

**T**he United States health care system is the most expensive per capita health care system in the world.<sup>1</sup> However, when compared with other developed countries on indicators such as health outcomes, quality, and efficiency, the United States ranks last. With rising health care costs and suboptimal performance on health care measures, there is increasing interest and urgency to address this paradox. One promising pathway toward improvement is the field of patient and family engagement.

Patient and family engagement strategies have shown such promise that they have been incorporated into the majority of recent efforts to improve health care quality. The National Strategy for Quality Improvement in Health Care, established as part of the Affordable Care Act, focuses on patient-centered care, “ensuring that each person and family is engaged as partners in their care” in order to advance health care quality improvement goals.<sup>2</sup> The Centers for Medicare and Medicaid Services describe patients and their families as “essential partners in the effort to improve the quality and safety of health care.”<sup>3</sup> The American Institutes for Research (AIR) defines patient and family engagement as “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system to improve health and health care.”<sup>4</sup> Other organizations have different definitions of patient and family engagement; however the key concepts are similar.<sup>5</sup> All definitions emphasize that specific action must be taken by patients, providers, and others in health care systems to create collaborative partnerships to improve both individuals’ health and the health care system.

It is important to remember that engaging patients and families requires more than a series of simple steps or a checklist of activities. Meaningful patient and family engagement necessitates a shift in the traditional culture of health care. It is about creating a partnership culture within health care. Though it is a significant undertaking, with leadership, collaboration, and perseverance, health systems can create cultures centered on patients and families, with the goals of improving patient experience, improving quality of care, and decreasing cost.

## The Need for Patient and Family Engagement

Patients have much to gain when patients and families provide input and when the responsibility for health is shared.<sup>6</sup> Research shows that patients who are more engaged in their care have lower medical costs, fewer hospital admissions, and improved health outcomes, such as a healthier diet, increased levels of physical activity, and weight loss for patients with diet-related chronic diseases.<sup>7,8</sup> However, a recent survey of American health care consumers found that one in three consumers is disengaged in their care. These individuals report a lower need for care, take less preventive action, have lower interest in resources, and are less financially prepared than consumers who are more engaged.<sup>9</sup>



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There are many factors that can contribute to lower levels of engagement. In the recent economic recession, many families had fewer resources to focus on health care.<sup>10</sup> Although the economy has recovered, many families are still experiencing economic hardship. Some families must choose to prioritize other needs like food and shelter. When individuals work more than one job to make ends meet, time off of work for health care visits may not be feasible. In addition to socioeconomic factors, there are also cultural barriers to patient engagement. Some racial and ethnic cultures have a history of mistrust with medicine and health care.<sup>11</sup> Others may practice traditional healing, prayer, meditation, or herbal supplementation they feel will not be supported by health care providers.<sup>11</sup> Patient and family engagement can be viewed as a means of health equity, with providers and systems focused on patient-centered care, and patients and families prepared to partner in a way they choose.

Research shows that patients and providers support engagement and believe that increased involvement in health care by patients and families can lead to improved experiences and outcomes.<sup>12</sup> In 2012, 63% of health care consumers were dissatisfied with the United States health care system, giving it a report card grade of C, D, or F. Health care organizations interested in boosting their scores should consider the benefits of patient and family engagement. One study found that patients who are highly engaged are 10 times more likely to report high patient satisfaction scores when compared to patients who are less engaged.<sup>13</sup> Increasing levels of patient and family engagement may lead to gains in patient satisfaction and experience of care scores.

In addition to becoming more involved in their own care and well-being, patients and families can also be involved in the governance and oversight of health care organizations and systems. Health care systems implementing patient engagement efforts have seen reductions in medical errors, hospital-acquired infections, and other serious safety events.<sup>14-16</sup>

### **Increasing Patient and Family Engagement**

Patient engagement can occur at multiple levels of the health care system.<sup>14,15</sup> In direct patient care, providers can include patients as partners in the care process, tailoring health decisions to their preferences and values, and communicating as a partner with patients and families. At the organizational level, hospitals, practices, and other provider organizations can include patients as advisors in the strategy and management of their organizations so that the delivery of care is informed by patient experiences. Practices, hospitals, and health systems can be designed to maximize communication and partnership with patients and families at every point in the care continuum. At the policy level, health policymakers can work with consumers in the development and implementation of policies and regulations that pertain to their care, and state and federal policies as well as private payer policies can provide incentives to practices that engage patients and families.<sup>4</sup>

Engagement can be present at every level in health care, on a continuum ranging from consultation all the way to true partnership and shared leadership.<sup>4</sup> Providers and systems must examine current engagement efforts and focus on strategies for improving patient engagement at all levels. Nationally, the Agency for Healthcare Research and Quality, AIR, Institute for Healthcare Improvement, the Institute for Patient- and Family-Centered Care, and the National Association for Healthcare Quality are all working to help health care providers and systems increase their engagement with patients and families. In North Carolina, Community Care of North Carolina (CCNC), North Carolina's Medicaid program's primary care case management contractor, takes a community and patient-centered approach to health care and seeks to engage patients in their care. Additionally, the North Carolina Quality Center (NCQC) has been at the forefront of patient and family engagement efforts in hospitals since its creation in 2004.<sup>17</sup>

## **NCIOM Task Force on Patient and Family Engagement**

The North Carolina Institute of Medicine (NCIOM) received grant support from The Duke Endowment to convene a task force on patient and family engagement in order to build upon current efforts in North Carolina. The NCIOM Task Force on Patient and Family Engagement was created in collaboration with CCNC, the North Carolina Division of Public Health within the Department of Health and Human Services, the NCQC of the North Carolina Hospital Association, the North Carolina Medical Society, and the Foundation for Nursing Excellence. The Task Force was charged with identifying and examining evidence-based, evidence-informed, and promising practices and strategies for increasing patient and family engagement.

The Task Force was chaired by Kimly Blanton, a patient family advisor with Vidant Health; Melanie Bush, assistant director of policy and regulatory affairs with the Division of Medical Assistance in the North Carolina Department of Health and Human Services; and Dr. Warren Newton, director of the North Carolina Area Health Education Centers Program and professor and chair of the Department of Family Medicine at the University of North Carolina at Chapel Hill School of Medicine.

In addition to the chairs, the Task Force was comprised of 41 members. The group included patients and family members, youth, caregivers, providers, insurers, and representatives from various health systems, community-based organizations, local health agencies, and several divisions within the North Carolina Department of Health and Human Services. There was a specific focus on ensuring the Task Force was representative of the state, including diversity of age, race, ethnicity, socioeconomic status, and region of the state. The Task Force met monthly from February 2014 to January 2015 for a total of 12 meetings.

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After reviewing best practices and evidence-based strategies for increasing patient and family engagement in direct care settings, hospitals, health systems, the community, and in policy, the Task Force developed and refined a set of recommendations that will catalyze patient and family engagement and improve health and health care systems in North Carolina.

This report contains nine chapters, the first being this brief introduction. The second chapter discusses the vision and mission of patient and family engagement through the framework and roadmap developed AIR. Subsequent chapters expand on change strategies of the AIR patient and family engagement roadmap.

**The Task Force developed a set of recommendations that will catalyze patient and family engagement and improve health and health care systems in North Carolina.**

## References

1. Davis K, Stremikis K, Squires D, Schoen C; The Commonwealth Fund. *Mirror, Mirror on the Wall, 2014 Update: How the U.S. Health Care System Compares Internationally*. New York, NY: The Commonwealth Fund; 2014. <http://www.commonwealthfund.org/publications/fund-reports/2014/jun/mirror-mirror>. Accessed May 1, 2015.
2. Agency for Healthcare Research and Quality. Working for quality: about the National Quality Strategy (NQS). Agency for Healthcare Research and Quality website. <http://www.ahrq.gov/workingforquality/about.htm>. Accessed February 1, 2015.
3. Centers for Medicare and Medicaid Services. Partnership for Patients: about the partnership. Centers for Medicare and Medicaid Service website. <http://partnershipforpatients.cms.gov/about-the-partnership/patient-and-family-engagement/the-patient-and-family-engagement.html>. Accessed February 1, 2015.
4. Carman KL, Dardess P, Maurer ME, Workman T, Ganachari D, Pathak-Sen E; American Institutes for Research. *A Roadmap for Patient and Family Engagement in Healthcare Practice and Research*. Palo Alto, CA: Gordon and Betty Moore Foundation; 2014. <http://patientfamilyengagement.org/#sthash.ZnjhnX9.dpuf>. Accessed March 1, 2015.
5. Institute for Patient- and Family-Centered Care. Frequently asked questions. Institute for Patient- and Family-Centered Care website. <http://www.ipfcc.org/faq.html>. Published December 29, 2010. Accessed March 1, 2015.
6. Conway J, Johnson B, Edgman-Levitan S, et al. *Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System. A Roadmap for the Future. A Work in Progress*. Bethesda, MD: Institute for Family-Centered Care; 2006. <http://www.hsi.gatech.edu/erfuture/images/c/c2/Family.pdf>. Accessed February 12, 2015.
7. Martins RK, McNeil DW. Review of Motivational Interviewing in promoting health behaviors. *Clin Psychol Rev*. 2009;29(4):283-293.
8. James J. Health policy brief: patient engagement. *Health Aff (Millwood)*. 2013;32(2):1-6.
9. Healthcare payment reform: transition from volume-based to value-based payments. Presented at: TriHealth Physician Hospital Organization; October 6, 2014. <http://www.trihealthpho.com/education-library/healthcare-payment-reform-transition-from-volume-to-value.aspx>. Accessed February 1, 2015.
10. Cutler DM, Sahn NR. If slow rate of health care spending growth persists, projections may be off by \$770 billion. *Health Aff (Millwood)*. 2013;32(5):841-850.
11. University of Massachusetts Medical School, Office of Community Programs. *Physician Toolkit and Curriculum*. Washington, DC: US Dept of Health and Human Services; 2004. <http://minorityhealth.hhs.gov/assets/pdf/checked/toolkit.pdf>. Accessed February 2015.
12. Smedley BD, Stith AY, Nelson AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. Washington, DC: National Academies Press; 2003.
13. Mosen DM, Schmittiel J, Hibbard J, Sobel D, Remmers C, Belows J. Is patient activation associated with outcomes of care for adults with chronic conditions? *J Ambul Care Manage*. 2007;30(1):21-29.
14. New England Healthcare Institution. Preventing Medication Errors: A \$21 Billion Opportunity. New England Healthcare Institution website. [http://www.nehi.net/bendthecurve/sup/documents/Medication\\_Errors\\_%20Brief.pdf](http://www.nehi.net/bendthecurve/sup/documents/Medication_Errors_%20Brief.pdf). Accessed February 1, 2015.
15. Millenson M; Health Quality Advisors. *Building Patient-Centeredness in the Real World: The Engaged Patient and the Accountable Care Organization*. Washington, DC: National Partnership for Women and Families; 2012. <http://www.nationalpartnership.org/research-library/health-care/building-patient-centeredness-in-the-real-world.pdf>. Accessed March 1, 2015.

16. Kaufman J, Dokken D. Family presence: Why, what, and how? Presented to: NCIOM Task Force on Patient and Family Engagement; August 14, 2014; Morrisville, NC. [http://www.nciom.org/wp-content/uploads/2014/04/BT\\_PFE\\_8-14-14.pdf](http://www.nciom.org/wp-content/uploads/2014/04/BT_PFE_8-14-14.pdf). Accessed March 1, 2015.
17. Community Care of North Carolina. News and updates. Community Care of North Carolina website. <http://www.communitycarenc.com/about-us/update-archive/>. Accessed February 1, 2015.