Patient and Family Advisory Councils:

Advancing Culturally Effective Patient-Centered Care

March 2016

Introduction

"Equity is no longer a separate initiative, but is equal to quality ... it is a strategic imperative in our organization."[1]

-Knitasha Washington, Executive Director, Consumers Advancing Patient Safety, Chicago, IL

In recent years, hospitals across the United States have pursued patient and family engagement strategies to improve satisfaction and the quality of care. A leading engagement strategy is the creation of Patient and Family Advisory Councils (PFACs) – groups of current and former patients and family members who collaborate with a hospital or health system's staff to address pressing challenges confronting the organization. New Hampshire hospitals are finding that listening to patients in this structured way can facilitate meaningful organizational improvement that impacts quality of care and patient outcomes.[2]

The diversity of the state's population is increasing. Minority populations were responsible for 50 percent of the population gain in New Hampshire from 2000 to 2010.[3] In light of this trend, it is important for hospitals to ensure that their Patient and Family Advisory Councils reflect this diversity. Diverse patients experience different challenges while interacting with the healthcare system and are more likely to experience barriers to care.[4]

Engaging diverse PFACs benefits organizations:

- Hospitals learn about the very different ways in which patients and families may experience health and healthcare services
- Individuals from populations most likely to experience health disparities provide insight into barriers to receiving care so that hospitals may address them
- PFACs and providers use the knowledge gained to co-develop culturally appropriate strategies that increase patient engagement

Patients who have access to care and are engaged are more likely to adhere to treatment plans and take an active role in managing their health, leading to improved health outcomes, fewer avoidable hospital readmissions, and increased likelihood of pursuing necessary follow-up care.[5] In addition to the benefits outlined above, PFACs can raise the healthcare organization's public profile and brand recognition and increase patient safety[6,7] Diverse PFACs support a process of organizational improvement that positions healthcare organizations to deliver quality health care to current and future patient populations.[8] This brief provides guidance for healthcare organizations that seek to develop diverse and effective PFACs.

"The first step to knowing what the patient wants is to talk to them."[9]

-Craig Williams, COO, Elliot Health System, Manchester, NH

While many healthcare organizations strive to be patient-centered and describe themselves as such, not all of these organizations have formal channels through which to gather meaningful patient and family input.[10] The PFAC addresses this gap and advises the organization from a patient and family perspective. PFACs are actively involved in program development and organizational change. Their input increases the likelihood that their organizations will focus on improvements that are relevant and meaningful to the communities they serve.[11] When combined with efforts to solicit diverse patient perspectives by actively recruiting PFAC members from racial, ethnic, and linguistic minority groups, and those from varying socioeconomic strata, age groups, and ability/disability groups, PFACs also serve to enhance cultural effectiveness and improve staff cultural awareness.

The PFAC approach has gained momentum since payers began emphasizing the importance of the patient's experience of care. In 2008, Massachusetts became the first and only state to institute a law requiring the establishment of PFACs in every acute care and rehabilitation hospital in the state.[12] In New Hampshire, the Foundation for Healthy Communities recognized the need for increased patient and family engagement and hired a patient-family advisor to consult with all New Hampshire hospitals.[13] In 2014, five New Hampshire hospitals had established PFACs. The number grew to 17 hospitals by the end of 2015.[14]

Patient and Family Advisory Councils generally meet formally on a monthly basis to discuss issues that members and/or staff have "identified as needing improvement and/or input."[15] Members of PFACs often sit on hospital staff committees and report back to the PFAC after committee meetings. Members also may participate in employment orientation presentations for medical residents and new employees and/or serve as patient and family liaisons on clinical units.[16]

Nationally, Patient and Family Advisory Council activities have resulted in operational benefits for the institutions they serve by:[17]

Text of PFAC Law

"The department 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."

Source: M.G.L. c111 § 53E (enacted in Massachusetts, 2008). Enforced by Massachusetts Department of Public Health, Hospital Licensure Regulation 105 CMR 130.1800 & 1801.

- Strengthening cooperation and understanding between staff and diverse patients and families
- Increasing opportunities for staff to receive actionable input and feedback, both positive and negative, from those they serve
- Improving mechanisms for ensuring services are truly meeting consumer needs and not just fulfilling the needs of the majority demographic group

"In order for us to achieve quality, we have to pursue equity. You have to understand who your organization is serving – not just in the aggregate, but including the subpopulations."[18]

-Knitasha Washington, Executive Director, Consumers Advancing Patient Safety, Chicago, IL

Currently, diverse racial, ethnic, and linguistic groups encounter disparities in care delivery, quality of care, and health outcomes, both in New Hampshire and nationwide.[19] For example, non-Hispanic Black women living in New Hampshire have a cancer-related death rate nearly twice that of Caucasian women in the state.[20]

Cultural effectiveness is one way of addressing health and healthcare disparities. One of the key elements of culturally effective organizations is community engagement.[21] Actively recruiting participants in a way that creates a diverse PFAC that is reflective of the population in an organization's catchment area productively engages community members. Healthcare organizations that recruit for and host diverse PFACs are better positioned to understand what is important to consumers so that their perspectives can be factored into safety, efficiency, and quality improvement decision making and planning.[22]

Patients from diverse backgrounds may experience their interactions with the healthcare system differently than Caucasian patients.[23] For example, research shows that some minority patients perceive racial discrimination in the delivery of care, which can affect satisfaction and future care-seeking behavior.[24,25,26] During Berkshire Medical Center's (Pittsfield, MA) Spanish-only PFAC meetings, the organization found that participants raised issues that were markedly different from the issues discussed during PFAC meetings held in English.[27] The adage "we don't know what we don't know" applies. If Berkshire Medical Center did not host recurring Spanish-speaking PFAC meetings, it might not have gained awareness of the issues raised by this group. Now this medical center has an alternative method of learning how this important customer group experiences the organization's services and how the organization can improve services to address the needs of Spanish-speaking patients.

Notable PFAC Activities

- Training to improve patient and family understanding of the informed consent process
- Driving organization-wide adoption of "golden behaviors" to improve staff-patient interactions
- Developing language-specific PFAC meetings that revealed patient concerns that may never have surfaced otherwise

Source: Health Care For All. (2014). PFAC 2014: A review of 2013 Massachusetts Patient & Family Advisory Council reports. Boston: Author.

Healthcare organizations can make use of PFACs in a variety of ways. For example, a survey of patients may reveal findings that administrators cannot explain or do not know how to address. A diverse PFAC can offer insight and advice on the meaning of the findings and suggest ways in which patients and families might like to see them addressed. The PFAC can then take a role in co-leading committees and initiatives meant to produce positive change. When an organization has a better, more holistic sense of the needs and viewpoints of diverse consumer groups, it is better able to implement change that improves the experience for everyone.

Patient and family engagement is particularly beneficial to patients and healthcare systems if it actively involves those who are the least likely to have a voice and/or the least likely to be successful in managing their own health.[28] Patient and family engagement through PFAC membership can be a useful approach to relationship-building with consumers who may be disconnected and distrustful of the health system due to historical mistreatment and other factors.

Four steps for developing a diverse PFAC

Healthcare organizations can take concrete steps to facilitate PFAC diversity using the steps detailed below. These steps are informed by research on healthcare workforce diversity and cultural effectiveness conducted by Brandeis University for the Healthcare Employer Research Initiative.

1. Collect data on the composition of the patient population, workforce, and PFAC

By consistently collecting and analyzing patient and community race, ethnicity, and language data, hospitals can assess the extent to which their PFAC is reflective of the community served and whether the organization needs to make adjustments.

- Determine whether the PFAC is representative of the patient groups you wish to engage. If not, begin actively recruiting additional members.

2. Employ a multi-pronged approach to PFAC member recruitment

Without explicit attention to diversity, New Hampshire hospitals can end up with homogenous representation on their PFACs by recruiting through established networks. To identify and recruit diverse PFAC candidates, hospitals must use alternative recruitment methods to gain access to populations that traditionally are less engaged with the health system.

- When recruiting new PFAC members, conduct outreach to community leaders, ethnic community-based organizations (e.g., churches and social clubs catering to minority populations), and local and state organizations working to improve minority health or reduce health disparities.
- Advertise in publications and other media that cater to minority populations.
- Identify diverse candidates through the use of open-ended questions on patient satisfaction surveys and engage interpreter services in PFAC recruitment.
- Address and assuage concerns potential recruits may raise about their perceived lack of qualifications to join and participate in the PFAC.

3. Demonstrate commitment to diverse communities through messaging

In the healthcare sector, reputation matters. Word of mouth, or messages transmitted through informal networks, remains the primary source of physician referrals.[29] These messages can also impact an organization's reputation in the community. A hospital's commitment to diversity and equity, including its commitment to recruiting diverse PFAC members, can positively impact these communications.

- Construct a public message demonstrating a commitment to diversity and equity. Seek PFAC feedback on the message and work with community leaders to identify how to most effectively speak about health care with groups that have different cultural perspectives. Use these opportunities to recruit diverse PFAC members.

4. Empower PFAC members to contribute to meaningful organizational change

Effective PFAC meetings facilitate a two-way educational exchange between hospital staff and patients/community members. This engagement results in knowledge that is subsequently incorporated into organizational policies and procedures, resulting in care that is more culturally aware.

- Actively solicit feedback from each PFAC member and encourage sharing of diverse perspectives.
- Create a welcoming environment at PFAC meetings that allows everyone to feel comfortable and safe contributing ideas.
- Determine whether one or more interpreters are needed to support full participation and accurate communication at PFAC meetings.
- Make transportation and child care available for members, as needed, and accommodate members' work schedules when planning meetings to facilitate full participation in the PFAC.

Moving Forward

The strategies highlighted in this issue brief fulfill the dual goal of bringing the hospital into the community and, conversely, bringing the community into the hospital. As healthcare organizations adjust their business models and pursue agendas that seek to improve cultural effectiveness and population health, the strategies outlined here can increase the likelihood that all populations in an organization's catchment area receive the high-quality care they need. Organizations that employ these strategies can gain increased understanding of the ways in which they may better serve increasingly diverse populations by addressing consumer needs, improving their position as culturally effective organizations.

Resources and Guidance

AHRQ Guide to Patient and Family Engagement in Hospital Quality and Safety
http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/guide.html
This guide includes a section about working with patients and families as advisors.

AHA Patient and Family Engagement Resource Compendium
http://www.hret-hen.org/topics/pfe/20160104-PFEcompendium.pdf
This resource provides an overview of the literature and includes a section called "Engaging to Reduce Disparities."

Creating a Patient and Family Advisory Council: A Toolkit for Pediatric Practices
http://medicalhome.nichq.org/resources/pfac-toolkit
This toolkit provides step-by-step guidance on creating PFACs for pediatric practices.

Partnering to Improve Quality and Safety: A Framework for Working with Patient and Family Advisors
http://www.hpoe.org/resources/hpoehretaha-guides/1828
This framework includes "how to" steps for hospitals seeking to improve patient and family engagement.

Institute for Patient and Family Centered Care:

- Annual Reports of PFACs and Committees
  http://www.ipfcc.org/advance/topics/annual-reports.html
  Provides advice on creating annual PFAC reports and offers several samples of existing reports.
- Creating Patient and Family Advisory Councils
  http://www.ipfcc.org/advance/Advisory_Councils.pdf
  Outlines the key functions and benefits of PFACs.
- Partnering with Patients and Families to Enhance Safety and Quality: A Mini Toolkit
  http://www.ipfcc.org/tools/Patient-Safety-Toolkit-04.pdf
  Provides tools for organizations building partnerships with patients and families to improve the quality and safety of health care. Includes sample PFAC application form and tips for facilitators.
- Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future
  http://www.ipfcc.org/pdf/Roadmap.pdf
  Provides case studies and research findings on the impact of patient- and family-centered change.
- PFAC Network
  http://pfacnetwork.ipfcc.org/main/summary
  As a meeting place for those involved with PFAC work, this network offers discussion forums, a blog, and special topic groups.

Endnotes

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- **Perspectives and Practices of New Hampshire Health Care Employers: Improving Quality, Reducing Costs, and Planning for the Future by Building Culturally Effective Health Care Organizations** (November 2013). http://iasp.brandeis.edu/pdfs/2013/Perspectives_Practices.pdf
- **Missing Persons? Health Care Workforce Diversity in New Hampshire** (March 2014). http://iasp.brandeis.edu/pdfs/2014/missing.pdf
- **Strengthening New Hampshire's Health Care Workforce: Strategies for Employers and Workforce Development Leaders** (December 2014). http://iasp.brandeis.edu/pdfs/2014/Workforce.pdf
- **Culturally Effective Healthcare Organizations: A Framework for Success** (April 2015). https://iasp.brandeis.edu/pdfs/2015/CE.pdf
- **The Networked Workforce: Maximizing Potential in Health Careers** (August 2015). https://iasp.brandeis.edu/pdfs/2015/Networked.pdf
- **Improving Quality and Performance: Cultural Competence and Workforce Diversity Strategies** (January 2016). http://iasp.brandeis.edu/pdfs/2015/improvingquality.pdf

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