



Promising Practices for Meaningful Consumer Engagement: Examples of Hospitals in Massachusetts

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Key Terms Defined:

- *Patient-Family Advisory Council (PFACs)*
- *Patient-Family Advisors (PFAs)*

Background:

In 2010, the state of Massachusetts enacted legislation requiring all hospitals create and maintain Patient and Family Advisory Councils (PFACs).

Learn more about the legislation and read the annual reports submitted by PFACs here: <https://www.hcfama.org/patient-and-family-advisory-councils-pfacs>

PFAC Engagement in Research:

According to research conducted in 2016, out of 111 hospitals, about 10% of PFACs in Massachusetts are engaged in research activities, with about half engaged in study planning and design and about one-quarter around implementation. The following examples highlight some promising practices among these 11 hospitals.

1. Hospitals should educate their PFACs about Research Being Conducted

In a 2015 survey of the state's PFAC members (n=240) in 2015, 44% were not familiar with any research taking place at their institution. Despite this lack of knowledge, 42% were interested in potentially providing input to these studies. As part of their orientation and ongoing education, Massachusetts' Health Care For All recommends that the states' PFACs should, at the very



least, help members learn about clinical research being conducted at their institution, as it is an important part of clinical care. At the very least, this yearly education should include:

- the number and types of clinical research studies being funded at their institution, as well as their sources of funding;
- how patients at their institution learn about opportunities to participate in research studies, and
- how research is supported across the hospital.

In one Massachusetts hospital, the PFAC hosted a panel discussion for furthering PFAC involvement with research, featuring seven patients. In addition, research fellows have come to PFAC meetings to introduce themselves and their research to PFAC representatives.

2. Hospitals Should Use a Systemic and Transparent Selection Process for Patient-Family Advisors (PFAs) to Serve as Advisors in Research Studies

Researchers are often challenged to find appropriate and interested PFAs in their area of research.ⁱ Left on their own, they often rely on word-of-mouth or other informal recruitment processes. This informal process can lead to overreliance on a few individuals, who often become the only patient advisor sought by researchers. The process can also continue to distance the PFAC from involvement in research. At one Massachusetts hospital, one experienced PFA described her involvement in research at her institution as purely “accidental.” Because she is still the only PFAC member involved in research, she is concerned that the PFAC does not see research as central to its work.

To address this issue, in two Massachusetts hospitals, PFAs and a list of “Advisors in Waiting” complete an interested form around lived experiences and related interests around research studies. Another hospital systematically collects resumes from members to streamline the process of matching patient advisors to projects of their interest. These data are categorized and stored, so they can be contacted easily when requested by researchers.

To promote their interest in research, the PFAC at one hospital organized a “PFAC Day” in order to play their part in reaching out to researchers in disease centers and other hospital staff.

3. Hospitals Should Use a Systemic and Transparent Process to Select Appropriate Research Studies for PFAC Engagement

In some hospitals, PFACs have instituted a selection process for PFA engagement in research. In Massachusetts, there are a few examples of how these requests are accommodated:

- Researchers seeking PFAs at one hospital need to first present their research proposal to the PFAC. They complete a form detailing research objectives which is vetted by certain members prior to their presentation.
- At another hospital, the entire PFAC is presented with the objectives of a study seeking advisors. The PFAC decides whether they would like advise on the study.



- Another hospital mandates that at least two patient advisors must be a part of each study.

Even when PFAs are recruited by investigators to serve as study advisors, one Massachusetts hospital noted it was important for the PFAC to build connections among external advisors and PFAC members serving as advisors on other studies. These connections are critical: one Massachusetts PFA lamented that her hospital has an established research advisory council, but had no contact with the PFAC.

4. PFACs should be Appraised of Ongoing PFA Involvement in Studies

As representatives of the PFAC, PFAs serving on research studies should report back to the PFAC about their work. This can help remind the PFA of her/his representation of the PFAC to the study and encourage the PFAC to initiate ongoing activities in other studies.

5. Hospitals Should Use a Staff Liaison to Facilitate Partnerships between Researchers and Patient Advisors

A staff member or an experienced PFAC leader can serve as important facilitators of meaningful research engagement; many PFAs in Massachusetts see this role as critical. At one Massachusetts hospitalⁱⁱ, a PFAC leader acts as a neutral facilitator to support the implementation of meaningful engagement throughout each stage of research. This PFAC leader serves 3 important functions:

Orients the research team around PFAC engagement

- coordinates an initial team meeting and ensures appropriate accommodations are made to facilitate PFAC involvement (such as a frequency of and location for meetings which can be sustained, flexibility to address specific patient/family needs, preferred methods of communication)
- helps researchers understand that successful PFAs engagement requires acknowledging and addressing their needs (such as assessing their level of experience with research, ensuring their understanding at each stage of research, and providing an adequate stipend to support their involvement)
- coordinates and facilitate initial meeting between PFAs, PI and other researchers; and
- promotes relationship-building between PFAs

Helps plans PFA engagement

- helps the team develop a plan for PFA involvement throughout all phases of the study, and ensures expectations for each role are clearly communicated and agreed upon

Serves as ongoing facilitator throughout research implementation



- attends meetings to continue facilitation and role clarification, including
 - asking questions to promote sharing and clarification of information the PFAs may not understand
 - supporting researchers to check that PFAs understand their role and research content at each stage of research
- conducts regular “check-ins” with PFAs and researchers individually to ensure:
 - researcher needs are being met by PFA engagement
 - PFA feedback is being integrated in a meaningful way
- supports troubleshooting and identify solutions to partnership challenges

6. Hospitals Should Provide Orientation and Training (for both PFAs and researchers)

Training is critical for PFAs and researchers alike.

A basic understanding of the scientific process is necessary for PFAs to participate in research.

In Massachusetts, it is unclear how well the PFAs are prepared for their participation in research activities. For example, a member who is deeply involved in research at their institution expressed mixed feelings about being a part of the manuscript writing process. While glad to offer edits, she was reluctant about reviewing copious amounts of dense scientific material. Researchers wishing to engage PFAs need to “adopt a new role as teachersⁱⁱⁱ” to accommodate for varying degrees of knowledge and experience with research concepts. At a minimum, training should include

- how research questions are developed (and the need for outcomes that matter)
- equipoise
- research ethics
- components of a grant application
- basic concepts around
 - clinical research including rigor, validity and reliability, equipoise
 - analysis, including power, confounding bias and chance
 - basic concepts around screening, recruitment, retention and consent processes, including the use of plain language
 - interpreting and analyzing data such as n collected, CIs, adjusted analysis, p-values, correlation and causation
- how research results are disseminated and how medical practice changes

In one Massachusetts hospital, the description of the “process of peer review and challenges to the conclusions of newly published research are often met with surprise from PFAs if they do not have a research background. As lay people, PFAs may come into this process regarding researchers as unquestionable experts; sharing this vulnerability helps even out the power dynamic, creates an allegiance between PFA and researchers and helps PFAs understand the importance of scientific rigor.^{iv}” This understanding helped PFAs in one study become more motivated to understand study fundamentals, as they grasped the importance of helping the PI create a rigorous study.



PLANETREE

Similarly, researchers need a basic understanding of how to meaningfully engage PFAs in the research process. While time, resources, and experience in engagement is often limited^v, it is critical that researchers build skills to help them manage issues of disagreement between and among PFAs and researchers and transform the PFAs perspectives into meaningful changes in research design, implementation and dissemination.^{vi}

Increasing knowledge, enhancing skills and changing attitudes are all critical in these trainings. As summarized in a recent article, “[r]esearchers should see [PFAs] as equal partners and consider them as a reliable component of the team, rather than simply an additional variable or complication; both parties have to clearly know their roles and the importance of those roles independent from each other. Thus, reciprocal cultural competence is a vital feature of [patient engagement in research], and partnerships should include a mutual understanding of partners’ needs, capacities and goals, with conflicts solved promptly and explicitly.”^{vii}



II. Review, Design and Conduct of Research: How PFAs are Engaged

Meaningful engagement means that PFA involvement is ongoing, and not isolated to one activity or event on the study. Here are some examples of engagement in review, design and conduct of research:

1. Influencing Study Design and Data Collection

It is important that PFAs be engaged as early as possible in the research process – preferably before a proposal is submitted-- so that they can steer agendas and outcomes and provide a values context, which will improve study design and applicability, ensure a relevant perspective and prevent them from being relegated only to review of established protocols.^{viii}

Even if research aims are established before PFAs are engaged in research, it is critical that they remain broad at the outset so advisor input can revise specific aims to include aims that are meaningful in patient lives. For example, in one study at a Massachusetts hospital^{ix}, additional aims were added to a study to measure the ability of the patient to return to work and decreasing the extent to which patients reported feeling like a burden to family and other caregivers. Researchers and PFAs also refined the study intervention, methods and measures to allow for optimal interactions with patients. For example, they

- gave input on specific components of the intervention, such as ‘Who would you want to be told to call with questions/concerns after discharge and what is the best way to present this information in the discharge summary?’
- provided feedback on clarity and presentation of patient-facing documents
- refined tools created for clinicians involved in the intervention
- refined proposed survey content
- added new focus area for evaluation: PFAs felt that it was important to assess which piece of the intervention patients liked most, rather than solely assessing the most effective component, as proposed by researchers. This new perspective led the team to add a focus group to assess which intervention component patients liked most.

2. Influencing Study Implementation

At one Massachusetts hospital^x, PFAs met with a Research Assistant who enrolled patients in a study who performed a mock intake interview; the PFAs then discussed and provided feedback to the Research Assistant on patient-friendly language and behaviors. Throughout the study, PFAs also reviewed enrollment progress, troubleshooting intervention challenges and monitoring input from patient participants.

3. Influencing Study Dissemination

At one Massachusetts hospital^{xi}, PFAs practiced reading preliminary results and discussing their interpretations in preparation for the final stages of the study.



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