

Comprehensive patient engagement across the health care continuum is a challenging task for health systems. Welcoming, encouraging, and supporting patient and family engagement in direct care, as discussed in Chapter Five, is the first level of engagement for patients, families, and organizations according to the Framework for Patient Engagement.¹ Moving to the next level of engagement requires patients and families to be involved in organizational design and governance.¹ Creating opportunities and roles for patients and families to influence the design and governance of health care organizations is critical to ensure their voices are heard and that health care organizations and systems are responsive to their needs.

Involving Patients and Families in Organizational Decision Making

There are many ways health care organizations can integrate patient and family perspectives and experiences into their organizational decision making.¹ Patient and family representatives serving on governing boards and advisory committees within the health care system can share their perspectives on how policies and processes affect those served by the health care system. Including patients on the governing board can also help ensure that the health care organization is responsive to the community's health care needs and experiences. For this reason, federally qualified health centers have a federal mandate that the majority of their board members be individuals served by their centers.^a Health care organizations often have numerous advisory committees, some of which focus on system wide issues like safety while others focus on specific services within the system like cancer or women's health.¹ Vidant Health, a regional health system serving 29 counties in eastern North Carolina, has prioritized including patients and family members on committees, interview teams, facility design and renovation teams, the development team for the electronic medical record patient portal, and editorial review committees for patient and family education.² Creating opportunities throughout health care organizations for patients and family members to influence decisions can help ensure health care organizations are meeting the needs of the communities they serve. Therefore, the Task Force recommends:

Recommendation 6.1: Include Patients and Families on Health Care Organization Boards and Committees

Health care organizations should appoint a minimum of two patients (or family members) to boards and advisory committees within their organizations. To the extent possible and practical, patients (or family members) should represent the diversity of the community served by the health care system. Patients (or family members) should



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a Section 330 of the Public Health Act (42 U.S.C. §254b).

receive training and mentoring to help prepare them to be productive board and committee members.

See also Recommendation 8.3.

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Patient and Family Advisory Councils

Creating a patient and family advisory council (PFAC) is another strategy to ensure the needs and concerns of patients and families are heard and used to inform decision making. PFACs are teams of patients and families working with providers and staff to provide an opportunity to engage patient perspectives in the planning, implementation, and evaluation of health care services and programs.³ Patient and family advisors serve as consumer representatives and provide an important perspective to the design and delivery of health care systems and help ensure the focus of health care is centered on the patient and the family.³ PFACs provide an opportunity to improve understanding and cooperation, and promote meaningful partnership among patients, families, providers, staff, and health care organizations.³ PFACs also provide an efficient and effective approach to elicit the unique perspectives of patients on issues that impact their care. Patient and family advisors benefit from their participation in PFACs because participation in a PFAC allows them to learn skills that may be new to them, including facilitation and listening skills. Participation in a PFAC gives patients and families an opportunity to enhance their understanding of the health care system, while providing a means to advocate for patient and family-centered health care in their communities. PFACs also provide the opportunity for patients and families to give back to their communities and build relationships.

Health systems have engaged patient and family advisors in many key roles such as quality and safety initiatives, facility planning, staff education, patient/family education, and staff hiring.^{2,4,5} Health care systems across North Carolina, including UNC Health System, Duke University Health System, Wake Forest Baptist Medical Center, Vidant Health, and many regional hospitals, have PFACs addressing various issues. For example, Onslow Memorial Hospital's PFAC has provided recommendations that have led to improved signage throughout the hospital, making the lobby more welcoming, changing the hospital's visitation policy so that patients define their family, and revising patient education literature. Involving patients at the organizational level has resulted in positive outcomes including improved patient satisfaction, efficient facility design, and improved health system reputation.⁶ Although many health systems that have established PFACs report positive qualitative outcomes, there is less documentation of key quantitative indicators such as reduced costs or improved patient outcomes.

Health systems that have PFACs have identified several challenges in fairly and effectively including consumers at the organizational level.⁷ One of the most critical challenges is addressing the gap between consumer knowledge and health professional knowledge.⁷ PFACs have also had difficulty identifying appropriate and diverse consumer participants, determining their roles, and establishing an equitable voice among advisory council members. Several strategies have been developed to more fully engage PFAC members including: designating a staff member of the organization for consumers to contact for regular concerns as well as for meeting briefings and debriefings; providing training and education for PFAC members; and creating a peer-to-peer exchange between organizations implementing PFACs.⁷

In North Carolina, the North Carolina Quality Center supports patient and family engagement efforts, including the creation and integration of PFACs, in hospitals around the state.^b The Quality Center helps health organizations with PFACs overcome some of the challenges they face in integrating PFACs into their organization's decision making process. In 2015, the Quality Center plans to host a learning network of hospital patient engagement or experience staff.^b The Quality Center also plans to invite patient and family advisors, hospital engagement or experience staff, and advocates to a summit to learn from each other and share best practices.^b The Quality Center work on patient engagement will also continue within their other program areas of patient safety and quality.

The NCIOM Task Force on Patient and Family Engagement reviewed the research on PFACs' impact on patient engagement, and recommends:

Recommendation 6.2: Engage Patients and Families in the Governance and Operation of Health Care Organizations (PRIORITY RECOMMENDATION)

- a) **Health care organizations including, but not limited to, accountable care organizations, health systems, provider regional networks, and payers, should develop patient and family advisory councils (PFACS) to provide input into the governance and operation of health care at all levels. PFACs should represent the community that the agency or health care organization serves.**

- b) **North Carolina Area Health Education Centers, in partnership with the North Carolina Hospital Association, should convene a statewide group of patients and families to help coordinate advocacy, capacity building, inventory, and support other PFACs.**

^b Koeble C. Executive Director, NC Quality Center, Senior Vice President, NC Hospital Association. Personal (telephone) communication. February 20, 2015.

References

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