

Part 3: How Health Care Reform Changes the Role of Patients

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Leaders and decision-makers in health care have come to recognize that there is no way to improve health outcomes and contain costs without the full participation of patients.

Existing approaches to engaging patients are not enough. To change the way we deliver and pay for health care, we must make patient involvement and decision-making a reality rather than simply a well-intentioned idea. And in order to be successful in patient engagement, we need to be sure that there are connections to the real world in which people live so that patients can be active participants when they receive care and when they return home. This is a priority for MeHAF, so when we funded payment reform initiatives from 2010–2014, we asked grantees to explore how to ensure meaningful patient engagement – especially for those who are uninsured and underserved – as they developed their innovations in payment and delivery systems. Here is some of what our grantees, and we, learned.

Protect and promote conversation between patients and providers

Patient engagement is more than trying to get patients to do their part to lose weight or take their medications correctly. If we want to truly understand what gets in the way of good health and what makes it possible, we must foster the opportunities for everyone in the care setting to engage in conversations with patients.

We foster this when we ensure that providers have the time and incentives to have these conversations, and when both providers and patients have the skills to build the relationships that create fertile ground for these conversations. Providers are not usually interested in reforms that do not appear to be in the best interest of their patients, or that do not recognize the value of the provider-patient relationship. For example, one of our grantees, HealthInfoNet, relies on provider and health system support to meet its goal of collecting health care data and compiling it into information that supports provider-patient interactions. But providers are most willing to get involved only when HealthInfoNet shows how their work will directly benefit patients and the provider-patient relationship. <https://vimeo.com/134978645>.

One-on-one conversations give providers insight into how patients choose to use the health care system. Our assumptions are often incorrect, as Linda Foley from Aroostook Medical Center and Barbara Sorondo from Eastern Maine Medical Center learned when they were exploring how to reduce inappropriate emergency department and walk-in-clinic use, and promote use of primary care medical homes. They thought that most of those who used the emergency and urgent care settings for routine care did not have insurance, or had low "patient activation," meaning they were not very involved in their care.

But after talking with patients, they learned that these presumed barriers were not really the issues. Many patients have insurance and are highly involved in their own care, and make the decision to use the emergency and urgent care settings because of things like after-hours availability and access to many services in one place. <https://vimeo.com/134978642>.

If we want systems of care that work, we must create everyday channels of communication with patients that give us a window to their world – the priorities and circumstances that lead to their health care choices.

Invite patients to participate in the “big” conversations about the health care system

In addition to fostering the small, everyday conversations in health care, reform efforts must include patients in big conversations about health care policy and what our health care system should look like.

Vanessa Santarelli, CEO of the Maine Primary Care Association, explains that community health centers have made a start by having over 51 percent of the Board made up of patients from the health center. “One of the unique features of the community health centers is the patient-directed nature of the care ... patients have a direct say in decisions made around the type of care that’s provided,” says Santarelli. “In addition to Board participation, some centers have a patient advisory committee to seek out more feedback from those that maybe aren’t sitting on the Board.”

If we want patients to have meaningful participation in conversations and choices about health care, we must provide them with good information. Prescription Policy Choices learned from watching pharmaceutical companies that powerful change is possible when we inform the triumvirate of health care decision makers: payers/employers, providers and patients. Diane Boaz, who managed the project, observed “how desperately both physicians and consumers want information.” When both patients and providers have evidence-based information that they can review together, the decision-making process is strong and the decisions are sound.

Patients should be able to easily connect with one another

Patients want to talk to other patients who have been through an illness, condition or treatment they are facing. Especially when it comes to lifestyle interventions, patients may take advice and coaching more easily from a fellow patient or someone who has “been there” than they will from a health care provider. One grantee, MaineGeneral’s Prevention Center, started the Peer Navigator Program to capitalize on this tendency to seek out peer support. Patients (or recent patients) lead workshops or work one-on-one with other patients to help them manage their chronic diseases. Providers see the difference it makes; their patients are making lifestyle changes the provider never thought the patients would be able to make. It is important that our delivery and payment systems support this kind of peer interaction.

<https://vimeo.com/134978643>.

Health care systems must take into consideration the real world where patients live

Patients are only “patients” when they are interacting with the health care system. Most of the time they are people pursuing their day-to-day activities in the real world, at work or with families and friends.

One of our grantees is meeting its community’s need for health in the “real world” by reaching people through the workplace. The Healthy Maine Streets initiative is working with micro-businesses – those with ten or fewer employees – to bring worksite wellness to their employees. People spend much of their time at work, and these small businesses are creating environments in which employees can make good decisions for their health. This is one way to promote the

ongoing conversation between health care and the communities in which people live, work and make most of their health decisions.

Bringing health and wellness to the community is one important strategy, and bringing the real world to the health care setting is another. We must equip patients and providers to have conversations about barriers to self-care as part of their clinical visits. There must be a payment structure that encourages providers to ask, listen and discuss patient constraints as well as patient perceptions and beliefs about health and disease. Providers cannot assume that patients are merely unwilling to do their part for their care; we must be sure that patients are *able* and *enabled* to do their part.

Patient navigators and care coordinators can make the connections to the community for patients. Maine Quality Counts is testing one model, Community Care Teams, as part of its Maine Patient-Centered Medical Home initiative. Helena Peterson, Program Manager, describes the Community Care Teams as a multi-disciplinary team of nurse care managers, social workers, pharmacists and health coaches who “meet the patient where they are physically and geographically, by going out into homes and out into the community.” The Care Team also meets them where they are financially, socially and psychologically, to understand their needs around transportation, food, housing and behavioral health, because “even the most robust [primary care] practice is only designed to do so many different pieces of health care.” <https://vimeo.com/134978644>.

Hospitals also see the value of connecting to the community to meet the complex needs of patients. For one grantee, Mercy Health System, what started as an initiative to better manage the costs of charity care became a quest to understand and address the social determinants of health. Rather than simply providing charity care, the hospital has worked to create a “medical neighborhood” to meet the many psychosocial needs of their patients. The focus is no longer limited to providing urgent health care services, but goes farther to working with social service organizations to meet patients’ basic needs in an effort to reduce the need for health care interventions in the long term. Melissa Skahan of Mercy Health System says, “Without [focusing on] the social determinants, you are never going to get where you need to. I don’t think it’s the health care system’s role to necessarily fix [these problems], but ... to empower and identify the assets and then help build the system.” <https://vimeo.com/134978646>.

Role change is hard. Things will be a little uncomfortable for a while

Like all payment reform initiatives, reforms that increase patient engagement must be evaluated. We should, however, be cautious about evaluating these initiatives based on “smile sheets,” or how happy and satisfied providers, insurers and patients are in the short-term. Role change and power shifting is difficult work in any system, and we can expect it to be especially challenging for our massive health care system. It is good and necessary to shift the role of the patient from a passive to a more active one, and to introduce new players such as navigators and care teams into the health care system. But it may not be comfortable. Some patients, providers and payers may embrace the changes right away, but many others will be perplexed at best or profoundly uncomfortable about the shift in roles and power. It may take some time before it feels right.

It's up to all of us to amplify the patient's voice

There is no single advocacy group to further the interest of patients and represent their needs. It is up to those of us who fund innovation in health care to build patient engagement and patient empowerment into the system. Instead of seeing patient engagement as a tool in the toolbox, we need to see it as an essential element of all reform efforts. We must always ask: does this proposed innovation, payment structure or delivery system help or hinder the conversation between a provider and a patient? Does it help us to hear the patient's voice, or does it mute that voice? The answers to these questions may mean the difference between reaching or falling short of our most important reform goals: to avoid wasting health care dollars, and to invest in high-quality care delivered with wisdom and humanity.

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