

What We're Learning: **Engaging Patients Improves Health and Health Care**

The Challenge

People who are actively engaged in their health care are more likely to stay healthy and manage their conditions by asking their doctors questions about their care, following treatment plans, eating right, exercising, and receiving health screenings and immunizations.¹ Patients without the skills to manage their health care incur costs up to 21 percent higher than patients who are highly engaged in their care.²

Patient engagement starts with giving patients the tools they need to understand what makes them sick, how to stay healthy, and what to do if their conditions get worse. It means motivating and empowering patients to work with clinicians—to be active participants in their care by asking questions, knowing their medications and medical history, bringing friends or relatives to appointments for support, and learning about care that may be unnecessary. It can also mean giving them a seat at the table to improve the care that hospitals and doctors' offices provide. Patients who know how to navigate the health care system often have different perspectives than those who provide their care, and can offer insights on how to overcome the barriers that patients face to help improve care.

Not all patients are the same, so there are many different ways to engage them, depending on a patient's skills and interests. The American Institutes for Research developed a [three-level framework](#) to guide patient engagement by matching patients with activities that align with their interest in and knowledge of health and the health care system.³ First-level patients are becoming engaged in managing their own care. Second-level patients provide input to health care organizations, including doctors' offices, to help improve care for all patients. Third-level patients are involved in efforts to influence community-wide programs, policies, laws, and regulations in health care. [Aligning Forces Humboldt](#), which leads the *Aligning Forces for Quality* (AF4Q) effort in Humboldt County, Calif., also developed a [framework](#) to guide patient engagement in its projects, based on patients' skills and interests.

Across the country, organizations leading the AF4Q initiative are engaging patients at all levels to improve care in their communities.

Aligning Forces for Quality

AF4Q is the Robert Wood Johnson Foundation's signature effort to lift the overall quality of health care in 16 targeted communities across America. These briefs distill some of the key lessons learned by these regional alliances of providers, patients, and payers as they work to transform their local health care and provide models for national reform.

The Facts



Patients without the skills and confidence to manage their own health care incur costs up to 21 percent higher than patients who are highly engaged in their care.⁴



Patients are stepping up to the plate. Nearly half (47 percent) of patients have brought a friend or a relative to a doctor's appointment so that they could help ask questions and understand what the doctor was saying.



Almost three in five patients have taken a list of their current medications to a doctor's appointment.⁵

What's Working

Improving the quality and value of health care is at the heart of AF4Q, the Robert Wood Johnson Foundation's signature effort to lift the overall quality of health care in 16 targeted communities. Lessons from AF4Q demonstrate how:



Programs that encourage **collaboration** among patients can help them learn to better manage their own health.



Although doctors may be reluctant to make their practices **transparent**, involving patients in quality improvement efforts can generate valuable insights and better processes.



Engaging patients to influence health care systems or policy takes both time and resources, but is critical for true culture change.



Collaboration

Programs that encourage collaboration among patients can help them learn to better manage their own health.

Educating patients about their health empowers them with the knowledge needed to stay healthy. Since 2008, [Aligning Forces Humboldt](#) has engaged more than 1,000 patients in its [Our Pathways to Health](#) chronic disease self-management workshops. The six-week program helps patients with chronic conditions—including high blood pressure, high cholesterol, diabetes, obesity, chronic pain, and heart conditions—learn how to manage their conditions in a supportive environment with peers facing similar challenges. Many of the program's graduates become so impassioned that they train to become workshop leaders. Initially, the program relied on word-of-mouth recommendations from enthusiastic alumni, public service announcements, and newspaper articles to recruit attendees. Those efforts didn't go far enough, however, so program leaders began working with doctors' offices to refer patients with chronic illnesses.

A program led by the [Greater Detroit Area Health Council \(GDAHC\)](#), which spearheads the local AF4Q effort, took a similar approach by working with patients at risk for developing heart disease. The six-month [Cardiac Disease Prevention Exercise Program](#) included twice-weekly sessions with exercise specialists, educational sessions with primary care physicians and dietitians, free pedometers, and a cooking demonstration to encourage participants to adopt heart-healthy behaviors. As with the Pathways workshops, peer support was integral to this program, as participants leaned on one another to stay motivated and accountable for integrating healthy behaviors into their daily lives. Physician involvement also played an important role, as the chair of the program was a primary care physician who personally invited some of the participants and worked one-on-one with participants throughout the program. After participants lost weight and lowered their blood pressure, GDAHC began working with program graduates to reach out to other community organizations to implement similar exercise programs.

FAST FACT: Since 2008, the [Our Pathways to Health](#) program has provided **94 workshops** to more than **1,000 participants**, with **720 graduating** from the program by attending at least four workshops.

"I came into this six-week program a death-fearing, self-pitying, chronically ill person. Now I am mainly chronically well."

—EUNICE NOACK,
OUR PATHWAYS TO
HEALTH PARTICIPANT

Resource Guide:

Review a compendium of tools and techniques that AF4Q alliances use for patient engagement.



Transparency

Although doctors may be reluctant to make their practices transparent, involving patients in quality improvement efforts can generate valuable insights and better processes.

“It’s very motivating for patients to share their experiences with providers and see that they truly care but hadn’t previously been aware of patients’ perspectives.”

— KIM HUMPHREY,
CONSUMER REPRESENTATIVE
AND COORDINATOR OF
THE PATIENT AND FAMILY
LEADERSHIP TEAM IN MAINE

A growing number of primary care practices are integrating patients’ unique perspectives into quality improvement efforts to improve the experiences of patients and clinicians alike, and ensure that patients are at the center of care. [Aligning Forces Humboldt](#) and [Aligning Forces for Quality – South Central Pennsylvania \(SCPA\)](#) both work with local primary care practices to incorporate [Patient Partners](#) into quality improvement teams.

Before implementing the Patient Partners program, clinicians in SCPA were fearful of exposing deficiencies to patients. However, practices found that being transparent helped patients understand how the system works. The alliances mitigated anxiety among doctors by holding open discussions about the potential challenges of partnering with patients and how to overcome them. One key to successful partnerships is a direct invitation from the physician’s practice to the patient. Program leaders also recommend that patient advisory groups start by taking small steps, such as reviewing how the practice uses its phone system or seeking feedback on efforts already underway, to improve care. The groups have found that clear expectations, structured meetings, and asking patients for feedback through meeting evaluations increases the satisfaction of both patients and clinicians. Patient Partners have helped practices adopt new techniques to provide better care, from giving parents a laminated reminder card to schedule well child visits on their way out of the office to creating “brown bag medication review” appointments so patients and their doctors can review all their medications.

FAST FACT: The **Patient Partners program in SCPA** now includes **36 practices** serving more than **125,000 patients** and focuses on patient communication and self-management in York and Adams counties.



Engagement

Engaging patients to influence health care systems or policy takes both time and resources, but is critical for true culture change.

“The council offers a place where I can contribute my experience as a patient and career coach for people with chronic health conditions toward creating a more patient-centric system of care. With MHQP, I know that my time and perspective are valued and put to action.”

— ROSALIND JOFFE, PATIENT
AND CO-CHAIR OF MHQP’S
PATIENT AND PUBLIC
ENGAGEMENT COUNCIL

Involving patients in programs to improve the overall health and health care in a community helps ensure that the population’s needs are understood and met. With this in mind, [Massachusetts Health Quality Partners \(MHQP\)](#), which leads the AF4Q initiative in the Greater Boston area, decided to include patients in its leadership by creating the Patient and Public Engagement Council (PPEC). PPEC members draw on their experiences as patients and family members to help MHQP establish strategic goals and develop public reports on the quality of care provided in the community. By fostering relationships with patient leaders, MHQP receives valuable feedback on high stakes projects, like its recent work with *Consumer Reports* to develop the publication’s first-ever rating of patient experiences with nearly 500 primary care offices in Massachusetts. For this project, PPEC members worked in collaboration with physicians to make sure the reports were not only fair and balanced, but also displayed in a format that consumers could easily understand.

MaineGeneral Health, an integrated health system, began working with the [Maine Health Management Coalition \(MHMC\)](#), a member of the local AF4Q initiative, after losing its status as a preferred hospital based on rankings reported publicly by MHMC. One way MaineGeneral worked with MHMC to get back on the preferred list was to [form a steering committee representing state employees](#) who received incentives, such as lower co-pays, for going to preferred hospitals. By including patients in the process, MaineGeneral was able to accelerate improvement activities and meet all of its goals by the end of its second year as an accountable care organization (ACO), getting back on MHMC’s preferred list.

- 1 Hibbard JH and Cunningham PJ. *Research Brief No. 8: How Engaged Are Consumers in Their Health and Health Care, and Why Does It Matter?* Washington: Center for Studying Health System Change, 2008, www.bschange.com/CONTENT/1019/1019.pdf (accessed December 2013).
- 2 James J. "Health Policy Brief: Patient Engagement." *Health Affairs*, February 14, 2013, healthaffairs.org/healthpolicybriefs/brief_pdfs/healthpolicybrief_86.pdf (accessed December 2013).
- 3 James J.
- 4 James J.
- 5 Kaiser Family Foundation and Agency for Healthcare Research and Quality. *2008 Update on Consumers' Views of Patient Safety and Quality Information*. Washington: Kaiser Family Foundation and Agency for Healthcare Research and Quality, 2008, www.kff.org/kaiserpolls/upload/7819.pdf (accessed December 2013).