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Health Policy Brief

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Patient Engagement. People actively involved in their health and health care tend to have better outcomes—and, some evidence suggests, lower costs.

WHAT'S THE ISSUE?

A growing body of evidence demonstrates that patients who are more actively involved in their health care experience better health outcomes and incur lower costs. As a result, many public and private health care organizations are employing strategies to better engage patients, such as educating them about their conditions and involving them more fully in making decisions about their care.

"Patient activation" refers to a patient's knowledge, skills, ability, and willingness to manage his or her own health and care. "Patient engagement" is a broader concept that combines patient activation with interventions designed to increase activation and promote positive patient behavior, such as obtaining preventive care or exercising regularly. Patient engagement is one strategy to achieve the "triple aim" of improved health outcomes, better patient care, and lower costs.

This Health Policy Brief summarizes key findings on patient engagement published in the February 2013 issue of *Health Affairs*.

WHAT'S THE BACKGROUND?

Modern health care is complex, and many patients struggle to obtain, process, communicate, and understand even basic health information and services. Many patients lack health literacy, or a true understanding of their medical conditions. What's more, the US health care system often has seemed indifferent to patients' desires and needs. Many practitioners fail to provide the information that patients need to make the best decisions about their own care and treatment. And even when patients do receive detailed information, they can be overwhelmed or lack confidence in their own choices. Those with low levels of health literacy find it difficult to follow instructions on how to care for themselves or to adhere to treatment regimens, such as taking their medicines.

Recognizing these problems, the 2001 Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, called for reforms to achieve a "patient-centered" health care system. The report envisioned a system that provides care that is "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." Out of this recognition, in part, the field of patient engagement has emerged.

FRAMEWORKS FOR ENGAGEMENT: There are many aspects to patient engagement. Kristin Carman of the American Institutes for Research and coauthors propose a framework that conceptualizes patient engagement taking place on three main levels (Exhibit 1).

The first level is direct patient care, in which patients get information about a condition and

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answer questions about their preferences for treatment. This form of engagement allows patients and providers to make decisions based on the medical evidence, patients' preferences, and clinical judgment. In the second level of engagement, organizational design and governance, health care organizations reach out for consumer input to ensure that they will be as responsive as possible to patients' needs. In the third level, policy making, consumers are involved in the decisions that communities and society make about policies, laws, and regulations in public health and health care.

SHARED DECISION MAKING: One strategy consistent with the first level of engagement described by Carman and coauthors is shared decision making, in which patients and providers together consider the patient's condition, treatment options, the medical evidence behind the treatment options, the benefits and risks of treatment, and patients' preferences, and then arrive at and execute a treatment plan. The strategy is often used with patients who have "preference-sensitive" conditions or treatment options—that is, they may or may not choose particular treatments, or to be treated at all, depending on their own feelings about the risks versus the benefits of treatment, their ability to live well with their conditions, or other factors.

For example, although one patient with knee pain may wish to have knee replacement surgery, another may worry about the risks that the surgery may not completely relieve pain or restore mobility and may choose to forgo it in favor of managing the pain with medication and weight loss. In such cases, there are multiple, reasonable treatment options, each with their own risks and benefits, and the "correct" path forward should be guided by a patient's unique needs and circumstances.

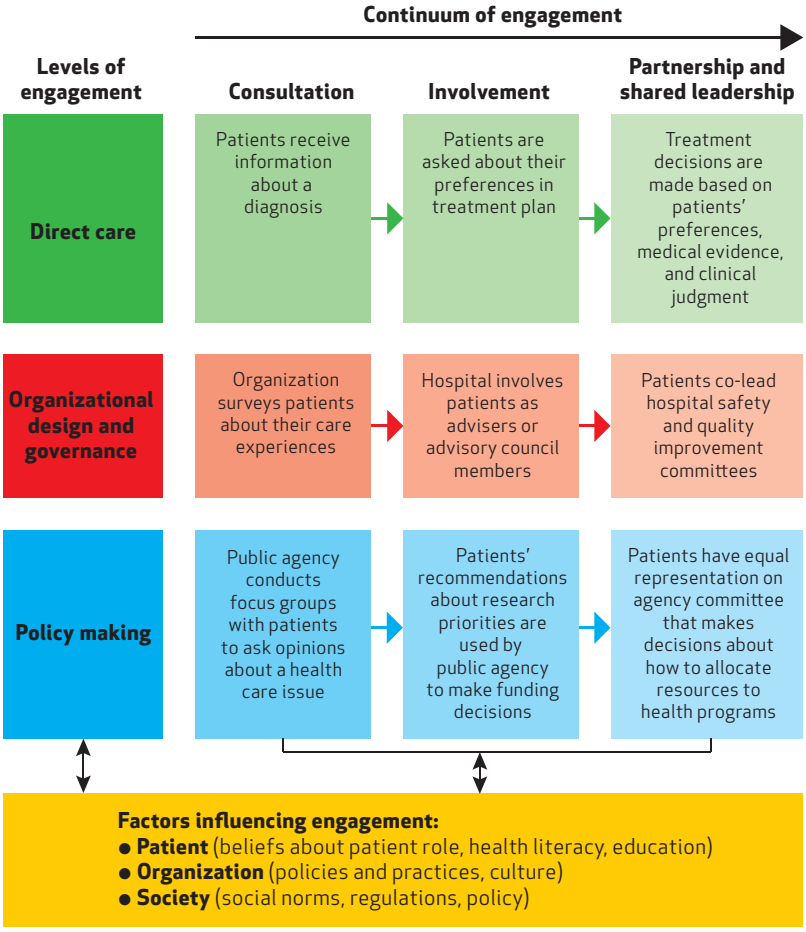
France Légaré and Holly Witteman at the Université Laval in Quebec note that shared decision making involves several essential elements. First, providers and patients must recognize that a decision is required. Next, they must have at their disposal, and understand, the best available evidence. Finally, they must incorporate the patient's preferences into treatment decisions.

There are various modalities through which shared decision making can be conducted. A typical process is to use decision aids—leaflets, books, videos, websites, and other interactive media—that give patients information on the risks and benefits of various treatment options and help them make the choice that most reflects their personal values. Some organizations, such as the Informed Medical Decisions Foundation and the private company Health Dialog, have developed balanced, expert-reviewed decision materials. Using these decision aids, shared decision making can be conducted in person between providers and patients, or remotely, as described below.

David Veroff at Health Dialog and coauthors conducted a large randomized study involving patients with one or more of six different preference-sensitive conditions: heart conditions, benign uterine conditions, benign prostatic hyperplasia, hip pain, knee pain, and back pain. One group of patients received enhanced decision-making support by trained

EXHIBIT 1

A Multidimensional Framework for Patient and Family Engagement in Health and Health Care



SOURCE Kristin L.Carman, Pam Dardess, Maureen Maurer, Shoshanna Sofaer, Karen Adams, Christine Bechtel, and Jennifer Sweeney, "Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies," *Health Affairs* 32, no. 2 (2013): 223–31. **NOTE** Movement to the right on the continuum of engagement denotes increasing patient participation and collaboration.

21%

Increased medical costs
Patients with the lowest activation scores—having the least skills and confidence to actively engage in their own health care—incurred costs up to 21 percent higher than patients with the highest activation levels.

health coaches over the phone, by mail, and via the Internet. The other group received only a usual level of support from these coaches. In both cases, the coaches gave patients knowledge and awareness of their treatment options, helped them to sort out their treatment preferences, and encouraged them to communicate those preferences to their health care providers. The primary difference between the groups was the proportion of participants receiving health coaching was higher in the enhanced support group.

Patients who received enhanced decision-making support ultimately had overall medical costs that were 5.3 percent lower than for those receiving only the usual support. They also had 12.5 percent fewer hospital admissions and 20.9 percent fewer preference-sensitive heart surgeries. The authors concluded that shared decision making through these relatively low-cost, remote models can extend the benefits of patient engagement to broad populations.

PATIENT ACTIVATION: Many studies have shown that patients who are "activated"—that is, have the skills, ability, and willingness to manage their own health and health care—experience better health outcomes at lower costs compared to less activated patients. In an effort to quantify levels of patient engagement, Judith Hibbard of the University of Oregon has developed a "patient activation measure"—a validated survey that scores the degree to which someone sees himself or herself as a manager of his or her health and care.

Hibbard and coauthors studied the relationship between patients' activation scores and their health care costs at Fairview Health Services, a large health care delivery system in Minnesota. In an analysis of more than 30,000 patients, they found that those with the lowest activation scores, that is, people with the least skills and confidence to actively engage in their own health care, incurred costs that averaged 8 to 21 percent higher than patients with the highest activation levels, even after adjusting for health status and other factors (Exhibit 2). And patient activation scores were shown to be significant predictors of health care costs.

BROADER PATIENT ENGAGEMENT: Consistent with the second and third levels of engagement that Carman and coauthors describe are programs in which health care organizations structure themselves to meet patients' needs and preferences—and in which those preferences help to shape broader responses on a societal scale. An example is the Conversation Project and the Conversation Ready Project—two efforts to elicit patients' attitudes and choices about end-of-life care and predispose providers to give care consistent with those choices.

The Conversation Project, initiated by Boston-based journalist Ellen Goodman and colleagues, is a grassroots public campaign that encourages people to think about how they want to spend their last days and to have open and honest discussions with their families and health care providers. By having these important conversations before a crisis occurs, patients can consider and clearly communicate their wishes and forestall situations in which those decisions are made by others and not fully aware.

The Conversation Ready project, initiated by Maureen Bisognano, president and chief executive of the Institute for Healthcare Improvement, and IHI colleagues, is an effort to make certain that the nation's health systems and providers have the skills to elicit and receive patients' and families' views about end-of-life care, document them, and carry them out. Ten "pioneer" health care organizations working with the institute have committed to being "Conversation Ready" within one year—and to developing replicable and scalable models of change that others can adopt as well.

For example, one of the systems, Gundersen Lutheran, which is based in LaCrosse, Wisconsin, has created Respecting Choices—a 501(c)3 not-for-profit aimed at engaging individuals in end-of-life decision making. Among other actions, the health care system prompts all patients at the age of 55 to discuss their wishes with their primary care provider.

EXHIBIT 2

Predicted Per Capita Costs of Patients by Patient Activation Level

2010 patient activation level	Predicted per capita billed costs ($)	Ratio of predicted costs relative to level 4 PAM
Level 1 (lowest)	966**	1.21**
Level 2	840	1.05
Level 3	783	0.97
Level 4 (highest)	799	1.00

SOURCE Judith H. Hibbard, Jessica Greene, and Valerie Overton, "Patients with Lower Activation Associated with Higher Costs; Delivery Systems Should Know Their Patients' 'Scores,'" *Health Affairs* 32, no. 2 (2013): 216–22. **NOTES** Authors' analysis of Fairview Health Services billing and electronic health record data, January–June 2011. Inpatient and pharmacy costs were not included. PAM is Patient Activation Measure. $^{**}p < 0.05$

WHAT ARE THE ISSUES?

Researchers have identified a number of common factors and obstacles that may need to be overcome to carry out effective patient engagement and activation strategies. Some are attributable to patients and their characteristics and proclivities and others to those of providers.

1.5%

Opt-out rate
After being enrolled by default in a program to receive preferred medications, only 1.5 percent of patients opted out when given the chance.

FACTORS INVOLVING PATIENTS: For patients to engage effectively in shared decision making, they must have a certain degree of health literacy. Howard Koh, assistant secretary for health at the Department of Health and Human Services, and his coauthors propose a new Health Literate Care Model that assumes that all patients are at risk of not understanding their health conditions or how to deal with them. Health care organizations adopting this model would work to increase health literacy and patient engagement over the entire care span.

Koh and colleagues propose, for example, that health care organizations first adopt the Care Model, formerly known as the Chronic Care Model, a mode of delivering health care that draws on clinical information systems, decision support, and self-management support to provide comprehensive care for chronically ill patients. Then, health literacy strategies would be incorporated into the model, such as the "teach-back" method, in which providers ask patients to explain back to them what the patients have learned, their own understanding of their condition, the options available to them, and their intentions to act on the information.

"Patient activation scores were shown to be significant predictors of health care costs."

DIVERSE BACKGROUNDS: Elizabeth Bernabeo and Eric Holmboe of the American Board of Internal Medicine examined shared decision making and concluded that it is "patient specific." Specifically, they said, a patient's degree of engagement may be affected by such factors as cultural differences, sex, age, and education, among others. As a result, specific competencies, such as language skills or an awareness and understanding of religious beliefs, may be required on the part of clinicians and delivery systems to effectively engage patients with diverse cultural backgrounds and socioeconomic status.

COGNITIVE ISSUES: Robert Nease and colleagues of Express Scripts have noted that there are well-known limitations to human decision-making skills and the ability to maintain attention that serve as barriers to patient engagement. They argue that there may be better ways to influence patients' decision making, such as through "choice architecture," in which decisions to be made are structured so as to "nudge" a patient toward a particular choice. For example, in a pilot study by Express Scripts, patients were required to use preferred, lower-cost drugs before they could "step up" to other options. They were given information about the step-therapy program and given 60 days in which to "opt out" if they wanted to switch to a nonpreferred medication. The opt-out rate was only 1.5 percent, indicating that choice architecture is a potential alternative to other patient engagement approaches.

AVERSION TO CONSIDERING COSTS: One area in which it may be especially hard to engage patients is considering costs in the context of making decisions about their health care. Roseanna Sommers, a Yale Law School student, and coauthors convened 22 focus groups of insured people and asked them about their willingness to weigh costs when deciding among nearly comparable clinical options—for example, to receive a computed tomography scan or undergo a more expensive magnetic resonance imaging after having had a severe headache for three months. Most participants were unwilling to consider costs and generally resisted the less expensive inferior options.

The authors identified a number of factors that lead patients to ignore cost. These factors include patients' preference for care they perceive to be the best, regardless of expense; an inclination to equate cost with quality; inexperience in considering trade-offs among cost and quality; disregard for costs borne by insurers or society as a whole; and the impulse to act in one's own self-interest even though resources are limited.

One antidote to consumers' aversion to considering costs might be giving them cost and quality information that they find most useful and relevant to their concerns. Jill Matthews Yegian of the American Institutes for Research and coauthors found that consumers want to be able to compare information about individual physicians and to obtain cost data that reflect their own out-of-pocket expenses for an entire episode of care, not for individual procedures and services. Therefore, the authors contend, state and federal policy makers should look for ways to assemble such infor-

mation and make it clear and accessible for consumers.

FACTORS INVOLVING PROVIDERS: A recurring theme in the February 2013 issue of *Health Affairs* is the need for significant changes in the culture and operations of medical practice to implement patient engagement strategies. Studies have identified numerous barriers, including time constraints, insufficient provider training, a lack of incentives, and information system shortcomings.

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Barriers to shared decision making
Overworked physicians, insufficient provider training, and clinical information systems that failed to adequately track patients.

In one study, Grace Lin of the University of California, San Francisco, and coauthors explored the use of decision aids—DVDs and booklets about colorectal cancer screening and treatment for back pain—at five primary care clinics in Northern California that expressed a willingness to use them. Despite that support, the actual distribution rates for these items remained low, even after staff training sessions and other promotional activities. Some physicians felt that patient input was not warranted, although others had difficulty moving away from traditional physician-directed decision making. Most physicians cited a lack of time as a major barrier.

That perspective echoed a finding in the systematic review of 38 studies by Légaré and Witteman, which was that clinicians pointed most frequently to time constraints as the primary barrier, even though there was "no robust evidence that more time is required to engage in shared decision making in clinical practice than to offer usual care."

Mark Friedberg of the RAND Corporation and coauthors evaluated a three-year demonstration project on shared decision making conducted at eight primary care sites in different parts of the United States. They discovered three main barriers to implementing shared decision making: overworked physicians, insufficient provider training, and clinical information systems that failed to track patients throughout the decision-making process. The researchers note that payment reforms and incentives may be needed for shared decision making to take hold.

"More research will be needed to determine best practices for engaging patients."

WHAT ARE THE POLICY IMPLICATIONS?

Federal and state policy makers have embraced patient engagement as a strategy to address health care costs and improve quality. Here are some of the ways.

The Affordable Care Act identifies patient engagement as an integral component of quality in accountable care organizations (ACOs) and in patient-centered medical homes. Shared decision making is so valued in the law that a separate section (3506) calls for new Shared Decision-Making Resource Centers to help integrate the approach into clinical practice. No funds have yet been appropriated to implement this section, however.

Patient engagement is also central to Section 3021 of the law, which creates the Center for Medicare and Medicaid Innovation. Under the law, the center is to examine how support tools can be used to improve patients' understanding of their medical treatment options. The health care law also created the Patient-Centered Outcomes Research Institute, charged with funding research that will assist patients, caregivers, clinicians, payers, and policy makers in making informed health decisions.

Because patient activation can be directly linked to improved outcomes, a measurement of patients' level of activation could be adopted as an intermediate measure for ACOs, patient-centered medical homes, and other new and emerging delivery and payment structures, Hibbard and her coauthors observe. The need for additional measures of patient engagement is discussed further below.

STATE POLICY: In 2007 Washington became the first state to enact legislation encouraging shared decision making and decision aids to address deficiencies in the informed consent process. The legislation also required a pilot project to study shared decision making in clinical practice. Massachusetts is also incorporating patient engagement into its health policies. Now, to be certified by the state, ACOs and medical homes must include shared decision making. Patient engagement and consumer choice will also be fundamental to health insurance exchanges, where as of October 2014 people and small businesses will be able to shop for coverage.

So-called "navigators" and federally supported, state-run consumer assistance agencies will be able to assist consumers with their purchasing, as well as with issues that arise with their health coverage. Rachel Grob of National Initiatives and coauthors reviewed state efforts to meet the law's consumer assistance goals and found that in fewer than half the states, consumers are getting the assistance they need to navigate a rapidly chang-

ing health insurance marketplace. Other states are much further behind, suggesting that more will have to be done to ensure that consumers across the country are getting adequate assistance.

WHAT'S NEXT?

Despite evidence that has been compiled to date of the importance of patient engagement, experts in the field agree that more research will be needed to determine best practices for engaging patients, as well as to more fully demonstrate the relationship of patient engagement to cost savings. In the meantime, considerable efforts are under way to hold health care organizations accountable for engaging patients.

For example, the National Committee for Quality Assurance, a nonprofit organization that tracks the quality of care provided by health plans and health care organizations, requires a variety of assessments to determine how actively patients are being engaged in their health and care. Organizations wishing to be certified as meeting requirements for patient-centered medical homes, for example, must undertake surveys of patients that ask about whether clinicians engage them in shared decision making or provide support for them to manage their conditions. But there is wide agreement that even more could be done to measure how and how well health care organizations engage patients, and help to realize individuals' full potential to maintain and improve their health.■

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