



HEALTH CARE FOR ALL

2015 Annual Assessment of
Massachusetts Patient and Family Advisory
Councils:
Progress and Opportunities for Improvement

December 2015

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Executive Summary

This is an extraordinary moment in the history of health reform for the country and for the Commonwealth of Massachusetts. Nine years after the implementation of our state's health reform efforts, and seven years after Massachusetts enacted the law requiring all hospitals to create and maintain Patient and Family Advisory Councils (PFACs), efforts are focusing more and more on health delivery system transformation. As a part of this transformation, we must achieve quality, patient-centered care in the Commonwealth; such care must include meaningful consumer engagement in the development and implementation of hospital policies and procedures.

This year, Health Care For All (HCFA) reviewed PFAC reports from 69% of the state's hospitals and rehabilitation hospitals. Our analysis generated the following accomplishments and challenges:

- PFACs have expanded their activities to cover nearly every area suggested or mandated by the law.
 - Almost all have formal policies and operating procedures and created yearly goals.
 - The majority of PFACs include a family member or patient as chair or co-chair and has at least 50% of their members are patients or family members.
 - Most are providing recommendations on patient education, patient- provider relationships, and on quality improvement initiatives – with almost half of PFACs serving on standing hospital committees around quality improvement.
 - 90% of PFACs are now sharing their reports with their hospital Boards, up from 50% last year; and almost 30% of PFACs have members sitting on Board level committees.
- Collectively, PFACs reported almost 250 distinctive accomplishments in their work to improve patient care in 2015. The vast majority of these accomplishments focused on reviewing and informing hospital policies and procedures; about half were initiated by the PFAC itself.
- PFACs have increased their activities around current health care quality issues, particularly around care transitions, end of life planning and improving health care proxies.
- Most PFACs continue to face challenges as they work to ensure that their membership reflects the diversity of their communities and of patients seeking care at their institutions. Attracting new members –and making the case for their engagement in the Councils—is an additional concern. Other challenges concerned issues around PFAC function and hospital integration.
- Some PFACs have found it difficult to have their members serve on hospital-wide committees in which their presence is questioned.
- Only about half of PFACs are provided information about their hospitals' quality measures.

HCFA was a vigorous proponent of the PFAC law, as it creates a vital point of consumer engagement at our state's health care institutions. As the lead consumer advocacy organization in the State, HCFA has provided technical assistance, training and networking opportunities to help strengthen patient and family engagement through hospital PFACs. As we look ahead to the next five years of PFAC work, HCFA will continue to support hospitals in meeting the state mandate, as well as focus on the meaningful integration of the patient and family voice into hospital policies and procedures that impact patient care.

Based on our analysis, we outline the following seven opportunities for improvement, in our own work and in that of each PFAC.

1. **Continue to encourage meaningful PFAC reporting:** The law states that PFACs must report their progress each year in a manner that is publically accessible. HCFA will continue to work with the PFACs to develop easier ways of reporting their progress, as well as encourage more PFACs to post their reports online.
2. **Foster the development of data-driven yearly goals and objectives for meaningful engagement in policy and program development, as well as in the delivery of care:** This year, HCFA plans to support PFACs in better understanding how hospital data related to patient needs can help inform the establishment of yearly goals and objectives.
3. **Continue to develop realistic goals and measurable objectives to assist in self-assessment:** While goals are overarching principles that guide decision making, objectives are specific, measurable steps that can be taken to meet the goal. HCFA will aim to assist PFACs in developing goals and objectives in an easy way so that they can evaluate their successes or the outcomes of their efforts.
4. **Continue to foster greater sense of community engagement and diversity:** There is a clear lack of ethnic, racial and geographic diversity among PFAC memberships, which is a particularly challenging issue. Over the next year, HCFA will provide additional assistance to PFACs so that they can better understand their catchment areas, increase community engagement and diversify their membership.
5. **Continue to engage hospital leadership to integrate PFAC members in Board and hospital committees:** HCFA will help PFACs identify their own goals for engagement along the Patient and Family Engagement Framework, and ensure that activities go beyond providing feedback on an existing hospital initiative. We believe that integrating PFAC members on standing and ad-hoc committees, as well providing as a feedback loop between the PFAC, committees, and hospital leadership, is critical for success.
6. **Create an “Auxiliary Role” for interested patient and family volunteers:** a number of PFACs continue to struggle with having too many demands on their time, while others expressed concern that their time is not used efficiently. HCFA will help outline other options for consumer engagement for projects that may be better suited for succinct feedback from other volunteers.
7. **Advocate for meaningful patient and family engagement in research being conducted at hospitals:** Including consumers in research design is as a natural extension of consumer engagement in Patient and Family Centered Care, improving the quality of health care and the care experience. Throughout 2016, HCFA will be undertaking a number of activities to better understand where such engagement is taking place, which PFACs might be interested in such engagement, and how HCFA can help support their interest and engagement with researchers.

I. Introduction

Nine years after the implementation of our state’s health reform efforts, and seven years after Massachusetts enacted the law requiring all hospitals to create and maintain Patient and Family Advisory Councils (PFACs), PFACs are continuing to collaborate with their hospitals in some impressive ways to improve the patient care experience. As we work to achieve quality, patient-centered care in the Commonwealth, it is critical that we ensure meaningful consumer engagement in the development and implementation of hospital policies and procedures. And, as the Commonwealth is driving toward health delivery system transformation, there will be increasing expectations being placed on hospitals to ensure the health of their local populations.

As the lead consumer advocacy organization in the State, Health Care For All (HCFA) believes that it is critical to have meaningful consumer engagement at all levels of care—from direct patient care to the development and implementation of policies and procedures. In fact, one of the critical features of patient-centered care is collaboration, in which patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation, and evaluation as well as in the delivery of care¹.

Massachusetts Patient and Family Advisory Councils (PFACs) are an important vehicle in which patients and family members are working to improve the quality of health care and the care experience. To our knowledge, there are 81 Hospital-wide PFACs in Massachusetts acute care and rehabilitation hospitals. Individuals serving in these PFACs act as representatives for health care consumers across the Commonwealth.

Since 2010, HCFA has provided technical assistance, training and networking opportunities to help strengthen patient and family engagement through hospital PFACs. HCFA is guided by a PFAC Advisory Board, made up of 42 PFAC members from 30 Councils across the state. In 2016, the Board is reorganizing into the “PFAC Leadership Network,” to provide more strategic direction for this work. Massachusetts Patient and Family Advisory Councils are joining together 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 in the Commonwealth.



Bringing the perspectives of patients and families directly into the planning, delivery, and evaluation of health care, and thereby improving its quality and safety is what patient- and family-centered care is all about. ... when health care administrators, providers, and patients and families work in partnership, the quality and safety of health care rise, costs decrease, and provider and patient satisfaction increase.

Institute for Patient- and Family-Centered Care, Advancing the Practice of Patient- And Family-Centered Care: How To Get Started, 2014.

There are many examples of how Massachusetts PFACs are contributing to improving patient care, from advising on patient education materials to leading a new quality initiative. This report highlights the successes and increasing influence of Massachusetts PFACs during 2014-2015, while also outlining potential opportunities for improved engagement in 2016 and beyond.

Methodology

Each year, HCFA collects and summarizes hospital PFAC annual reports. PFAC Advisory Board members and HCFA revise the questions based on the previous year's reports. This year we used a web-based survey in Qualtrics to encourage easy reporting; more than 90% of reporting hospitals used our suggested format. Usable data was extrapolated into the Qualtrics program for those not using our format.

This year, HCFA reviewed reports for 67 hospitals (out of 97) across the Commonwealth. Some institutions are home to multiple PFACs, in addition to their hospital wide PFAC. These PFACs often function independently from one another, with separate membership and goals. Our report therefore uses the PFAC as a unit of analysis (n=71), rather than the institution.

For questions in which fewer than 75% of PFACs answered, we explicitly state that number in the tables, charts, and graphs that appear.

I. PFAC Compliance with Massachusetts Law and Regulations

The 2008 law and subsequent regulations by the Massachusetts Department of Public Health (see Appendix) outlined a number of requirements and recommendations. This year, there has been important progress in this area.

Reporting Hospital PFAC Activity

The law states that annual PFAC reports be made publicly available either electronically, or other means, and to the Department of Public Health upon request by October 1 of each year. Out of 97 institutions required to provide these reports, 69% were made available to us in time to be included in this report. (See list of institutions in Appendix.) About 64% of hospitals have a link to the report on their website, up from 57% last year.

Formal Policies and Role of Patient Chair

By-laws or policies and procedures are required by the Massachusetts PFAC regulations and are also important to the effective functioning of any type of committee. The number of PFACs with by-laws and/or agreed-upon policies and procedures has increased to 90% from 73% last year. 85% of PFACs functioning in the Commonwealth are either chaired or co-chaired by a patient or a family member, slightly up from 72% last year.

Suggested Areas and Activities of Focus

The law suggests broad areas of advisory activity, as outlined in Table 1 below. For the most part, PFACs provided recommendations in quality improvement initiatives and patient education, and in

Areas Outlined in Legislation	Percent PFACs reporting participation
Quality improvement initiatives	88%
Patient education on safety and quality matters	81%
Patient and provider relationships	69%
Institutional Review Boards	11%
Other Areas	14%
None	6%

patient-patient provider relationships. This year saw significant increases in advisement in Quality Improvement, Patient Education and Patient and Provider Relationships, and slightly less in Institutional Review Boards (IRBs).

Table 1: Areas of participation

As shown in table 2, less than 50% of PFACs report engagement in hospital-wide activities that were suggested in the legislation. These figures are similar to those from 2014. Additional areas of focus and self-reported successes are detailed in section IV.

Hospital Wide Activities Suggested in Legislation	Percent PFACs reporting participation
Served as members of standing hospital committees that address quality	47%
Served as members of task forces	42%
Served as members of advisory boards/groups or panels	40%
Served as members of awards committees	13%
Served on selection of reward and recognition programs	11%
Served on search committees and in the hiring of new staff	10%
Served as co-trainers for clinical and nonclinical staff, in-service programs, and health professional trainees	10%
Other Hospital Wide activities*	25%
None	19%

*Ethics Committee; Planning Advisor Appreciation Event; participating in Patient Safety Awareness week activities; participating in focus groups; Reviewing a research survey about advance care planning; Participating in retreats; Assisting with the e-newsletter; Care Rounds; Nursing Orientation; Secret Shopper Pilot; Patient Education Committee; Global Health Initiative, Inpatient Care Improvement; Pediatric Multi Disciplinary leadership; Partners Patient Gateway; Clinical Education Sheets; Pediatric Clinical Operations; Charter project; PFAC publications; Survivorship; Transition of Treatment; Communications; Epic Transition; Ethics Committee; Reward and Recognition Committee; Access-related projects; Construction projects; Digital strategy projects; Experience projects; Family-centered care projects; Family Education projects; IPASS projects; Patient Portal Committee; Process improvement projects; Research-related projects; Life Choice tissue and Organ Donation Education Program

Table 2: Hospital wide activities

Community Representation

PFAC regulations state that at least 50% of the membership should be composed of current or former patients and family members, a standard being met by most PFACs in 2015. Regulations also state that PFACs should be representative of the communities served by the hospital. In order to ensure that a variety of experiences and perspectives inform the work of the council and of the hospital, PFACs must reflect voices from all communities that receive care at the hospital.

Different communities can often have very different experiences of care as well as needs and concerns.

The PFACs reporting diverse ethnic and racial membership were:

1. Lowell General Hospital
2. Southcoast Hospitals
3. Baystate Medical Center
4. Carney Hospital
5. Shriners Hospital for Children

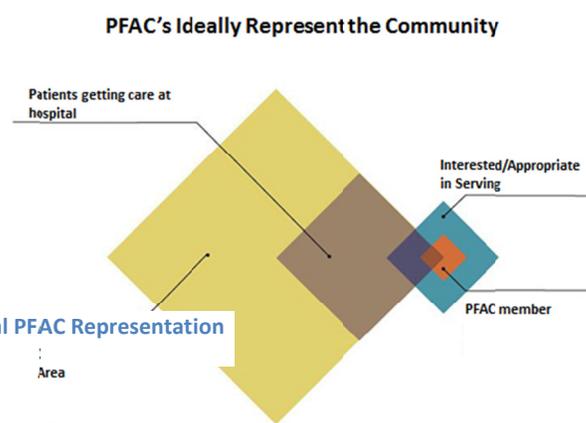


Figure 1: Ideal PFAC Representation

This year, HCFA sought additional information, as illustrated in Figure 1, to get a better sense of how well PFACs represented their communities or the patients seeking care within their institution. Because only about 40% of PFACs could report complete information on these questions, we cannot make any broad conclusions. Many PFACs

have noted significant and ongoing challenges in this area. We hope to have more complete data next year.

Opportunities for Improvement: Compliance with Laws and Regulations

Continue to Promote PFACs and their Role: PFACs must report their progress each year in a manner that is publically accessible. Members of the hospital community, both patients and staff, as well as the institutions' greater catchment area, should be able to easily access information about the PFAC and its efforts. This report is a simple way to highlight the important work of the PFACs and its importance to the hospital leadership. HCFA will continue to work with the PFACs to develop easier ways of reporting their progress.

Address the need for diversity, community representation and engagement: Many PFACs asked for help in diversifying their membership. Over the next year, HCFA will focus on providing additional assistance to PFACs in order to better reflect their communities.

II. PFAC Influence and Function within Hospitals

While it is encouraging to report that more PFACs are participating in the content areas and activities outlined by the law, and that leadership of the PFACs is shared between patients and hospital staff, it is also critical to examine the impact and extent of such engagement.

Forming Yearly Goals and Meeting Agendas

We continue to see an increase in the formation of yearly goals and in collaboration on how goals are set. This year 93% of PFACs have developed goals, in contrast to 71% last year. 76% of PFACs reported developing these goals in a collaborative manner.

PFAC goals are summarized below and sorted into two broad categories. Most concerned PFAC processes rather than projects directly related to patient care. Most of the stated goals—even when it concerned patient care—lacked specificity or any type of progress measure. Goals such as these make it difficult for PFACs to evaluate their successes or the outcomes of their efforts.

“...in a growing number of instances where truly stunning levels of improvement have been achieved, organizations have asked patients and families to be directly involved in the process. And those organizations' leaders often cite this change—putting patients and families in a position of real power and influence, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history.”

Institute for Healthcare Improvement. Seven Leadership Leverage Points For Organization-Level Improvement In Health Care, 2008

PFAC Goals Related to PFAC Processes	PFAC Goals Related to Hospital Policy or Procedures
Increase participation to include members from primary catchment area/ Increase racial and ethnic diversity/Recruit new members	To promote the concept of patient-centered care throughout the hospital.
Increase participation on standing hospital committees	Partner with senior hospital leadership to improve patient experience.
Increase feedback from patients.	Increase PFAC member participation in training and developing orientation materials for hospital staff.
Collect outcome data to help evaluate and validate the	Increase hospital administration participation in PFAC meetings.

PFAC Goals Related to PFAC Processes	PFAC Goals Related to Hospital Policy or Procedures
influence and productivity of the work of the PFAC.	
Develop new orientation material.	Evaluate the Better Together Campaign as it applies to our existing Visitor Policies.
Increase member knowledge of PFAC activities in the region.	Work with RN staff to find ways of reducing noise on the inpatient units, especially during evening hours.
Educate members re: Patient Satisfaction Metrics and Organizational Goals/ Provide training and educational workshops for PFAC members	Develop notices to foster the importance of washing hands during flu season.
One or more PFAC community members will become an active and ongoing participant in a standing hospital committee.	Work with the Pharmacy Department to provide feedback on their proposed inhaler brochure.
Create PFAC informational brochure and distribute to outpatient offices, inpatient units and at community events.	Engage with Rehab Therapies and RN Leadership regarding the topic of fall prevention.
Work with the Marketing Department to develop a PFAC logo or 'stamp of approval' for any projects or programs.	Discuss opportunities with nursing for role of PFAC in mentoring unit PFCC patient committee development.
Utilize IT to support tracking tools of all PFAC activities and volunteer hours.	Utilize IT to support tracking tools of all PFAC activities and volunteer hours.
Increase collaboration with volunteers.	
Increase PFAC participation in hospital-wide initiatives.	
Collaborate with all PFACs at hospital.	

Table 3: Goals for 2015, sorted by goal focus.

The creation of meeting agendas is another indication of efficacy and utility of meetings. More than half of the PFACs reported that the process for developing and distributing their meeting agendas was a collaborative effort between the staff and membership.

Hospital Support for PFACs

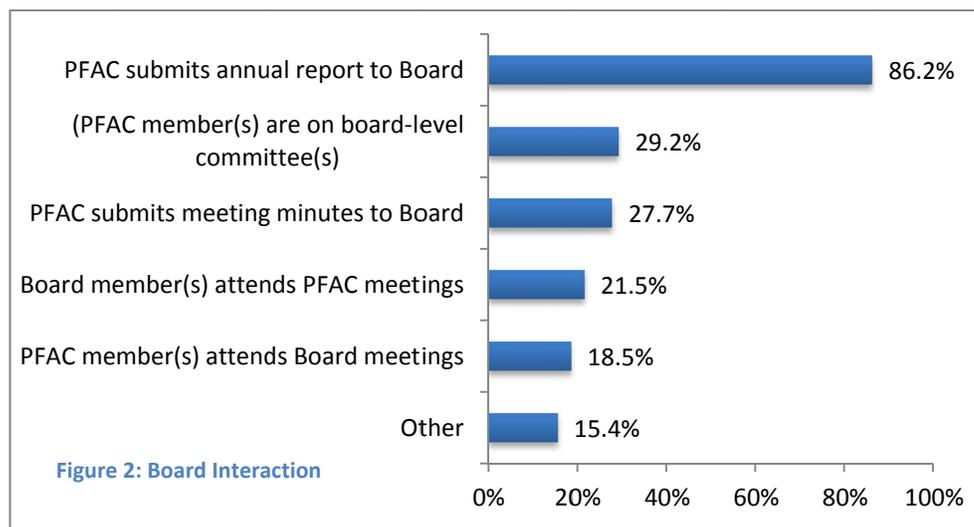
Most PFACs are providing meals and/or subsidies for parking to help support volunteer efforts. However, they are not yet providing support to members in key areas that may well limit their ability to cultivate diversity in membership. These include provision of childcare, translator and interpreter services, and conference call options for meetings.

PFAC Interaction with Hospital Board of Directors/Hospital Leadership

It is particularly encouraging to see that hospital governing bodies and leadership have a growing awareness of PFAC

activities and priorities. More than 86% of PFACs are now sharing their reports with the Board, up from 50% last year; and almost 30% of PFACs have members sitting on Board level committees, up from 17% last year. Despite this progress, as illustrated in Figure 2, we still see minimal interaction with the Board and PFACs, as

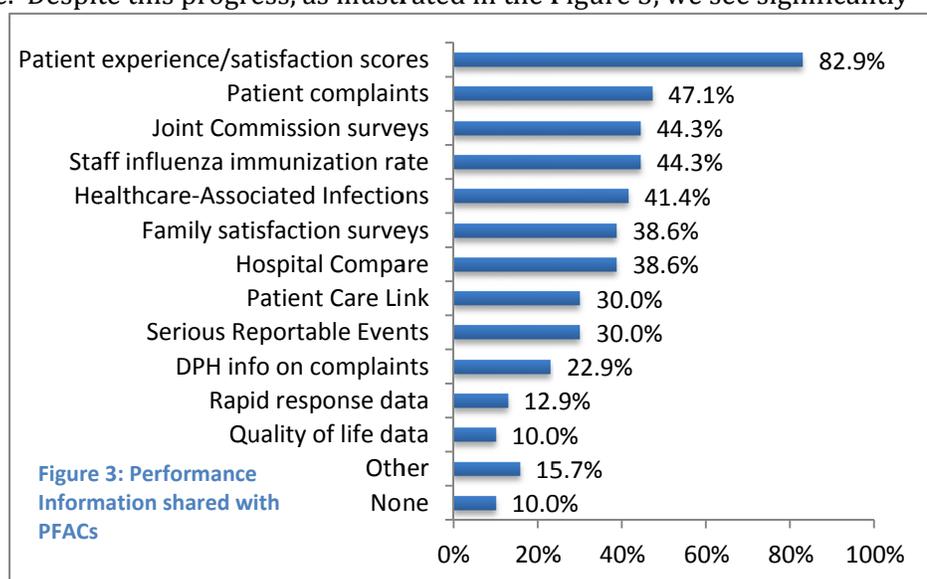
shown in the significant drop off between the first and every other activity shown.



Public Hospital Information Shared with PFACs

One way in which PFACs can be engaged in improving patient-centered care is to be part of the hospitals' quality measures reports. This year, PFACs reported increases in sharing data in every type of reporting measure. Despite this progress, as illustrated in the Figure 3, we see significantly

less data being shared other than patient satisfaction scores; none of the other measures were shared with more than half of the PFACs.



Activities Related to National and State Priority Areas

HCFA asked PFACs to report on their involvement with activities related to a number of state or national quality care initiatives, particularly relevant to Health System Transformation initiatives. As shown in Figure 4, the area with the highest percentage of PFAC involvement was in improving information for patients and families (77%), as it was in previous years. PFACs reported increases in activity in each and every area, with significant increases in activities around care transitions (59%), end of life planning (47%) and improving health care proxies (59%).

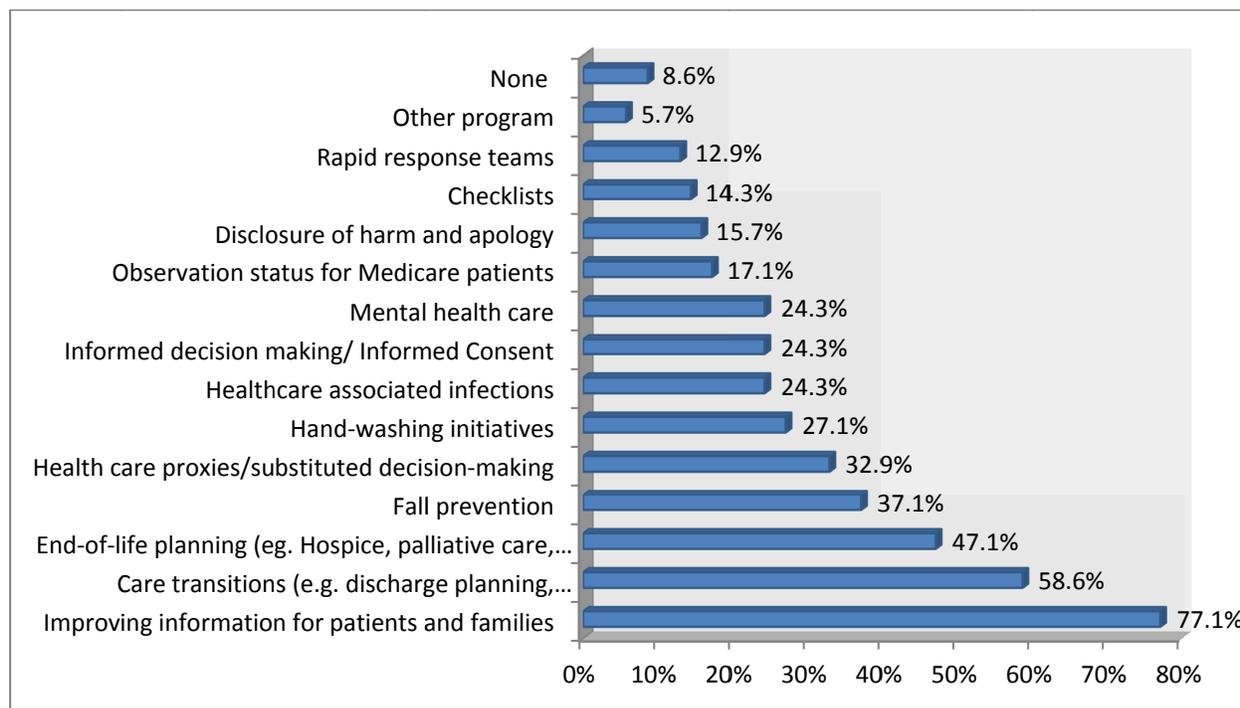


Figure 4: Percentage of PFAC activities related to state or national priority.

Opportunities: PFACs Function and Influence

Foster the development of data-driven yearly goals and objectives for meaningful engagement in policy and program development, as well as in the delivery of care. HCFA will plan to offer technical assistance and offer support to PFACs so that they have a better understanding of how hospital data related to patient needs can help inform yearly goals and objectives.

Continue to develop realistic goals and measurable objectives to assist in self-assessment.

While goals are overarching principles that guide decision making, objectives are specific, measurable steps that can be taken to meet goals. HCFA will offer support to assist PFACs in developing goals and objectives so that they can more easily evaluate their annual successes or the outcomes of their efforts.

Continue to foster greater engagement between the PFAC and hospital leadership. While almost 90% of PFACs provide their annual reports to the hospital Board, less than half are engaged in other ways. It is critical that we continue supporting and expanding the “feedback loop” between the PFAC and the Board/hospital leadership. We believe that integrating PFAC members on standing and ad-hoc committees, as well providing as a feedback loop between the PFAC, committees, and hospital leadership, will enhance the likelihood of their success.

III. Reported Success and Impact

PFACs were asked to report on three of their year's greatest overall accomplishments, as well as those concerning quality of care initiatives. PFACs reported almost 250 distinctive accomplishments in their work towards improving patient care.

HCFA's ongoing support of PFACs focuses on the meaningful integration of the patient and family experience into hospital policies and procedures that impact patient care. Adopting published frameworks^{2 3 4 5} on patient and family engagement in institutional settings, HCFA has developed a working framework to help us categorize stated PFAC accomplishments into three broad levels of involvement and influence, as illustrated below. (See Appendix for more information on the framework.)

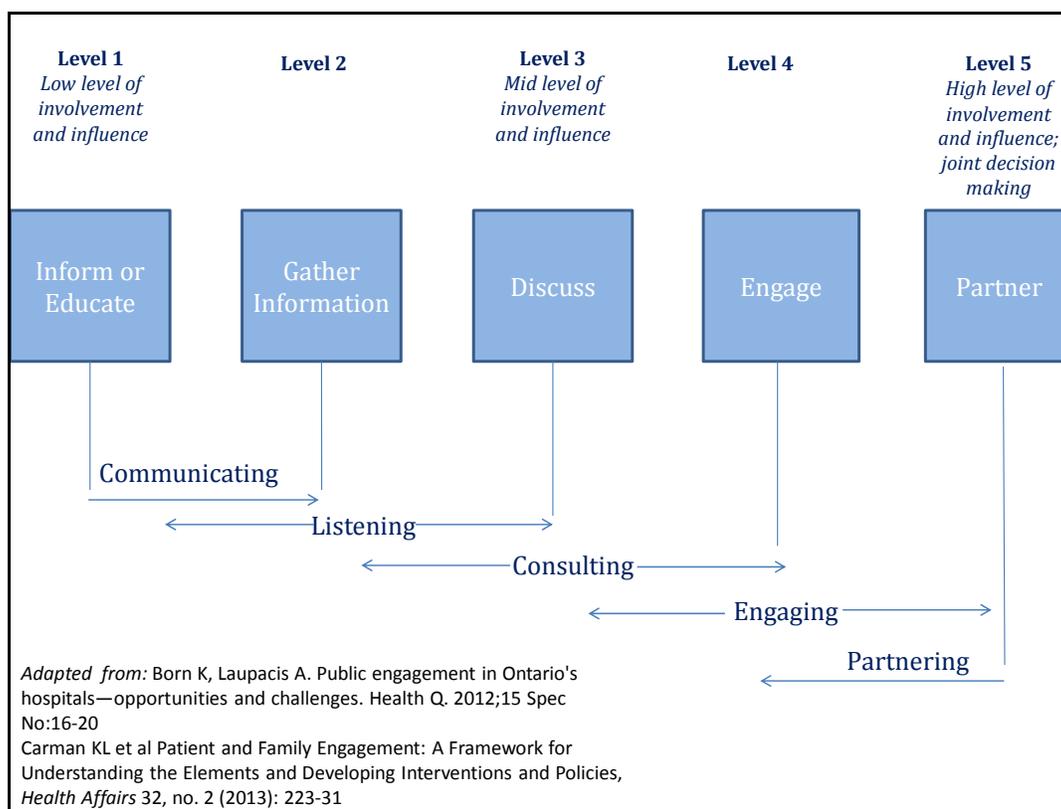


Figure 5: Patient and Family Engagement Framework in PFACs

Based on the language used to describe accomplishments, we organized each by impact level according to the Framework. The most frequently named “successful” activities focused on levels 1 and 2-- informing staff and providing feedback on distinct products, materials, initiative or reports. Some PFACs reported engagement in decision making or in driving new initiatives to improve patient care, which fall under level 3 or 4. It does not appear PFACs are yet operating under level 5.

Sample Accomplishments by Impact Level <i>(See Appendix for data summary by impact level)</i>		
Inform/Educate/Participate Levels 1-2	Discussion/Review Level 3	Engagement Level 4
<p>Worked with the Compliance and Quality Departments to update the patient sign-in sheets used in our outpatient offices to ensure patient confidentiality.</p> <p>Consulted on a project to improve information for patients and families about the discharge process.</p>	<p>Reviewed Surgical Day Care brochure</p> <p>Evaluated and recommended changes to the disclosure of harm and apology process.</p>	<p>Conducted comprehensive service review and identified gaps in patient centeredness or unmet needs of following hospital services.</p> <p>Created the HUSH committee, which addresses patient comfort through noise reduction.</p>

Opportunities to Expand Success and Impact

The large number of accomplishments reported indicates a strong connection between patients and families and the hospitals in which they serve. Moving forward, we look forward to helping ensure that more activities have a meaningful and lasting impact on improving care.

Continue to support PFACs focus on meaningful engagement of the patient and family experience into hospital policies and procedures that impact patient care. HCFA's focus is to help PFACs identify their own goals for engagement along the Patient and Family Engagement Framework, and help encourage a greater sense of engagement along the spectrum of engagement levels.

Enhance ongoing tracking of PFAC activities through the "Feedback Loop" and impact/outcome measurement: Better understanding how, where and if feedback is used is a critical component of effective work. HCFA will provide assistance to interested PFACs to move toward integration and focus on Level 4 engagement levels.

Expand focus on activities that go beyond providing feedback on existing hospital initiatives: This is the heart of the PFAC mandate in Massachusetts: patients and families can have a meaningful and lasting impact on improving care at their host imitations. HCFA will continue to encourage PFAC direction of specific projects or areas of inquiry.

As listed elsewhere in this report, HCFA will also plan to

- Foster the development of data-driven yearly goals and objectives for meaningful engagement in policy and program development, as well as in the delivery of care.
- Continue to develop measurable goals and objectives to assist in self-assessment.
- Continue to foster greater PFAC engagement between the Board, Hospital-wide committees, and Hospital Leadership.

IV. Identified Challenges

57 PFACs provided a total of 160 distinct challenges, which concern issues around PFAC function, hospital integration or acceptance of PFAC members, and significant concerns around recruitment and diversity (see Appendix for full list.) The following quotes provide an important context to the most common problems identified.

Example: Internal PFAC Challenge	Example: Hospital Challenge	Example: Recruitment and Retention Challenge
<p><i>“One of the most difficult barriers has been and continues to be consistent PFAC ...involvement. Because our membership spans a wide geographic location, it is often difficult for members to take off of work to commute to the hospital mid-week. We have attempted to change the times of the meeting to fit needs of the members, within the past year, but the time of day doesn’t seem to alter the attendance greatly.”</i></p>	<p><i>“In general, staff and physicians are not comfortable having patients on committees. There is concern and uncertainty about how the hospital will be perceived (yet) the committees who now have an advisor appreciate their input.”</i></p>	<p><i>Our PFACs continue to struggle with accurately representing the community that we provide care to. This is something we have attempted to address, but with little success in the last few years. We continue to actively recruit and engage diverse potential advisors, yet we fail to maintain their interest or commitment to the PFAC.</i></p>

Addressing the Challenges

Continue to engage hospital leadership to integrate PFAC members in Board and hospital committees: HCFA’s focus in 2016 is to help PFACs identify their own goals for engagement along the Patient and Family Engagement Framework, and help to ensure that activities go beyond providing feedback on an existing hospital initiative. We believe that integrating PFAC members on standing and ad-hoc committees, as well providing as a feedback loop between the PFAC, committees, and hospital leadership, is critical for success.

Continue to address the need for diversity and additional recruitment: Diversity and recruitment remain particularly challenging issues for almost every PFAC across the Commonwealth. Over the next year, HCFA will provide additional technical assistance and tools to help PFACs in increase and diversify their membership.

Create an “Auxiliary Role” for interested patient and family volunteers: A number of PFACs continue to struggle with having too many demands on their time, while others expressed concern that their time is not used efficiently. HCFA will help outline other opportunities for consumer engagement for projects that may be better suited for succinct feedback from other volunteers.*

* One hospital has 93 active advisors, 15 of whom are currently on the hospital wide PFAC. Activities such as focus groups, surveys, and material review are often referred to these volunteers, and they provide a ready group of candidates for PFAC membership.

V. PFAC Involvement in Research

In recent years, there has been growing national interest in fostering meaningful engagement of patients and consumers throughout the research process—from topic selection through design and conduct of research to dissemination of results. Across the country and in Massachusetts, some PFACs have already started to become engaged in such efforts. Patient-centered outcomes research (PCOR) is a type of research comparing two or more healthcare options available to patients to determine what works best in particular circumstances. More than 40 of these types of research projects have been funded in Massachusetts by the Patient-Centered Outcomes Research Institute (PCORI), and all are required to engage patients and consumers in their research design and implementation.

We believe that (engagement in research) can influence research to be more patient-centered, useful, and trustworthy and ultimately lead to greater use and uptake of research results by the patient and broader healthcare community.

Patient-Centered Outcomes Research Institute

While half of reporting PFACs stated they provided information on PCOR to their PFACs, it appears that PFACs have limited participation in research activities. For example, only eight PFACs have members participating on hospital Institutional Review Boards. None reported any specific successes or challenges focused on research engagement.

Opportunities for PFAC Engagement in Research

One of HCFA's priorities – concurrent with the activities of several of Massachusetts' largest PFACs – is to build the capacity of interested PFACs to be engaged in research design, conduct and dissemination of results. We believe there is great value in advocating for meaningful patient and family engagement in research.

In 2015, HCFA received a grant from the Patient Centered Outcomes Research Institute to support our work with the Massachusetts PFACs. Throughout 2016, HCFA will be undertaking a number of activities to better understand where such engagement is taking place, which PFACs might be interested in such engagement, and how HCFA can help support their interest and engagement with researchers.

VI. Conclusion

In only seven years after Massachusetts enacted the law requiring all hospitals to create and maintain PFACs, PFACs continue to deepen their engagement in the development and implementation of hospital policies and procedures to improve the patient care experience.

As we work to achieve the highest quality patient-centered care in the Commonwealth, it is critical that such care include meaningful consumer engagement in the development and implementation of hospital policies and procedures. As state efforts are focusing more and more on health delivery system transformation, with new expectations on hospitals, we believe the role of PFACs is becoming ever more important.

As we look ahead to the next five years of PFAC work, HCFA looks forward to continuing to support hospitals in meeting the state mandate, as well as focus on the meaningful integration of the patient

and family voice into hospital policies and procedures that impact patient care. The following represent our goals for 2016-7:

1. **Continue to encourage meaningful PFAC Reporting:** The law states that PFACs must report their progress each year in a manner that is publically accessible. HCFA will continue to work with the PFACs to develop easier ways of reporting their progress, as well as encourage more PFACs to post their reports online.
2. **Foster the development of data-driven yearly goals and objectives for meaningful engagement in policy and program development, as well as in the delivery of care:** This year, HCFA plans to support PFACs in better understanding how hospital data related to patient needs can help inform the establishment of yearly goals and objectives.
3. **Continue to develop realistic goals and measurable objectives to assist in self-assessment:** While goals are overarching principles that guide decision making, objectives are specific, measurable steps that can be taken to meet the goal. HCFA will aim to assist PFACs in developing goals and objectives in an easy way so that they can evaluate their successes or the outcomes of their efforts.
4. **Continue to foster greater sense of community engagement and diversity:** There is a clear lack of ethnic, racial and geographic diversity among PFAC memberships, which is a particularly challenging issue. Over the next year, HCFA will provide additional assistance to PFACs so that they can better understand their catchment areas, increase community engagement and diversify their membership.
5. **Continue to engage hospital leadership to integrate PFAC members in Board and hospital committees:** HCFA's focus is to help PFACs identify their own goals for engagement along the Patient and Family Engagement Framework, and ensure that activities go beyond providing feedback on an existing hospital initiative. We believe that integrating PFAC members on standing and ad-hoc committees, as well providing as a feedback loop between the PFAC, committees, and hospital leadership, is critical for success.
6. **Create an "Auxiliary Role" for interested patient and family volunteers:** a number of PFACs continue to struggle with having too many demands on their time, while others expressed concern that their time is not used efficiently. HCFA will help outline other options for consumer engagement for projects that may be better suited for succinct feedback from other volunteers.
7. **Advocate for meaningful patient and family engagement in research being conducted at hospitals:** Including consumers in research design is as a natural extension of consumer engagement in Patient and Family Centered Care, improving the quality of health care and the care experience. HCFA will be undertaking a number of activities to better understand where such engagement is taking place, which PFACs might be interested in such engagement, and how HCFA can help support their interest and engagement with researchers.

Appendices

Appendix A: Survey Template



HEALTH CARE FOR ALL

Health Care For All

FY 2015 Patient and Family Advisory Council Annual Report Template

Under Massachusetts law, all PFACs are required to write annual reports each year and to make them available to members of the public upon request. To assist you in collecting information, Health Care For All (HCFA) has developed this revised report template with 6 sections, with the hope that you will use it to complete your report for the fiscal year 2015 (October 1, 2014 – September 30, 2015).

We encourage you to submit your hospital's PFAC report through an on-line survey to ease reporting burden. Follow [this link](#) to complete the FY 2015 PFAC Report. Once the survey is completed, you will be directed to a summary of your responses, which you will be able to save as a PDF or copy and paste into another document for your own reporting.

HCFA recognizes the importance of supporting the work of the PFACs and facilitating cross-PFAC learning and sharing. **Your PFAC report should be made publically available and sent back to us (using the attached word document or preferably the on-line survey) no later than October 1, 2015.**

If you have questions or concerns, please contact Margo Michaels at mmichaels@hcfama.org.

2014 Patient and Family Advisory Council Annual Report

Please list

1. Hospital Name:
2. Year PFAC Established:
3. Staff PFAC Contact (name and title):
4. Staff PFAC Contact E-mail and Phone:

Note: The following questions only concern PFAC activities in fiscal year 2015.

Section 1: PFAC Organization

5. Our PFAC has (check the best choice)

- By-laws
- Agreed-upon policies and procedures
- Neither

6. (If neither) Our PFAC manages itself through (describe in 1500 characters or fewer): _____

7. Our PFAC recruits new members using the following approaches (check all that apply) Word of mouth

- Promotional efforts within institution to patients
- Promotional efforts within hospital to providers or staff
- Through existing members
- Facebook and Twitter
- Recruitment brochure
- Hospital publications
- Hospital banners and posters
- Through care coordinators
- Through patient satisfaction surveys
- Through community based organizations
- Through houses of worship
- At community events
- Other
- None

8. If other, describe (in 1500 characters or fewer): _____

9. Our PFAC chair or co-chair is a patient or family member.

- Yes
- No

10. Our PFAC chair or co-chair is a hospital staff member.

Yes

No

11. This person's position title _____

12. This person is the official PFAC staff liaison

Yes

No

13. Our PFAC has a total of ___ staff members.

14. Our PFAC has ___ current or former patients or family members.

15. The name of the hospital department supporting the PFAC is: ___

16. If not mentioned above, the hospital position of the PFAC staff liaison is ___

17. The hospital reimburses PFAC members for the following costs associated with attending or participating in meetings (check all that apply)

Provide free parking

Provide meals

Provide translator or interpreter services

Provide assistive services for those with disabilities

Provide meeting conference call or webinar options

Provide mileage or travel stipends

Provide financial support for child care or elder care

Provide stipends for participation

Provide on-site child or elder care

Provide reimbursement for attendance at annual PFAC conference

Provide reimbursement for attendance at other conferences or trainings

Provide gifts of appreciation to PFAC members annually

Cover travel expenses to attend conferences

Provide other supports

None

18. If other, describe (in 1500 characters or fewer): _____

Section 2: Community Representation

The PFAC regulations require every PFAC to represent the community served by the hospital.

19. Our catchment area is geographically defined as:

20-25. Our catchment area is made up of the following demographic percentages:

	RACE					ETHNICITY	
	%	%	%	%	%	%	%
	American Indian or Alaska Native	Asian	Black or African American	Native Hawaiian or other Pacific Islander	White	Latino	Not Latino
Our catchment area is made up of the following ethnic and racial groups							
In FY 2015, the our institution provided care to patients from the following ethnic and racial groups							
In FY 2015, our PFAC <u>patients and family members</u> came from the following ethnic and racial groups							

26. Our PFAC is undertaking the following activities to ensure appropriate representation of our membership in comparison to our patient or catchment area (describe):

n/a

Section 3: PFAC Operations

27. Our process for developing and distributing agendas for our PFAC meetings (choose one):

- The staff develops the agenda and sends it out prior to the meeting
- The staff develops the agenda and distributes it at the meeting
- PFAC members develop the agenda and send it out prior to the meeting

- PFAC members develop the agenda and distribute it at the meeting
- The PFAC has a collaborative process between staff and patients/family members to develop and distribute the agenda
- None
- Other process

28. If collaborative process, describe: _____

29. If other process, describe: _____

30. The PFAC goals set for FY 2015 were:

31. The PFAC goals for FY 2015 were (check the best choice):

- Developed by staff and reviewed by PFAC members
- Developed by PFAC members and staff

32. Our PFAC has the following subcommittees (check all that apply):

- Government relations
- Recruitment
- Emergency Department
- Education and Communication
- Family Support
- Policies and Procedures
- Palliative Care
- Annual Reports
- Publications
- Nominations
- Marketing
- Behavioral Health
- Medication Safety
- Hospital Safety
- None
- Other

33. If other, describe (in 1500 characters or fewer): _____

34. Our PFAC interacts with the Hospital Board of Directors in the following ways (check all that apply):

- PFAC submits annual report to Board
- PFAC submits meeting minutes to Board
- PFAC member(s) attends Board meetings
- Board member(s) attends PFAC meetings
- PFAC member(s) are on board-level committee(s)
- None of the above
- Other

35. If other, describe (in 1500 characters or fewer): _____

36. This is the url/link to the PFAC section on our hospital's website:

- We don't have such a section on our website

37. Describe the PFAC's use of email, listservs, or social media:

- We don't communicate through these approaches

Section 4: Orientation and Continuing Education

38. The PFAC had ___ new members this year

39. Our PFAC orientation program this year was provided by ___ staff and ___ PFAC members

40. The content included (check all that apply):

- Meeting with hospital staff
- A general hospital orientation
- Information on concepts of patient- and family-centered care (PFCC)
- Information on patient engagement in research
- PFAC policies, member roles and responsibilities
- Information on health care quality and safety
- History of the PFAC
- A "buddy program" with old members
- How PFAC fits within the organization's structure
- Other

41. If other, describe (in 3000 characters or fewer): _____

42. PFAC members are considered hospital volunteers and therefore (check all that apply):

- Attend hospital volunteer trainings
- Require immunizations or TB checks
- Require CORI checks
- Not applicable
- Other

43. If other, describe: _____

44. Our PFAC provides education to our members on the topic patient-centered outcomes research

- Yes
- No

Section 5: FY 2015 PFAC Impact and Accomplishments

45-50. The three greatest accomplishments of our PFAC were:

Accomplishment (describe each in 3000 characters or fewer)	Idea originated from PFAC	Idea originated from Department/Committee/Unit that requested PFAC input
Accomplishment 1	<input type="checkbox"/>	<input type="checkbox"/>
Accomplishment 2	<input type="checkbox"/>	<input type="checkbox"/>
Accomplishment 3	<input type="checkbox"/>	<input type="checkbox"/>

51-56. (If not already listed above) Our PFAC's three greatest accomplishments in relation to quality of care initiatives in FY 2015 include

Quality of Care Accomplishment (describe each in 3000 characters or fewer)	Idea originated from PFAC	Idea originated from Department/Committee/Unit that requested PFAC input
Accomplishment 1	<input type="checkbox"/>	<input type="checkbox"/>
Accomplishment 2	<input type="checkbox"/>	<input type="checkbox"/>
Accomplishment 3	<input type="checkbox"/>	<input type="checkbox"/>

57-59. The greatest three challenges our PFAC had (describe each in 3000 characters or fewer):

57. Challenge 1

58. Challenge 2

59. Challenge 3

60. Our PFAC provided advice or recommendations to the hospital on the following areas mentioned in the law (check all that apply):

- Quality improvement initiatives
- Patient education on safety and quality matters
- Patient and provider relationships
- Institutional Review Boards
- Other
- None

61. If other, describe (in 1500 characters or fewer): _____

62-63. PFAC members participated in the following activities mentioned in the law (check all that apply):

- Serve as members of task forces; number of people serving____
- Serve as members of awards committees; number serving____
- Serve as members of advisory boards/groups or panels
- List names of each group _____ and number serving on each____
- Serve on search committees and in the hiring of new staff; number serving____
- Serve as co-trainers for clinical and nonclinical staff, in-service programs, and health professional trainees; number serving____
- Serve on selection of reward and recognition programs; Number serving____
- Serve as members of standing hospital committees that address quality
(List) names of each group _____ and number serving on each____
- Other areas of service not listed above;
(List) names of each group _____ and number serving on each____
- None

64. The hospital shared the following public hospital performance information with the PFAC (check all that apply):

- Serious Reportable Events
- Healthcare-Associated Infections
- Department of Public Health (DPH) information on complaints and investigations
- Staff influenza immunization rate
- Patient experience/satisfaction scores

- Patient complaints
- Patient Care Link
- Joint Commission surveys,
- Hospital Compare
- Family satisfaction surveys
- Quality of life data
- Rapid response data
- None
- Other

65. If other, describe (in 1500 characters or fewer): _____

66. The process by which this public hospital performance information was shared (describe in 1500 characters or fewer):

67. Our PFAC activities related to the following state or national quality of care initiatives (check all that

apply): Healthcare-associated infections

- Rapid response teams
- Hand-washing initiatives
- Checklists
- Disclosure of harm and apology
- 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 for Medicare patients
- Mental health care
- None
- Other 68. If other, describe (in 1500 characters or fewer): _____

Section 6: PFAC Annual Report

69. The hospital shares the PFAC annual reports with PFAC members:

Yes

No

70. Massachusetts law requires that the PFAC report be available to the public. Our hospital:

Posts the report online

Provides a phone number or e-mail to use for accessing the report

Other

71. If other, describe (in 1500 characters or fewer): _____

Appendix B: 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:

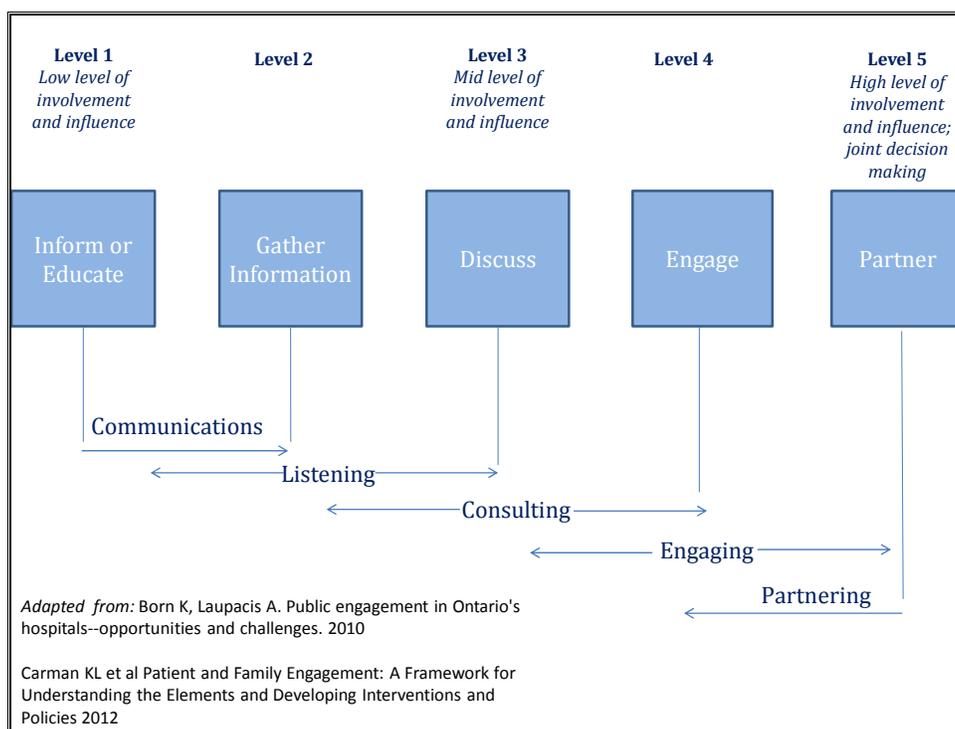
<http://www.mass.gov/eohhs/docs/dph/regs/105cmr130.pdf>

(Sections 130.1800 and 130.1801)

1. PFACs must be established by October 2010.
2. PFACs must meet at least quarterly.
3. At least 50% of PFAC members must be current or former patients and/or family representatives.
4. PFAC membership should reflect the community served by the hospital.
5. 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.
6. It is recommended that each PFAC have a patient or family member as a chair or co-chair.
7. Minutes of PFAC meetings, including accomplishments, must be sent to the hospital’s governing body.
8. 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 C: Framework for Engagement

HCFA's ongoing support of PFACs focuses on the meaningful integration of the patient and family voice into hospital policies and procedures that impact patient care. Adopting published frameworks on patient and family engagement in institutional settings,⁶⁷⁸⁹ HCFA is using this framework below to help us categorize stated PFAC accomplishments into three broad levels of involvement and influence.



Patient and Family Engagement Framework in PFACs

From Health Canada

Level 1 Inform/Educate when:

1. Factual information is needed to describe a policy, program or process
2. A decision has already been made (no decision is required)
3. The public needs to know the results of a process
4. There is no opportunity to influence the final outcome
5. There is need for acceptance of a proposal or decision before a decision may be made
6. An emergency or crisis requires immediate action
7. Information is necessary to abate concerns or prepare for involvement
8. The issue is relatively simple

Level 2 Gather Information/Views when:

1. The purpose is primarily to listen and gather information
2. Policy decisions are still being shaped and discretion is required

3. There may not be a firm commitment to do anything with the views collected (we advise participants from the outset of this intention to manage expectations)

Level 3 Discuss or Involve when:

1. We need two-way information exchange
2. Individuals and groups have an interest in the issue and will likely be affected by the outcome
3. There is an opportunity to influence the final outcome
4. We wish to encourage discussion among and with stakeholders
5. Input may shape policy directions/program delivery
6. What is the main purpose of the public involvement exercise?
7. Is it to inform/educate, gather information/views, discuss through a two-way dialogue; fully engage on complex issues; or partner in the implementation of solutions

Level 4 Engage when:

1. We need citizens to talk to each other regarding complex, value-laden issues
2. There is a capacity for citizens to shape policies and decisions that affect them
3. There is opportunity for shared agenda setting and open time frames for deliberation on issues
4. Options generated together will be respected

Level 5 Partner when:

We want to empower citizens and groups to manage the process

1. Citizens and groups have accepted the challenge of developing solutions themselves
2. We are ready to assume the role of enabler
3. There is an agreement to implement solutions generated by citizens and groups

Appendix D: PFAC Compliance with Massachusetts Law and Regulations

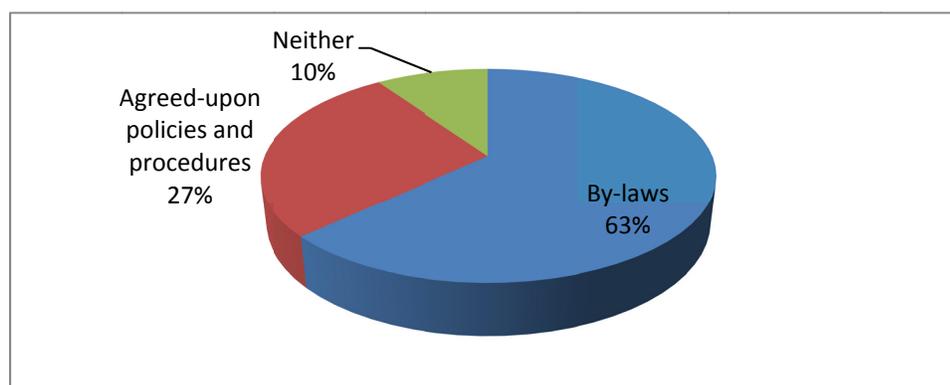


Figure 6: Percentage of PFACs with By-laws or Policies and Procedures

Hospital Wide Activities Suggested in Legislation	Percent PFACs reporting participation
Served as members of standing hospital committees that address quality	47%
Served as members of task forces	42%
Served as members of advisory boards/groups or panels	40%
Served as members of awards committees	13%
Served on selection of reward and recognition programs	11%
Served on search committees and in the hiring of new staff	10%
Served as co-trainers for clinical and nonclinical staff, in-service programs, and health professional trainees	10%
Other Hospital Wide activities*	25%
None	19%

*Ethics Committee; Planning Advisor Appreciation Event; participating in Patient Safety Awareness week activities; participating in focus groups; Reviewing a research survey about advance care planning; Participating in retreats; Assisting with the e-newsletter; Care Rounds; Nursing Orientation; Secret Shopper Pilot; Patient Education Committee; Global Health Initiative, Inpatient Care Improvement; Pediatric Multi Disciplinary leadership; Partners Patient Gateway; Clinical Education Sheets; Pediatric Clinical Operations; Charter project; PFAC publications; Survivorship; Transition of Treatment; Communications; Epic Transition; Ethics Committee; Reward and Recognition Committee; Access-related projects; Construction projects; Digital strategy projects; Experience projects; Family-centered care projects; Family Education projects; IPASS projects; Patient Portal Committee; Process improvement projects; Research-related projects; Life Choice tissue and Organ Donation Education Program

Appendix E: PFAC Influence and Function within Hospital

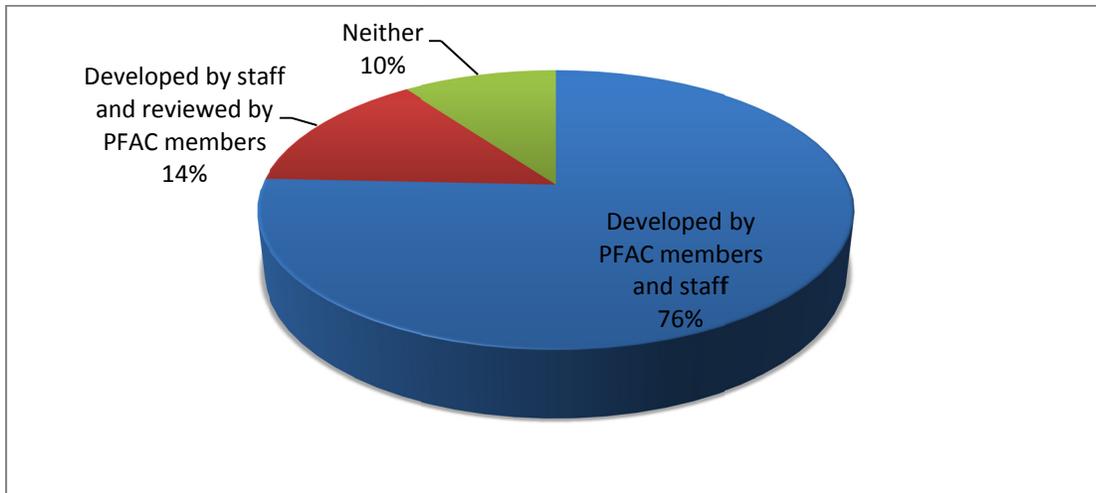


Figure 7: Process for developing goals for the 2015 Fiscal Year

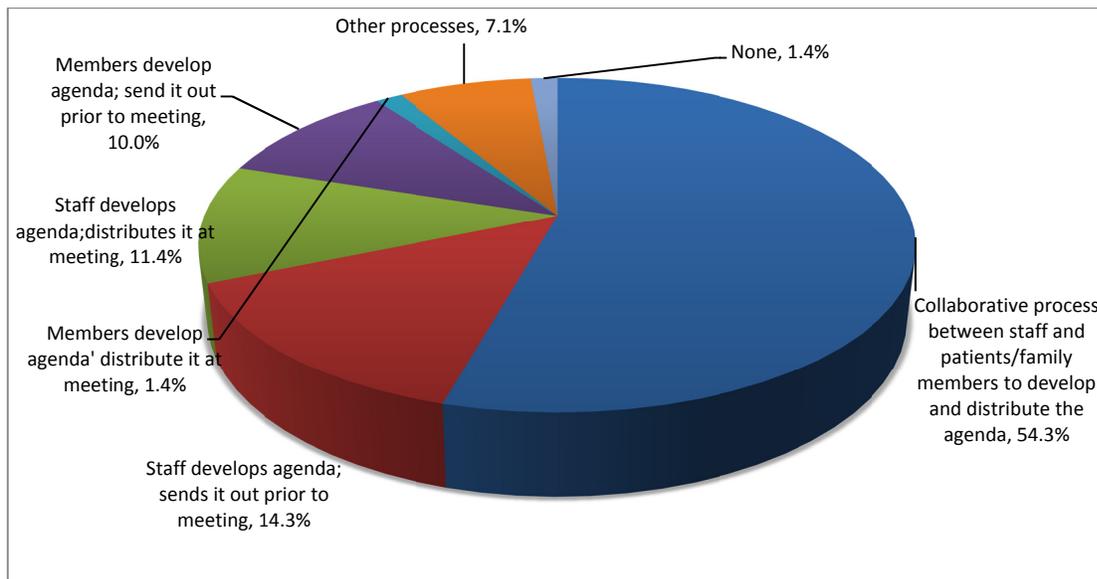


Figure 8: PFAC processes for developing and distributing their agenda.

Appendix F: Reported Successes and Challenges (red shading shows PFAC initiated)

Figure 9: Top three PFAC accomplishments sorted by level of impact. With 62 PFACs provided at least one of PFACs responding, 144 general accomplishments were shared. Accomplishments that were initiated by the PFAC itself are highlighted in red.

Top Three PFAC Accomplishments by Impact Level [†]		
Inform/Educate/Participate Levels 1-2	Discussion/Review Level 3	Engagement Level 4
During the Ebola outbreak and concerns about its impact in the United States, the Chief Medical Officer reviewed the Hospital Ebola preparedness plan with the PFAC.	Streamlined second patient survey to offer a quick and easy means to solicit feedback from patients at the time of their visits, then reviewed the surveys together and developed action plans to address patient concerns.	Pediatric Council started an off treatment initiative, collaborating with psycho-social staff. Collaborated on a project related to Protected Health Information and HIPAA.
	Participation in the development of an annual community health needs assessment survey that when administered to our community population will be able to guide goal development for new and existing services and better utilize our hospital resources.	End of Life Medical Resident Training—PFAC members trained residents and participated in workshop sessions.
Provided input in the design & implementation of the new Urgent Care center.	Discussion and participation into the development of a volunteer greeter program within the hospital that will direct patients and visitors to the services and departments they seek.	Piloting a peer to peer support program for child and parent support that is currently being created due to the research and idea generation from the PFAC.
	Achieved consistent and productive representation of the Patient and Family Advisory Council at the Patient Flow Committee.	Initiated a community based group for children focusing on physical fitness, nutrition, and peer support run by our Rehabilitation Program, called B-Fit.
Two members participated in the Emergency Department new charter groups	Evaluated and recommended changes to the disclosure of harm and apology process.	Creation and implementation of a patient comfort cart that is taken on rounds of inpatient floors to ensure that patients have access to items they may have left at home including books, magazines, pens and paper, toiletries, etc.
Made recommendations to the engineering department to improve the visibility in the parking lot of the hospital.	Conduct quarterly rounds throughout the entire facility.	Initiated the procurement and installation of an information and education kiosk in the outpatient services department.
Provided input on the rebranding and standardization of patient communications for access to CHA services	Discussed Emergency Department HCAHP scores with nurse manager	Conducted comprehensive service review and identified gaps in patient centeredness or unmet needs of following hospital services.
Reviewed all the directional signage throughout the hospital, noting any confusing or inconsistent signs.		Planned End of Life/Palliative Care Event

[†] For PFACs that did not use the template that we provided and did not explicitly indicate which their greatest accomplishments were, we included the first three in our analysis. Due to the myriad responses that we received, and a desire to avoid redundancy, we limited responses to those responses that were clear in describing the role of the PFAC for the endeavor

Inform/Educate/Participate Levels 1-2	Discussion/Review Level 3	Engagement Level 4
Oncology patient satisfaction improvement-- PFAC advisor made recommended changes to the physical environment, making it less cancer centric and more patient centered.		
Reviewed Surgical Day Care brochure.		
Emergency Room Awesome Beginnings Standard and Training Simulation Initiative— provided mandatory education and simulation training for Emergency Room and ancillary staff.		
Provided input in the design & implementation of the new Urgent Care center.		
Involvement in Surgery Modernization project which involves building new operating rooms.		

Appendix F: Reported Successes and Challenges (red shading shows PFAC initiated)

Figure 10: Top three PFAC accomplishments in quality of care initiatives, sorted by level of impact. 41 PFACs provided at least 1 accomplishment related to quality of care, with a total of 97 distinct accomplishments. Accomplishments that were initiated by the PFACs themselves are highlighted in red.

Top Three PFAC Accomplishments by Impact Level: Quality of Care [‡]		
Inform/Educate/Participate Level 1	Discussion/Review Level 3	Engagement Level 4
Two PFAC patient advisors have been working with hospital staff and other community members in the planning for the upcoming Quality of Life event.		Created the HUSH committee, which addresses patient comfort through noise reduction.
Advising on advance care planning and end-of-life planning projects.	Improving care transitions-- PFAC consulted on a project called Flip the Discharge, to improve information for patients and families about the discharge process.	Acute Elderly Care (ACE) Unit implementation and growth—PFAC member acted as a patient advocate, made patient care rounds with the multidisciplinary medical team and developed the model for the ACE unit working with the staff.
Provided an advisory role with the CHART grants to improve the care provided to the behavioral health patients.	One member working actively with the Discharge Delays Task force to ensure that the patients are transitioned into the community in efficient and effective manner.	Oncology PFAC focused on creating a new patient handbook for patients with new cancer diagnosis
Worked with the Finance Department to review the price estimating tool to ensure compliance with the Price Transparency Law and to ensure ease of access for patients.	Continued active involvement on hospital Quality & Safety Committees.	Drove the formation of educational materials on what to expect in an Emergency Department visit.
Gave input to the nursing department on the implementation of the No Pass Zone that the hospital was in the planning stages to assist with having all staff trained on not passing a patient room that had a nurse call light on.	Conducted hand-hygiene audits periodically throughout the year. Worked directly with Infection Control to generate simple trainings, materials, and helpful pointers to prepare our non-clinical Advisors to conduct these audits on our inpatient units.	
Provided insight on ways to improve the discharge process and associated documentation.	The Behavioral Health Sub Committee addressed the needs of our behavioral health clients, leading to the addition of dedicated nursing staff for our behavioral health patients and the development of the role of Patient Care Assistants (PCA's).	
Becoming involved with Care Transitions Collaborative and providing input to patient discharge planning.	Eliminating Preventable Harm—advisors working on Workgroup, responsible for designing a communication portal for patients and families that ideally will enhance communicate and eliminate preventable harm	

[‡] For PFACs that did not use the template that we provided and did not explicitly indicate which their greatest accomplishments were, we included the first three in our analysis. Due to the myriad responses that we received, and a desire to avoid redundancy, we limited responses to those that were clear in describing the role of the PFAC

Top Three PFAC Accomplishments by Impact Level: Quality of Care[‡]		
Inform/Educate/Participate Level 1	Discussion/Review Level 3	Engagement Level 4
Consulted on work underway to collect copayments at the time of service as well as to improve the registration process overall.		
Information for patients and families about online resources (e.g. Caring Bridge, Lotsa Helping Hands) to update friends and family on patient's medical status.		
Contributed feedback to a variety of health system projects and initiatives, including Neighborhood for Health, an interdisciplinary outpatient medical neighborhood, where patients will go to more easily access a variety of services and specialties to help manage chronic illness and promote wellness.		
Members actively involved in hospital-wide initiative focused on strengthening the culture of patient-centered excellence (A Place Where You Matter initiative workshops and staff sessions).		
Worked with the Compliance and Quality Departments to update the patient sign-in sheets used in our outpatient offices to ensure patient confidentiality.		

Top Three Identified PFAC Challenges⁵

Internal PFAC Challenges

Ensuring meaningful engagement in ongoing activities , not just advisor role

Inability and/or reluctance from the members to join some of the already established hospital committees due to timing and availability issues but also a level of anxiety in joining technically advanced/ clinical committees- 7 responses

“Engaging all of our current advisors to the fullest possible potential. We strive to present on topics that are interesting and valuable to all, yet we fail to always engage to the point where concrete improvement or changes are being made. Sometimes the topic is not interesting, but the tasks are concrete and seeking direct input, and other times the topic is very interesting, yet we fail to connect the presentation back to the patient-experience or a specific process improvement.”

Hospital Challenges

Integrating members into hospital committees, especially as they are being formed; important to gain acceptance of PFAC-9

True integration into the work of the hospital.

Shaping the hospital culture to include PFAC members on Quality and Safety committees. Most members are not available during the work day.

Identifying hospital committees that are not peer-review protected so that PFAC members might participate

“Our PFAC would like to serve on other hospital committees. There has been some reluctance from these groups, to have patient and family members at the table while patient information is being reported. We have suggested that the PFAC attend the beginning of a meeting and then are dismissed so that the committee can then proceed with their work. We have also reminded leadership that the PFAC members have had confidentiality training and have signed agreements with the hospital.”

“In general, staff and physicians are not comfortable having patients on committees. There is concern and uncertainty about how the hospital will be perceived. The committees who now have an advisor appreciate their input.”

Recruitment and Retention Challenges

Recruitment -13 responses
Retention -2

“It is important to increase PFAC membership to support meaningful dialogue and participation in hospital initiatives.”

“Very few candidates and those who expressed an interest had conflicts with time and competing priorities such as work and child care.”

“The vast majority of our patients have very complex medical needs; resistant to commitment upon discharge due to these challenges” -2

Recruitment of a diverse membership that represents our community -20

Recruitment and schedule availability of patients and family from diverse backgrounds to commit to PFAC meetings- 4

⁵ For PFACs that did not use the template that we provided and did not explicitly indicate which their greatest accomplishments were, we included the first three in our analysis. Due to the myriad responses that we received, and a desire to avoid redundancy, we limited responses to those responses that were clear in describing the role of the PFAC for the endeavor

Internal PFAC Challenges	Hospital Challenges	Recruitment and Retention Challenges
<p>Planning Patient Family Advisory Council meetings at a time that is most convenient for all members and Inconsistent attendance at person meetings—23 <i>“Additional challenges surrounded continuation of work projects with rotating attendance. As members ebbed and flowed in and out of PFAC, we at times lost traction with some long standing work projects or idea generation.”</i> <i>“One of the most difficult barriers has been and continues to be consistent PFAC parent involvement. Because our membership spans a wide geographic location, it is often difficult for members to take off of work to commute to the hospital mid-week. We have attempted to change the times of the meeting to fit needs of the members, within the past year, but the time of day doesn’t seem to alter the attendance greatly.”</i></p>	<p><i>“While our PFAC has been successful in working with various departments specifically requesting our involvement, efforts to date to broaden the impact of PFAC have been more separate than integrated.”</i></p>	
<p>Turnover/Attrition-8 Several of the topics discussed have a learning curve and turnover of PFAC members can be challenging. Turnover of PFAC members creates need for replacement and different role commitments among members. Sustaining momentum; morale and group focus were hindered by meeting cancellations</p>	<p><i>“More direction from the hospital on meaningful projects/goals for the PFAC to work on. The PFAC members feel that there must be various projects or programs that could benefit from their input.”</i></p>	<p><i>Our PFACs continue to struggle with accurately representing the community that we provide care to. This is something we have attempted to address, but with little success in the last few years. We continue to actively recruit and engage diverse potential advisors, yet we fail to maintain their interest or commitment to the PFAC.</i></p>
<p>We meet for 1 hour once a month and it seems that projects, etc. move very slowly.</p>	<p>Funding, Resource and Supports--the growing need for more administrative secretarial support & personnel, PFAC office space, PFAC development of tools (data collection, recruitment materials, etc.) and Tech supports. 4</p>	<p>True integration into the work of the hospital.</p>
<p>Getting work done in the time allotted is always a challenge. We are exploring how having sub-groups working on a specific initiative in-between meetings may work for us.</p>	<p>Many PFAC priorities were postponed due to other priorities in the hospital. 3</p>	<p>Lack of PFAC input requests in hospital projects and initiatives.</p>
<p>Lack of visibility to the community and hospital staff/need for promotion-5 Follow-up between PFAC quarterly meetings.</p>	<p>Patient experience survey reports are shared at every meeting, and depending on patient census levels, are difficult to improve.</p>	<p>Minimal participation in improvement projects Timeliness of corporate complying with committee suggestions for changes. We just continue to check in and ask for the changes to be implemented.</p>

Internal PFAC Challenges	Hospital Challenges
<p>Demand--Capacity to meet the demand for PFAC services and participate in committee work. / Setting priorities for PFAC work that parallels PFAC goals and purposes.</p> <p>A greater number of staff wishing to consult with our PFAC than we could accommodate during the course of PFAC meeting.</p>	<p>Change in leadership/ownership and learning about new initiatives related to that change.³</p>
<p>Ongoing knowledge and participation in all the patient care initiatives taking place. Because of the volume of programs and a rapidly changing health care environment, PFAC is working to be present at all times</p>	<p>Increase the amount of services offered at the hospital. Members have voiced concern that the number of specialists available in the community is limited.</p>
<p>Conflict between volunteers and staff around role of PFAC to be community focused rather than internally focused.</p> <p>With a group of limited size, we must be cautious in what we take on as a council</p>	<p>Inadequacy of the present EMR to assist patients in understanding the billing process.</p> <p>Implementation of PFAC member suggested projects/priorities, given restraints of organizational resources (people, budget, space, etc.).</p>
<p>Inability for all to attend Healthcare for All's Annual Conference</p> <p>Differentiating roles and responsibilities for members such as community members being patient/family advocates.</p>	<p>Maintaining a board member on PFAC</p> <p>Multiple reporting and regulatory requirements make it difficult to take on additional projects/initiatives. Hospital administrators and providers are overburdened.</p>
<p>Providing information and projects which resonate with each member while balancing this with sharing qualitative and quantitative data.</p> <p>Identifying and promoting participation opportunities within operational processes and committees</p>	<p>Physical plant and age of the building provides challenges to have the space to improve care, access and patient flow in the Emergency Department.</p> <p>Hospital signage- The PFAC has identified that signage should be improved within the hospital, but only some improvements implemented</p>
<p>Trying to find meaningful agenda items that pertain to our LTA population.</p> <p>Becoming a visible presence in the hospital and defining what our committee's role and function is.</p>	
<p>Finding the right project for the committee to work on.</p> <p>Challenged to allow time in meetings to reflect on the goals and interests of the PFAC members and cultivate group cohesion through collaborating on advisor-initiated projects.</p>	
<p>Getting materials to all committee members in a timely manner so that preliminary work can be done outside meetings, thus giving the committee more informed discussion time.</p>	
<p>Managing volunteer workload with committee needs.</p> <p>Adherence to term limits</p>	
<p>Sharing metrics // distill information for our PFAC members in order to bring value to the conversation in a way that also enhances patient care.</p>	
<p>Involving PFAC proactively for their input prior to time sensitive hospital projects being initiated.</p>	
<p>Sustaining members - keeping members engaged and interested</p>	
<p>Reward and recognition of PFAC volunteers</p>	

Table 4: Top three challenges sorted by type.

Appendix E: List of Massachusetts Acute Care Hospitals and Rehabilitation Hospitals/ Hospitals Reporting in 2015

1. Athol Memorial
2. AdCare Hospital
3. Anna Jaques Hospital
4. Arbour Hospital
5. Arbour-Fuller Hospital
6. Arbour-HRI Hospital
7. Austen Riggs Center
8. Baystate Franklin Medical Center
9. Baystate Medical Center
10. Baystate Noble Hospital
11. Baystate Wing Hospital
12. Berkshire Medical Center
13. Beth Israel Deaconess Hospital-Milton
14. Beth Israel Deaconess Hospital-Needham
15. Beth Israel Deaconess Hospital-Plymouth
16. Beth Israel Deaconess Medical Center
17. Beverly Hospital
18. Boston Children's Hospital
19. Boston Medical Center
20. Bournewood Hospital
21. Braintree Rehabilitation Hospital
22. Bridgewater State Hospital
23. Brigham and Women's Faulkner Hospital
24. Brigham and Women's Hospital
25. Cambridge Health Alliance
26. Cape Cod Hospital
27. Carney Hospital
28. Clinton Hospital
29. Cooley Dickinson Hospital, Inc.
30. Dana-Farber Cancer Institute, Inc.
31. Edith Nourse Rogers Memorial Veterans Hospital
32. Emerson Hospital
33. Falmouth Hospital
34. Fairlawn Rehabilitation Hospital
35. Fairview Hospital
36. Franciscan Hospital for Children
37. Good Samaritan Medical Center
38. Hallmark Health Corporation
39. Harrington Hospital

Yellow highlight: no report provided

Green highlight: report provided late,
not included in analysis

40. HealthSouth Rehabilitation Hospital of Western Massachusetts
41. HealthAlliance Hospitals, Inc.
42. Hebrew Rehabilitation Center
43. Heywood Hospital
44. High Point Treatment Center, Inc.
45. Holy Family Hospital
46. Holyoke Medical Center
47. Kindred Hospital Boston
48. Kindred Hospital Boston North Shore
49. Kindred Hospital Northeast - Stoughton
50. Lahey Hospital & Medical Center
51. Lawrence General Hospital
52. Lemuel Shattuck Hospital
53. Lowell General Hospital
54. Marlborough Hospital
55. Martha's Vineyard Hospital
56. Massachusetts Eye and Ear Infirmary
57. Massachusetts General Hospital
58. Massachusetts Hospital School
59. McLean Hospital
60. Mercy Medical Center
61. MetroWest Medical Center
62. Milford Regional Medical Center
63. Morton Hospital and Medical Center, Inc.
64. Mount Auburn Hospital
65. Nantucket Cottage Hospital
66. Nashoba Valley Medical Center
67. Vibra Hospital of Southeastern Massachusetts
68. New England Baptist Hospital
69. New England Rehabilitation Hospital
70. New England Sinai Hospital
71. Newton-Wellesley Hospital
72. North Shore Medical Center (NSMC)
73. Pembroke Hospital
74. Saint Anne's Hospital
75. Saint Vincent Hospital
76. Shriners Hospital for Children
77. Shriners Hospital for Children-Boston
78. Signature Healthcare Brockton Hospital
79. South Shore Hospital
80. Southcoast Hospitals Group
81. Spaulding Rehabilitation Hospital Boston
82. Spaulding Hospital for Continuing Medical Care

Cambridge

83. Spaulding Rehabilitation Hospital Cape Cod
84. St. Elizabeth's Medical Center
85. Sturdy Memorial Hospital
86. Tewksbury Hospital
87. The Meadows of Central Massachusetts (a
Vibra rehab center)
88. Tufts Medical Center
89. UMass Memorial Medical Center
90. Vibra Hospital of Western Massachusetts
91. Vibra Hospital of Western Massachusetts
Central Campus
92. Western Massachusetts Hospital
93. Westwood Lodge Hospital
94. Whittier Rehabilitation Hospital-Bradford
95. Whittier Rehabilitation Hospital-Westborough
96. Winchester Hospital
97. Worcester Recovery Center and Hospital

REFERENCES

¹ Institute for Patient- and Family-Centered Care

² Born K, Laupacis A. Public engagement in Ontario's hospitals—opportunities and challenges. *Health Q.* 2012;15 Spec No:16-20.

³ Carman KL et al Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies, *Health Affairs* 32, no. 2 (2013): 223-31

⁴ Building a Culture of Person-Centered Care in Ontario. Rep. Cancer Care Ontario, 2014/15. Web. 17 Nov. 2015. <<https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=347910>>.

⁵ The Health Canada Policy Toolkit for Public Involvement in Decision Making Corporate Consultation Secretariat, Health Policy and Communications Branch 2000 http://www.hc-sc.gc.ca/ahc-asc/pubs/_public-consult/2000decision/index-eng.php#a11

⁶ Born K, Laupacis A. Public engagement in Ontario's hospitals--opportunities and challenges. *Health Q.* 2012;15 Spec No:16-20.

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⁸ Building a Culture of Person-Centered Care in Ontario. Rep. Cancer Care Ontario, 2014/15. Web. 17 Nov. 2015. <<https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=347910>>.

⁹ The Health Canada Policy Toolkit for Public Involvement in Decision Making Corporate Consultation Secretariat, Health Policy and Communications Branch 2000 http://www.hc-sc.gc.ca/ahc-asc/pubs/_public-consult/2000decision/index-eng.php#a11