

**Spotlight**

# Patient and Family Advisory Councils in Hospitals: Building Partnerships to Improve Care

Lynn Friss Feinberg  
*AARP Public Policy Institute*

Hospitals and other health care organizations are embarking on a wide range of quality improvement efforts that enhance the care and services provided, improve outcomes, and lead to real organizational change. One key strategy adopted by hospitals to achieve better care is to form Patient and Family Advisory Councils (PFACs) to engage consumers in identifying what has gone well and what can be improved. PFACs support a culture of health care grounded in the principle of patient- (or person-) and family-centered care.\*

A report from the National Academies of Sciences, Engineering, and Medicine concludes that family-centered care should be elevated alongside person-centered care in delivery system reform.<sup>1</sup> Hospital practices to promote consumer and family engagement include a focus on patient- and family-centered care<sup>2</sup> and shared decision making.<sup>3</sup>

These concepts are based on the fundamental principle of involving consumers and their family caregivers as partners in care. Not only is family caregiving increasingly complex, but there is a growing need to better support families' involvement in the delivery of health care and long-term services and supports. Family caregivers play an especially

**PFACs have greatly expanded in the past decade to assist hospitals in the implementation of patient and family engagement initiatives, including addressing issues related to family caregiving.**

important role when older adults are not physically or cognitively able to participate in their own care, when family members are tasked with decision making, and when they are expected to provide complex care in the home following hospital discharge.

This *Spotlight* describes the history and emergence of PFACs in hospitals. It highlights how hospitals are engaging patients and families in PFACs and what engagement activities are being adopted.

\* This *Spotlight* uses the term *patient* to refer to people who are hospitalized because it is the term typically used in the traditional medical model and in hospitals. However, the terms *person* or *person centered* are increasingly used in the field, especially outside of health care settings and in the community. These terms are preferred because they intentionally look beyond the medical and physical needs of the individual, and emphasize continuity of care and support, and quality of life.



**Public Policy  
Institute**

For more information on this article, please [visit the Public Policy Institute Web site.](#)

This *Spotlight* also recommends how PFACs can be broadened to include the unique perspectives of family caregivers of older adults into quality improvement activities.

### What Are Patient and Family Advisory Councils and How Did They Get Started?

PFACs provide a mechanism for involving patients and families in policy making; facility design; and the planning, delivery, and evaluation of hospital care.<sup>4</sup> These councils are generally composed of between 5 and 20 patients and family members who use their firsthand hospital knowledge to see how hospital care and experiences might be improved.

PFACs vary in how they are set up, their mission, and composition. Some hospitals or units within them, such as cancer centers or neonatal intensive care units, launch the councils for specific populations. Other PFACs focus on certain areas such as culturally and linguistically appropriate services and materials, palliative care and end-of-life issues, discharge and transition planning, patient safety, or other change initiatives. Although PFACs were started in hospitals, they are becoming more common today in primary care settings too.<sup>5</sup>

Thirty years ago (1987) the US Surgeon General, C. Everett Koop, called for the US health care system to shift from system-centered to family-centered care.<sup>6</sup> While his report's call for action was intended to improve the lives of children with special health care needs and their families, it set the stage for the movement toward patient- and family-centered care for people of all ages with unmet health or functional needs.

PFACs were started in children's hospitals in the late 1990s, but have spread to other hospitals to involve adult consumers in care delivery and promote the integration of patient and family engagement more deeply into hospitals' organizational culture. According to one national estimate, today more than 2,000 hospitals—or about 40 percent of hospitals in the United States—have a PFAC.<sup>7</sup>

Nearly two decades ago the Institute for Patient- and Family-Centered Care developed guidelines for creating the concept of patient and family advisors (see next section) through the formation of PFACs in hospitals.<sup>8</sup> Since then, the Institute has provided a range of resources to hospital and health system

administrators, health professionals, and others to advance the understanding and practice of including the perspective of patients and families in health care, based on four concepts: (a) dignity and respect, (b) information sharing, (c) participation, and (d) collaboration.<sup>9</sup>

Only one state (Massachusetts) requires all hospitals to have a PFAC. Under that state's law, which became effective in 2008, all hospitals were mandated to launch a PFAC by October 2010, to meet at least quarterly, and to ensure that at least 50 percent of PFAC members were current or former patients and/or family representatives.<sup>10</sup>

Pennsylvania has taken another approach. In 2013, the Hospital & Healthsystem Association of Pennsylvania formed the first state hospital association–sponsored Patient and Family Engagement Advisory Council in the United States. The council includes patients, family members, and health care professionals from across Pennsylvania. It serves as a resource to assist hospitals to improve patient outcomes and satisfaction by implementing strategies to ensure patient- and family-centered care.<sup>11</sup> In addition to the larger advisory council, a subcommittee composed exclusively of consumers and family members has been established.

### Who Are Patient and Family Advisors, and How Are They Selected and Supported?

A patient or family advisor serving on a PFAC is an individual or family member who has firsthand knowledge of care in the hospital, and who can work in partnership with others to better understand the patient or family experience of care.<sup>12</sup>

- At the Hospital of the University of Pennsylvania, advisors are volunteers carefully selected for their ability to present a balanced assessment and promote positive change.<sup>13</sup>

Successful PFACs reflect the diversity of the communities the hospital serves. If hospitals are unable to recruit former patients and their families to serve on an advisory council, they may reach out to community-based groups, local houses of worship, or organizations that serve older adults to recruit advisors.

Patients and families participating on PFACs need appropriate training and orientation to their role. They also need information about the mission, goals, and priorities of the hospital or health system; a review of the importance of privacy and confidentiality; and

an understanding of the issues and strategies to be addressed by the PFAC.

Some PFACs set up a designated mentor for new consumer and family members to offer ongoing support and guidance. Mentorship helps ensure that advisors understand and are comfortable in their roles, and remain confident in their participation on a PFAC.

Successful PFACs have a hospital staff member as a staff liaison who is responsible for coordinating the work of patient and family advisors. He or she also informs the hospital staff about the work and accomplishments of the PFAC. This requires gathering examples of PFAC accomplishments and communicating them to hospital leaders, staff, and clinicians to ensure engagement and partnerships.

Leadership is an important attribute of a successful PFAC. Leadership is necessary at all levels of the hospital, including administration, professional direct care (such as physicians, nurses, social workers, pharmacists), and operations. It is also important for hospital leaders to attend meetings of PFACs to discuss ways to improve care and seek input from PFAC members.

- At the Anne Arundel Medical Center in Maryland, the chief nursing officer regularly attends meetings of the center's PFAC, for example.<sup>14</sup>

Hospitals use a range of measures to examine the impact of their PFAC, including hospital readmission rates, patient and family satisfaction scores, and measurements of patient harms.<sup>15</sup>

- At MedStar Health, a health system in the Baltimore–Washington, DC, area, all PFACs create what is known as *S.M.A.R.T. goals*. The acronym stands for specific, measurable, attainable, relevant, and time bound. They enable the PFACs to track progress objectively, and create a structure for accountability.<sup>16</sup>

### What Are Examples of PFAC Activities and Impact?

PFACs undertake a range of activities. Some have worked on eliminating defined visiting hours so that people can see their hospitalized family members at any time, or improving communication with nurses and physicians. Others have worked on making sure that patients and their families understand the details concerning their medicines (such as purpose, dosage,

and regimen) both in the hospital and when they are discharged back to their home.

In 2014, the PFACs in Massachusetts reported on their involvement in specific national or state priority areas. The areas with the greatest percentage of PFAC activities were in improving information for patients and families (68 percent) and improving care transitions (32 percent).<sup>17</sup>

PFACs can provide important feedback on hospital stay and experience of care. They can discuss what went well, what could have been done better, and what aspects of care could be improved. PFACs can also help develop or revise written, verbal, or audiovisual materials, such as handbooks or videos on patient information or care instructions.<sup>18</sup>

There is some evidence that PFACs have had a positive impact on patient safety in hospitals (such as handwashing, wrong-site surgery prevention, and reducing medication errors)<sup>19</sup> and improved informational materials for consumers and families.<sup>20</sup>

- The Anne Arundel Medical Center in Maryland utilized its PFAC to revise the hospital's visitation policy. As of 2011, patients' families can visit 24 hours a day.<sup>21</sup>
- The Siteman Cancer Center at Barnes-Jewish St. Peters Hospital in Missouri uses its PFAC to ensure that patients and their family members are recognized as key partners of the health care team, develop family education and communication materials, and raise awareness of ways to help patients and their families better navigate through the health care system.
- The Georgia Regents Health System in Augusta, Georgia, has more than 80 trained patient and family advisors who are members of PFACs and are represented in all facets of the health system. In 2015, the Family Advisory Council helped create discharge instructions to improve patient care from hospital to home.<sup>22</sup>

In January 2017, the New York State Health Foundation awarded a grant to the Institute for Patient- and Family-Centered Care to understand the prevalence and roles of PFACs in New York hospitals. The final report will summarize best practices in New York and summarize promising practices in other states to inform policy and practice in other states' efforts.<sup>23</sup>

## Policy Implications: Addressing Family Caregiver Needs from Hospital to Home

PFACs have greatly expanded in the past decade to assist hospitals in the implementation of patient and family engagement initiatives, including addressing issues related to family caregiving. Yet most of the councils have focused on developing an improved culture of safety, and improved patient outcomes and satisfaction with care. Opportunities exist to utilize PFACs to expand patient- and family-centered care and serve as a forum to engage family caregivers as partners in care.

Addressing the needs of family caregivers of older adults is especially important because they are often tasked with providing care and support after hospitalization. Landmark research in the 2012 AARP Public Policy Institute and United Hospital Fund *Home Alone* study shows that family caregivers are increasingly expected to perform complex medical/nursing tasks for the patient at home with very little training from clinicians.<sup>24</sup>

In May 2013, the Centers for Medicare and Medicaid Services issued revised guidance for hospitals setting expectations that patients and family caregivers be actively involved throughout the discharge planning process, including receiving appropriate training and referrals to community services.<sup>25</sup> However, the guidelines do not explicitly say how hospitals must involve family caregivers or how training of family members on performing complex care tasks should take place. To address these gaps, states have moved forward to advance policies that address the needs of family caregivers who are expected to provide care and support after a hospitalization.

Since 2014, 39 states, territories, and the District of Columbia, to date, have passed the Caregiver Advise, Record, and Enable (CARE) Act. The law calls on hospitals to identify family caregivers (with the patient's permission) and record those names in the medical record, notify the family caregiver of the discharge plans as soon as possible, and instruct him or her on how to perform medical/nursing tasks that he or she is expected to carry out at home, after the patient leaves the hospital.<sup>26</sup>

Implementation of CARE Act policies and principles, therefore, lies at the heart of PFACs' purpose and work. Thus, PFACs in CARE Act states should take the lead on building effective implementation

strategies for the CARE Act. The enactment of this law creates incentives for using PFACs to advise on ways to better identify and support family caregivers of people who are hospitalized, including enabling them to be better prepared to provide medical/nursing tasks to their family member transitioning from hospital to home.

PFACs could also provide guidance on methods of training family members on performing complex care tasks, providing tools to identify referrals to appropriate community resources for the consumer and the family caregiver to ensure continuity of care, and disseminating promising practices to share with other hospitals and health systems.

## Conclusion

PFACs are a potentially important tool to involve consumers and families in efforts to improve care delivery in hospitals, and in fact have already begun to take root in this role. One way these councils can enter their next phase and truly lead cultural change is by incorporating practical and systematic ways to address the needs of family caregivers of older adults, who are often unprepared to provide complex care to the patient at home after a hospitalization.

PFACs can be viewed as a strategy and feedback loop for CARE Act implementation in the states. Utilizing the experiences of family caregivers on PFACs holds promise for improving caregiver identification in hospitals, discharge planning, training on medical/nursing tasks, and smoother transitions from hospital to home.

- 1 National Academy of Sciences, Engineering, and Medicine, *Families Caring for an Aging America* (Washington, DC: National Academies Press, 2016).
- 2 Lynn F. Feinberg, *Moving Toward Person- and Family-Centered Care* (Washington, DC: AARP Public Policy Institute, March 2012), [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/ltc/2012/moving-toward-person-and-family-centered-care-insight-AARP-ppi-ltc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/moving-toward-person-and-family-centered-care-insight-AARP-ppi-ltc.pdf).
- 3 "Health Policy Brief: Patient Engagement," *Health Affairs*, February 14, 2013, [http://healthaffairs.org/healthpolicy/briefs/brief\\_pdfs/healthpolicybrief\\_86.pdf](http://healthaffairs.org/healthpolicy/briefs/brief_pdfs/healthpolicybrief_86.pdf).
- 4 "Guide to Patient and Family Engagement in Hospital Quality and Safety," Agency for Healthcare Research and Quality, last modified February 2017, accessed May 9, 2017, <http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/index.html>.
- 5 Anjana E. Sharma et al., "How Can We Talk about Patient-Centered Care without Patients at the Table? Lessons

- Learned from Patient Advisory Councils,” *Journal of the American Board of Family Medicine* 29, no. 6 (2016): 775–84.
- 6 C. Everett Koop, *U.S. Surgeon General’s Report: Children with Special Health Care Needs: Campaign ’87* (Rockville, MD: US Department of Health and Human Services, 1987), <https://profiles.nlm.nih.gov/ps/access/NNBCFR.pdf>.
  - 7 Barbara Lewis, *PFACs: Where’s the Money? The Financial Impact on Hospitals* (Southlake, TX: The Beryl Institute, 2014), [http://c.ymcdn.com/sites/theberylinstitute.site-ym.com/resource/resmgr/White\\_Papers/PFACReport.pdf](http://c.ymcdn.com/sites/theberylinstitute.site-ym.com/resource/resmgr/White_Papers/PFACReport.pdf).
  - 8 Institute for Patient- and Family-Centered Care, *Creating Patient and Family Advisory Councils* (Bethesda, MD: Institute for Patient- and Family-Centered Care, revised 2002), [http://www.ipfcc.org/resources/Advisory\\_Councils.pdf](http://www.ipfcc.org/resources/Advisory_Councils.pdf).
  - 9 Institute for Patient- and Family-Centered Care, *Advancing the Practice of Patient- and Family-Centered Care in Hospitals* (Bethesda, MD: Institute for Patient- and Family-Centered Care, January 2017), [http://www.ipfcc.org/resources/getting\\_started.pdf](http://www.ipfcc.org/resources/getting_started.pdf).
  - 10 Today, there are about 93 PFACs in Massachusetts working to improve care. Deborah Wachenheim, *Patient and Family Advisory Councils: The Massachusetts Experience* (Middleton, MA: Patient Safety & Quality Healthcare, 2015), <https://www.psqh.com/analysis/patient-and-family-advisory-councils/>.
  - 11 The Hospital & Healthsystem Association of Pennsylvania, “Patient and Family Engagement Success Story,” The Hospital & Healthsystem Association of Pennsylvania, Harrisburg, PA, March 2014, [https://www.haponline.org/Portals/0/docs/Initiatives/Improving\\_Patient\\_Experience/Patient\\_Family\\_Centered\\_Care/PA\\_HEN\\_Patient\\_and\\_Family\\_Engagement\\_Success\\_Story\\_Apr2014.pdf?ver=2014-04-24-000000-000](https://www.haponline.org/Portals/0/docs/Initiatives/Improving_Patient_Experience/Patient_Family_Centered_Care/PA_HEN_Patient_and_Family_Engagement_Success_Story_Apr2014.pdf?ver=2014-04-24-000000-000).
  - 12 Institute for Patient- and Family-Centered Care, *Advancing the Practice*.
  - 13 Regina Cunningham and M.K. Walton, “Partnering with Patients to Improve Care,” *The Journal of Nursing Administration* 46, no. 11 (2016): 549–51.
  - 14 Agency for Healthcare Research and Quality, *Guide to Patient and Family Engagement*.
  - 15 Patient & Family Health Care Leadership Network, *Patient and Family Health Care Leadership: A Resource Compendium* (Washington, DC: Patient and Healthcare Leadership Network, Summer 2015), <https://nam.edu/wp-content/uploads/2015/07/PFHCL-Resource-Compendium-rev17Jul15.pdf>.
  - 16 Health Research & Education Trust, *Partnering to Improve Quality and Safety: A Framework for Working with Patient and Family Advisors* (Chicago, IL: Health Research & Educational Trust, March 2015), [http://www.hpoe.org/Reports-HPOE/2015/2015\\_patient\\_fam\\_engagement\\_FINAL.pdf](http://www.hpoe.org/Reports-HPOE/2015/2015_patient_fam_engagement_FINAL.pdf).
  - 17 Health Care for All, *A Review of 2014 Massachusetts Patient and Family Advisory Council Reports* (Boston, MA: Health Care for All, 2014), [https://www.hcfama.org/sites/default/files/2014\\_pfac\\_report\\_final.pdf](https://www.hcfama.org/sites/default/files/2014_pfac_report_final.pdf).
  - 18 “Strategy 1: Working with Patients and Families as Advisors,” Agency for Healthcare Research and Quality, last modified June 2013, accessed May 9, 2017, <http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html>.
  - 19 Yves Longtin et al., “Patient Participation: Current Knowledge and Applicability to Patient Safety,” *Mayo Clinic Proceedings* 85 (2010): 53–62.
  - 20 Mike J. Crawford et al., “Systematic Review of Involving Patients in the Planning and Development of Health Care,” *British Medical Journal*, 325, no. 7375 (2002): 1263.
  - 21 Crawford et al., “Systematic Review.”
  - 22 “Patient Advisory Councils,” Augusta University Health Systems, accessed May 9, 2017, <http://www.augustahealth.org/patient-family-centerd-care/advisory-councils/advisory-councils>.
  - 23 “Institute for Patient- and Family-Centered Care, Inc.,” New York State Health Foundation, accessed May 12, 2017, <http://nyshealthfoundation.org/our-grantees/grantee-profile/institute-for-patient-and-family-centered-care-inc-jan-2017>.
  - 24 Susan C. Reinhard, Carol Levine, and Sarah Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* (Washington, DC: AARP Public Policy Institute; New York, NY: United Hospital Fund, October, 2012).
  - 25 Centers for Medicare and Medicaid Services, “Revision to State Operations Manual, Hospital Appendix A— Interpretative Guidelines for 42 CFR 482.43, Discharge Planning,” May 17, 2013, <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-13-32.pdf>.
  - 26 Susan C. Reinhard and Elaine Ryan, *From Home Alone to the CARE Act: Collaboration for Family Caregivers* (Washington, DC: AARP Public Policy Institute, 2017).

---

Spotlight 29, November 2017

© AARP PUBLIC POLICY INSTITUTE  
601 E Street, NW  
Washington DC 20049

[Follow us on Twitter](#)  
[Follow us on Facebook](#)  
[Visit our Web site](#)

For more reports from the Public Policy Institute, [visit the Public Policy Institute Web site](#).

**AARP**<sup>®</sup>  
Real Possibilities

**Public Policy  
Institute**