Ensuring Patient and Family Engagement
A Professional Nurse’s Toolkit

Luc R. Pelletier, MSN, APRN, PMHCNS-BC, FAAN;
Jaynelle F. Stichler, DNSc, RN, NEA-BC, FACHE, FAAN

PATIENT- AND FAMILY-CENTERED CARE has been the focus of professional nursing, and if you ask any nurse or other health care provider if they provide patient-centered care (PCC), they will answer with a resounding “yes.” Unfortunately, there is little written about the actual definition or attributes of patient- or family-centered care and there are few actual measures of PCC. Patient satisfaction has long been the proxy for PCC. Pelletier and Stichler1 recently offered a definition of PCC and a conceptual model that demonstrates the integrated nature of the concept that includes patient empowerment, engagement, and activation.

Professional nurses have been engaging patients and families in their own care for decades. The Accountable Care Act has changed the focus on how patients are moved from “complying” or “adhering” to medical or nursing directives to truly being “engaged” or “activated”; making decisions based on what they know will help them improve their health status. Patient and family engagement (PFE) is being viewed in a whole new context. Patients must be prepared to care for themselves to improve, maintain, and sustain their health both to prevent chronic and acute illness and to prevent readmissions after hospital discharge. Patients must be empowered with information, engaged in their care and decisions about their health, and activated to manage their health or condition over time.

Professional nurses have the opportunity to ask themselves: Do I truly engage patients in their care? How do I engage them? Is my view of the patient’s and family’s involvement facility- or episode-focused? How do I know when patients are fully engaged? How do I manage a patient who does not want to be engaged in decisions or his or her care?

Nurses play a pivotal role in empowering patients, engaging them in their care, and ensuring that they are fully activated to be personally accountable for their own health. The term “patient- or person-centered care” has recently become interchangeable with the term “patient engagement.” Patient and family engagement has been defined and made
operational by professional and government agencies with interest in improving the quality of patient care. They view patient engagement as an essential component to achieving quality outcomes. These agencies individually and collectively provide a call to action for providers to engage patients and families in their health and/or plan of care. The purpose of this column is to provide exemplars and resources that can serve as a toolkit for professional nurses as they seek ways to engage and activate patients through knowledge, partnership, and collaboration.


American Board of Internal Medicine Foundation (http://www.choosingwisely.org). The American Board of Internal Medicine Foundation has developed a “Choosing Wisely” campaign to focus on unnecessary tests and procedures, thus eliminating waste in the health care system. The campaign has been adopted by 50 specialty societies, and Consumer Reports is providing technology to consumers to partner with their providers. For example, the American College of Emergency Physicians has developed a list of tests and procedures that consumers should question when receiving care.

American Institutes for Research (http://www.air.org). American Institutes for Research’s mission is “to conduct and apply the best behavioral and social science research and evaluation towards improving people’s lives, with a special emphasis on the disadvantaged.” With a goal of promoting PFE in hospitals, a Guide to Patient and Family Engagement was prepared at the direction of the Agency for Healthcare and Research and Quality. It included the following definition of PFE:

A set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations . . . the desired goals of patient and family engagement include improving the quality and safety of health care in a hospital setting.

This definition emphasizes the importance of patient engagement as a central focus of patient- and family-centered care. The report indicates that patient engagement is the result of the individual characteristics, perspectives, and needs of patients, families, and providers; the organizational structures and processes that influence patient engagement; and hospital-based interventions that facilitate patient engagement.

The American Institutes for Research worked with other stakeholders to develop and test the evidence-based practices in the guide. The project team included the Institute for Patient and Family-centered Care, Consumers Advancing Patient Safety, The Joint Commission (TJC), and the Health Research and Educational Trust. Other organizations included Planetree, the Maryland Patient Safety Center, Aurora Health Care, and Emory University Hospital.

The Advisory Board Company (http://www.advisory.com). The Advisory Board Company, a research and technology consulting firm, has developed various products to assist health care leaders in promoting PFE. They believe that ongoing case management of chronic care populations can lead to value. Case management cannot be successful without engaging the patient in the process. In Competing on Patient Engagement: Forging a New Competitive Identity for a Value-Driven Marketplace, the authors propose 9 health care imperatives in 3 areas: recover lost value in episodes of care, create new value through ongoing care management, and add value through population management.

maintains the “Working for Quality” site (see US Department of Health and Human Services later). Integrating behavioral health in primary care is an emphasis the AHRQ addresses through its “The Academy” Web portal. Patient engagement through shared decision making is highlighted as a key part of this integration and reports, and tools are made available to visitors to the site.5

**American Hospital Association** (http://www.aha.org). American Hospital Association’s Engaging Health Care Users: A Framework for Healthy Individuals and Communities presents various best practices from hospitals and health care systems that have developed and implemented PFE strategies at the health care team level. These strategies include evidence-based practices such as bedside rounding, bedside end-of-shift reports, rapid response teams, and medication reconciliation.6(p33)

**Center for Advancing Health** (http://www.cfad.org). The Center for Advancing Health, founded in 1992, believes that patients are responsible for participating “actively and knowledgeably” in their own care. They define “patient engagement in health care consists of the actions we take to benefit from that care.” They have established an “Engagement Behavior Framework” that places the patient and the family in control of their health and wellness, and they propose 43 engagement behaviors that can result in an activated consumer. These behaviors are categorized under “find safe, decent care; communicate with health care professionals; organize health care; pay for health care; make good treatment decisions; participate in treatment; promote health; get preventive health care; plan for the end of life; and seek health knowledge.”8

**Centers for Medicare & Medicaid Services** (http://partnershipforpatients.cms.gov). Centers for Medicare & Medicaid Services’ initiative, Partnership for Patients, is “a public-private partnership working to improve the quality, safety, and affordability of health care for all Americans.”9 The initiative stresses the importance of an informed patient and family and encourages more than 3700 participating hospitals to share PFE best practices. Their current resources are categorized under Hospital-Acquired Conditions, Healthcare-associated Infections, Hospital Leadership and Organizational Culture, and Readmissions and Care Transitions. Best practices from facilities across the country can be downloaded from its site. Resources range from posters promoting hand hygiene to frameworks for leadership improvement.

**The Joint Commission** (http://www.jointcommission.org). The Joint Commission’s Speak Up campaign was initiated in 2002 and encourages active involvement of patients in their own care. The Speak Up Web site offers free brochures, flyers, and videos for consumers in English and Spanish regarding 21 campaigns such as “Know Your Rights” and “Planning Your Follow-up Care.” Speak Up materials can be downloaded or ordered from TJC.10 In 2010, TJC published Advancing Effective Communication, Cultural Competence, and Patient-and Family-centered Care: A Roadmap for Hospitals, a guide for engaging patients and their families.11

**National Quality Forum** (http://www.qualityforum.org). National Quality Forum’s National Priorities Partnership, made up of 52 national organizations, envisions a time “when healthcare is consistently safe, affordable, equitable, and effective. Where no one is harmed as they heal. And when all Americans, and the communities they live in, are healthier than they are today.”12 Patient and family engagement is listed as the first priority for the National Priorities Partnership, and professional nursing has a critical role.13

**Nursing Alliance for Quality Care** (http://www.naqc.org). The Nursing Alliance for Quality Care (NAQC), which originated at the George Washington University, is currently managed by the American Nurses Association. Membership includes nursing and consumer organizations. Its mission is to “advance the highest quality, safety, and value of consumer-centered health care for all individual patients, their families, and their communities.”14(p1)
2012, NAQC leadership convened an expert panel to develop a white paper on nursing’s role in PFE. Following the expert panel meeting, the NAQC held a national conference and vetted its proposed consensus paper, *Nursing’s Contributions to Fostering Patient Engagement*, which was published in 2013. 

The NAQC’s guiding principles, based on patient engagement as a cornerstone of quality and safe patient care, were released in 2011.

**Planetree** ([http://www.planetree.org](http://www.planetree.org)). In developing the Planetree model as a method to achieve PCC, the founders Frampton et al. stated that PCC respects patients’ perspective, prepares them to participate in their own care, and is the most effective approach to improve health care quality. These authors indicated that patients expect quality, technical care as a basic element of quality care, but they also expect “respect, kindness, privacy, information, autonomy, choices and inclusion.”

More recently, Planetree and the Picker Institute published a *Patient-Centered Care Improvement Guide*, in which the authors provide the reader with ideas on how to engage patients and families in organizational improvement activities.

**US Department of Health and Human Services** ([http://www.ahrq.gov/workingforquality/index.html](http://www.ahrq.gov/workingforquality/index.html)). The US Department of Health and Human Services has defined a National Strategy for Quality Improvement in Health Care (the National Quality Strategy or NQS). Its 3 broad aims include better care, health people/healthy communities, and affordable care. The NQS is a requirement of the Affordable Care Act. To achieve the 3 aims, 6 priorities have been established. The second priority is “ensuring that each person and family is engaged as partners in their care.”

The agency’s Web site has reports and tools to help nurses create evidence-based engagement strategies. The “Priorities in Action” section of the Web site provides exemplars of PFE strategies from across the country. The National eHealth Collaborative, a private-public partnership managed by the US Department of Health and Human Services Office of the National Coordinator for Health Information Technology, provides a framework for enhancing information technology to support patient engagement. Their “Patient Engagement Framework” guides health care organizations in developing and strengthening patient engagement strategies through the use of eHealth tools.

All of these organizational definitions of patient- and family-centered care include patient engagement that is characterized with shared involvement and control in care decisions. Accountable care for all Americans can be achieved only when every person is knowledgeable, engaged, empowered, and fully activated to be responsible for his or her own health. Quality measurements must focus on the extent that patients are engaged in their care rather than simple measures of patient satisfaction. Professional nurses can use the resources and tools described here to enhance the services they provide and engage patients and families each and every day.

**REFERENCES**


