and Ear Institute
Massachusetts General Hospital
McLean Hospital
Mercy Medical Center
MetroWest Medical Center
Milford Regional Medical Center
Morton Hospital
Mount Auburn Hospital
Nantucket Cottage Hospital
Nashoba Valley Medical Center
New England Baptist Hospital
New England Rehabilitation Hospital
New England Sinai Hospital
Newton-Wellesley Hospital
Noble Hospital
North Shore Medical Center
Norwood Hospital
Saint Anne's Hospital
Saint Vincent Hospital
Shriners Hospital for Children: Boston
Shriners Hospital for Children: Springfield
Signature Healthcare Brockton Hospital
Southcoast Health System
South Shore Hospital
Spaulding Hospital Cambridge
Spaulding Hospital North Shore
Spaulding Rehabilitation Hospital Boston
Spaulding Rehabilitation Hospital Cape Cod
St. Elizabeth's Medical Center
Sturdy Memorial Hospital
Tufts Medical Center and Floating Hospital for Children
UMass Memorial Medical Center
Whittier Rehabilitation Hospital-Bradford
Whittier Rehabilitation Hospital-Westborough
Winchester Hospital

Hospital 2014 PFAC Reports Not Shared with HCFA and Not Reviewed

Holy Family Hospitals
Kindred Hospital: Boston North Shore
New Bedford Rehabilitation Hospital

Appendix E: HCFA Recommended 2014 PFAC Annual Report Template

Hospital Name:

Date of Report:

Year Covered by Report:

Year PFAC Established:

Staff PFAC Contact (name and title):

Staff PFAC Contact E-mail and Phone:

PFAC Organization

1. Does your PFAC have by-laws and/or policies and procedures? If so, please attach them with your report or send a link to access them on-line.
2. How do you recruit PFAC members?
3. Is the PFAC chair or co-chair a patient or family member?
4. If there is a hospital staff chair or co-chair, what hospital position does that person hold?
5. Are at least 50% of PFAC members current or former patients or family members?
6. What hospital department supports the PFAC? What is the hospital position of the PFAC staff liaison?
7. Does the hospital reimburse PFAC members for any costs associated with attending meetings and/or provide any other assistance (eg. free parking, child or elder care, translation or interpretation services, conference calls, meals, mileage reimbursement or other travel stipends, etc.)?
8. The PFAC regulations require every PFAC to represent the community served by the hospital. What is your PFAC/hospital doing to comply with this requirement?
9. Who sets agendas for PFAC meetings?
10. Does the PFAC have subcommittees? If yes, please list and describe them.
11. How does the PFAC interact with the Board of Directors (Check or circle all that apply)
 - a. PFAC submits annual report to Board
 - b. PFAC submits meeting minutes to Board
 - c. PFAC member(s) attends Board meetings
 - d. Board member(s) attends PFAC meetings
 - e. PFAC member(s) are on board-level committee(s)
 - f. None of the above
 - g. Other
12. Is there a PFAC section on the hospital website?

13. Does your PFAC use social media and if so, how?

Orientation and Continuing Education

14. Describe the PFAC orientation for new members. Include in description how often it is given, by whom, and the content covered. Please include any requirements for PFAC members as hospital volunteers (eg. hospital volunteer trainings, immunizations, CORI checks, TB checks, etc.).

PFAC Impact and Accomplishments

15. The law allows a hospital to engage its PFAC in a broad consulting role. Did the PFAC provide advice or recommendations to the hospital on any of the following areas specifically mentioned in the law (Check or circle all that apply):

- a. Patient and provider relationships
- b. Institutional review boards
- c. Quality improvement initiatives
- d. Patient education on safety and quality matters

16. Did PFAC members engage in any of the following activities mentioned in the law? (Check/circle all that apply):

- a. Members of task forces
- b. Members of standing hospital committees that address quality (list committees and how many PFAC members serve on each)
- c. Members of awards committees
- d. Members of advisory boards
- e. Participants on search committees and in the hiring of new staff
- f. Co-trainers for clinical and nonclinical staff, in-service programs, and health professional trainees
- g. Participants in reward and recognition programs

17. Was any of the following public hospital performance information shared with the PFAC? (Check/circle all that apply.)

- a. Serious Reportable Events
- b. Healthcare-Associated Infections
- c. Department of Public Health (DPH) information on complaints and investigations
- d. Staff influenza immunization rate
- e. Other hospital performance information shared: please describe _____

18. Did PFAC quality of care initiatives relate to any of the following state or national quality of care initiatives: (Check/circle all that apply.)

- a. Healthcare-associated infections
- b. Rapid response teams
- c. Hand-washing initiatives
- d. Checklists
- e. Disclosure of harm and apology
- f. Fall prevention
- g. Informed decision making/informed consent
- h. Improving information for patients and families
- i. Health care proxies/substituted decision making
- j. End of life planning (e.g., hospice, palliative, advanced directives)
- k. Care transitions (e.g., discharge planning, passports, care coordination & follow up between care settings)
- l. Observation status for Medicare patients
- m. Mental health care
- n. Other-please describe

19. Describe the PFAC's specific accomplishments in relation to quality of care initiatives during the past year. **Please note for each initiative undertaken,**

- a. did the idea arise directly from the PFAC

Or

- b. did a department, committee or unit request PFAC input on the initiatives?

PFAC Annual Report

20. Does the hospital share the PFAC annual reports with PFAC members?

21. How do you make the PFAC report accessible to the public?

Goals

22. Does your PFAC set goals? If yes, what are they? (Please list.)

(Note: As your PFAC sets goals, you should keep in mind the requirements and recommendations in the Massachusetts PFAC law and regulations.)

Appendix F: HFCA 2014 PFAC Report Review Tool

1. Hospital name

2. Does your PFAC have by-laws and/or policies and procedures?

- Yes, either by-laws or policies and procedures
- No, PFAC does not have either by-laws or policies and procedures
- Unable to determine from report

3. Is the PFAC Chair or c-chair a patient or family member representative?

- Yes
- No
- Unable to determine from report

4. Are at least 50% of PFAC members solely representing a patient or family perspective, e.g., not also a hospital staff perspective?

- Yes
- No
- Unable to determine from report

5. If a hospital staff person serves as PFAC Chair or Co-Chair, what is his/her hospital position?

6. How frequently does the PFAC meet? This is the full PFAC, not a PFAC committee meeting.

7. How does the PFAC recruit new members? (We are looking for innovative ideas & efforts targeted to improve community representation.)

8. Describe the new PFAC member orientation. Include how often orientation is given, by whom, and content covered. In particular, please note anything that is PFAC-specific, e.g., goes beyond the general hospital volunteer orientation.

9. Does the hospital provide supports or reimburse PFAC members for costs associated with attendance at meetings? (Select all that apply.)

- Parking
- Meals
- Mileage or public transportation assistance
- Stipend
- On-site child or elder care
- Off-site child or elder care financial support
- Interpreter/translator or other language communication assistance
- Conference call participation/webinar
- Other (please specify)
- Unable to determine from report

10. What is the hospital or PFAC doing to comply with PFAC law that members represent the communities the hospital serves? This can be demographic representation as well as services utilized.

- Yes, information about representation is in PFAC report
- Unable to determine from report

11. Who sets the agenda for PFAC meetings?

- All PFAC members have input into agendas
- Co-chairs determine the agenda

- Hospital PFAC liaison suggests/determines agenda
- Unable to determine from report

12. Does the PFAC have committees or workgroups of its own? (This question is NOT about hospital committees on which PFAC members participate.)

- No, the PFAC does not have its own committees or workgroups
- Yes, the PFAC has committees or workgroups. These are listed in the text box.
- Unable to determine from report

13. To what extent does the PFAC interact with (or have access to) the hospital's Board of Directors or governing body? (Check all that apply.)

- PFAC annual report is shared with board or governing body
- Minutes from PFAC meetings are shared with Board or governing body
- Board members attend PFAC meetings
- PFAC members attend Board or governing body meetings
- PFAC members are on Board-level committees
- Other
- Unable to determine from report

14. Is there a PFAC section on the hospital website?

- Yes
- No
- Unable to determine from report

15. Does this PFAC use social media?

- Yes (if yes, please describe how PFAC uses social media in text box below)
- No
- Unable to determine from report

16. PFAC state law allows hospitals to engage PFAC in broad consulting roles. Did PFAC advise hospital in any of the following areas?

- Patient and provider relationships
- Institutional review boards
- Quality improvement initiatives
- Patient education on safety and quality matters
- Unable to determine from report

17. Did the PFAC engage in any of the following activities mentioned in the state law? (Check all that apply.)

- Members of task forces
- Members of standing hospital committees that address quality
- Members of awards committees
- Members of advisory boards
- Participate on hospital staff search committees
- Co-train for clinical or non-clinical staff, in-service programs, health professional trainees
- Participate in reward or recognition programs
- Unable to determine from report

18. Was any of the following public information about hospital performance shared with the PFAC? (Check all that apply.)

- Serious Reportable Events (SRE)
- Healthcare-associated infections (HAI)
- Dept. of Public Health information on complaints and investigations
- Staff influenza immunization rate
- Other hospital performance information (Please describe in text box.)
- Unable to determine from report

19. Were PFAC members engaged in quality of care initiatives related to national or state hospital priorities noted below? (Check all that apply.)

- Healthcare acquired infections
- Public reporting of hospital performance
- Rapid response teams
- Hand washing initiative
- Checklists for surgical or non-surgical procedures
- Apology and disclosure of harm
- Fall prevention
- Informed decision making/informed consent
- Improving information for patients and families
- Health care proxies/substituted decision making
- End of life planning (e.g., hospice, palliative, advanced directives)
- Care transitions (e.g., discharge planning, passports, care coordination & follow up between care settings)
- Observation status of Medicare patients
- Mental health
- Unable to determine from report

20. List the PFAC's specific accomplishments over the past year. For each accomplishment, (if possible to determine from PFAC report), note if it was a PFAC-generated quality of care initiative or the initiative of another hospital department, committee, or entity.

21. What goals or quality improvement projects has the PFAC set for the coming year? (Please list all noted in the report.)

- Yes, PFAC report mentions goals for 2015. Please note these in the text box (can be summarized).
- None. PFAC did not set goals or target quality improvement projects.
- Unable to determine from report

22. Is the PFAC annual report shared with PFAC members?

- Yes
- No
- Unable to determine from report

23. Does the hospital make the PFAC report accessible to the public either by posting to the hospital's website or noting how to request a copy?

- Yes, report is posted or website notes how to request a copy
- No, PFAC report is not posted to hospital website nor are there instructions on how to request a copy
- Unable to determine from report

24. Did the PFAC use the HCFA report template or incorporate HCFA report items into its own report?

- Yes
- No
- Unable to determine from report

25. What is this PFAC doing well that should be shared with other PFACs? We will use this information to recognize PFAC initiatives that can be adopted by other PFACs. In the past, reviewers have recognized impressive PFAC activity such as a successful member diversity initiative, a successful community engagement initiative, a successful quality improvement project, an ongoing relationship with a hospital leader, a user-friendly report, etc.

26. What in this PFAC report stands out to you as amiss and in need of attention?

Appendix G: Report Review Committee

Opinions expressed in this report are those of the Report Review Committee members listed below.

Thank you to the following HCFA and PFAC volunteers for their contributions to this report:

- Kathy Campanirio
- Kevin Dow
- Monica Huaza
- James O'Connor
- Elizabeth Pell
- Tami Rich
- Nicola Truppin
- Barbara Williams

HCFA Staff

- Deb Wachenheim

For more information about this report, please contact Deb Wachenheim, Patient/Family Organizer and Coalition Coordinator at Health Care For All, dwachenheim@hcfama.org or 617-275-2902.

Visit the Health Care For All website at www.hcfama.org.