

# NATIONAL PRIORITY: PATIENT AND FAMILY ENGAGEMENT

*Engage patients and families in managing their health and making decisions about their care*

**OUR VISION:** We envision healthcare that honors each individual patient and family, offering voice, control, choice, skills in self-care, and total transparency, and that can and does adapt readily to individual and family circumstances, and to differing cultures, languages, and social backgrounds.

## Why is Patient and Family Engagement a National Priority?

Too many of us move through the healthcare system as passive recipients of care, rather than as central members of our healthcare team. Many patients are not asked how they want to be treated or what their experiences are like; they may not feel adequately informed or involved in decisions about their care; they frequently do not understand important information healthcare professionals discuss with them; and they often do not have the knowledge or support to maintain and improve their health.

Although most of our national healthcare expenditures are for the treatment of chronic conditions, patients and families bear most of the burden for the day-to-day management of chronic care. Patients and their families need access to appropriate tools and support that equip them with the knowledge, skills, and abilities to effectively manage their health. An understanding of self-management strategies can help patients avoid exacerbations or setbacks, which can lead to burdensome and preventable treatments and hospitalizations. Engaged patients—those who seek out information about their condition and work collaboratively with their providers—are more likely to demonstrate healthy self-management behaviors (such as diet, exercise, and weight management) as well as disease-specific health management behaviors (such as keeping a diary of glucose levels when you have diabetes).<sup>26</sup> Patients who are engaged as active partners in their healthcare team, and who

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participate in the management of their personal health, are vital to achieving better health outcomes, lower service utilization, and lower costs.<sup>27</sup>

Patients can become more actively engaged in their care with the help of their professional caregivers. By seeking feedback on patients' and families' experiences of care, healthcare professionals can make improvements in quality and deliver care that is more patient centered and responsive to their patients' needs. By providing the right kind of information and decision support, patients can be empowered to assume a more active role in determining their course of treatment and can make choices concordant with the evidence-based recommendations of their healthcare professional and their own personal values and preferences.

Healthcare decisionmaking can be complex. Many times there is not one best treatment option; rather, there are several that have varying risks and benefits that require thoughtful consideration by the patient, with the help of his or her healthcare provider. Options for low back pain, for example, can range from very conservative treatment, such as physical therapy, to more aggressive interventions, such as spinal surgery.

The choice a patient makes should be based on a clear understanding of the options and their trade-offs and should be consistent with his or her values, preferences, and life situation. When fully aware of the risks and benefits, patients may opt for care that is less invasive in nature; this is particularly true for

those patients with conditions that have multiple treatment alternatives and tradeoffs to consider.<sup>28</sup>

Some studies have shown that shared decisionmaking can reduce the number of patients choosing more invasive surgical procedures by 21 to 44 percent without adversely impacting health outcomes.<sup>29</sup>

More and more, healthcare professionals are using decision aids to help their patients make the best decision. The use of such aids has been demonstrated to improve patient decisionmaking by increasing knowledge and active participation, creating more realistic expectations, reducing uncertainty and decisional conflict, and improving the alignment of value and choice.

### **Making Patient and Family Engagement a National Priority Will:**

**REDUCE HARM.** Many patients do not fully understand the instructions given to them by healthcare professionals. In the United States, health literacy—the ability to obtain, process, and understand information that is communicated regarding health status and healthcare—is poor, with only 12 percent of American adults having the skills to manage their own healthcare proficiently.<sup>30</sup> A recent study indicates that 78 percent of patients discharged from the emergency department do not adequately comprehend important information or instructions, leaving them at risk of improperly managing their condition(s) and potentially experiencing harm (e.g., adverse drug events). Perhaps more concerning, the majority of these patients do not realize that they are not understanding the information presented to them.<sup>31</sup>

**REDUCE DISPARITIES.** Health outcomes are known to vary widely among different groups based on race, ethnicity, gender, socioeconomic status, and other variables.<sup>32</sup> Additionally, functional health literacy is worst among the elderly and low-income populations, leaving those who are the most in need of healthcare the least able to

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understand the information intended to help them.<sup>33</sup> Today, almost 50 million Americans speak a language other than English at home, and 23 million have limited English proficiency.<sup>34</sup> In order to identify opportunities to improve the care

provided to different populations, healthcare professionals need information regarding patient experience of care. This information is essential for identifying tools and strategies that are culturally and linguistically appropriate and that will ideally lead to better care.

**REDUCE DISEASE BURDEN.** Self-management programs, which teach problem-solving skills, have been more effective than information-only patient education in improving clinical outcomes.<sup>35</sup> One study targeting Hispanics indicates that such programs also can produce good outcomes in minority populations, including improved health status (e.g., reduced health distress, fatigue, and pain/physical discomfort), improved health behaviors (e.g., increased exercise, communication with healthcare professional, and mental stress management), and reduced healthcare utilization.<sup>36</sup> Good communication and education lead to better results: Asthma patients who receive self-management education and regular follow-up with a healthcare professional have reported a reduction in hospitalizations and emergency department visits and fewer work days lost.<sup>37</sup>

**REDUCE WASTE.** Patients need a full understanding of their treatment options, along with the benefits, risks, and tradeoffs associated with those options, to make informed decisions about their care. There is growing evidence that patients who receive this kind of decision support tend to make more conservative (and potentially less costly and less risky) decisions. One study of arthritis patients, for example, found that only 15 percent of those identified as possible candidates for knee surgery actually wanted the surgery—a far greater number were attracted to more conservative treatment options.<sup>38</sup>

## Patient and Family Engagement: Examples of Actions

The concept of patient-centered care has become more mainstream in recent years, and more healthcare organizations are striving to offer care that is individualized and tailored to their patients' needs and preferences. This can be challenging, given the diversity of our population, but it is possible. Chronic disease self-management programs can be tailored to specific populations, such as those offered for Spanish-speaking Hispanics with chronic conditions in Tomando Control de su Salud (Taking Control of Your Health) programs. These programs offer workshops in community settings, such as churches, libraries, and hospitals, and they bring together Spanish-speaking individuals with similar chronic conditions. Courses are taught in Spanish (without the use of translators) and in ways that address cultural differences. Participants, when compared with other usual-care patients, have demonstrated improved health status, health behavior, and self-efficacy (the belief that one has the ability to adopt certain behaviors), as well as fewer emergency room visits.<sup>39</sup>

At the Dartmouth-Hitchcock Medical Center (DHMC) in Lebanon, New Hampshire, patients with a positive breast biopsy are no longer contacted by the radiologist first and then immediately scheduled for an appointment with a surgeon. Instead, each patient completes a screening questionnaire and uses web-based decision aids to gain a better understanding of their treatment preferences. Healthcare professionals use this information to tailor their consultations to each patient to ensure that the patient's ultimate decision is consistent with her expressed preferences. The healthcare professional provides additional information, as appropriate, to assist the patient in better understanding the risks and benefits of the options as the patient makes her decision. DHMC's Center for Shared Decision Making offers additional decision aids developed by the Foundation for Informed Medical Decision Making for a host of conditions, including back pain, heart disease, and prostate disorders.<sup>40</sup>

More and more healthcare organizations are seeing the benefits of understanding how their patients and families view their experience of care. Feedback from patients and their families is critical to understanding the value of the services provided and offers invaluable information about areas that may need improvement. Healthcare payers are also realizing the importance of this information. Beginning in July 2007, the Centers for Medicare & Medicaid Services changed its payments to hospitals to require use of the Hospital Consumer Assessment of Healthcare Provider and Services (HCAHPS) survey instrument in order to receive their full payment. This survey asks patients 27 questions pertaining to their hospital experience and produces data that hospitals can use for quality improvement and that consumers can use to compare hospital performance and get meaningful information for their own decisionmaking.<sup>41</sup>

# PATIENT AND FAMILY ENGAGEMENT:

## HOW WILL WE GET THERE?

The Partners will work together to ensure that:

**Goal: All patients will be asked for feedback on their experience of care, which healthcare organizations and their staff will then use to improve care.**

To get there, all healthcare organizations and settings, including individual and group practices, hospitals, nursing homes, assisted living facilities, community health centers, ambulatory settings, and hospice, home health, end stage renal disease, and behavioral health providers will administer and publicly report on patient experience surveys. Healthcare organizations and their staff will use this information to improve the quality of care they provide and to eliminate disparities in quality and outcomes. Benefit designs and payment methods will reward healthcare organizations that demonstrate improved patient experience of care and reduction of disparities. This information will be made available in ways that can inform the patient's choice of healthcare organization.

**Goal: All patients will have access to tools and support systems that enable them to effectively navigate and manage their care.**

To get there, healthcare organizations and their staff will offer or facilitate access to culturally and linguistically appropriate tools and practices that have been demonstrated to support patient engagement and self management. Benefit designs and payment methods will support the availability and use of such tools and systems; reward healthcare organizations that demonstrate improvement in outcomes and reduction of disparities; and provide incentives for patients to use such tools and support systems.

**Goal: All patients will have access to information and assistance that enables them to make informed decisions about their treatment options.**

To get there, healthcare organizations and their staff will use proven and culturally and linguistically appropriate strategies and tools to enable patients to understand all treatment options and to make decisions consistent with their values and preferences. Benefit designs and payment methods will support the use and availability of such strategies and tools; reward healthcare organizations that demonstrate improvement in outcomes and reduction of disparities; and provide incentives for patients to use such tools to make appropriate decisions about their care.