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Patient and Family Engagement Strategies

This section provides an overview of varying strategies for, and definitions of, patient and family engagement.

Research shows patients and their families who actively engage with their health care teams have better outcomes, often choose less expensive options when participating in shared decision-making, and express greater satisfaction with their health care experiences.[1] As the **Institute of Medicine (IOM)** stated in its 2012 publication, ***Best Care at Lower Cost: The Path to Continuously Learning Health Care in America***,

> "When patients, their families, other caregivers, and the public are full, active participants in care, health, the experience of care, and economic outcomes can be substantially improved. A learning health care system is anchored on patient needs and perspectives and promotes the inclusion of patients, families, and other caregivers as vital members of the continuously learning care team."

In the same report, the IOM goes on to say, "Improved patient engagement is associated with better patient experience, health, and quality of life and better economic outcomes, yet patient and family participation in care decisions remains limited."[2]

The Triple Aim, developed by the **Institute of Healthcare Improvement (IHI)**, is a framework that describes an approach to optimizing health system performance. Adopted by the **Centers for Medicare and Medicaid Services (CMS)**, its goals are to simultaneously improve the experience of care, improve the health of populations, and reduce per capita costs of health care. Don Berwick, MD, MPP, former administrator for CMS said, "The most direct route to the Triple Aim is through implementation of patient- and family-centered care in its fullest form."[3]

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[1] Stewart, M., et al. The Impact of Patient-Centered Care on Outcomes, *Journal of Family Medicine*, 2000.Sep;49(9):796-804.

[2] Institute of Medicine. (2012). *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*. S-23.

[3] Berwick, D. *Keynote Address, The 5th International Conference on Patient- and Family-Centered Care,* Institute of Patient- and Family-Centered Care, June 3, 2012 Washington, DC.

It is not uncommon to find webinars, conferences, scholarly articles, and the popular press using the term patient engagement to attract interest. Depending on the audience, the meaning and definition of patient engagement can vary widely. Some examples of this variation include:

The Center for Advancing Health (CFAH) defines patient engagement as "actions people take to support their health and benefit from health care."[4] In early 2013, CFAH began a small study by conducting 30 interviews with health care stakeholders about the definition and potential strategies to support/facilitate engagement. Their recently released report, ***Here to Stay – What Health Care Leaders Say About Patient Engagement*** listed six broad themes that emerged from these interviews:

- Engagement is active
- The health care system doesn't make engagement easy.
- Everyone benefits from engagement
- Engagement is demanding and many are unprepared.
- Partnerships are required.
- It's like the Wild West.

A report**, *Patient and Family Engagement: PFCMH Research Agenda***, was presented at the May 2013 Patient-Centered Medical Home Conference.[5] The report included an extensive literature review and cited numerous definitions that have been used by respected health care organizations. Despite the differences, the report noted:

> "All articulate the importance of: Partnerships among patients, family members, and health care providers; Patients and family members being viewed as essential members of the health care team; Valuing and using patient and family expertise, insights, and perspectives in the design, implementation, and evaluation of programs and policies."

Additionally, this report strongly encouraged the explicit use of the term patient and family engagement stating:

> "We believe it is imperative to be explicit and consistent in the inclusion of the word "family." Families are key to promoting health and wellness, … Systems need to be in place … encouraging and supporting patients to define their family and how they want them involved in care. Maintaining a broad definition of family, such as the one promoted by the American Academy of Family Physicians, *"a*

[4] Jeffress, D. Interview on Engagement, January 2013, Center for Advancing Health. http://www.cfah.org/engagement/research/engagement-behavior-framework

[5] Baker, B., Cene, C., Johnson, B., Wells, N., & Turchi, R. (2013, May). Patient and family engagement: PFCMH research agenda. Presented at the PCMH Research Conference II, May 2013 Chicago, IL.

group of individuals with a continuing legal, genetic and/or emotional relationship is critical to ensuring that a patient's choices about who will participate in their care are respected."

The December 2013 report, ***Patient and Family Engagement: Partnering with Patients, Families, and Communities for Health: A Global Imperative*****,** Report of the Patient and Family Engagement Working Group 2013, from the World Innovation Summit for Health (WISH) states:

> "Involving people in healthcare is very powerful...Engagement is multi-dimensional. It can take the form of a very personal event, such as a shared decision between an individual patient and healthcare professional; or it can be a systematic public event, such as a health literacy campaign. It can be targeted at improving provider performance, as when patient and family advisors and healthcare professionals redesign healthcare services together; or it can be targeted at informing patient behavior, as through self-management programs for chronic disease. It can begin with simple information-sharing, move on to dialogue, and evolve into partnership. Whatever form it takes, engagement changes the focus, from taking action to improve health and healthcare for the people, to taking action with the people – a simple yet radical notion… Engagement is a mutual relationship." [6]

Rather than focusing on a narrow definition of engagement, the WISH report embraces the notion that behavior change is required of health care professionals as well as patients and families to achieve global health.

The **National Partnership for Women & Families** developed the term, "collaborative patient and family engagement" as a change strategy. Collaborative patient and family engagement is described as partnerships that are embraced at four levels:

- In the clinical encounter...patient and family engagement in direct care, care planning, and decision-making;
- At the practice or organizational level... patient and family engagement in quality improvement and health care redesign;
- At the community level...bringing together community resources with health care organizations, patients, and families; and
- At policy levels...locally, regionally, and nationally."[7]

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[6] Edgman-Levitan, S., Brady, C., & Howitt, P. (2013). *Patient and family engagement: Partnering with patients, families, and communities for health: A global imperative. Report of the Patient and Family Engagement Working Group 2013*. Paper presented at the World Innovation Summit for Health, Doha, Qatar.

[7] Carman KL, Dardess P, Maurer M, Sofaer S, Adams K. Bechtel C, Sweeney J. Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs*. 2013; 32(2): 223-231.

The above definition, which emphasizes collaboration with patients and families at all levels of the health care system, was a key principle of family-centered care in groundbreaking work with the U.S. Surgeon General C. Everett Koop in 1987. Family-centered care and collaboration with families was foundational to Surgeon General Koop's Campaign for Children with Special Health Care Needs (CSHCN) and to building of the HIV/AIDS system of care. For more than 25 years, this collaborative model for both providing services and designing the systems of service delivery has guided a variety of important programs including the creation of the federal HIV/AIDS Bureau, the expansion of pediatric emergency services,[8] the development of children's mental health services,[9] and the Recovery Model endorsed by SAMHSA and the Department of Veterans Affairs.

In 2014, the National Patient Safety Foundation's (NPS) Lucian Leape Institute released ***Safety Is Personal: Partnering with Patients and Families for the Safest Care***. This report emphasized the safety benefits when effective partnerships are created between those who provide care and those who receive it. While the ultimate responsibility of safety lies with health care leaders and professionals, the roadblocks to engaging patients and families must be addressed in order to build meaningful partnerships.[10]

This ongoing national dialogue around patient and family engagement encourages health care leaders to assume leadership in setting expectations around this important issue. In order to create the conditions that promote engagement, Medicaid programs have a unique role in ensuring that programs and services set goals and work to achieve effective partnerships with the clients and families they serve.

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[8] Johnson, B.H. (2000). Family-centered are: Four decades of progress. *Families, Systems, & Health,* 18(2), 133-156.

[9] Shelton TL, Jeppson ES, Johnson BH. Family-Centered Care for Children with Special Health Care Needs. Bethesda, MD: Association for the Care of Children's Health; 1987.

[10] Edgeman-Levitan, S., and Shaller, D., SAFETY IS PERSONAL Partnering with Patients and Families for the Safest Care March 2014 http://www.npsf.org