

## **Guiding Principles for Patient Engagement**

Patient engagement is a critical cornerstone of patient safety and quality. NACQ has grounded its approach to this topic by recognizing the primary importance of *relationships* between engaged patients and families and their providers of care. The following are principal assumptions that guide NAQC in addressing care that is patient-centered.

- 1. There must be a dynamic partnership among patients, their families, and the providers of their healthcare, which at the same time respects the boundaries of privacy, competent decision making, and ethical behavior.
- 2. This relationship is grounded in confidentiality, where the patient defines the scope of the confidentiality. Patients are the best and ultimate source of information about their health status and retain the right to make their own decisions about care.
- 3. In this relationship, there are mutual responsibilities and accountabilities among the patient, the family, and the provider that make it effective.
- 4. Providers must recognize that the extent to which patients and family members are able to engage or choose to engage may vary greatly based on individual circumstances. Advocacy for patients who are unable to participate fully is a fundamental nursing role.
- 5. All encounters and transactions with the patient and family occur while respecting the boundaries that protect recipients of care as well as providers of that care.
- 6. Patient advocacy is the demonstration of how all of the components of the relationship fit together.
- 7. This relationship is grounded in an appreciation of patient's rights and expands on the rights to include mutuality.
- 8. Mutuality includes sharing of information, creation of consensus, and shared decision making.
- 9. Health care literacy is essential for patient, family, and provider to understand the components of patient engagement. Providers must maintain awareness of the health care literacy level of the patient and family and respond accordingly. Acknowledgment and appreciation of diverse backgrounds is an essential part of the engagement process.



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#### NAQC Member Organizations

AARP

American Academy of Nurse Practitioners

> American Academy of Nursing

American Association of Colleges of Nursing

American College of Nurse-Midwives

> American Nurses Association

American Organization of Nurse Executives

Association of Nurses in AIDS Care

Association of periOperative Registered Nurses

> Consumers Advancing Patient Safety

Institute of Pediatric Nursing

Mothers Against Medical Error

National Council of State Boards of Nursing

National League for Nursing

National Organization of Nurse Practitioner Faculties

National Quality Forum

Nurse-Family Partnership

There is a lack of consensus in the literature for terms used in discussing patient engagement. The NAQC has chosen to use the following definitions of terms.

# **Definitions:**

<u>PATIENT-CENTERED CARE -</u> Honors the whole person and family, respects individual values and choices, and ensures continuity of care. When care is patient-centered, patients will say, "they gave me exactly the help I want (and need) exactly when I want (and need) it." (Adapted from RWJF Aligning Forces for Quality, Transforming Care at the Bedside).

<u>ENGAGEMENT</u> - "Actions individuals must take to obtain the greatest benefit from the health care services available to them." (Center for Advancing Health, 2010, p. 2).

<u>ENGAGEMENT BEHAVIOR FRAMEWORK (EBF) -</u> EBF provides a model with ten measurable expectations for an individual's behavior. These behaviors facilitate people seeking and utilizing safe care. They also guide an orientation toward patient-centeredness. (Gruman, Holmes-Rovner, French, Feffress, Sofaer, Shaller, & Prager, 2010).

- 1. Find safe, decent care
- 2. Communicate with health care professionals
- 3. Organize health care
- 4. Pay for health care
- 5. Make good treatment decisions
- 6. Participate in treatment
- 7. Promote health
- 8. Get preventive health care
- 9. Plan for the end of life
- 10. Seek health knowledge

<u>**PATIENT ACTIVATION**</u>- "Individual's knowledge, skill, and confidence for managing his/her own health and health care." (Hibbard, J.H. and Mahoney, E., 2010, p.377).

<u>PATIENT ACTIVATION MEASURE (PAM)</u> - A valid and highly reliable scale that reflects a developmental model of activation. In this model, there are four stages that a patient must take to be activated in their care. (Hibbard, Stockard, Mahoney, & Tusler, 2004).

- 1. Believing the patient role is important
- 2. Having the confidence, knowledge, and other resources necessary to take action
- 3. Actually taking action to maintain and improve one's health
- 4. Staying the course even under stress

# PATIENT BILL OF RIGHTS

This phrase is commonly understood by health care professionals and many consumers, but exists in many variations, so it may be problematic to reference. The American Hospital Association first published a Patient Bill of Rights in the 1970's - it has since been updated to the "Patient Care Partnership" brochure (http://www.aha.org/advocacy-issues/communicatingpts/pt-care-partnership.shtml). Multiple versions have been considered by the U.S. Congress. The U.S. Advisory Commission on Consumer Protection and Quality published a version in 1998 which is often referenced. The 2010 Affordable Care Act provided a new version which focused on rights to treatment unencumbered by "egregious practices of the insurance industry".

http://www.healthreform.gov/newsroom/new\_patients\_bill\_of\_rights.html). Many national organizations (such as the American Cancer Society, NIH clinical trials) provide their own bill of rights.

#### **Summary:**

In both patient engagement models, the provider must adopt interventions, attitudes and behaviors that can support and encourage the patient and family, designing interventions and care that meets the individual patient and family needs. Using these models as the guiding assumptions for creating the patient/family and provider relationship can support patient-centered care and result in engaged and activated consumers of health care.

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